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Stronger together: increasing access to ataxia education for caregivers with limited English proficiency

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Doctoral Project

STRONGER TOGETHER:
INCREASING ACCESS TO ATAXIA EDUCATION FOR CAREGIVERS WITH LIMITED ENGLISH PROFICIENCY

by

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DEDICATION

I would like to dedicate this work to my family, whose unwavering inspiration, encouragement, and support have carried me through every challenge and triumph along this journey. To my partner, Chudi — your steadfast belief in my abilities and gentle nudges forward have been my grounding force. Thank you for standing by me with patience, perspective, and unwavering love. Your own resilience, strength and hard work encouraged me through each step. To my parents, your boundless encouragement, faith in me and unconditional love have been the foundation of my academic pursuits. You gave me the courage to keep going, even when the road felt uncertain. Thank you for instilling in me the values of perseverance, integrity, and lifelong learning. To my sister Carly, your humor, light, and ability to find joy even in the most stressful moments have reminded me to laugh and breathe. Your presence has been a reminder of the importance of balance and perspective.

This work is as much yours as it is mine. Thank you for walking alongside me.

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ABSTRACT

Occupational therapy has a growing emphasis on addressing health equity through inclusive, evidence-based caregiver education (Berdahl & Kirby, 2019; Chen et al., 2018). Caregivers with limited English proficiency (LEP) often face significant barriers when supporting loved ones with ataxia transitioning from inpatient rehabilitation to home. These challenges, including limited health literacy, limited access to health information, and reduced caregiver confidence, can negatively impact care quality and patient outcomes. Despite the known risks, there is limited guidance in the occupational therapy literature on best practices for supporting LEP caregivers in rehabilitation settings.

This doctoral project (1) utilizes a needs assessment to better understand the experiences of LEP caregivers of individuals with ataxia, (2) draws upon Pechansky's Theory of Access, Adult Learning Theory, and the Occupational Justice Framework to design an educational intervention, (3) develops accessible materials including plain-language handouts, visual supports, and in-person interpreter-supported training sessions,

(4) implements the program with occupational therapy staff along the continuum of care, and (5) evaluates caregiver and clinician feedback to assess feasibility and impact.

The evidenced literature suggests that caregivers experienced increased confidence, reduced anxiety, and expressed appreciation for accessible and culturally responsive education. Clinicians reported improved caregiver engagement and communication. Barriers remain, including interpreter availability and varying literacy levels, yet the overall response supports the expansion of such programs. This project contributes to occupational therapy by promoting inclusive caregiver education, addressing systemic barriers to access, and offering a scalable model for advancing occupational justice in linguistically diverse healthcare settings.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ABI	Acquired brain injury
ADL	Activities of Daily Living
AHA	American Heart Association
AI	Artificial Intelligence
AJOT	American Journal of Occupational Therapy
AOTA	American Occupational Therapy Association
BU	Boston University
CBIS	Certified brain injury specialist
DME	Durable Medical Equipment
EBP	Evidence-based practice
IADL	Instrumental Activities of Daily Living
IDT	Interdisciplinary Team
IRB	Institutional Review Board
LEP	Limited English Proficiency
LHE	Long-handled equipment
OT	Occupational Therapy
OTAC	Occupational Therapy Association of California
OTP	Occupational Therapy Practitioner
OTPF	Occupational Therapy Practice Framework
TBI	Traumatic brain injury
WHO	World Health Organization

CHAPTER ONE – Introduction

1.1 Background

This project addresses the critical need for caregiver education in managing patients with cerebellar ataxia following a stroke. These patients often experience challenges in balance, speech, swallowing, and daily living activities, as well as emotional and psychological impacts such as frustration, anxiety, and depression (Tremblay et al., 2022). Specifically, this paper aims to fill the literature gap on caregiver education for ataxia, targeting families from lower socioeconomic backgrounds with limited English proficiency (LEP) and migrant populations. A comprehensive literature review will identify existing research and educational materials on ataxia and caregiver education and specific informational gaps. This project will consider the target audience's cultural diversity, developing culturally sensitive educational materials that reflect language preferences, cultural norms, and health beliefs. These materials may include brochures, videos, and online resources.

Research shows that while caregivers aware of their knowledge gaps seek out resources, they often encounter challenges finding accessible information. In a study on ataxia conducted in the United Kingdom, patients reported that 'the majority of respondents (33/35, 94%) had read about ataxia online. Patients most frequently sought information about 'support,' while caregivers most often accessed information on 'support' or 'treatment information' (Sheard, 2019). The study highlights the need for lay/plain language summaries on ataxia, which half of the respondents were aware of, though fewer than half utilized these tools. Those who accessed these summaries found them 'easy to read' and noted that 'understandable summaries are 'important,' 'useful,' and 'empowering' for patients' (Sheard, 2019). This need for lay/plain language summaries aligns with the project's goal of creating culturally sensitive and easy-to-understand educational materials for LEP caregivers.

1.2 Problem Statement

A major challenge identified is the lack of accessible, comprehensive educational resources tailored to caregivers' needs, particularly for marginalized groups (Schaffler et al., 2019). These populations often face additional barriers to healthcare information access, including language and cultural differences, as well as limited resources (Al Shamsi, 2020). This lack of accessible information exacerbates the already demanding role of caregiving. This project envisions creating an evidence-based, culturally inclusive program free from biases through a thorough literature review and collaboration with healthcare professionals, researchers, and translators. This collaborative approach ensures that the information provided is relevant and tailored to the target audience's needs, fostering a sense of inclusion. The project will address these challenges by developing and disseminating educational materials in multiple languages, ensuring they are culturally sensitive and easy to understand. By addressing these factors and creating accessible educational materials, this doctoral project aims to significantly improve patients' and caregivers' quality of life, instilling hope for the future and optimism about the potential for positive change.

Effective patient and caregiver education is essential for promoting patient independence in managing ataxia. Occupational therapy identifies multiple categories of occupation: activities of daily living (ADLs), instrumental activities of daily living (IADLs), health management, rest and sleep, education, work, play, leisure, and social participation (AOTA, 2020, p.7). Without adequate education and intervention, patients with ataxia face a higher risk of falls, which can lead to repeated hospitalizations. In 2022, "average hospital adjusted expenses per inpatient day in the United States was $3,025, with California the highest at $4,337/day and Mississippi the lowest at $1,425/day" (AHA, 2023). Falls are prevalent among stroke patients, with incidence rates ranging from 7% within the first week post-stroke to 73% within the first year after hospital discharge (Kerse et al., 2008). Preventing and managing falls is essential to improving the quality of life for individuals with ataxia.

1.3 Purpose of the Project

This project aims to develop culturally sensitive educational materials that reflect language preferences, cultural norms, and health beliefs. These materials will include handouts, videos, and online resources to ensure accessibility for caregivers with limited English proficiency. Caregivers who support an estimated 14.7 million Americans—a number that has risen over the past decade (Wolff et al., 2016)—play a critical and valued role in patient care. However, caregiver well-being can deteriorate with strain and burnout, especially if the care recipient experiences significant suffering (Schulz & Beach, 1999; Adelman et al., 2014). To provide quality care, caregivers must understand ataxia symptoms and management strategies, yet there is a significant gap in the literature on best practices and innovative caregiver support approaches. Evidence-based guidelines for this population remain limited (Winser et al., 2015). The World Health Organization states, "Health literacy is not solely an individual responsibility; governments and health systems must also provide clear, accurate, and accessible information for diverse audiences" (WHO, 2016). Health literacy, the ability to understand and apply health information to make informed decisions, plays a "central role" in addressing health inequities worldwide, affecting both affluent and impoverished populations (WHO, 2016). Enhanced health literacy empowers patients to take charge of their health, participate in community health efforts, and demand government accountability on health equity issues. Thus, addressing health literacy needs, especially in disadvantaged and marginalized societies, accelerates progress in reducing health inequities (WHO, 2016). Improving health literacy enables marginalized populations to make informed decisions about their health, ultimately enhancing quality of life.

1.4 Significance of the Project

Occupational therapy emphasizes a commitment to occupational justice, defined as “a justice that recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class, or other differences” (AOTA, 2020, p.4). With a rapid increase in immigrant populations and asylum seekers, there is a need for educational materials in multiple languages to support integration and well-being (Lehti et al., 2018). Service providers must address these needs by developing resources that promote educational and health integration, recognizing academic performance as an important indicator of integration and access to essential services (Lehti et al., 2018).

A strong indicator of a patient's potential for resuming meaningful activities is caregiver involvement (Rowland et al., 2008). Common goals include enabling patients to regain independence in ADLs like dressing, bathing, and using the restroom. Accessible caregiver education is fundamental to supporting patients in these tasks, and occupational therapy, with its holistic approach, is well-positioned to contribute to ataxia interventions. Occupational therapy can significantly enhance patient outcomes and promote greater independence by addressing individual abilities, environmental factors, occupations, barriers, and goals. Holistic approaches are integral to occupational therapy worldwide and are well-supported in literature. For instance, in a national survey conducted in the United States, “more than 80 percent of occupational therapists using the Model of Human Occupation (MOHO) in their practice reported that this model supported holistic, occupation-focused, client-centered, and evidence-based practice” (Asbjørnslett et al., 2023). McColl highlighted that a "holistic view of disability differs sharply from a medical understanding," seeing disability as a typical life experience with potential for personal growth and development. This view shifts the focus to achieving balance and living life within the constraints of disability (McColl, 1994). Holistic approaches are sensitive to cultural differences and diversity, considering how individuals think about health and illness and utilize healthcare services (Kinébanian, 2010). Occupational therapists are uniquely equipped to create programs aimed at community-based population health.

Contributing factors to these challenges include healthcare inequities and disparities. Patients with ataxia often lack access to specialized providers, including neurologists, occupational therapists, physical therapists, and speech therapists, which can lead to frustration and poor outcomes (Daker-White et al., 2013). Many neurologists and patients report that ataxia is a "problematic diagnosis of uncertainty," mainly when a definitive diagnosis is unavailable. This situation can lead to what clinicians call "ongoing diagnostic doubt," a burden patients and providers share (Daker-White et al., 2013). Limited access to healthcare professionals and resources, especially for marginalized communities, results in delayed diagnoses and worsens outcomes for patients with ataxia (Riley, 2012). Furthermore, social determinants of health, such as financial constraints, exacerbate these challenges by limiting access to essential services like diagnostic tests, assistive devices, and medications. Factors like socioeconomic status, race, ethnicity, education level, and geographic location significantly impact healthcare access and outcomes, with marginalized communities often facing more significant barriers (CDC, 2022). Caregiver well-being also affects healthcare outcomes; caregivers experiencing high levels of strain or burnout may unintentionally contribute to increased healthcare usage by the care recipient (Ankuda et al., 2017).

1.5 Research Questions

Some key questions that this author’s research seeks to answer are the following: What are the most effective communication strategies for caregivers of ataxia patients with limited English proficiency? How do caregiver training techniques impact patient outcomes? What cultural considerations should be incorporated into educational materials for ataxia caregivers? Despite extensive medical literature on ataxia's clinical features and management, a significant gap exists in standardized education and protocols for patients and caregivers (Daker-White et al., 2013). Ataxia, a symptom arising from diverse causes such as genetic disorders or acquired conditions, requires unique management strategies based on its varied presentations (Ashizawa et al., 2016). This diversity complicates efforts to create universally applicable educational resources. Additionally, as a relatively rare disorder, ataxia receives less public attention and research funding than more common neurological conditions, leaving a need for comprehensive, standardized guidelines and resources tailored to patient needs (Ashizawa, 2016). Beyond motor coordination, ataxia may impact cognition, speech, and sensory functions, necessitating complex educational materials that are difficult to standardize (Vogel et al., 2024).

1.6 Theoretical Framework

Traditional biomedical approaches like the biomechanical model may hinder comprehensive patient education. This model, focused on biological factors like pathology, typically views the patient as a passive care recipient and often overlooks individual experiences, psychosocial factors, and environmental influences (Leslie et al., 2021). As Kumar (2018) noted, the "medical model" emphasizes reassurance over patient involvement, which can exclude patients from actively participating in their healthcare decisions. In contrast, the PEOP model (Person-Environment-Occupation-Performance) represents a holistic, client-centered approach that acknowledges the influence of social, emotional, and environmental factors on health outcomes (Leslie et al., 2021). Patient-centered care, which includes accessible information through technology and active participation, empowers individuals and respects their unique needs and goals (Kumar, 2018). By focusing on the interplay between a patient's context, routines, and social environment, this model supports a holistic view essential for ataxia care (Baum, 2015). This project is also grounded in Pechansky's Theory of Access, which highlights the importance of accessibility in healthcare resources, and Adult Learning Theory, which emphasizes engagement in learning materials tailored to the learner’s background and needs.

Poor health literacy also complicates the management of ataxia, as patients and caregivers must often seek out information on their own, navigating complex medical literature for insights into treatment, support, and therapy options (Sheard, 2019). Research has shown limited health literacy correlates with poorer health-related knowledge across various conditions (Gazmararian et al., 2003). Low health literacy is associated with increased hospitalizations, emergency care usage, medication mismanagement, and worse overall health outcomes, particularly among older adults and racial minorities (Berkman et al., 2011). Addressing health literacy, especially for marginalized communities, is vital for improving health outcomes and reducing health disparities.

To address these challenges, this author proposes developing educational materials that are culturally relevant, accurate, and available in multiple languages. The materials will be designed with practical and essential information in an accessible format, using visual aids and multimedia resources where appropriate. This author also seeks to empower caregivers by providing practical skills, coping mechanisms, support networks, and information on community resources. Creating, disseminating, and effectively utilizing these educational materials within target communities will be central to the author's capstone project.

1.7 Overview of Chapters

This author will examine existing research on ataxia education, health literacy challenges, and culturally sensitive caregiving materials in the following chapters. Next, the researcher will describe the research design, data collection methods, and participant selection for the project's methodology. Following, the author will present findings from qualitative and quantitative analyses. Lastly, the author will interpret findings, discuss implications for practice, funding, and dissemination, and suggest areas for future research.

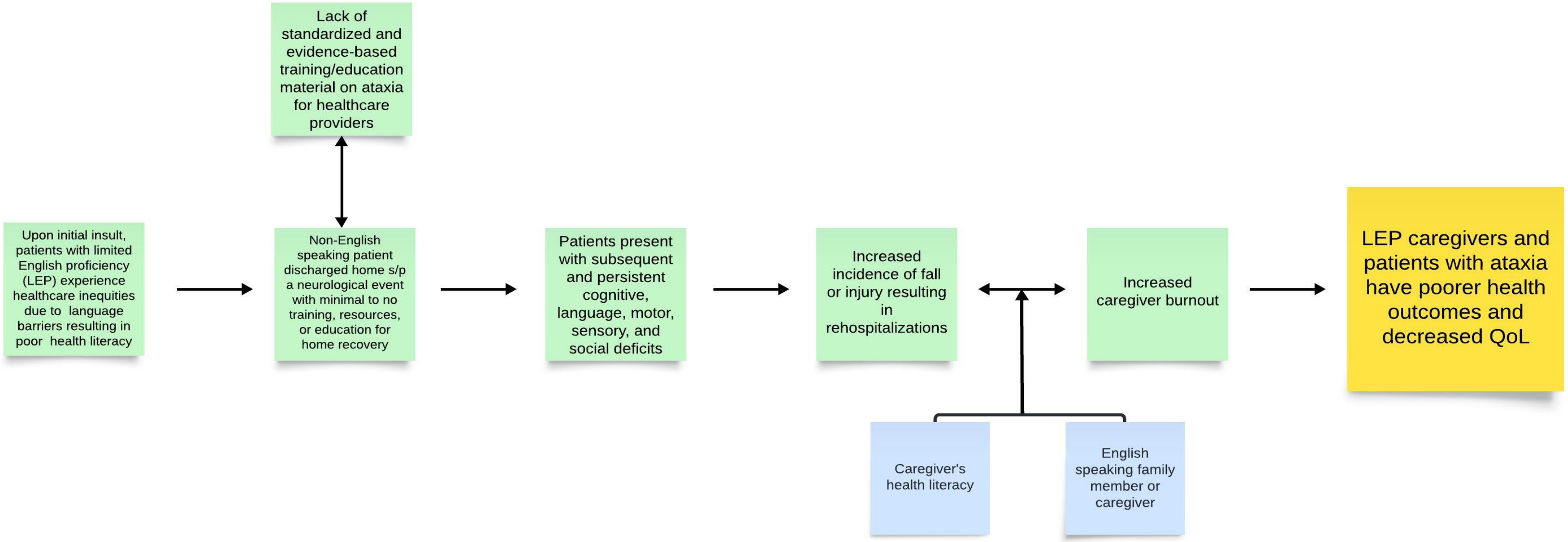
CHAPTER TWO – Project Theoretical and Evidence Base

2.1 Introduction

In Figure 2.1, the explanatory model, patients with limited English proficiency (LEP) discharged home after a neurological event, such as a stroke or traumatic brain injury, with subsequent ataxia often face poorer health outcomes and a decreased quality of life due to insufficient training, resources, and education for home recovery (Karliner, 2012). Without adequate translation, training, and resources, patients may struggle to manage their condition correctly, leading to complications such as poor medication adherence, ineffective symptom management, and a higher likelihood of readmission to the hospital (Karliner, 2012). The challenges, including understanding discharge instructions, obtaining prescriptions, medication concerns, follow-up questions, new or worsening symptoms, and other clinical issues, are compounded by the limited availability of culturally and linguistically appropriate educational materials and support services (Malevanchik et al., 2021). Malevanchik et al. (2021) review how the transition from hospital to home is a vulnerable period for all patients, especially those with limited English proficiency (LEP). Additionally, patients with LEP and their caregivers may struggle to communicate their needs and concerns to healthcare providers, leading to feelings of isolation and inadequate support. Al Shamsi (2020) discusses how language barriers can pose challenges in terms of achieving high levels of satisfaction among medical professionals and patients, providing high-quality healthcare, and maintaining patient safety, as well as hindering the ability of caregivers to receive and understand

Figure 2.1

Explanatory Model



critical medical instructions and educational resources provided by healthcare professionals. However, the U.S. Department of Health and Human Services has partnered with an organization focusing on culturally and linguistically appropriate services (CLAS) to improve the quality of services provided to all individuals, which will ultimately help reduce health disparities and achieve health equity (Think Cultural Health, 2024). According to a systematic review published in the Oman Medical Journal, more than 65% of patients who did not speak the local language experienced barriers to healthcare, including 20% who did not seek healthcare services because of fear of misunderstanding healthcare providers (Al Shamsi et al., 2020). There is vast evidence surrounding health inequities in the United States. However, health professionals can provide positive health outcomes for diverse populations by tailoring services to an individual's culture and language preferences, promoting a more empathetic and understanding healthcare system. Resources currently exist for physicians, nursing, maternal health, and behavioral health, but a standard for therapy is lacking.

