

PATIENT-CENTERED EDUCATION AND CARE COORDINATION INITIATIVE TO
IMPROVE SELF-MANAGEMENT SKILLS IN LATINOS WITH MULTIPLE SCLEROSIS

A Doctor of Nursing Practice Project Report

by

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BSN, University of Phoenix, 2013
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This Doctor of Nursing Practice Project Report meets the standards for scope and quality of Texas A&M University-Corpus Christi College of Nursing and Health Sciences and is hereby approved.

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DEDICATION

I want to share the credit of my work with my husband Gerardo Galvan and our two beautiful boys, Gerardo Jr. and Caleb. For their unending support and sacrifice to make my dream possible, I am thankful. I would like to thank God for being with me through this journey and allowing me to get to this point in my professional life.

To God be the glory.

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ABSTRACT

Multiple sclerosis (MS) is a chronic, disabling neurological disease that attacks young adults. Similar to many other chronic conditions in patients with MS, self-management skills can improve the quality of patients' lives. However, improvement of self-management skills remains a challenge in patients with chronic diseases, especially Latino patients with MS who struggle with language barriers and low health literacy. This quality initiative project involved the implementation of a new process for educating MS patients and coordinating their physical and occupational referrals in a privately owned neurology outpatient clinic in an urban city of Texas. A one-group, pre-test/post-test design guided the project. Baseline data were collected in the first week, followed by eight weeks of implementing changes. There was a statistically significant improvement in pre-education and post-education Multiple Sclerosis Self-Management Revised Scale (MSSM-R) scores. Post-intervention score ($M = 94.7$, $SD = 3.6$) was significantly higher than before intervention score ($M = 80.7$, $SD = 7.7$, $t(7) = 5.600$, $p = .001$, $d = 1.97$). This quality initiative project demonstrates that culturally sensitive, patient-centered education and care coordination can positively impact MS knowledge, communication, and self-management skills in Latinos with MS.

Keywords: Latinos, multiple sclerosis, Multiple Sclerosis Self-Management Revised Scale, quality improvement initiative, patient-centered care coordination

Patient-Centered Education and Care Coordination Initiative to Improve Self-Management Skills
in Latinos with Multiple Sclerosis

INTRODUCTION

An estimated one million people live with multiple sclerosis (MS) in the United States (Wallin et al., 2019). MS cases in Latinos or Hispanics have been underrepresented, which makes it hard to have a proper estimate for its prevalence among the populations. (Khan, 2015). MS is a devastating chronic disease that affects young adults in the prime time of their lives, causing irreversible physical and mental disability (Giovannoni et al., 2016). This demyelinating disease is more common in women than in men, with a 3.1:1 female to male ratio (Miclea et al., 2019). MS affects not only the quality of life but also the length of life of a person. A recent study shows a seven-year shorter life expectancy and almost a three-fold higher mortality in MS than in the general population (Lunde et al., 2017). Latino patients with MS face particular barriers that make managing this chronic illness even more difficult. These disparities are influenced by socio-demographic, behavioral, social, and societal factors, including language and cultural barriers, lack of access to health care, and structural discrimination (NIMHD, 2018). A recent study shows that Hispanic patients were 40% less likely to see an outpatient neurologist compared to non-Hispanic Whites (Mercado et al., 2020). Through patient education and coordination of specialty care, specifically physical therapy (PT) and occupational therapy (OT), this quality improvement (QI) initiative aimed to improve self-management skills in Latino adults with MS attending an outpatient neurology specialty clinic in Texas. Except when

referenced statistics specifically refer to “Hispanics¹,” the “Latino²” designation will be primarily used in this project to refer to people mostly of Mexican origin whose native language is Spanish.

Hispanics comprise 39.7 % of Texas’s total population (United States Census Bureau, 2019). Genetic diversity in Hispanics can affect the MS’s risk, clinical expression, and long-term outcomes (Amezcuca et al., 2017). Hispanics present with MS about three to five years younger and have more severe disease than non-Hispanic whites (Amezcuca & McCauley, 2020). Unfortunately, this is a progressive disease, so the younger the presentation, the more time for the disease to cause disability. Studies show that Hispanics with MS who immigrated at a later age to the United States are twice as likely to have an ambulatory disability than US-born Hispanics with MS (Obiwuru et al., 2017). Statistics show that approximately 40% of all people with MS in the United States rely on some form of disability insurance for their income (National Multiple Sclerosis Society, 2020).