2.2 Caregiver Challenges and Responsibilities

Caregivers play a vital role in managing ataxia-related challenges, such as dysphagia, fall prevention, and cognitive deficits. However, they often lack the necessary training to address these complexities effectively. Rajmohan Rammohan (2023) discusses how inadequate discharge planning and transitional care programs can raise readmission rates, thus negatively impacting patients' and caregivers' quality of life. Rammohan (2023) argues that a patient-centered approach is crucial for education before discharge, instructing providers to use understandable language while considering culturally sensitive approaches. Dr. Allison Squires (2018) writes about the three critical times when healthcare providers should use interpreters: at admission, during patient education, and at discharge; she elaborates further when discussing how an interpreter will decrease the risk that patients will be readmitted because the patient may seek clarification on medication management and other discharge instructions. LEP patients and their caregivers are at a higher risk for adverse events than English-proficient patients, as their limited language proficiency can negatively impact safe and effective health care. Per the Joint Commission (2021), these patients can be at greater risk for falls, pressure sores, and a greater chance of readmissions, and they are less likely to seek follow-up from their providers. Robert John Adams (2010) discusses how people with less health literacy are less likely to ask clinicians questions or for clarification. He explains how health literacy is the responsibility of healthcare systems and providers as they are who dictate the patient's interaction with healthcare, including the physical setting, available times, communication style, content and mode(s) of information provided, attitudes to the provision of information, and definitions of concepts such as sound health decision making and compliance. It is then the healthcare provider's responsibility to deliver education to the patient and the caregiver understanding. A family member or caregiver with high health literacy can positively impact a patient's discharge and post-hospitalization care. It also alleviates stress by promoting understanding and better communication between the patient and their healthcare team. A patient-centered approach, incorporating culturally sensitive education and professional interpreters, is essential to improving discharge outcomes (Squires, 2018). Without such support, LEP caregivers are at higher risk of miscommunication, stress, and burnout.

2.3 Theoretical Framework

Two theoretical models underpin this project: Bandura’s Social Learning Theory (SLT) and Penchansky and Thomas’s Theory of Access**.** These frameworks guide the development of accessible caregiver education programs. Albert Bandura's Social Learning Theory (SLT) provides a framework for understanding how individuals learn behaviors, skills, and attitudes through observation, imitation, and modeling, according to Rumjuan (2020). Applying this theory to LEP patients with ataxia can offer insights into how better training and resources might be developed and implemented. According to the SLT, people learn by watching others and by observing behaviors, the outcomes of those behaviors, and the context in which behaviors occur. People are even more likely to adopt behaviors they see modeled by others if the models are perceived as holding some authority or expertise. Rumjaun (2020) stated that this model has four key components: attention, retention, reproduction, and motivation. Thus, the individual must pay attention to the model, remember what was observed, reproduce or perform the behavior, and be motivated to adopt the behavior.

Educational materials should include videos or demonstrations showing proper management techniques for ataxia, medication adherence, and other care tasks. These should feature models that patients and caregivers can relate to culturally and linguistically. Materials should be engaging and culturally relevant to capture the attention of LEP patients and their caregivers. This might include using culturally appropriate language, symbols, and examples. Caregivers can learn effective care techniques by observing healthcare professionals or trained peers through live demonstrations or instructional videos. Caregivers should have opportunities to practice what they have observed in a supervised setting, receiving feedback to improve their skills (reproduction and motivation). Establishing support groups where patients and caregivers share experiences and strategies can provide real-life models for effective behavior and problem-solving. Being part of a supportive community can increase motivation to adopt and maintain new behaviors as individuals see others successfully managing similar challenges. Leveraging technology to provide remote learning opportunities can help bridge the gap for LEP patients—telehealth sessions where healthcare providers model care techniques and interactive online resources can enhance learning and retention. Use bilingual healthcare providers or interpreters to ensure patients and caregivers understand the modeled behaviors and instructions. Training healthcare providers in cultural competence can improve the quality of interactions and the relevance of the care provided. Short videos showing how to correctly take medications, featuring caregivers and patients from similar cultural backgrounds. Workshops where caregivers practice techniques such as helping patients with ataxia to walk safely, with guidance from professionals who speak their language. Regular meetings where caregivers and patients share their experiences and solutions are facilitated by a bilingual coordinator, and scheduled telehealth sessions where healthcare providers can visually demonstrate and review care techniques with patients and caregivers.

Bandura's Social Learning Theory emphasizes the importance of observational learning, modeling, and motivation in acquiring new behaviors and skills; as stated in the book Science Education in Theory and Practice, "the learner must pay attention to the model for observational learning to take place" (Rumjaun, 2020). Applying these principles to the challenges faced by LEP patients and their caregivers can enhance the effectiveness of training and resources. By providing culturally and linguistically appropriate models, facilitating opportunities for observation and practice, and fostering supportive communities, healthcare providers can improve these patients' health outcomes and quality of life.

Penchansky and Thomas's Theory of Access also provides a valuable framework for understanding access to health care and its relevance to providing sufficient caregiver education to caregivers with LEP who care for patients with ataxia with access, reflecting the fit between the providers' and clients' characteristics and expectations. McLaughlin (2002) writes, "They grouped these characteristics into five As of access to care: affordability, availability, accessibility, accommodation, and acceptability." The first "A" in the theory, accessibility, relates to how caregiver education materials should be easily accessible, i.e., educational content in multiple languages, ensuring that caregivers with LEP can access it. Next is availability. Education, training, and resources should be readily available at reasonable times and locations, such as caregiver training after usual therapy hours or on weekends, online modules, or virtual workshops for caregivers with other responsibilities during the typical workday. Next is acceptability with an emphasis on cultural competence. Caregiver education must respect diverse cultural backgrounds and address language barriers, providing materials in plain language, which can improve acceptability. Next would be affordability, as cost should not be a barrier to the education provided. It is essential to offer free or low-cost educational resources to ensure that caregivers can access vital information regardless of their financial situation or language proficiency skills. The last "A" in theory is adequacy (or accommodation), which tailors education to meet caregivers' specific needs, such as interpreters, visual aids, or videos, to enhance understanding.

Bandura's Social Learning Theory and Penchansky and Thomas's Theory of Access offer critical insights into improving caregiver education for patients with ataxia with LEP. Bandura's emphasis on observational learning and modeling highlights the need for culturally and linguistically appropriate educational models. At the same time, Penchansky and Thomas's framework ensures that these educational resources are accessible, available, acceptable, affordable, and adequate. By integrating SLT and the Theory of Access, caregiver education programs can better address linguistic, cultural, and logistical barriers, ultimately improving patient outcomes.

2.4 Review of the Literature

The guiding questions of this literature review were as follows: (1) Is there evidence of limited literature for caregivers of patients with ataxia?; (2) Is there evidence that there is a higher rate of re-injury/rehospitalization for LEP patients s/p stroke with subsequent ataxia?; (3) Is there evidence that caregiver burnout negatively impacts care?;

(4) Is there evidence that LEP patients discharged home s/p stroke with ataxia receive limited training, education, and resources? and (5) Is there evidence that a caregiver's language and education level improves patient outcomes?

2.5 Summary of the Evidence Base

A comprehensive search of two databases (PubMed and CINAHL) as well as a search of the American Journal of Occupational Therapy (AJOT) was undertaken using a combination of search terms: caregiver, education, limited English proficiency, ataxia, burnout, health literacy, occupational therapy, activities of daily living, daily living skills, quality of life, cerebellum, and rehospitalization. Limits were set for date, language, and type of publication. In the present review, studies were included if: a) a portion of the subjects were identified as having ataxia AND b) activities of daily living AND c) caregivers were discussed; ataxia AND daily living skills were discussed; caregivers AND d) occupational therapy AND quality of life OR burnout were addressed.

Criteria for exclusion included: a) a publication date greater than fifteen years from the present, 2) an article in a language other than English or Spanish, or 3) an article not in a peer-reviewed journal. 1,873 articles were identified by the author for review, and 44 were identified for critical appraisal.

Eleven studies provided literature on ataxia (Chien et al., 2022; Choi et al., 2018; Del Guidice et al., 2023; Joyce et al., 2022; Lowit et al., 2021; Marquer et al., 2014; Miyai et al., 2012; Potashman et al., 2023; Radmard et al., 2023; Romano et al., 2015; Stephen et al., 2019). Eleven studies investigated rehospitalization rates for ataxic patients with LEP (Al Shamsi et al., 2020; Anderson et al., 2020; Davies et al., 2016; Do et al., 2023; Karliner et al., 2012; Luan et al., 2017; Malevanchik et al., 2021; Shah et al., 2015; Squires et al., 2018; Tyagi et al., 2018; Yang et al., 2023). Studies investing if caregiver burnout negatively impacts care comprised seven of the articles (Broxson et al., 2020; Garcia et al., 2019; Leykum et al., 2022; Penning et al., 2016; San et al., 2017; Sharifian et al., 2021; Sohkhlet et al., 2023). Seven studies investigated if ataxic LEP patients discharged home receive limited training, education, and resources (Denny et al., 2024; Hawkes et al., 2015; Hsia et al., 2011; Jimenez et al., 2020; Malevanchik et al., 2021; Shah et al., 2015; Vargas et al., 2023). Studies investigated if caregiver's language and education level improve patient outcomes comprised eight of the articles (Andrade et al., 2022; Bombard et al., 2018; Garcia et al., 2013; Hahn et al., 2020; Lopez Vera et al., 2023; Maletsky et al., 2023; Noorulhuda et al., 2023).

Similarities and Differences

2.6 Ataxia and Rehabilitation Literature

Studies highlight the importance of a multidisciplinary rehabilitation approach, integrating occupational, physical, and speech therapies for ataxia management (Chien et al., 2022; Miyai et al., 2012). While some research focuses on rehabilitation (Marquer et al., 2014), others emphasize pharmacological interventions, reflecting diverse treatment perspectives (Romano et al., 2015). Eleven studies provided literature on ataxia (Chien et al., 2022; Choi et al., 2018; Del Guidice et al., 2023; Joyce et al., 2022; Lowit et al., 2021; Marquer et al., 2014; Miyai et al., 2012; Potashman et al., 2023; Radmard et al., 2023; Romano et al., 2015; Stephen et al., 2019). One was a systematic review (Marquer et al., 2014), one was a randomized control trial (Romano et al., 2015), one was a cross-sectional study (Lowit et al., 2021), and eight studies were reviews (Chien et al., 2022; Choi et al., 2018; Del Guidice et al., 2023; Joyce et al., 2022; Miyai et al., 2012; Potashman et al., 2023; Radmard et al., 2023; Stephen et al., 2019). The articles discussed a comprehensive examination of cerebellar ataxia, focusing on various aspects such as rehabilitation, assessment, treatment, and the impact of ataxia on the patient's quality of life. A focus was the importance of a multidisciplinary rehabilitation approach, which includes physical, occupational, and speech therapies tailored to the specific needs of patients with cerebellar ataxias, such as postural and balance disorders (Chien et al. 2022; Miyai et al. 2011; Marquer et al., 2014). The articles differed on the assessments they chose to employ, such as the Scale for the Assessment and Rating of Ataxia (SARA) to evaluate ataxia in mild ischemic stroke patients (Choi et al., 2018) and ataxia rating scales (Potashman et al., 2022). However, the articles confer that assessment is crucial for effectively tailoring rehabilitation strategies. The articles also differed on the best treatment modalities. For instance, Del Giudice et al. (2023) discuss advocates for immune-targeted therapies, while Romano et al. (2015) presented findings from a randomized controlled trial on the effects of riluzole in hereditary cerebellar ataxia. This highlights a divergence in treatment approaches, with some studies focusing on rehabilitation and others on pharmacological interventions. The articles underscore the importance of rehabilitation and assessment in managing cerebellar ataxia, highlighting distinct treatment modalities that may impact the patient's quality of life.

2.7 *Rehospitalization risks for patients with ataxia*

The research underscores that language barriers significantly impact healthcare outcomes, increasing the risk of miscommunication, misunderstanding of discharge instructions, and inadequate follow-up care (Karliner, 2012; Shah et al., 2015). Professional medical interpreters are critical in mitigating these risks (Malevanchik et al., 2021). However, one study suggests that healthcare systems may compensate for language disparities in acute stroke cases (Anderson, 2020). One article reviewed was a systematic review (Do et al., 2023); six articles were research studies (Al Shamsi et al., 2020; Davies et al., 2016; Malevanchik et al., 2021; Shah et al., 2015; Tyagi et al., 2018; Yang et al., 2023); one was a qualitative study (Anderson et al., 2020) and two were review articles (Squires et al., 2018; Karliner et al., 2012). The articles overwhelmingly discussed how language barriers can substantially impede effective healthcare delivery. Al Shamsi et al. (2020) conducted a systematic review that outlines the various implications of language barriers, including miscommunication, reduced patient satisfaction, and poorer health outcomes. This is echoed by Karliner et al. (2012) and Shah et al. (2015), who specifically investigated how language barriers affect patients' understanding of hospital discharge instructions, highlighting that LEP can lead to misunderstandings that compromise patient safety and continuity of care and adversely affect stroke care and outcomes. Anderson’s 2020 qualitative study was an outlier challenging the notion that language disparity significantly affects time-sensitive care in acute ischemic stroke cases. The study suggests that despite language barriers, patients still receive timely interventions, indicating that healthcare systems may have adapted to mitigate these challenges in critical situations (Anderson et al., 2020).

The role of professional medical interpreters in bridging communication gaps was a significant theme throughout the articles. Malevanchik et al. (2017), Davies et al. (2015), and Do et al. (2023) highlight how the involvement of professional interpreters can significantly enhance the quality of care for patients with language barriers, leading to improved clinical outcomes and patient satisfaction. Yang et al. (2023) focused on the strategies employed by healthcare systems to communicate with hospitalized patients with LEP during the COVID-19 pandemic, providing insights into adaptive measures taken in response to unprecedented challenges. Except for one, the articles underscore the significant negative impact of language barriers on healthcare delivery and patient outcomes.

2. 8 Caregiver Burnout and Quality of Life

Caregiver stress and burnout can negatively affect caregiver well-being and patient recovery (Garcia et al., 2019; Leykum et al., 2022). Studies highlight gender-based disparities in caregiving stress, with female caregivers often experiencing higher emotional strain (Penning & Wu, 2016). Enhancing caregivers' health literacy—mainly through tailored, accessible education—can improve patient outcomes (Hahn et al., 2020). Of the articles reviewed, three were original research articles (Broxson et al., 2020; Penning et al., 2016; Sohkhlet et al., 2023), one was a systematic review (Garcia et al., 2019), and three were review articles (Leykum et al., 2022; San et al., 2017; Sharifian et al., 2021). A common theme among the articles was how caregiver stress impacts caregivers' and patients' well-being. Broxson (2020) emphasized that caregiver stress can lead to adverse outcomes, including declines in physical health, increased mental health issues, and a decreased quality of life. This sentiment is echoed by Leykum et al. (2022), who highlight the need for recognizing and supporting caregivers to improve health outcomes, noting that caregivers often neglect their health due to the demands of caregiving. Similarly, Sohkhlet et al. (2023) observed that caregivers of stroke patients experience significant stress during their loved one's rehabilitation, which can adversely affect their mental health. Burnout is another common thread in the literature. Garcia et al. (2019) conducted a systematic review exploring how healthcare providers' burnout can compromise patient safety.

An illuminating insight provided by Penning and Wu (2016) is how the caregiving relationship and gender influence caregiver stress and mental health. They highlight that caregiving experiences are not uniform but are shaped by the specific relationship between the caregiver and the care recipient (e.g., spouse, child, or non-family member) and the caregiver's gender. Their research reveals that caregivers in spousal relationships often experience higher stress levels than those caring for parents or other relatives, likely due to the emotional intensity and greater responsibility often associated with spousal caregiving. Additionally, the study uncovers significant gender differences in caregiving stress and mental health. Female caregivers, for instance, are more likely to experience emotional strain, anxiety, and depression compared to male caregivers. This gender disparity is linked to societal expectations, where women are often seen as primary caregivers, leading to an imbalance in caregiving responsibilities.

Resources for patients with ataxia

Research reveals significant disparities in stroke and ataxia care for LEP populations, including delays in care, lower health literacy, and reduced access to rehabilitation services (Hawkes et al., 2015; Jimenez et al., 2020). Many caregivers report difficulties accessing information in their preferred language, further exacerbating inequities (Vargas et al., 2023). Addressing these barriers requires targeted interventions, including culturally responsive education and improved interpreter services (Denny et al., 2024). Of the literature reviewed, one was a review article (Denny et al., 2024), and six were research articles (Hawkes et al., 2015; Hsia et al., 2011; Jimenez et al., 2020; Malevanchik et al., 2021; Shah et al., 2015; Vargas et al., 2023). Denny et al. (2024) emphasize that despite the availability of data highlighting disparities surrounding social determinants of health, interventions to address them remain limited. Hsia et al. (2011) write that social and attitudinal barriers significantly contribute to these disparities. Hawkes et al. (2015) highlight that Spanish-speaking populations often have lower stroke knowledge, which can hinder timely access to care, which is echoed by Shah et al. (2015), who note that patients with limited English proficiency are more likely to experience delays and poorer health outcomes. The articles span the continuum of care, with Jimenez et al. (2020) exploring the transition to outpatient care after traumatic brain injury for Hispanic and Latinx children, highlighting barriers such as transportation issues and insufficient communication with clinicians. The issues persist as Malevanchik et al. (2021) discussed post-discharge patient-reported issues related to limited English proficiency after leaving acute care. Overall, these studies collectively emphasize that disparities in stroke care are multifaceted, driven by both structural and interpersonal factors that disproportionately affect marginalized populations. The research highlights the need for more comprehensive and culturally responsive interventions to address language barriers, health literacy, and access to care, particularly for LEP patients. Without targeted efforts to bridge these gaps, the inequities in stroke outcomes will likely persist, further widening the divide in healthcare access and quality for vulnerable communities.

2.9 Caregiver's health literacy and education

Caregivers play a prominent role in the patient's recovery; thus, their health literacy and education level can impact their care, primarily upon discharge. Of the studies reviewed, one was a scoping review (Andrade et al., 2022), one article was a systematic review (Bombard et al., 2018), and five were research articles (Garcia et al., 2013; Hahn et al., 2020; Lopez Vera et al., 2023; Maletsky et al., 2023; Noorulhuda et al., 2023). Several studies address the importance of health literacy in caregiving contexts. Garcia et al. (2013) discuss how low health literacy among caregivers can negatively impact the health outcomes of elderly patients, while Hahn et al. (2020) suggest that enhancing caregivers' health literacy can lead to better coping strategies and health outcomes. Studies emphasize effective communication in caregiving, specifically in the caregiver's preferred language, to ensure quality care (Vera et al., 2023). However, the systematic review by Bombard et al. (2018) outlines patient engagement strategies to improve the quality of care, emphasizing the role of patient involvement in healthcare decision-making. Noorulhuda et al. (2023) examine ethical concerns in communication between patients, family members, and healthcare providers, emphasizing the importance of addressing ethical dilemmas in diverse healthcare settings. These studies highlight caregivers' critical role in patient outcomes, particularly concerning health literacy and communication. Ensuring caregivers have access to culturally sensitive information in their preferred language is essential for supporting patients' recovery and long-term care. The research underscores the need for healthcare systems to focus on patient-centered care and empower caregivers with the necessary tools and knowledge. Addressing ethical concerns and promoting patient and caregiver engagement in decision-making are essential steps toward improving the quality of care and reducing health disparities.

This chapter highlights the substantial challenges faced by LEP caregivers of patients with ataxia, including communication barriers, inadequate training, and caregiver burnout. Bandura’s Social Learning Theory and Penchansky and Thomas’s Theory of Access provide robust frameworks for addressing these issues through observational learning, tailored education, and improved access to culturally competent resources. The author’s literature review underscores the pressing need for enhanced caregiver education and support to reduce health disparities and improve patient outcomes. Future research should explore the implementation of structured caregiver training programs and their impact on long-term health outcomes. By bridging these gaps, healthcare providers can empower caregivers with the tools they need to navigate ataxia management successfully, ultimately leading to better health and quality of life for patients and their families.

CHAPTER THREE – Overview of Current Approaches and Methods

3.1 Introduction

Ataxia, a neurological condition marked by impaired coordination and balance, places immense caregiving responsibilities on family members and close caregivers. Managing this condition requires knowledge, confidence, and access to adequate resources—yet many caregivers, particularly those with LEP, face overwhelming barriers. These challenges extend beyond the condition itself; they involve navigating healthcare systems, understanding treatment options, and ensuring the best possible quality of life for the individual receiving care. Education plays a pivotal role in addressing these gaps. Research consistently shows that well-structured caregiver education programs improve caregiving confidence and patient outcomes (Schulz & Sherwood, 2008). However, not all interventions are equally effective, and accessibility remains a key issue. This chapter explores the impact of caregiver education on ataxia management, the effectiveness of different educational methods, and the unique needs of caregivers with LEP. The guiding questions of this search were as follows: (1) Is there evidence that education and resources have helped caregivers for patients with ataxia?; (2) What methods or formats of caregiver education have shown to be effective in improving caregiver knowledge and confidence in managing care for patients with ataxia?; and (3) How does identifying the needs of caregivers, including those with LEP, influence the ability to provide targeted interventions for patients with ataxia?

The relationship between caregiver education and improved patient outcomes is well-documented. Caregivers who receive structured training demonstrate greater confidence, reduced stress, and improved ability to assist with daily activities such as mobility, feeding, and medication management (Brodaty & Donkin, 2009). The format of these interventions plays a crucial role in their effectiveness. For instance, studies have demonstrated that online and in-person training can improve caregiver engagement and knowledge retention. Hutson et al. (2021) found that interactive video-based online training was more effective in boosting caregivers' feelings of competence than self-guided web links, indicating that the training format plays a crucial role in its effectiveness (Hutson et al., 2021). Recognizing that caregivers have unique needs, particularly those with LEP, is essential. Tailoring support to meet these needs is critical for enhancing the efficacy of interventions. The importance of understanding the cultural context of caregiving was echoed by Todorova et al. (2016), who pointed out that caregivers expressed a desire for training that acknowledges the cultural significance of their roles. This inclusive approach, which respects and incorporates the cultural context of caregiving, improves the effectiveness of educational interventions and leads to better caregiving outcomes. It also empowers caregivers, making them feel more confident in their roles and integral to the caregiving process. Thus, educational interventions can significantly impact caregiver knowledge and confidence, but their success hinges on the delivery format and the consideration of caregivers' unique needs, particularly for those with LEP.

3.2 Summary of the Evidence Base

While education can be transformative, accessibility remains a persistent challenge. Many caregiver training programs assume proficiency in English and do not provide culturally tailored content, making it difficult for LEP caregivers to engage with the material thoroughly. Language barriers hinder learning and contribute to feelings of exclusion in healthcare settings. Studies highlight that caregivers from linguistically diverse backgrounds strongly desire training that acknowledges their cultural and linguistic needs. In healthcare, professional interpretation services are often limited, leaving caregivers to rely on informal translations from family members or struggle with complex medical jargon. The need for clear communication is urgent. Without it, critical details regarding symptom management, medication schedules, and emergency responses can be lost, leading to preventable complications. One promising approach to overcoming these barriers is the development of multilingual and culturally sensitive educational resources. Research has shown that engagement and satisfaction improve significantly when caregiver training materials are available in multiple languages and adapted to reflect cultural caregiving norms. This inclusive approach, which respects and incorporates the cultural context of caregiving, improves the effectiveness of educational interventions and makes caregivers feel respected and valued in their roles.

A comprehensive search of two databases (PubMed and CINAHL), as well as a search of the American Journal of Occupational Therapy (AJOT), was undertaken using a combination of search terms: caregiver, education, limited English proficiency, ataxia, resources, knowledge, intervention, confidence, health literacy, occupational therapy, activities of daily living, daily living skills, quality of life, cerebellum, and rehospitalization. Limits were set for date, language, and type of publication. In the present review, studies were included if: a) a portion of the subjects were identified as having ataxia AND b) activities of daily living AND c) caregivers were discussed; ataxia AND daily living skills were discussed; caregivers AND d) occupational therapy AND interventions OR knowledge. Criteria for exclusion included: a) a publication date greater than fifteen years from the present, 2) an article in a language other than English or Spanish, or 3) an article not in a peer-reviewed journal. 55 articles were identified by the author for review, 40 fully met the inclusion criteria, and 28 were identified for critical appraisal.

Nine studies investigated the availability of helpful educational strategies and resources for caregivers of patients with ataxia (Borch-Johnsen, 2023; Contesse, 2024; Corben et al., 2014; Cruz-Oliver et al., 2021; Dambi et al, 2017; Hartman et al., 2012; Knowles et al., 2021; Liu et al., 2020; Rumiati et al., 2021). Studies investigating effective methods or formats of caregiver education to improve knowledge and confidence comprised an additional seven articles (Cruz-Oliver et al., 2016; Levinson et al., 2020; Liu et al., 2017; Noel et al., 2022; Ohno et al., 2019; Ploeg et al., 2018; Wantonoro et al., 2023). While the remaining twelve studies reported on caregivers' stress and needs, including those with LEP for targeted interventions (Black et al., 2013; Houtven et al., 2010; Jeong et al., 2015; Mausbach et al., 2010; Ploeg et al., 2017; Rodriguez et al. 2021; Sen, 2022; Sentell & Braun, 2012; Napoles et al, 2010; Ugalde et al., 2019; Whitebird et al., 2012; Zhao et al., 2019).

3.3 Evaluative Summary

In-person trainings offer hands-on learning opportunities, allowing caregivers to practice techniques under healthcare professionals' guidance. These sessions often include simulations, demonstrations, and interactive discussions, which help caregivers develop both technical and emotional caregiving skills. Studies have found that caregivers who attend structured in-person training significantly improve their ability to assist with ADLs (Bennett & Liddle, 2008). Research evaluating these methods, however, indicates variable effectiveness depending on the caregivers' language proficiency, educational background, and access to resources. For example, studies that included culturally sensitive adaptations and translated materials observed better engagement and reported higher levels of caregiver satisfaction than standard approaches (Duran-Kiraç et al., 2023). Dambi et al. found that educational workshops significantly enhanced caregivers' understanding, demonstrating the effectiveness of hands-on training approaches (Dambi et al., 2017).

Digital education offers flexibility and accessibility, particularly for caregivers balancing multiple responsibilities. Video-based training programs have been incredibly effective, allowing caregivers to learn independently and revisit material as needed. Research indicates that video tutorials tailored to diverse caregiver populations enhance comprehension and confidence, mainly when they include subtitles in multiple languages (Borch-Johnsen et al., 2023). Technology-based interventions, including mobile apps and online platforms, have gained popularity for their convenience. Many apps provide step-by-step caregiving instructions, symptom-tracking tools, and direct access to professional guidance. Borch-Johnsen's research emphasizes the importance of tailoring video content to meet the needs of diverse caregiver populations, ensuring that the information is comprehensible and usable (Borch-Johnsen, 2023). The future of caregiver education looks promising, as studies consistently show that blended approaches, which combine online and in-person components, yield the most significant improvement in caregiver knowledge and skill retention. Blended models that combine in-person and online training have emerged as the most effective approach (Kang & Kim, 2021). By integrating digital resources with face-to-face interactions, caregivers receive the best of both worlds—flexibility in accessing content and real-time support from professionals

Various methods have been explored to address caregivers' challenges, focusing on educational interventions, web-based resources, and structured support programs. Educational interventions have been a prominent approach to enhancing caregiver knowledge and well-being. Rumiati et al. (2021) found that structured educational interventions for stroke caregivers improved their knowledge and reduced caregiver burden. These findings underscore the potential of educational programs to empower caregivers, equipping them with the necessary skills to manage their caregiving responsibilities effectively and instilling hope for the future of caregiver support.

Web-based interventions have also emerged as a viable method for supporting caregivers. Ploeg et al. (2018) conducted a systematic review and meta-analysis, revealing that web-based interventions can improve mental health outcomes and reduce caregiver burden. Zhao et al. (2019) further corroborated this by demonstrating that such interventions enhance caregivers' mental health. The flexibility and accessibility of online resources make them particularly appealing, as they can be tailored to meet the unique needs of caregivers, regardless of their geographical location.

Despite the growing body of evidence supporting caregiver education, challenges remain. Many existing programs fail to account for the diversity of caregivers' experiences, particularly those from underserved communities. Additionally, the long-term impact of caregiver training is not always well-documented, as many studies focus on short-term knowledge gains rather than sustained outcomes. Many studies, such as those by Hartmann et al. (2012) and Knowles et al. (2021), highlight the variability in intervention effectiveness based on caregiver demographics and their specific challenges. For example, caregivers from marginalized backgrounds or those with lower levels of education often report higher levels of unmet needs and stress (Black et al., 2013). This suggests that interventions may not be universally effective and may require customization to address the diverse experiences of caregivers. Moreover, the reliance on self-reported measures in many studies raises concerns about the validity of the findings. For instance, Jeong et al. (2015) pointed out that subjective questionnaires often assess caregiver burden and quality of life, which may only capture part of the scope of caregivers' experiences. This limitation can lead to an incomplete understanding of the effectiveness of interventions and the actual impact of caregiving on health outcomes.

Identifying the unique needs of caregivers, particularly those with LEP, is crucial for developing interventions that are both accessible and effective. Research highlights that caregivers with LEP often feel overlooked in standard training programs predominantly delivered in English and require more cultural sensitivity. For instance, Rodriguez et al. emphasize that professional interpretation is essential for patients with LEP to ensure they receive appropriate care, as language barriers can lead to feelings of exclusion and misunderstanding in healthcare settings (Rodriguez et al., 2021). This underscores the necessity for tailored interventions that account for language and cultural needs, which can significantly reduce barriers and foster better caregiver engagement and comprehension (Sentell & Braun, 2012). Studies indicate that targeted interventions, such as multilingual resources and culturally adapted content, significantly improve caregiver confidence and caregiving outcomes. For example, Nápoles et al. discuss the importance of developing culturally sensitive interventions for caregivers, noting that such adaptations can lead to better psychosocial health outcomes for diverse caregiver populations (Nápoles et al., 2010). This paper emphasizes the importance of tailoring interventions to account for language and cultural needs, as it can reduce these barriers, fostering better caregiver engagement and comprehension.

3.4 Quality and Limitations of Current Research

There were several weaknesses found among the studies that have significant implications. They suggest that while educational and web-based interventions can be beneficial, there is a need for ongoing evaluation and adaptation of these programs to ensure they meet the needs of all caregivers (Chi & Demiris, 2014). Future research should focus on developing more robust methodologies, including mixed methods approaches that combine quantitative and qualitative data to provide a more comprehensive view of caregiver experiences and intervention effectiveness

(Cristancho-Lacroix et al., 2015). The landscape of caregiver support is evolving, with educational and web-based interventions showing considerable potential. However, the effectiveness of these methods is contingent upon their adaptability to the diverse needs of caregivers. Addressing the identified weaknesses in the research will be crucial for drawing reliable conclusions and implementing effective support strategies for caregivers in various contexts. The quality and limitations of current research in caregiver support interventions reveal significant insights into the effectiveness of these programs and the challenges that researchers face in drawing robust conclusions. This evaluative summary synthesizes findings from various studies to highlight the strengths and weaknesses of existing research methodologies and their implications for future studies.

One of the primary strengths of current research is the increasing use of systematic reviews and meta-analyses to evaluate caregiver interventions. For instance, Ploeg et al. conducted a systematic review that provided comprehensive insights into the effectiveness of web-based interventions for caregivers, demonstrating a positive impact on mental health outcomes. Such rigorous methodologies enhance the reliability of findings and allow for a more nuanced understanding of the effectiveness of different interventions. Similarly, Ugalde et al. emphasized the importance of systematic reviews in consolidating evidence on cancer caregiver interventions, which can inform best practices in clinical settings.