Background

Review of Literature

Hispanics’ lack of awareness of MS, its treatments, and their different illness perceptions could affect disease management (Obiwuru et al., 2017). Latino patients with MS face particular barriers that make managing this chronic illness even more difficult. There are racial and ethnic

¹ Hispanic refers to people who speak Spanish or descendants of those from Spanish-speaking countries (Cuncic, 2020).

² Latino refers to geography: specifically, people from Latin America, including Central America, South America, and the Caribbean (Cuncic, 2020).

effects that suggest Hispanics to be a high-risk population for early disability and worse prognosis (Moccia, 2016). MS literature suggests that health literacy is one of the most effective factors on the knowledge level controlling and preventing the disease (Jafari, 2020). D'hooghe et al. (2016) conducted a cross-sectional survey among all persons with MS registered by the Flemish MS society, Belgium; a total of 1372 participants were included. The study found a reduced risk of progression in participants with relapsing-remitting onset MS and higher education levels.

MS patients are faced with multiple decisions, including choosing a disease-modifying drug with different mechanisms of action and different side effects and lifestyle choices that can affect their MS progression. Today, many patients draw upon information from the internet to learn about their disease. Moccia et al., 2016 conducted a search by entering “multiple sclerosis” on the international version of Google and identified that the narrative complexity of patient-oriented MS-related websites might prevent the successful transmission of health care information, inducing patients and caregivers to refer to more easily readable but less accurate sources of information. There is a gap between the readability of websites’ content and the need for information for people with MS, making an imperative call to the MS health care team to fill this gap and be the principal source of information for patients with MS.

Waltrip et al. (2021) conducted a study using an online survey assessing relapse characteristics and interactions with the HCPs. Participants were 18 years and older, diagnosed with MS, and currently using a disease-modifying therapy. The mean age of the 126 participants was 49.2 years, 81.0% were female, and most (80.2%) had one or more relapses in the past two years. Less than half (46.0%) reported they were highly likely to contact their HCP during a relapse.

Self-management education has been shown to improve chronic conditions. For example, Poureslami et al. (2016) demonstrated improvement in a short version of a validated chronic obstructive pulmonary disease (COPD) Self-Efficacy Scale' results in Mandarin and Cantonese-speaking patients after exposure to a culturally specific self-management educational video in a single-center randomized clinical trial. Another randomized clinical trial with 711 subjects led by Rice et al., 2015 demonstrated improvement in self-reported asthma management behaviors in participants after exposure to an individualized asthma education session delivered by lay volunteers. Marincic et al. (2019), in a multisite study through retrospective chart review of 392 records, found that in patients with diabetes, programs offering access to diabetes self-management education resulted in improved glycemic control and risk reduction of other comorbidities, including high cholesterol.

In addition to the need to improve patient education, care coordination has become a high priority for healthcare systems and management. Care coordination has been recognized as an essential aspect of high-quality health care delivery, and failure of care coordination results in medication errors and frustration among patients and caregivers (Srivastava & Prakash, 2018). The rising prevalence of chronic diseases and the disability progression that patients with MS face drove this QI initiative to improve patients' knowledge so they could better communicate with their providers, be more involved in their health decision-making, and improve their self-management skills.

Description of the Problem in the Setting

People with long-term health conditions play an important role in managing their health, and patients with MS are no exception; they need to be empowered and knowledgeable about this complex disease. MS presents with a wide variety of symptoms, involving some of the

original symptoms, including intention tremor, nystagmus, and scanning speech (Tauil et al., 2019). Today, the MS symptoms list has grown to include muscle weakness, loss of coordination, cognitive impairments, vision problems, and bladder and bowel dysfunctions (Fasczewski et al., 2020). Approximately 85% of people with MS report gait disturbances as their main complaint, and within 15 years of MS onset, up to 50% of them will require walking assistance (Kalron & Frid, 2015). Galli et al. (2015) have shown progressive gait disturbances directly correlated with increased disability scores in patients with MS.

An additional compounding problem is the intricate rules from different health insurances, making the coordination of needed health services complicated and time-consuming. Referrals for subspecialties, such as physical therapy, can take several weeks to be processed, delaying the scheduling of patients for evaluation. In this neurology outpatient clinic, there was no tracking of referrals resulting in long waiting periods for additional services or patients not receiving services at all due to insurance barriers and time delays, leaving only the providers to determine the patients' progress until specialty visits were scheduled. Referral delays also resulted in fragmented communication between the neurologist and the physical therapist. Coordinated physical therapy (PT), occupational therapy (OT), and mental health care services reduce morbidity in MS (Roddam et al., 2019).