Despite these strengths, several limitations persist in the current body of research. A significant concern is the variability in study designs and outcome measures, which complicates the generalization of findings across diverse populations. For example, studies often employ different metrics to assess caregiver burden and quality of life, leading to inconsistent results. Jeong et al. highlighted that relying on self-reported measures can introduce bias, as caregivers may underreport their burden due to social desirability or lack of awareness of their needs. This variability can obscure the actual effectiveness of interventions and limit the ability to draw definitive conclusions.

Many studies have focused on specific populations, such as caregivers of individuals with dementia or cancer, which may not be representative of the broader caregiver population. Black et al. (2013) pointed out that caregivers from minority backgrounds often experience unique challenges that are not adequately addressed in existing research. This lack of diversity in study samples raises concerns about the findings' external validity and the interventions' applicability to various caregiver demographics. Another area for improvement is the often short-term nature of interventions and follow-up assessments. Many studies evaluate the immediate effects of educational programs without considering the long-term sustainability of benefits. This focus on short-term outcomes can lead to an incomplete understanding of the lasting impact of interventions on caregiver well-being.

The implications of these limitations are profound. They suggest that while current research provides valuable insights into caregiver support interventions, there is a critical need for more standardized methodologies and diverse study populations. Future research should prioritize longitudinal studies that assess the long-term effects of interventions and mixed methods approaches that combine quantitative and qualitative data to capture the complexity of caregiver experiences. Additionally, researchers should strive to include underrepresented populations to ensure that findings apply to a broader range of caregivers. While the quality of research on caregiver support interventions has improved through systematic reviews and rigorous methodologies, significant limitations remain. Addressing these weaknesses will be essential for advancing the field and ensuring that interventions are effective and inclusive for all caregivers.

Caregiving for individuals with ataxia is a complex, demanding role, but education serves as a powerful tool to support those providing care. By equipping caregivers with knowledge, skills, and confidence, we improve their well-being and enhance outcomes for the individuals they care for. However, education must be accessible, inclusive, and adaptable to make a genuine difference. Healthcare professionals, researchers, and policymakers must work together to ensure that every caregiver has the necessary resources regardless of language proficiency or background. Through continued innovation and collaboration, the world can build a future where all caregivers feel supported, competent, and empowered in their vital roles.

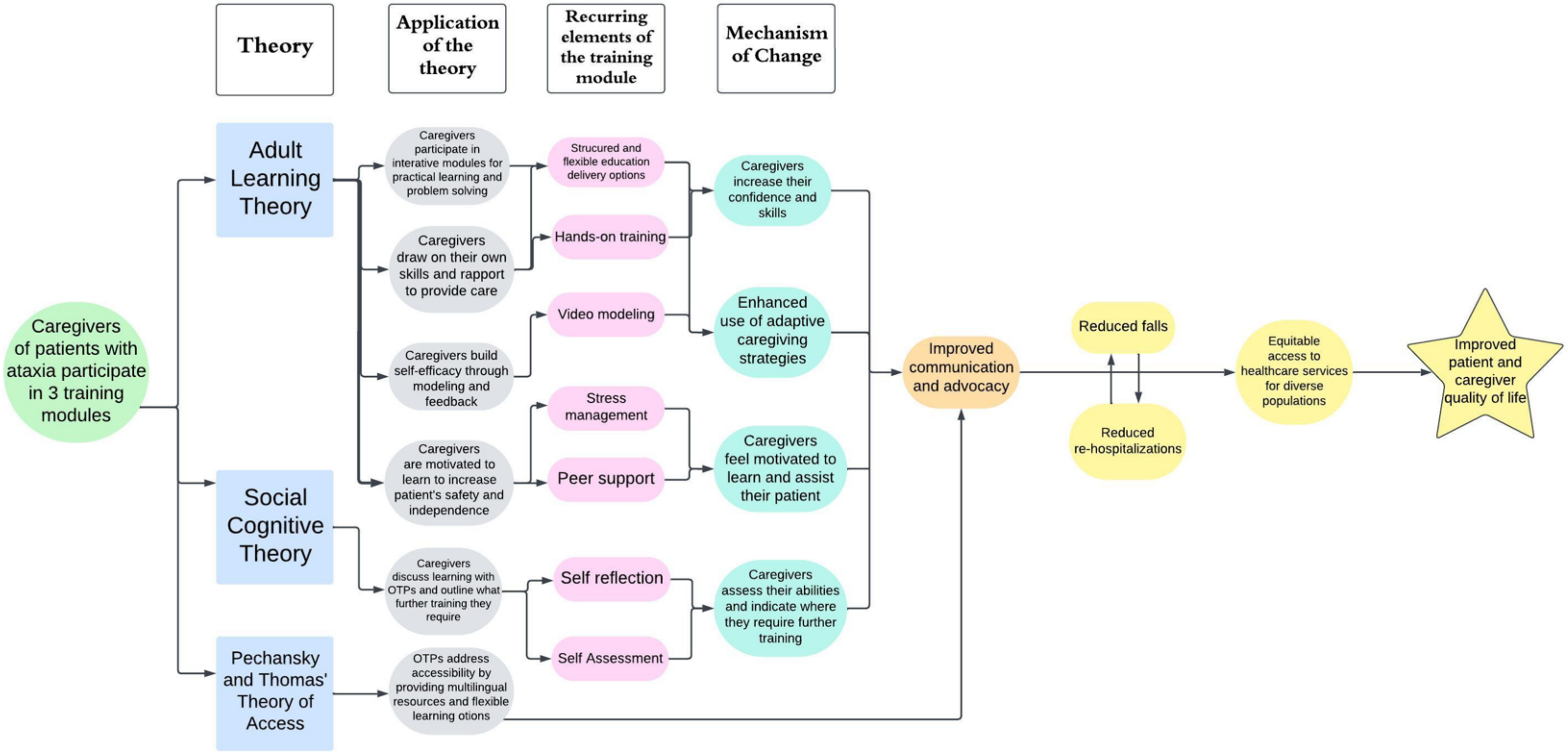
CHAPTER FOUR – Description of the Proposed Program

4.1 Introduction

The proposed program is a unique and proactive educational initiative designed to empower caregivers of patients with ataxia, particularly those with limited English proficiency (LEP). It stands out for its focus on equipping caregivers with practical, compassionate, and culturally sensitive care skills. By enhancing caregiver confidence and fostering effective communication strategies, the program aims to improve patient outcomes by addressing barriers to healthcare access and understanding. Grounded in Pechansky and Thomas's Theory of Access and Adult Learning Theory, the program's design and implementation carefully consider the impact of environmental and cultural factors on caregiving practices. It offers engaging and practical training to cater to the diverse needs of caregivers. Patients with ataxia confront significant challenges related to mobility, coordination, balance, and communication, which affect their ability to engage in daily activities and fulfill social roles. For caregivers, managing these complexities can be overwhelming, especially when compounded by LEP, which can limit their understanding of training, instructions, and the ability to advocate for their patients effectively. These barriers often result in fragmented care, reduced adherence to therapeutic recommendations, and missed advocacy opportunities. The lack of access to interpreter services and culturally tailored educational resources further exacerbates these disparities. The following section introduces the explanatory model that underpins the program's design and implementation.

Figure 4.1

Explanatory Model for Caregiver Education



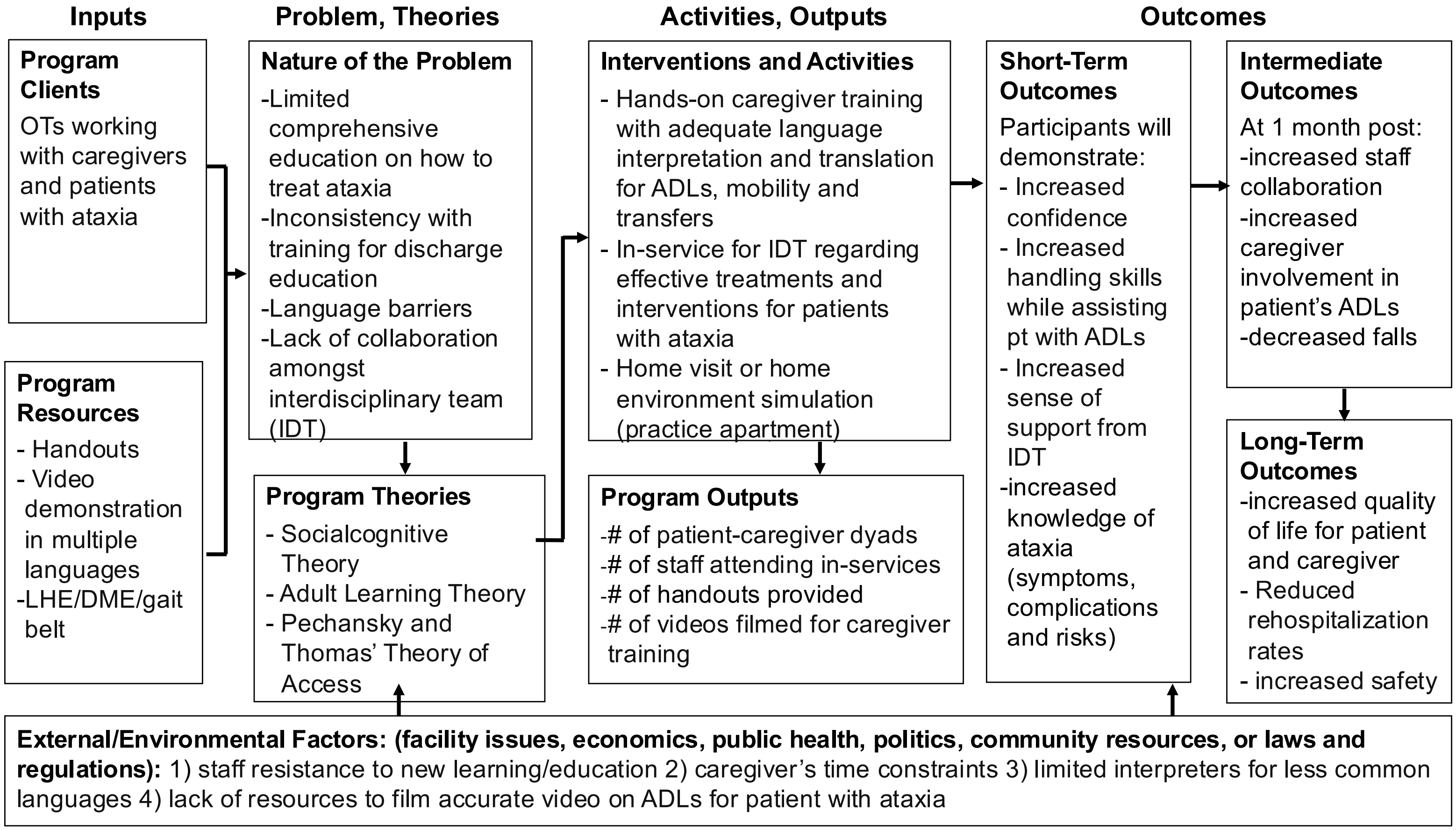
The program integrates a comprehensive explanatory model in Figure 4.1 that includes recurring elements of the training modules, application of the theory with cultural competence frameworks, caregiver empowerment models, and principles of health literacy as tenets throughout. Key elements of the program involve ensuring that training materials reflect the cultural and linguistic backgrounds of caregivers, providing hands-on instruction for essential caregiving tasks (such as safe shower transfers and adaptive strategies), simplifying medical information through visual aids (handouts and videos), and using accessible language to enhance comprehension and retention. Key stakeholders have varying levels of influence in this initiative. At the micro level, caregivers and patients with ataxia will benefit directly from improved communication, enhanced care practices, and better health outcomes. At the meso level, OTPs, community organizations, advocacy groups, and other healthcare providers can utilize the program to strengthen their support for caregivers, promoting more inclusive care practices. The program's role in promoting more inclusive care practices is crucial, as it can help to reduce disparities in caregiving and healthcare access. At the macro level, policymakers and healthcare administrators can use the program's outcomes to advocate for inclusive healthcare policies and allocate resources to health equity initiatives. This multi-level engagement creates a strong support network for caregivers and patients, driving systemic change.

The program is designed to address real-world challenges faced by caregivers. For instance, during discharge planning, an OTP might identify a caregiver struggling to understand discharge instructions due to a language barrier. The OTP would then enroll the caregiver in the program, where they can learn effective caregiving techniques and advocacy skills through training sessions. By providing multilingual resources, interactive training, and opportunities to join a support group, the caregiver gains confidence in managing caregiving tasks while connecting with a supportive community of peers. The program's primary goal is to reduce disparities in caregiving and healthcare access for patients with ataxia. It promotes continuity of care by teaching caregivers practical skills by having multiple check-in points before and after discharge from the inpatient setting. Caregivers, often integral to the healthcare process, may face heightened challenges when navigating the complex medical system due to LEP. During critical transitions, such as hospital discharges, miscommunication can lead to adverse health outcomes, increased readmission rates, and heightened stress for patients and their families (Flores, 2005). The program addresses these risks by equipping caregivers with the resources to overcome communication barriers. By improving health literacy, the program aims to create more equitable and inclusive healthcare experiences for patients with ataxia and their families. Ultimately, its success could serve as a model for addressing similar disparities in other chronic conditions and caregiver populations, thereby reducing disparities in caregiving and healthcare access on a broader societal level.

Figure 4.2

Full Logic Model

Program title: ***Accessible Education for Ataxic Patients***



Inputs

Program Clients

OTs working with caregivers and patients with ataxia

Program Resources

- Handouts
- Video demonstration in multiple languages
- LHE/DME/gait belt

Problem, Theories

Nature of the Problem

- Limited comprehensive education on how to treat ataxia
- Inconsistency with training for discharge education
- Language barriers
- Lack of collaboration amongst interdisciplinary team (IDT)

Program Theories

- Socialcognitive Theory
- Adult Learning Theory
- Pechansky and Thomas' Theory of Access

Activities, Outputs

Interventions and Activities

- Hands-on caregiver training with adequate language interpretation and translation for ADLs, mobility and transfers
- In-service for IDT regarding effective treatments and interventions for patients with ataxia
- Home visit or home environment simulation (practice apartment)

Program Outputs

- # of patient-caregiver dyads
- # of staff attending in-services
- # of handouts provided
- # of videos filmed for caregiver training

Outcomes

Short-Term Outcomes

Participants will demonstrate:

- Increased confidence
- Increased handling skills while assisting pt with ADLs
- Increased sense of support from IDT
- increased knowledge of ataxia (symptoms, complications and risks)

Intermediate Outcomes

At 1 month post:

- increased staff collaboration
- increased caregiver involvement in patient's ADLs
- decreased falls

Long-Term Outcomes

- increased quality of life for patient and caregiver
- Reduced rehospitalization rates
- increased safety

External/Environmental Factors: (facility issues, economics, public health, politics, community resources, or laws and regulations): 1) staff resistance to new learning/education 2) caregiver's time constraints 3) limited interpreters for less common languages 4) lack of resources to film accurate video on ADLs for patient with ataxia

Clients Resources

- Clients: OTs working with caregivers and patients with ataxia.
- Resources: Handouts, video demonstration in multiple languages, LHE/DME/gait belt

Interventions Activities

- Hands-on caregiver training with adequate language interpretation and translation for ADLs, mobility and transfers
- In-service for interdisciplinary team (IDT) about effective treatments and interventions for patients with ataxia
- Home visit or home environment simulation (practice apartment)

Program Outputs

- # of patient-caregiver dyads
- # of staff attending in-services
- # of handouts provided
- # of videos filmed for caregiver training

Short-Term Outcomes

- Increased confidence
- Increased handling skills and ability to assist patient with ADLs
- Increased sense of support from IDT
- Increased knowledge of ataxia (symptoms, complications and risks)

Intermediate Outcomes

At one month post:

- Increased staff collaboration
- Increased caregiver involvement with patient’s ADLs
- Decreased falls

Long-Term Outcomes

- Increased quality of life for patient and caregiver
- Reduced rehospitalization rates
- Increased safety

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While the Explanatory Model outlines the theoretical underpinnings of the program, the Logic Model provides a structured approach to its implementation and evaluation. The proposed program's logic model, noted in Figure 4.2, visually represents its structure, illustrating how the initiative will operate. It acts as a conceptual map, highlighting the relationships among program components, resources, activities, and outcomes. This model assists in guiding implementation and evaluation. The model begins with inputs and resources, which include educational handouts, multi-language video demonstrations, long-handled equipment (LHE), durable medical equipment (DME), and gait belts. The program is based on key theoretical frameworks, such as Social Cognitive Theory, Adult Learning Theory, and Pechansky and Thomas' Theory of Access. These inform its design and implementation for teaching caregivers, OTP, and interdisciplinary team members (IDT).

The program's outputs are measurable results from activities, including the number of patient-caregiver dyads trained, IDT members attending in-service sessions, handouts distributed, and training videos created. These outputs directly contribute to short-term outcomes, such as increased caregiver confidence, improved handling skills for assisting patients with activities of daily living (ADLs), more significant support from the IDT, and enhanced knowledge about ataxia symptoms, complications, and risks. At the intermediate level, outcomes after one month include increased collaboration among staff, greater involvement of caregivers in patients' activities of daily living (ADLs), and reduced fall rates. Over time, the program aims to achieve long-term outcomes such as improved quality of life for both patients and caregivers, decreased rehospitalization rates, and enhanced overall safety. The logic model details effective program implementation and evaluation by outlining resources, interventions, and outcomes. It aligns with the program's goal of addressing barriers to equitable care for patients with ataxia and their caregivers.

4.2 Program Participants and Resources

The proposed program consists of several practical elements to ensure its successful implementation. The target participants are caregivers of patients with ataxia, particularly those with LEP. Caregivers will be identified through referrals from OTPs and other healthcare professionals who work directly with patients diagnosed with ataxia. Recruitment efforts will include a pre-discharge survey to assess caregivers' confidence levels, knowledge of ataxia, caregiving needs, and availability for training sessions two weeks before the patient's discharge from the inpatient setting. This survey will ensure that selected participants align with the program's goals and address their specific challenges effectively. The personnel carrying out the program will include OTPs and interpreters. The program coordinator will oversee the design, implementation, and evaluation of the training sessions. OTPs will conduct these training sessions, focusing on safe handling techniques, adaptive strategies, and effective patient communication. Interpreters will ensure caregivers understand the materials and feel supported throughout training. Desired characteristics for OTPs include cultural competence, strong interpersonal skills, and experience in training caregivers.

The program will primarily focus on inpatient rehabilitation, which may extend to simulated home environments, such as practice apartments designed for skills training.

To enhance accessibility, virtual sessions will also be available through an online platform that supports video conferencing and interactive learning. Necessary resources for the program include physical space for in-person training, computers, projectors, audio-visual presentation equipment, and adaptive devices such as reachers, tub transfer benches, gait belts, and transfer boards for demonstrations. Visual aids and handouts must be printed or digitized in multiple languages for distribution.

The outreach plan will engage OTPs and community organizations to foster collaboration and ensure the program's reach and sustainability. Initial outreach will involve a multifaceted approach that includes social media posts, conference lectures, and informational booths. These efforts will provide an overview of the program, highlight its benefits for caregivers and patients, and invite stakeholders to participate or support the initiative. Stakeholders interested in learning more can provide their contact information, allowing program developers to follow up with personalized emails, phone calls, video conferences, or in-person visits. During these interactions, specific questions will be asked to understand how stakeholders can contribute to or benefit from the program. For instance, OTPs may be questioned about their current challenges in supporting LEP caregivers or their interest in integrating the program into their discharge planning. To enhance the program's reach, the author will actively seek partnerships with advocacy groups, community health centers, and educational institutions, including occupational therapy schools. This comprehensive outreach strategy will help increase the program's visibility, attract participants, and establish enduring partnerships supporting its long-term success.

4.3 Intervention and Activities

The caregiver training program is structured into three comprehensive 60-minute modules to provide education, practical skills, and ongoing support for managing ataxia. The first module, which can be delivered in person or via video, will introduce caregivers to ataxia, including its causes, symptoms, progression, and challenges to daily life. It highlights evidence-based practice (EBP), emphasizing strategies for improving balance, coordination, functional mobility, and independence in ADLs. Caregivers will also explore the role of occupational justice in addressing systemic barriers to care and empowering patients through self-management and advocacy. This module includes discussions that help caregivers connect theoretical knowledge with practical application.

The second module focuses on hands-on, in-person training. Under the guidance of OTPs, caregivers will practice essential skills such as safe handling and mobility techniques, assisting with ADLs (e.g., dressing, eating, and bathing), and using adaptive equipment or assistive devices. Simulated scenarios will allow caregivers to build confidence in managing everyday activities, emergencies, and unexpected situations. Personalized feedback ensures caregivers leave this session prepared and equipped to support their loved ones effectively.

The third module emphasizes peer support and continued education. While participating in a group session, caregivers will discuss managing stress, improving patient communication, and navigating healthcare systems. Virtual peer support groups will provide opportunities to share experiences, seek advice, and discuss challenges, while asynchronous forums offer flexibility for caregivers to engage at their own pace.

These resources foster a supportive community and empower caregivers to stay informed and connected beyond the immediate training.

The program offers flexibility in delivery methods to accommodate varying schedules. While in-person attendance is prioritized for hands-on training, education sessions and peer support groups can be attended virtually. This combination of structured education, practical training, and community support ensures caregivers are well-prepared and confident in their roles, creating a comprehensive and accessible approach to ataxia care.

4.4 Program Outputs and Outcomes

The program aims to achieve several measurable outcomes, including the participation of 10 attendees who will complete all three 60-minute sessions. The educational materials produced for the program will consist of PowerPoint slides on ataxia education, handouts covering key strategies for activities of daily living (ADLs) and therapeutic exercises, and online resources for support groups. These materials will be distributed to participants in their target language to reinforce their learning and provide ongoing support. Collaboration with other OTPs will be essential as the program progresses along the continuum of care. One month after the program concludes, the author will oversee an assessment conducted by an OTP in the outpatient setting to evaluate whether participants demonstrate improved knowledge of occupational justice, ataxia management, and patient empowerment strategies. This will be measured through a post-discharge survey. The program aims to increase caregivers’ confidence and competence, as evidenced by self-reported surveys. Participants can then provide feedback on the program's content, format, and materials. Pre- and post-program assessments will measure immediate knowledge gains, helping to identify what additional training participants might benefit from in the outpatient setting. Feedback will also inform us of the utility of the materials. Within 2 to 6 months following discharge, participants will report improvements in their patient’s independence in ADLs and instrumental activities of daily living (IADLs). The program aims for caregivers to effectively integrate their learned strategies into their daily routines. The hope is that this stage will reflect a shift in practice, enabling caregivers to better advocate for their patients. In the long term, beyond seven months after discharge, the program will continue to promote its goals. The program will lead to lasting changes in care practices and perceptions of living with ataxia. Over time, the author anticipates reducing adverse health events, such as falls or hospital readmissions, among patients treated through this program. Long-term follow-up interviews will be conducted to assess sustained changes in patient outcomes, including improvements in quality of life. This multi-phase evaluation will provide insights into the program's immediate and long-lasting impacts.

4.5 Anticipated Barriers and Challenges

Implementing this program may face several external or environmental barriers that could affect its success. One potential challenge is staff resistance to change, mainly if the OTPs are accustomed to traditional methods of ataxia management and may be hesitant to adopt new strategies or EBP. Some OTPs might perceive the proposed changes as overly complex or time-consuming, leading to a lack of enthusiasm or full engagement with the program. Additionally, there may be challenges related to existing systems for implementation, such as limited resources and insufficient staffing for interpreters and translators. Inadequate OTP staffing may make carrying out the three-module structured program difficult. Non-supportive policies and procedures within an organization or healthcare system can hinder practical implementation. Suppose the organization has rigid policies or outdated practices that do not align with the principles of occupational justice or the proposed strategies. In that case, this can hinder the adoption of new approaches. Limited resources or insufficient time allocated for professional development may pose challenges, particularly in high-productivity settings where staff may not fully implement the outlined strategies in their practice.

Several approaches can be employed to address these barriers. First, to combat staff resistance, fostering a culture of collaboration and open communication is essential, highlighting the program's benefits for both patients and professional growth. Engaging organizational leaders early on to champion the program can provide crucial support and serve as role models for other staff members. Furthermore, OTPs can receive tailored training and ongoing support, including resources such as videos, case studies, and one-on-one coaching, to help staff recognize the immediate relevance and feasibility of the new practices. Providing a clear implementation plan to integrate the program's strategies into existing care plans is also vital. This can include offering sample handouts to provide caregivers and outlining practical steps for OTPs to follow when applying the new knowledge in their practice.

Establishing a support network among OTPs can facilitate the sharing of resources and strategies to address common challenges. Collaborating with leadership and policymakers within the organization is crucial for overcoming non-supportive policies and procedures. Advocating for policy changes that align with occupational therapy principles can be an integral part of the program. Support from the administration will help ensure the program's long-term sustainability. Additionally, utilizing EBP will highlight the program's positive impact on patient outcomes. This may help change the mindset of those resistant to change, fostering support for new procedures that align with the program's goals. By proactively addressing barriers and implementing effective strategies to mitigate them, the program can enhance its chances of success and sustainability, ultimately leading to meaningful improvements in patient outcomes.

4.6 Summary and Conclusion

The program aims to educate OTPs and caregivers by providing them with EBP for managing ataxia and promoting occupational justice. The three 60-minute modules will cover an introduction to ataxia, a therapeutic plan for improvement, and a support group session. Key components of the program include a strong emphasis on education, hands-on learning, and flexible delivery methods. These elements address critical gaps in the management of ataxia by enhancing knowledge, confidence, and practical skills. The program emphasizes empowering patients to manage their health and well-being actively. By following Pechansky and Thomas's Theory of Access, the program ensures that it addresses the availability, accommodation, affordability, and acceptability of care. This approach considers the ongoing challenges OTPs face in providing adequate care for individuals with ataxia, ensuring that barriers to participation and implementation are considered and that the program is more inclusive and accessible. By prioritizing accessibility, cultural competence, and interdisciplinary collaboration, the program aligns with Pechansky and Thomas's Theory of Access to ensure equitable care delivery. While this program offers a structured, multi-component approach, alternative strategies such as AI-driven translation tools or community-based caregiver networks may also enhance LEP caregiver education. Future research should compare these methods to determine their relative effectiveness in different healthcare settings. By integrating best practices in adult learning and occupational therapy, this initiative strives to reduce disparities in ataxia care, ultimately improving outcomes for both caregivers and patients.

CHAPTER FIVE – Program Evaluation Research Plan

5.1 Introduction

In the previous chapters, this project explored the background and significance of caregiver education for individuals with ataxia, reviewed relevant literature, and outlined the methodology for program development. Building upon these foundations, Chapter 5 focuses on evaluating the effectiveness of the educational intervention and the role of stakeholder engagement in ensuring its success. This chapter details the program evaluation framework, research design, stakeholder involvement, and the anticipated outcomes, which include improved caregiver knowledge and confidence, enhanced patient care outcomes, and the identification of effective educational delivery methods. These outcomes will help assess the impact of this initiative on caregivers and patients with ataxia.

5.2 Program Scenario and Stakeholders

This program, uniquely designed as an educational intervention, aims to enhance the skills and knowledge of caregivers of individuals with ataxia who have limited English proficiency (LEP). It focuses on bridging communication gaps, improving caregiving strategies, and promoting advocacy for patient needs. By prioritizing educational accessibility and caregiver empowerment, the program seeks to enhance the quality of care provided to individuals with ataxia and ultimately improve their health outcomes. The program not only serves caregivers of individuals with ataxia who require specialized guidance to support their loved ones effectively but also aids the patients themselves. Outcomes for patients with ataxia improve with increased caregiver knowledge and skills, support, and overall well-being. This is a collaborative effort, where interdisciplinary healthcare professionals, including occupational therapy practitioners (OTPs) with extensive experience in neurorehabilitation and rehabilitation specialists focusing on ataxia, can integrate findings from this program into their clinical practice to better support caregivers. Additionally, advocacy organizations, community health organizations, and policymakers involved in decisions regarding health equity and caregiver training programs will benefit from the knowledge shared in this program.

The program is designed to be accessible and flexible, using various delivery methods, both in-person and online, for various portions of the program. There will be in-person training in inpatient and outpatient settings, interactive videos, printed and digital educational materials in multiple languages, including but not limited to Spanish, Mandarin, and Armenian, and monthly peer support group meetings. By offering multiple delivery formats and materials in various languages, the program ensures inclusivity and accessibility for caregivers with differing technological proficiency levels or availability for in-person sessions. The program will be delivered by OTPs specializing in neurorehabilitation in conjunction with bilingual educators and interpreters to ensure effective communication with caregivers who speak languages other than English. The program will tie in community health and social workers experienced in caregiver support and advocacy group representatives who can provide resources and guidance on navigating healthcare systems, making all stakeholders feel valued and considered in the program's design.

The findings from the program evaluation are expected to have a significant impact on several groups. Caregivers and patient advocacy groups can use the insights to refine their caregiving approaches, while IDT members, namely OTPs, can better integrate evidence-based strategies into clinical practice. Hospital and rehabilitation center administrators can use this program to make informed decisions about caregiver training programs and patient support initiatives. Public health organizations, policymakers, and funding agencies may use the data to advocate for better caregiver education resources based on the program's effectiveness. The potential impact of the program evaluation on these stakeholder groups is significant and relevant, highlighting the importance of their involvement in this research and the potential positive changes they can bring about. This program has the potential to inspire hope for the future of caregiver education and healthcare accessibility, as it aims to bring about positive changes in the lives of caregivers and patients with ataxia.

This author recognizes the importance of ongoing evaluation and feedback to continuously improve and refine educational materials and programs. By soliciting input from caregivers, patients, healthcare professionals, and community members, this author will identify areas for improvement and adaptation, ensuring that the resources remain responsive to the evolving needs of the target demographics. The continuous and integral involvement of stakeholders in this process is valued and necessary for the program's success. This commitment to ongoing evaluation should reassure stakeholders about the program's adaptability and responsiveness to their needs, fostering a sense of reassurance and confidence in the program's effectiveness. An example scenario might be a local brain injury advocacy organization supporting individuals with ataxia recognizing and reporting a significant gap in educational resources for caregivers with LEP. Many caregivers struggle to access essential health information due to language barriers, leading to increased caregiver burden and suboptimal patient outcomes. The author seeks evidence-based solutions to improve caregiver education and requests an evaluation of this program's effectiveness. Through participation in the program evaluation, stakeholders will inform the author whether the educational interventions improve caregiver knowledge, confidence, and patient care outcomes. If successful, the findings will support the development of additional training programs, securing funding, and advocating for policy changes to enhance caregiver support nationwide.

5.3 Vision

The primary objective of this program evaluation is to determine the effectiveness of the educational intervention for caregivers of individuals with ataxia who have LEP. This research seeks to achieve several objectives through qualitative and quantitative data collection and analysis. These objectives are not just goals but the backbone of the research, guiding the process and ensuring a comprehensive program evaluation. They include assessing caregiver knowledge and confidence levels before and after participating in the program, identifying the most effective educational delivery methods for caregivers with LEP, evaluating the impact of improved caregiver education on patient health outcomes, examining barriers to learning and engagement that caregivers may face in the program, and exploring the long-term sustainability and scalability of the program for broader implementation. To ensure the validity and reliability of the data, this author will use a combination of pre-and post-program surveys, focus group discussions, and patient health records. These objectives guide the research process and ensure a comprehensive program evaluation.

This research aims to address significant gaps in caregiver education and contribute to the field of occupational therapy. By reducing disparities in caregiver education and offering accessible, multilingual learning resources at varying health literacy levels, this researcher can equip caregivers with practical strategies to manage ataxia-related challenges. Providing OTPs and IDT members with research-based recommendations for supporting caregivers with LEP is crucial. To further expand the reach of this program, it will be essential to support policy and program development by presenting data on the necessity of inclusive caregiver training initiatives. Finally, challenges such as language barriers and cultural differences can be addressed by identifying critical areas where caregiver education can reduce patient complications and improve quality of life. By fulfilling these objectives, the program evaluation will strengthen caregiver support systems and inform broader efforts in healthcare accessibility and occupational therapy best practices, inspiring hope for the future of caregiver education.