The unmet health care needs of patients with MS depend mainly on clinical factors such as disease stage and disease duration, whereas the social care needs are related to both clinical and socio-demographic factors (Ponzio et al., 2015). Thus, not all patients have the same needs, and their needs change over time, so patient empowerment with knowledge on MS symptoms, progression, and self-care and delivery of coordinated physical therapy services becomes crucial in this patient population.

The complex needs of patients with MS require care coordination, which can help break the barriers to evidence-based care, such as access to care, delay to care, transportation issues, access to medications, and communication with and between care providers. The Centers for Medicare and Medicaid (CMS) acknowledge that care coordination is a critical component of chronic care management, contributing to better health outcomes and cost reduction (CMS, 2015). Currently, the direct medical costs of MS in the United States may exceed \$ 10 billion a year (Zwibel & Smrtka, 2011). Care coordination and health-focused education of patients with MS may improve self-management skills for this population. This QI initiative was thought to be feasible in the neurology outpatient clinic because of the existing infrastructure required to accomplish the intervention.

This QI project was conducted in a privately owned neurology outpatient clinic in an urban Texas city, focusing on patients with MS; 40% of the patients identify as Hispanic or Latino. This percentage included patients who received MS care, including disease-modifying therapies and referrals for other needed services such as physical therapy or mental health services. Due to the complexity and nature of this disease, educating patients on all symptoms, disease types, treatment options, self-management skills, and health-related services that could benefit them was challenging. Hence, patients often received suboptimal education regarding their disease.

The project director (PD) conducted an assessment at the clinic to determine the existing gaps in care. I interviewed 30 patients and asked them how comfortable they were with their MS knowledge based on the information they received from providers and what they have learned about MS independently. Ten percent of patients' charts seen in a month that met the inclusion criteria of this QI initiative were reviewed. In addition, the PD looked for care plans or any

documentation of communication among physical therapists, occupational therapists, and neurologists. Only 10% of the patients had a recent referral to PT/OT, but none had an updated care plan. In addition, only one percent of the patients had their Expanded Disability Status Scale (EDSS) exam on file; The EDSS is a method of quantifying disability in MS and monitoring changes in the level of disability over time (MS Trust, 2020). Only one percent had documentation on patient education on any related MS topics, including self-care. The author found gaps in MS education documentation, EDSS exam, and no individualized care plan for each patient when sent for physical therapy.

Theoretical Frameworks

This Quality Improvement project was guided by the Plan-Do-Study-Act (PDSA), a model for improvement that provides a framework for developing, testing, and implementing changes leading to improvement (Institute for Healthcare Improvement, 2020). This project is the first PDSA cycle of quality improvement for Latino patients with MS attending a neurology clinic in Texas. In addition to the PDSA model, this QI initiative was guided by Dorothea Orem's Self-Care Deficit Theory of Nursing.

Dorothea Orem's Self-Care Deficit Theory of Nursing was developed between 1959 and 2001; it is considered a grand nursing theory (Orem's Self-Care Deficit, 2020). It comprises four related parts: the Theory of Self-Care, the Theory of Self-Care Deficit, the Theory of Nursing System, and the Theory of Dependent Care which addresses not only the individual in need of care but also the caregiver (Taylor & Renpenning, 2011). This theory was chosen to guide this QI initiative because its core goal is improving self-care in patients, and its principles support the patient to be self-reliant and responsible for their care. Successfully meeting universal and developed self-care requisites is an essential component of primary care prevention. A person's

knowledge of potential health problems is needed for promoting self-care behaviors. Orem's Self-Care Deficit Theory of Nursing guided the philosophy of practice change in this quality improvement project (see Figure 1).

Project Purpose

The purpose of this QI initiative was to improve the self-management skills of adult Latino patients with MS through bilingual educational videos and patient-centered care coordination, including physical and occupational therapy care. The clinical question guiding this quality improvement initiative was: In Latino adults with MS treated in a Texas neurology clinic, do bilingual MS educational videos and patient-centered care coordination including physical and occupational therapy care improve patient self-management skills over eight weeks? This project exemplified Essentials IV and VI of the American Association of Colleges of Nursing (AACN) Doctor in Nursing Practice (DNP) Essentials (AACN, 2020). Essential VI refers to professional collaboration for improving patient and population health outcomes, which this project fulfilled by delivering coordinated care by collaboration between subspecialties, including neurology, physical therapy, and occupational therapy. Essential IV encompasses information systems, technology, and patient care technology for the improvement and transformation of healthcare. This QI initiative met essential IV by incorporating technology to deliver educational sessions through virtual videos. Technology also facilitated coordinated care, including telemedicine visits, a patient portal for faster communication, and electronic medical records. Phone calls and faxes were used to communicate with subspecialties. The National Organization of Nurse Practitioner Faculties (NONPF) competency this QI initiative met was the health delivery system competency delivering culturally competent care by delivering

educational videos by a person whose primary language is Spanish, with Mexican background, who understands their culture and could relate to their beliefs, values, and customs.