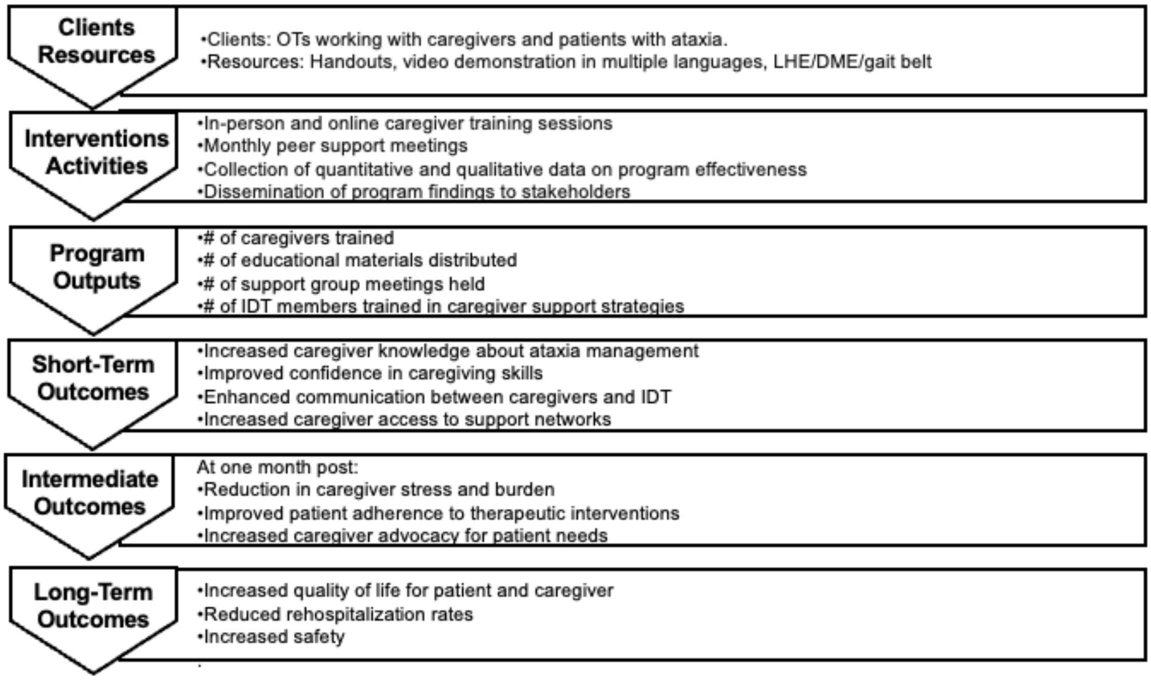
5.4 Engagement of Stakeholders

Successful completion of this research is a collaborative effort with key stakeholders who are integral to the program's outcomes. The most crucial stakeholder and research participant is the caregiver. The caregivers are volunteers who will participate in the program and provide feedback on its effectiveness. OTPs and IDT members are also key players who will help collect data, deliver training, and analyze program impact. These members work directly with hospital administrators and public health officials who facilitate access to resources and program implementation. Since these patients are important members of their community and society, engaging advocacy and community organizations to help promote the program, recruit participants, and provide logistical support is important. Lastly, institutional bodies such as the Institutional Review Board (IRB) or research departments play a crucial role in the research process. These entities may approve the study, ensure ethical research practices, and provide guidance on data analysis, ensuring the research is conducted responsibly and ethically.

Several engagement strategies will be implemented to foster stakeholder involvement. Program goals will be aligned with stakeholder interests by tailoring objectives to meet the needs and priorities of each stakeholder group. Regular communication and updates will be provided through progress reports and feedback sessions to refine program implementation. Stakeholder meetings will be hosted to discuss evaluation questions, data collection methods, and program improvements. Collaborative data collection will involve healthcare providers and advocacy organizations in gathering qualitative and quantitative data. Additionally, resource sharing and incentives, such as relevant materials, training opportunities, and other benefits, will be offered to encourage continued participation. The program evaluation will generate meaningful insights that contribute to advancing caregiver education and occupational therapy best practices by ensuring active engagement and investment from key stakeholders.

Figure 5.1

Simplified Logic Model for Use with Stakeholders



Clients Resources
- Clients: OTs working with caregivers and patients with ataxia.
- Resources: Handouts, video demonstration in multiple languages, LHE/DME/gait belt

Interventions Activities
- In-person and online caregiver training sessions
- Monthly peer support meetings
- Collection of quantitative and qualitative data on program effectiveness
- Dissemination of program findings to stakeholders

Program Outputs
- # of caregivers trained
- # of educational materials distributed
- # of support group meetings held
- # of IDT members trained in caregiver support strategies

Short-Term Outcomes
- Increased caregiver knowledge about ataxia management
- Improved confidence in caregiving skills
- Enhanced communication between caregivers and IDT
- Increased caregiver access to support networks

Intermediate Outcomes

At one month post:
- Reduction in caregiver stress and burden
- Improved patient adherence to therapeutic interventions
- Increased caregiver advocacy for patient needs

Long-Term Outcomes
- Increased quality of life for patient and caregiver
- Reduced rehospitalization rates
- Increased safety

As illustrated in Figure 5.1, the simplified logic model provides a structured overview of the intervention's impact pathway. It serves as a visual representation of how program resources, activities, and interventions will lead to desired outcomes. This model addresses limited access to linguistically and culturally appropriate caregiver education for individuals with ataxia in LEP communities. By illustrating the connection between resources, activities, outputs, and short-term, intermediate, and long-term outcomes, the logic model provides a clear roadmap for achieving the program's goals. The model highlights the importance of interdisciplinary collaboration, bilingual resources, and active caregiver involvement to ensure effective implementation and measurable impact. It guides the evaluation process, ensuring that the program systematically improves caregiver knowledge, reduces health disparities, and enhances the quality of life for individuals with ataxia and their families.

5.5 Preliminary Exploration and Confirmatory Process

The program evaluation will follow a participatory approach, fostering collaboration with key stakeholders to establish consensus on the program's objectives, activities, and evaluation logistics. Stakeholder consultations will be conducted through meetings with caregivers, OTPs, advocacy groups, and healthcare administrators to refine program goals and methodologies. Consensus-building meetings will provide a platform for stakeholders to discuss and validate key program components, ensuring alignment with their needs and expectations. Regular check-ins will establish feedback loops, allowing stakeholders to voice concerns and suggest modifications to enhance program delivery. Additionally, ethical and compliance reviews will be conducted with Institutional Review Boards (IRB) to ensure the research adheres to ethical guidelines and regulatory requirements. This confirmatory process ensures that stakeholders support and actively contribute to the program's success.

5.6 Program Evaluation Research Questions by Stakeholder Group

The key research questions for this evaluation will address the perspectives of various stakeholders. The study will explore whether the program enhances caregivers' ability to provide adequate care. OTPs will assess whether caregiver training improves patient function and participation along the continuum of care. Advocacy organizations will consider whether the program can serve as a model for broader caregiver education efforts. Healthcare administrators will evaluate whether trained caregivers contribute to improved patient outcomes and reduced hospital readmissions. Policymakers will examine how the data can inform future caregiver education and support policies. The primary research questions for evaluation will include both quantitative and qualitative aspects. Quantitative analysis will determine whether caregivers report increased confidence and skill levels after completing the program. At the same time, qualitative inquiry will explore caregivers' perceptions of the program's effectiveness, accessibility, and relevance to their needs. By addressing these questions, the research will provide valuable insights into the impact and effectiveness of caregiver education for individuals with ataxia, guiding future interventions and policy recommendations.

5.7 Eliciting Stakeholder Involvement and Ensuring the Evaluation Results will be Used

Identifying stakeholders and understanding their roles, involvement, and specific interests is essential in developing a caregiver education program for patients with ataxia. Recognizing stakeholders allows the program to align objectives with the needs and expectations of those affected by or benefit from the program. This engagement fosters collaboration, ensuring the caregiver education program is relevant and applicable. This inclusive approach ultimately leads to outcomes more likely to be embraced and utilized by the broader community. Table 1 summarizes key stakeholders and their respective roles in program implementation.

Table 5.1 Stakeholder Matrix

Stakeholder	**Type of Involvement**	**Possible Role**	**Specific Interests**
Author, as the Primary Investigator	P, I, R	Program development, oversight, and manuscript author	Successful implementation, caregiver outcomes, publication
IDT Staff	I, R	Intervention, implementation, and data collection	Clinical learning, successful caregiver training outcomes
Caregivers/Families	R	Providing feedback and refining the program	Adequate and accessible caregiver education, improved patient outcomes
Director of Research	P, I, R	Consultation on methodology, analysis, dissemination	Design rigor, robust outcomes, caregiver engagement

Key: P = Planning the program; I = Implementing the program; R = Reflecting on the process and recommending further development

5.8 Program Evaluation Research Questions

Formative and summative research questions play important roles in developing and evaluating the caregiver education program for patients with ataxia. Formative questions are crucial for shaping the early stages of the program, helping to define the scope, purpose, and methodology. These questions allow for feedback, enabling adjustments based on emerging insights. The Stakeholder Matrix in Table 2 summarizes formative and summative questions related to each stakeholder.

Table 5.2 Stakeholder Matrix

Stakeholder	Research Questions
Author, as the Primary Investigator	**Formative:** • Is the training manual easy to understand and follow? • Are the sessions practical for implementation within inpatient and outpatient rehabilitation? • Are there any challenges in delivering education to caregivers with limited English proficiency? **Summative:** • Will fidelity be maintained during program delivery? • Will staff observe improvements in caregiver understanding and skills?
IDT Staff	**Formative:** • Was the training manual easy to understand and follow? • Were the sessions practical to implement within the inpatient and outpatient settings? • Were there any challenges in delivering education to caregivers with limited English proficiency? **Summative:** • Was fidelity maintained during program delivery? • Did IDT observe improvements in caregiver understanding and skills? • Did IDT feel more confident in providing caregiver education?
Caregivers/ Families	**Formative:** • Was the information provided understandable and relevant? • Were cultural and language needs adequately addressed? **Summative:** • Did the program improve your ability to support your loved one during ADLs? • Did you feel more confident managing ataxia-related challenges?
Director of Research	**Formative:** • Does the program align with institutional goals for caregiver education and support? • Does the program meet compliance and licensing requirements? **Summative:** • Did the program demonstrate a clinically meaningful impact on caregiver and patient outcomes?

	• What was the program's engagement rate among caregivers? • Is the program suitable for publication and dissemination to broader healthcare audiences?

Integrating stakeholder feedback, adjusting based on formative findings, and conducting robust summative evaluations will ensure that the program addresses caregiver needs and contributes to improved patient outcomes.

5.9 Research Design

The research design for this program evaluation will employ a mixed methods approach, integrating qualitative and quantitative methodologies to assess program effectiveness comprehensively. To ensure a robust evaluation, multiple research designs will be incorporated. The formative research design will use a descriptive and exploratory qualitative methodology to assess program implementation, caregiver engagement, and barriers to participation through focus groups, interviews, and observational assessments. For the summative evaluation, a quasi-experimental research design will examine the relationship between caregiver education and patient outcomes, allowing for preliminary causation analysis while accommodating real-world constraints, such as the inability to assign participants randomly, for ethical reasons. In cases where random assignment is feasible, an experimental research design will be applied, with participants assigned to either an intervention group (caregivers receiving the educational program) or a control group (caregivers receiving standard care resources). This will help establish a more precise causal relationship between the program and its outcomes. Additionally, a mixed methods research design will integrate qualitative and quantitative data, collected concurrently or sequentially, to comprehensively understand caregiver experiences and program effectiveness. The qualitative component will add context and depth to the quantitative results, ensuring a well-rounded evaluation.

The qualitative data collection will include in-depth interviews with caregivers, healthcare providers, advocacy group representatives, and focus groups to gather insights on program accessibility and caregiver perceptions. Observational studies will examine caregiver-patient interactions post-intervention, while thematic analysis will be conducted on caregiver feedback and learning reflections. The quantitative data collection will utilize pre- and post-program surveys, measuring caregiver confidence, knowledge acquisition, and self-efficacy, as well as standardized patient outcome measures to assess changes in ataxia management and daily function. Additionally, statistical analyses will evaluate caregiver burden and stress levels before and after program participation, with longitudinal follow-up assessments to determine the program's sustained impact. This comprehensive research design will provide valuable insights into the program's effectiveness, inform future modifications, and contribute to the evidence-based practice of occupational therapy and caregiver support interventions.

5.10 Methods Section

This study will employ a mixed methods approach to evaluate the effectiveness of the caregiver education program, integrating qualitative and quantitative methodologies for a comprehensive assessment. A pilot study will evaluate the program's educational materials, incorporating feedback from the interdisciplinary team (IDT) and caregivers. Before data collection begins, IRB approval will be obtained to ensure ethical research practices, including informed consent procedures, participant protections, and adherence to research standards. Several measures will be implemented to protect participant privacy and confidentiality. Unique identification codes will be assigned in place of personal identifiers, and all participant information will be securely stored in encrypted, password-protected files. Access to data will be restricted to authorized research personnel only. A comprehensive data management plan will be in place to prevent data loss. Regular backups of electronic files will be maintained on secure cloud storage and external hard drives. Encrypted databases will store sensitive information, and physical copies of anonymized data will be kept in a locked filing system.

5.11 Qualitative Methodology

Data collection will occur in the inpatient and outpatient setting, beginning with an initial sample of 10 caregivers with LEP. The justification for this number is based on several key considerations. First, it aligns with the feasibility of a pilot study framework, allowing for an in-depth, qualitative understanding of caregiver experiences before scaling up the study. Resource constraints make starting with a manageable cohort essential, ensuring efficient data collection and program refinement. Research literature suggests that qualitative studies often reach thematic saturation with 10–12 participants, where additional data does not yield new insights (Hennink & Kaiser, 2022).

Furthermore, this initial cohort provides an opportunity for incremental expansion, allowing for future iterations of the program evaluation to broaden the sample size as needed. The qualitative data collection methods will include in-depth interviews with caregivers to explore program impact, focus groups with caregivers, healthcare providers, and program facilitators to gather qualitative insights, and thematic analysis of caregiver feedback to identify common themes and concerns. Data will be collected multiple times: before program initiation, after program completion, and at a three-month follow-up. All collected qualitative data will be transcribed and securely stored, including interview transcripts, focus group discussions, and open-ended survey responses. A thematic analysis approach will be employed to identify patterns and themes using manual coding and qualitative analysis software such as ATLAS.ti. The intercoder agreement will be established to ensure reliability, with multiple researchers reviewing the themes for consistency.

5.12 Quantitative Methodology

Surveys and assessments will be conducted in person and via secure online platforms. The same sample group from the qualitative study will participate in quantitative assessments. Data collection methods will include pre- and post-program surveys to measure changes in caregiver knowledge and confidence, standardized caregiver burden and stress assessment tools to evaluate emotional and functional impact, and patient health outcome measures to assess improvements in care quality. Data will be collected at three key intervals: pre-intervention, immediately post-intervention, and three months post-program. By integrating qualitative insights with quantitative outcome measures, this study ensures a robust and comprehensive evaluation of the program's effectiveness in improving caregiver knowledge, confidence, and patient outcomes. Data will be electronically entered into secure databases using Qualtrics, Excel, or REDCap tools. Statistical analysis will be conducted using SPSS or R, applying descriptive statistics, inferential statistics (e.g., t-tests, ANOVA, regression analysis), and effect size calculations to assess program impact. To reduce bias, strategies such as blind data coding, controlling for confounding variables, and conducting sensitivity analyses will be implemented, ensuring a rigorous and valid evaluation of the study findings.

Several measures will be implemented to address potential biases and enhance the reliability and validity of qualitative and quantitative findings. Culturally adapted surveys will be used, ensuring that interview questions are translated and tailored to the diverse language groups of participants. Anonymous feedback mechanisms will be available to encourage honest responses, reducing potential response bias. Neutral data collection methods will be employed, with bilingual facilitators trained in culturally responsive interviewing techniques conducting focus groups and interviews. Triangulation of data sources, incorporating interviews, surveys, and observational studies, will help cross-verify findings and minimize bias. Additionally, preliminary results will be shared with key stakeholders to validate interpretations and adjust conclusions where necessary, further ensuring the accuracy and applicability of findings.

5.13 Anticipated Strengths and Limitations

This study has several strengths that enhance its rigor and relevance. The comprehensive mixed-methods approach provides depth through qualitative analysis and breadth through quantitative measures, ensuring a well-rounded understanding of program outcomes. The study addresses critical health inequities by focusing on a linguistically diverse and underserved population. Stakeholder engagement throughout the research process further strengthens the validity and applicability of the findings. Multiple data collection time points also allow for short-term and long-term impact assessment. However, there are some limitations to consider. Participant attrition, particularly in follow-up data collection, may affect the completeness of the results. Variability in caregiver engagement levels could influence the intervention's impact, requiring careful consideration in the analysis. Cultural factors may also affect participant responses, necessitating thoughtful interpretation of qualitative findings. Furthermore, limited opportunities for randomization restrict the study's experimental rigor in establishing causation. By integrating qualitative insights with quantitative outcome measures, this study ensures a robust and comprehensive evaluation of the program's effectiveness in improving caregiver knowledge, confidence, and patient outcomes.

5.14 Conclusion

The study aims to assess the program's impact on caregiver knowledge, confidence, and patient outcomes by integrating qualitative and quantitative methodologies. The evaluation process emphasizes the importance of stakeholder engagement, ensuring that caregivers, interdisciplinary healthcare teams, advocacy organizations, and policymakers contribute to and benefit from the findings. Through structured data collection methods—including pre- and post-program surveys, focus groups, and observational studies—this research will provide critical insights into the most effective educational delivery methods for LEP caregivers. The anticipated outcomes highlight the program's potential to enhance caregiver preparedness, reduce health disparities, and improve patient care quality. Furthermore, by identifying challenges such as language barriers and caregiver engagement issues, the study will inform future adaptations to ensure accessibility and sustainability.

While the program evaluation presents significant opportunities for advancing occupational therapy best practices and caregiver education, limitations such as participant attrition and variability in engagement must be acknowledged. However, the research will contribute valuable evidence to support broader caregiver training initiatives by employing strategies to enhance validity and reliability, including stakeholder validation and data triangulation. Ultimately, this evaluation is a foundation for expanding caregiver education programs, advocating for policy changes, and integrating culturally and linguistically responsive resources into healthcare practice. The findings will inform the refinement of this specific program and contribute to the growing body of research on effective caregiver support interventions. By prioritizing accessibility, inclusivity, and interdisciplinary collaboration, this project aims to create meaningful and lasting improvements in the quality of care for individuals with ataxia and their families.

CHAPTER SIX – Dissemination Plan

6.1 Introduction

The proposed program stands out for its unique focus on providing accessible, culturally sensitive caregiver education for individuals supporting patients with ataxia and limited English proficiency (LEP). It acknowledges the communication barriers and unique caregiving challenges this population faces, and offers multilingual educational materials, visual aids, and interactive training sessions to enhance caregiver understanding of ataxia and improve care delivery. The program's emphasis on practical strategies for managing symptoms, promoting patient safety, and supporting daily function at home, along with its incorporation of interpreter support and feedback from LEP caregivers, aims to empower caregivers with the knowledge and confidence needed to provide effective, compassionate care while reducing caregiver stress and improving patient outcomes.

6.2 Local Resources

The program is bolstered by several in-kind local resources, reflecting a deep connection to the community and local healthcare network. Hospital-based interpreters are crucial in bridging communication gaps, particularly for caregivers with LEP. Their assistance significantly enhances the accessibility of educational materials, leading to improved understanding and adherence to care protocols. The Rancho Los Amigos Research Institute is pivotal in providing evidence-based resources and expert consultation in neurorehabilitation, which is crucial in tailoring interventions for caregivers. Integrating research findings into practical applications supports a more effective approach to caregiver education, promoting better care strategies tailored to ataxia. Engagement from occupational therapy practitioners (OTPs) who are specially trained in neurorehabilitation enhances program credibility and effectiveness. Their expertise in caregiver education, cultural competence, and program evaluation brings a comprehensive understanding of diverse caregiver needs and rigorous evaluation methodologies, which are essential for measuring the program's impact. Volunteering OTPs from Rancho Los Amigos who facilitate caregiver education courses contribute practical skills and knowledge, ensuring the training provided is relevant and applicable to real-world situations. The role of OTPs in designing caregiver education programs is critical as it emphasizes adaptability and competence in their newfound roles. This adaptability should reassure the audience of the program's potential success. Occupational therapy level II fieldwork students gain hands-on experience and contribute to program development, including creating instructional videos for caregiver support. This participatory approach fosters innovation and may result in more relatable and accessible learning materials for caregivers accessible anywhere, anytime. The collaboration across various sectors, including healthcare and academia, embodies a holistic approach to addressing the complex needs of caregivers. Evidence suggests that interdisciplinary collaborations improve service delivery and outcomes through shared knowledge and resources (Din et al., 2024). By pooling expertise from different fields, this program addresses immediate caregiver needs and lays the groundwork for sustainable, long-term support structures within the community. Table 6.1 outlines the projected expenses for the caregiver education program over its first two years, demonstrating how in-kind support and strategic resource allocation help minimize direct costs while ensuring program sustainability.

Table 6.1

Expenses for Caregiver Education Program

Expense	Year 1 Estimate	Year 2 Estimate	Justification
Personnel	$0	$0	The program will rely on volunteer OTPs and Level II fieldwork students.
Consultants	$2,000	$1,000	Expert consultants (e.g., neurorehabilitation-certified OTPs) will advise on curriculum development.
Equipment	$500	$200	Tablet or laptop for training sessions and caregiver follow-up.
Supplies	$800	$500	Workshop supplies: pens, notebooks, printouts.
Communication	$300	$200	Phone calls, interpreter coordination, and caregiver follow-up.
Materials Preparation	$1,000	$800	Printing of multilingual handouts, visual aids, and caregiver toolkits.
Travel	$400	$400	Local mileage reimbursement for facilitators and fieldwork students.
Facility Rental	$0	$0	Hospital space and classroom space are offered in-kind.
Hospitality items	$300	$300	Refreshments for caregivers during training.
Evaluation	$1,000	$1,500	Data analysis software and stipends for the program evaluator.
Dissemination	$3,600	$3,600	To share resources and findings of program
Total	**$9,900**	**$8,500**	

The budget for the program reflects many contributions provided by in-kind and local resources. All personnel, including OTPs and students, volunteer their time to reduce direct salary costs. Content experts may eventually be compensated as consultants for their curriculum design and program guidance expertise. A one-time purchase of a tablet or laptop will support digital program delivery, while supplies will cover hands-on materials used during workshops and training sessions. Communication costs will support outreach and coordination with caregivers and interpreters. Funds allocated for materials preparation will ensure that all handouts and toolkits are accessible, multilingual, and visually appropriate. Travel expenses will cover local transportation for facilitators and students attending workshops. Facility rental costs are waived thanks to in-kind support from hospital and university partners. Evaluation costs include software and expert input to monitor program outcomes and drive continuous improvement. Finally, a small budget for hospitality items will help create a welcoming, caregiver-centered environment during training. The potential impact of this program on the community is significant, as it will improve the quality of care for ataxia patients and reduce the stress and burden on their caregivers, ultimately leading to better health outcomes and a more equitable healthcare system. The potential positive impact of this program on the community should inspire hope and optimism, as it will improve the quality of care for ataxia patients and reduce the stress and burden on their caregivers, ultimately leading to better health outcomes and a more equitable healthcare system. Table 6.2 presents potential funding sources that align with the program’s goals of improving caregiver education and health equity, including federal and state grants, local foundations, and corporate partnerships.

Table 6.2

Potential Funding Sources for Accessible Caregiver Education Program

Source	**Details & Examples**
Federal Grants	**NIDILRR (National Institute on Disability, Independent Living, and Rehabilitation Research):** Funds disability-related education programs. Typical awards: $50,000–$500,000/year. **HRSA**: Funds caregiver health education in underserved communities.
State Grants	**California Department of Public Health (CDPH)** supports health equity and multilingual health education programs. The funding range is $25,000–$200,000.
Local Community Grants	**LA Care Community Health Investment Fund** supports Los Angeles caregiver access and education programs. Typical awards are $25,000–$75,000. **California Wellness Foundation:** Health equity and support programs, $50,000+.
Hospital/University Grants	**Rancho Los Amigos Foundation** supports neurorehabilitation and caregiver training programs. Typical awards are $5,000–$20,000. **USC Community Engagement Grants**: Supports local outreach projects, $2,000–$10,000. **Boston University Sargent College Research and Innovation Grants**: Internal support for student- or faculty-led pilot studies and program development. Typical awards: $1,000–$10,000.
Foundations	**Christopher & Dana Reeve Foundation**: Funds caregiver education and disability support initiatives. Average grant: $25,000. **Hearst Foundations:** Funds education and health equity projects. Typical grant: $50,000–$100,000.
Corporate Gifts/Grants	**Kaiser Permanente Southern California**: Supports health literacy and caregiver training—awards: $10,000–$50,000. **CVS Health Foundation:** This foundation funds chronic condition education and access to care. Awards range from $20,000 to $100,000.
Crowdsourcing	Platforms like GoFundMe, Classy, or Fundly. Community-backed efforts for caregiver education have raised $5,000–$15,000 for pilot programs.

6.3 Conclusion

The funding plan for this caregiver education program reflects a strategic blend of in-kind support, institutional collaboration, and external funding opportunities to ensure the initiative's successful launch and long-term sustainability. The program minimizes overhead while maximizing community involvement and relevance by leveraging the time and expertise of occupational therapy practitioners, students, hospital staff, and university partners. A budget has been developed to support critical elements such as consultant expertise, instructional materials, evaluation, and accessibility needs. Diverse funding streams may support the program's scope and goals, including federal and state grants, local community foundations, university-based resources, and corporate sponsorship. With strong community roots, interdisciplinary collaboration, and a precise alignment with current healthcare equity priorities, this program is well-positioned to receive funding and create a lasting impact for caregivers of patients with ataxia who have limited English proficiency.

CHAPTER SEVEN – Funding Plan

7.1 Introduction

The caregiver education program is designed to equip caregivers of patients with ataxia—particularly those with limited English proficiency (LEP)—with the knowledge, skills, and culturally appropriate resources needed to support safe and effective care at home. By providing linguistically accessible materials, interactive training sessions, and visual aids, the program effectively addresses common caregiving challenges associated with ataxia, such as fall prevention, communication strategies, and activities of daily living. The program not only promotes health literacy, caregiver confidence, and continuity of care following discharge from inpatient rehabilitation, but also significantly improves patient outcomes and enhances the quality of life for ataxia patients along the continuum of care.

7.2 Dissemination Goals

The long-term goal of disseminating this program is to influence institutional policy by advocating for the integration of linguistically and culturally appropriate caregiver education as a standard component of inpatient neurorehabilitation discharge planning. Short-term goals include piloting the program in a single inpatient rehabilitation unit, refining it based on caregiver and clinician feedback, and building partnerships with language access services to ensure ongoing delivery of caregiver training materials in multiple languages.

7.3 Primary Audience: Rehabilitation Professionals

Rehabilitation professionals play a critical role in preparing caregivers for the transition from inpatient rehabilitation to home care, particularly for patients with ataxia. One key message is that providing caregivers with language-accessible education before discharge significantly improves home safety, enhances patient outcomes, and reduces caregiver stress—especially when the caregiver has LEP. This training can be effectively integrated into existing workflows using brief, visual, and translated resources, empowering caregivers without creating additional documentation or workload burdens for staff. Most importantly, culturally and linguistically appropriate caregiver education is not just a courtesy—it is essential for equitable, patient-centered care. These messages can be effectively delivered by a bilingual occupational therapy practitioner (OTP) that is also certified as a brain injury specialist (CBIS).

7.4 Secondary Audience: Hospital Administrators and Policymakers

For hospital administrators and policymakers, the program underscores the importance of aligning discharge education with health equity goals. Implementing structured, language-accessible caregiver education not only supports organizational priorities but also enhances them by improving patient satisfaction scores, enhancing caregiver preparedness, and reducing preventable readmissions. This initiative is cost-effective, leverages existing staff and translation services, and aligns with federal and accreditation requirements such as those set by the Joint Commission regarding language access. By investing in culturally competent discharge education, healthcare systems can close care gaps for LEP populations and demonstrate a commitment to patient- and family-centered care. These messages are best communicated by influential spokespersons such as a respected official from the American Occupational Therapy Association (AOTA) or the Occupational Therapy Association of California (OTAC).

To engage rehabilitation professionals, the priority will be conducting an in-service workshop to introduce the caregiver education program and demonstrate how it can be easily integrated into discharge planning. This interactive session will take place in the first month of dissemination and will be led by the project developer, with support from the department supervisor. Following the workshop, written materials—including a one-page informational brief and a trifold brochure—will be distributed to staff to reinforce key concepts and serve as reference tools. These materials will be developed in the second month. In the third month, a short training video (approximately 5–7 minutes) will be produced with support from the hospital's media team. This video will show the caregiver education process and be used as an ongoing training tool for new and existing staff. Additionally, a peer-reviewed journal article detailing the program's development and preliminary outcomes will be submitted between months four and six to contribute to the broader academic community. This article will share best practices and promote adoption at other institutions.

Dissemination will begin in the second month with a formal administrative briefing. This 15-minute presentation will summarize the program's goals, impact on patient outcomes, and alignment with institutional priorities such as health equity and readmission reduction. The presentation will be supported by a professionally designed one-page fact sheet highlighting key data points and action recommendations. In month four, the project team will collaborate with the hospital's information technology (IT) or communications department to propose adding program resources to the internal intranet site. This will ensure ongoing staff access to educational tools and help institutionalize the program. To further expand reach, a proposal will be submitted in month five to present the project at a regional or national health equity or rehabilitation conference. If accepted, the presentation would likely occur between months seven and nine. It would offer an opportunity to share the model with other healthcare systems and advocate for broader policy adoption.

Table 7.1 outlines a preliminary budget developed to support the dissemination activities for both primary and secondary audiences. For the primary audience of rehabilitation professionals, the total estimated cost is $500. This includes $150 for workshop materials, such as printed handouts, and $200 for the design and printing of brochures. While the video will be produced in-house at no cost, $150 has been allocated for potential journal submission fees. For the secondary audience of hospital administrators and policymakers, the estimated budget is $600. This includes $50 for printing briefing materials and executive summaries and $500 for conference registration and travel to present the project at a professional meeting. Website or intranet updates will be supported through existing hospital resources at no additional cost. The total dissemination budget across both audiences is $1,100, which should be included as a line item in the overall Funding Plan under "Dissemination Expenses”.

Table 7.1 - *Preliminary dissemination budget*

Expense Category	**Primary Audience**	**Secondary Audience**	**Estimated Cost (USD)**
Workshop materials (printing, handouts)	$150	$150	$300
Brochure design and printing (100 copies)	$200	$200	$400
Video production (in-house support)	$0 (in-kind)	$0 (shared resource)	$0
Peer-reviewed journal submission fees	$150	$150	$300
Administrative briefing materials	–	$50	$50
Executive summary printing	–	$50	$50
Website/intranet support	–	$0 (in-kind)	$0
Conference registration and travel	–	$2,500	$2,500
Total Estimated Budget	**$500**	**$3,100**	**$3,600**

The success of the dissemination efforts will be evaluated using measurable outcomes aligned with each activity and target audience. For the in-service workshop, the evaluation will include pre- and post-session surveys to assess changes in staff knowledge, confidence, and intent to use language-accessible caregiver education materials. Attendance numbers and qualitative feedback will also be collected to gauge engagement and relevance. For the written materials (informational brief and brochure), success will be measured by tracking distribution numbers and gathering informal feedback from staff through follow-up discussions or surveys. The training video's impact will be evaluated by monitoring view counts and incorporating a brief knowledge quiz for viewers. The submission and acceptance of a peer-reviewed journal article will serve as a benchmark for broader academic dissemination, with citation tracking used to measure reach over time.

For the secondary audience, the evaluation of the administrative briefing will focus on changes in leadership attitudes and actions—specifically, whether there is formal approval or resource allocation to support broader implementation of the program. Metrics will include follow-up meetings, requests for additional information, and program inclusion in departmental agendas or quality improvement initiatives. The success of the executive summary will be based on whether it is shared among key decision-makers and referenced in planning documents. Website or intranet integration will be evaluated through usage analytics, such as page visits and downloads. For the conference presentation, an evaluation will include acceptance of the proposal, audience size, and post-session feedback from attendees, including interest in replicating the program at other institutions.

7.5 Conclusion

This dissemination plan outlines a multi-modal strategy for sharing the key messages and outcomes of a caregiver education program for patients with ataxia and caregivers with limited English proficiency. By prioritizing person-to-person contact, practical written resources, and accessible electronic media, the plan ensures that both clinical staff and institutional decision-makers receive targeted, actionable information. The plan emphasizes early engagement of rehabilitation professionals to drive implementation and evaluation, followed by strategic outreach to administrators and policymakers to support sustainability and scale. Evaluation measures are built into each activity to track real-world impact, and a modest but well-allocated budget supports cost-effective dissemination. Overall, this plan supports the long-term goal of institutionalizing equitable caregiver education practices and promoting health literacy for diverse patient populations within neurorehabilitation settings.

CHAPTER EIGHT – Conclusion

8.1 Introduction

The accessible caregiver education program developed through this doctoral project has the potential to meaningfully transform neurorehabilitation care for individuals with ataxia by centering the experience and needs of caregivers with limited English proficiency (LEP). Grounded in occupational therapy's core values of equity, inclusion, and occupational justice, this program addresses a long-standing gap in caregiver support: the lack of linguistically and culturally responsive education tailored to diverse populations navigating complex neurological conditions. By integrating key theories such as Pechansky and Thomas's Theory of Access, Albert Bandura's Social Learning Theory, and Adult Learning Theory, the program takes a systems-level approach to ensure that all caregivers, regardless of language background, have the tools, knowledge, and confidence to support their loved ones' recovery and engagement in daily life.

8.2 Innovation in Caregiver Education

This project introduces an innovative approach to caregiver education, particularly within inpatient rehabilitation settings. Unlike many health education interventions that adopt a one-size-fits-all approach, this program is distinct in its focus on caregivers who are often marginalized due to language barriers. By utilizing translated materials, plain language communication, visual supports, and trained interpreter collaboration, the program redefines accessibility to encompass linguistic, cultural, and cognitive dimensions, setting a new standard for caregiver support.

A pilot version of the program was implemented within the existing *ABI 101* education series, a foundational caregiver education class at the hospital. Due to a decrease in inpatient admissions of clients with ataxia during the implementation phase, the author shifted focus toward enhancing the *ABI 101* curriculum with explicit recommendations and content related to ataxia. A specific section on ataxia was incorporated, addressing balance, coordination challenges, and fall prevention strategies relevant to caregivers. This integration allowed the program to reach a broader audience while ensuring that ataxia-specific needs were not overlooked.

The program also diverges from traditional didactic methods by incorporating role-play, support groups, and peer learning to enhance engagement and comprehension. It empowers caregivers not only to retain information but also to internalize and apply it confidently in real-life scenarios. These strategies reflect a deep understanding of adult learning needs and situate caregivers as active partners in the rehabilitation process. This shift from passive recipients of information to empowered care partners represents a significant evolution in caregiver education, setting a precedent for future program development and inspiring all involved in the process with its potential for transformative change.

8.3 Improvement of Practice and Interprofessional Collaboration

The implementation of this program has the potential to significantly enhance interdisciplinary clinical practice. Occupational therapy practitioners, physical therapists, nurses, speech-language pathologists, and physicians often face challenges in engaging caregivers with Limited English Proficiency (LEP) due to language gaps, time constraints, or a lack of training in inclusive communication. This initiative provides a structured, interpreter-integrated program with ready-to-use materials and session guides, thereby reducing the burden on providers while enhancing the quality of caregiver engagement. It also models effective strategies for collaborative communication, helping clinicians develop more inclusive habits that can extend across their caseloads. The program fosters interprofessional collaboration by encouraging departments to collaborate and standardize caregiver education processes, thereby strengthening the overall discharge planning process and enhancing continuity of care from hospital to home.

8.4 Enhancing Client and Caregiver Well-Being

At its core, the program is designed to improve the well-being of both patients and caregivers. Research has consistently shown that caregiver preparedness is a strong predictor of patient outcomes, including functional recovery, hospital readmissions, and quality of life. LEP caregivers, however, often face compounded stress due to a lack of accessible information, reduced participation in care decisions, and limited opportunities to ask questions or express concerns. These challenges can lead to mismanagement of home routines, medication errors, or caregiver burnout. By equipping caregivers with linguistically appropriate tools and validating their role in the care team, this program has the potential to significantly reduce caregiver stress, increase confidence, and enhance the accuracy and consistency of home-based care. It also promotes cultural humility among providers, creating an environment in which caregivers feel seen, heard, and supported, fostering a sense of empathy and understanding among all involved.

This doctoral project will make significant contributions to the occupational therapy profession in several key ways. First, it exemplifies the application of occupational justice in practice by dismantling language-based barriers to caregiver education. Second, it demonstrates how occupational therapy practitioners can lead systems-level change through program development, caregiver advocacy, and inclusive design. The focus on caregivers as occupational beings, individuals who engage in caregiving as a meaningful, identity-shaping occupation, reinforces the profession's commitment to holistic, person-centered care. The program lays the groundwork for ongoing research and policy development. Its evaluative component, which includes both quantitative and qualitative measures of caregiver confidence and participation, can inform broader institutional strategies for the inclusion of LEP. The tools, frameworks, and protocols developed for this initiative can be adapted for other conditions and settings, serving as a replicable model for inclusive education across the continuum of care.

8.5 Long-Term Impact and Future Directions

As healthcare systems grow increasingly diverse, there is a pressing need for models that promote equitable access to information and support. This project anticipates that need by building a foundation for language justice in caregiver education. Future directions include integrating the program into electronic medical record systems for broader dissemination, training staff on interpreter-inclusive education methods, and expanding the program to community settings. The project has the potential to influence not just a single hospital unit but the culture of rehabilitation practice more broadly. This accessible caregiver education program represents a timely, necessary, and forward-thinking contribution to neurorehabilitation and the occupational therapy profession. It aligns with global calls for inclusive health communication, strengthens caregiver capacity, improves client outcomes, and models a justice-oriented approach to practice. By centering the voices of caregivers with Limited English Proficiency (LEP), rehabilitation professionals are challenged to reimagine what equitable care looks like and how occupational therapy practitioners can lead the way, instilling a sense of hope and optimism for the future.

APPENDIX A – Pre & Post *ABI 101* Survey

Caregiver’s Name: ___________________________________
Patient's Name: ____________________________
Date: _____________________________________
Patient's Occupational Therapist (OT): _____________________________________
Patient's Unit (Acute, Inpatient, Outpatient): ____________________________
Pre/Post Class

This survey is to determine your knowledge as the caregiver of patient with an acquired brain injury (ABI) prior to taking the *ABI 101* class and after further education during their stay on rehab.

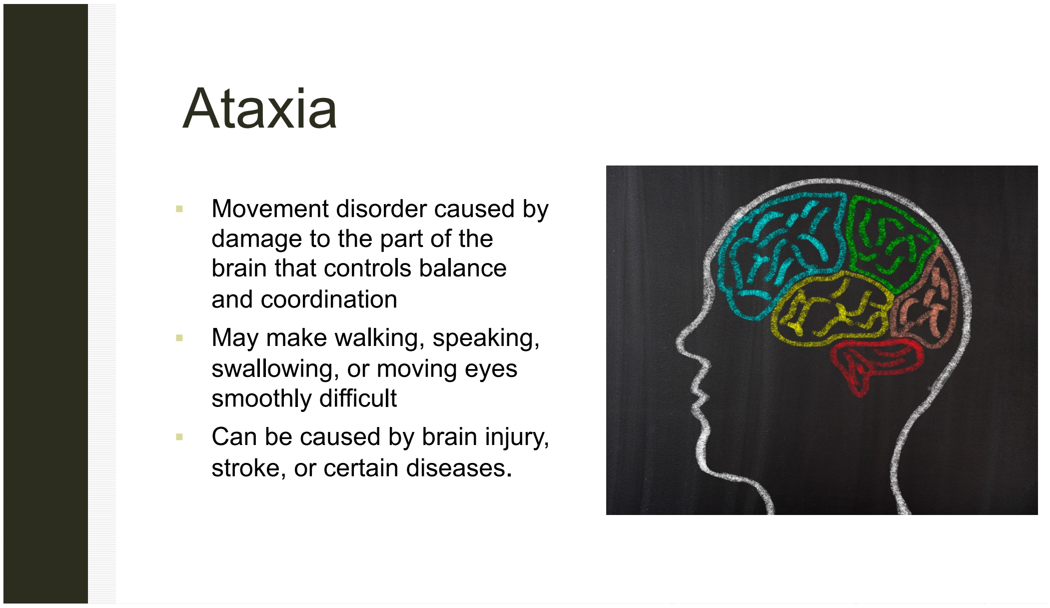
I received information and guidance on the problems that a brain injury can cause:

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Memory and concentration problems					
Slowness in processing different kinds of information					
Aggression					
Depression					
Stress disorders					
Hearing problems					
A feeling of dependence					

I received information and guidance that a brain injury may impair the patient’s:

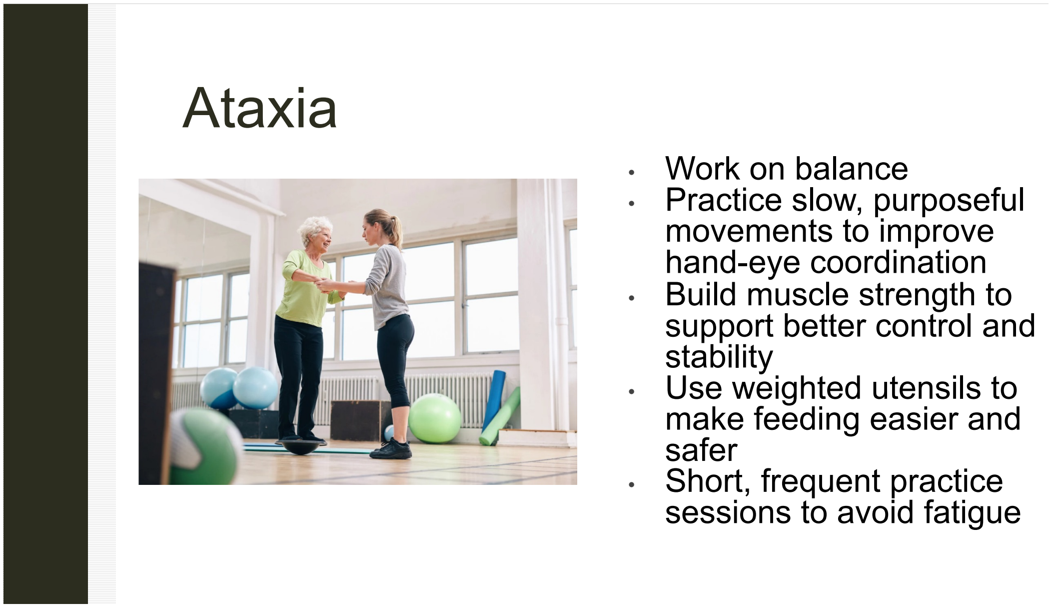
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
Ability to take care of themselves					
Ability to survive independently					
Functional outcome					
Interaction					
Ability to manage free time					
Financial performance					

APPENDIX B – *ABI 101* Ataxia PowerPoint Slides



Ataxia

- Movement disorder caused by damage to the part of the brain that controls balance and coordination
- May make walking, speaking, swallowing, or moving eyes smoothly difficult
- Can be caused by brain injury, stroke, or certain diseases.



Ataxia

- Work on balance
- Practice slow, purposeful movements to improve hand-eye coordination
- Build muscle strength to support better control and stability
- Use weighted utensils to make feeding easier and safer
- Short, frequent practice sessions to avoid fatigue

APPENDIX C – Executive Summary

Ataxia is a neurological condition that affects coordination, balance, and motor control. As individuals with ataxia transition from inpatient rehabilitation to home, family caregivers often become their primary support system. This transition presents unique challenges for caregivers with limited English proficiency (LEP). These individuals often face language barriers that prevent them from fully understanding medical information, instructions for home care, or rehabilitation techniques. As a result, caregivers may experience high levels of stress, confusion, and a lack of confidence in their ability to provide safe and effective care. These barriers affect caregivers, contribute to adverse patient outcomes, and compromise the overall quality of care after discharge.

To address these concerns, this researcher developed a caregiver education program for limited English proficiency (LEP) caregivers of patients with ataxia. The program, deeply rooted in cultural sensitivity, aims to improve caregiver confidence, knowledge, and communication while promoting patient safety and occupational justice. By recognizing and respecting the unique cultural backgrounds of caregivers, this program aims to ensure that all caregivers, regardless of their language ability, can effectively support their loved ones during the critical period of transitioning home from inpatient rehabilitation.

LEP caregivers are often excluded from traditional caregiver education programs due to the lack of language-accessible resources and the limited availability of interpreter support. The U.S. Department of Health and Human Services mandates that all healthcare entities receiving federal funding provide meaningful access to services for individuals with limited English proficiency. This requirement aims to improve health outcomes by ensuring effective communication among healthcare providers, patients, and their caregivers. However, the implementation of educational resources explicitly aimed at LEP caregivers in inpatient rehabilitation settings is often inconsistent and inadequately addressed (U.S. Department of Health and Human Services, Office for Civil Rights, 2016). This educational gap is particularly concerning for individuals caring for patients with complex conditions like ataxia, which require specialized support for mobility, balance, and daily living activities.

Project Overview

This caregiver education program is designed to address this gap through a multi-component intervention. The program includes bilingual and plain-language handouts that cover essential topics such as understanding ataxia, fall prevention, safe mobility and transfers, medication management, and recognizing signs that require medical attention. These handouts are written at a 5th- to 6th-grade reading level and include visual supports to enhance comprehension. In addition to written materials, the program will eventually offer short video demonstrations with step-by-step guidance for key tasks subtitled in multiple languages. These videos will reinforce learning and serve as ongoing resources that caregivers can reference at home.

A central program component is a hands-on caregiver training session in the inpatient rehabilitation unit. These sessions are led by occupational therapy practitioners

(OTPs) and supported by medical interpreters or bilingual staff. During the training, caregivers practice real-world care tasks in simulated home environments, allowing them to build confidence and ask questions in a safe and supportive setting. Finally, caregivers are offered a follow-up in the outpatient setting to reinforce learning, answer questions, and provide additional support.

The program is grounded in several theoretical frameworks. Pechansky's Theory of Access guided the development and evaluation of the program, ensuring that services were available, accessible, and acceptable to LEP caregivers. This theory emphasizes the importance of removing barriers to access, such as language and providing services in a way that is culturally sensitive and acceptable to the target population (Pechansky & Thomas, 1981). Adult Learning Theory informed the teaching strategies used in training sessions, emphasizing the importance of relevance, active learning, and respect for caregivers' lived experiences. The Occupational Justice Framework also shaped the program's overall approach, advocating for equitable opportunities for caregivers to participate meaningfully in their caregiving roles regardless of language ability or educational background (OTPF, 2020).

To better understand the needs of caregivers, the author conducted a needs assessment through surveys and interviews with caregivers, therapists, and interpreters. The feedback collected helped shape the program's content and delivery to reflect the caregivers' cultural, linguistic, and emotional needs (Bourke-Taylor et al., 2010). A pilot version of the program was implemented in an inpatient rehabilitation unit with a small group of LEP caregivers representing different language communities. Pre- and post-training surveys assessed caregiver confidence, perceived preparedness, and satisfaction with the education provided. Occupational therapy staff also provided feedback on the program's feasibility and value.

Key Findings

Preliminary findings suggest that caregivers felt more confident and less anxious after participating in the program. Caregivers appreciated the opportunity to ask questions, practice skills, and receive information in a format they could understand. Staff reported greater caregiver engagement and noted that communication improved when interpreters were integrated into the education process. Despite the challenges encountered, the overall feedback indicated strong support for the program's continuation and its potential for expansion, offering hope and optimism for the future of caregiver support.

Recommendations

Based on these results, the author recommends that hospitals and rehabilitation facilities formally adopt structured caregiver training programs for LEP families as part of their discharge planning process. Healthcare systems should invest in multilingual resources and partner with interpreters and cultural liaisons to co-design caregiver materials that reflect the diverse populations they serve. Additionally, OTPs and other rehabilitation providers should receive training on how to teach LEP caregivers and collaborate effectively with language access services. From a policy standpoint, there is a need to advocate for institutional support and dedicated time for caregiver education, particularly in underserved and linguistically diverse communities. These recommendations are not just a call to action but a source of inspiration for the future of caregiver support.

Conclusion

This caregiver education program offers a practical, person-centered solution to a long-standing health disparity. It provides caregivers of patients with ataxia the tools and support they need to care for their loved ones confidently and safely. By addressing the intersection of language, health literacy, and rehabilitation, the program not only promotes more equitable care but also reinforces the role of occupational therapy in advancing health justice (Levasseur & Carrier, 2012). This model can be adapted for other chronic conditions and settings, contributing to more inclusive and effective healthcare systems and inspiring all of us to strive for better health justice.

APPENDIX D – Fact Sheet

BOSTON UNIVERSITY

Stronger Together: Increasing Access to Ataxia Education for Caregivers with Limited English Proficiency (LEP)

Hannah Schmid, MS, OTR/L
PP-OTD Candidate

The Problem

(Damen, 2025)

- Ataxia is a progressive neurological condition characterized by impaired coordination affecting balance, gait, fine motor skills, and speech (Mariotti et al., 2005)
- In the U.S., approximately 8.5% of individuals aged five and older (nearly 25 million people) are classified as having LEP (Ramirez et al., 2023)
- LEP can lead to lower satisfaction levels due to significant barriers to healthcare access and communication, reduced inclusion in health-related discussions, and disparities in health outcomes (Smirnoff et al., 2018; Fernández et al., 2010; Linsky et al., 2010)
- Disproportionately affects LEP caregivers who communicate health information on behalf of others (Harris et al., 2017; Duong & Tran, 2024).

(Johns Hopkins Center, 2025)

The Solution

Introducing a culturally sensitive, multilingual caregiver education program, designed by occupational therapy practitioners (OTPs). The key features including multilingual educational materials and visual aids, interpreter-integrated, hands-on training from neurorehabilitation-certified OTPs, regular peer support groups facilitated by psychologists, and ongoing training throughout the continuum of care from inpatient rehabilitation to outpatient therapy upon discharge home.

Theory and Evidence-Base

- Pechansky's Theory of Access: Improving availability, accessibility, and acceptability of education for LEP caregivers
- Albert Bandura's Social Learning Theory: Advocating for equitable participation in caregiving role
- Adult Learning Theory: Building confidence through real-world practice, relevance, and reflection

Potential Funders

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR): ($50K–$500K/year)
- LA Care Community Health Fund ($25K–$75K)
- California Wellness Foundation ($50K+)
- Boston University Sargent College Grants ($1K–$10K)
- Rancho Los Amigos Foundation ($5K–$20K)
- USC Community Engagement Grants ($2K–$10K)
- Kaiser Permanente ($10K–$50K)

Estimated funding costs are $7,400 for the first year and $5,400 for the second year

(Renken, 2020)

Impact on Future Occupational Therapy Practice

- Increase caregiver confidence and competence in taking care of someone with ataxia
- Promote health equity through language-accessible education
- Reduce falls, readmissions and caregiver burnout
- Enhance community and clinical partnerships

Next Steps

- Expand the pilot program using in-kind resources and volunteer staff
- Evaluate program outcomes using qualitative and quantitative measures
- Disseminate findings through conferences, social media, and community health networks
- Scale the program across additional healthcare settings

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