Project Aims

The first specific aim of the project was to achieve a statistically and clinically significant increase in the mean scores on the MSSM-R scale from pre- to post-education. The rationale for choosing this goal was supported by Poureslami et al. (2016), who found a statistically significant improvement of scores on the MSSM-R scale from pre- to post-patient educational intervention using educational videos. The second aim was to improve the clinic's coordination and individualization of PT and OT for the patient by 75% in eligible participants from pre- to post-implementation. The rationale for selecting this goal was based on the practice MS guidelines described by the American Academy of Neurology and its subcommittee report of a systematic review of rehabilitation in MS (Haselkorn et al., 2015).

METHODS

Project Design

This quality improvement initiative used a pre and post-design to improve self-management skills through patient-centered education and care coordination in a neurology outpatient clinic. The staff from the neurology outpatient clinic embrace patient education but faced difficulties, including limited-time allocation for teaching and the language barrier. Providers understand that communication with other disciplines is an essential component of delivering care to the MS population. This QI initiative was aligned with the providers' philosophy of caring for this population, so they were able to envision a successful implementation of this project in the clinic. The minimal time allocated for patient education in a fast-paced neurology outpatient clinic was the reason for selecting this design. Barriers that

affected the success of this project included the current COVID-19 pandemic, which made it difficult to recruit patients. Second, the multiple insurance intricacies made the process more time-consuming. Having a PT case manager in the team helped mitigate the encountered barriers by coordinating the referrals with different PT agencies. Using videos for PT exercises at home and telehealth follow-up visits helped ease the barrier encountered with the pandemic. Please refer to Table 1 for facilitators and countermeasures to mitigate these various risk factors.

Three educational sessions empowered the patient with increased knowledge of MS and MS self-management skills; and encouraged them to become more involved in decision-making regarding their treatment plan. The educational sessions were provided to the patient via short videos. MS knowledge, management skills, and decision-making involvement were measured using a pre-and post-Multiple Sclerosis Self-Management Revised Scale score (MSSM-R; Saadat et al., 2020).

A PT care manager tracked the PT/OT referrals to help with coordination. A care plan was added to each participant's electronic medical record (EMR) and updated as needed, including initial evaluation of patients' individualized goals. A completed (EDSS) exam was scan in the EMR to have a baseline and help monitor disability over time and be able to offer timely interventions. Patient-centered care coordination was measured by conducting a chart review one month before implementation and post-implementation to determine the number of educational sessions patients had received or attended, documentation of coordinated referrals with PT and OT, and up-to-date care plans including PT and OT, and a completed EDSS.

Ethics Considerations

This project plan was reviewed by Texas A&M University-Corpus Christi (TAMUCC) Research Compliance Office and received a determination of "Not Human Subjects Research"

and permission to proceed as a quality improvement project. Refer to the Letter of Determination in Appendix A. The clinic manager provided a letter of support agreeing to fully support the project and acknowledged the collection of Personal Health Information (PHI) for QI purposes only (Appendix B). Personal Health Information was collected for QI purposes only, and confidentiality was protected using alphanumeric identifiers on all collected data and analysis.

Setting

This quality improvement project was conducted in a privately owned neurology outpatient clinic located on the north side of San Antonio, Texas. This clinic was one of only three MS clinics in San Antonio offering specialized care in MS and patients who live near Mexican border towns and the Rio Grande Valley of Texas. Approximately 20% of patients travel long distances, approximately 250 miles, to see a neurology specialist. The clinic was operated by one neurologist specializing in MS, two family nurse practitioners (NPs), and medical assistants (MAs). Providers delivered care to about three thousand established patients with MS. The patient population was approximately 40 % Latino, 10% African American, and 50% Caucasian.

Participants

A convenience sample was recruited from all interested patients established in this clinic during the two months before starting the project and meeting the criteria. Established patients were included if they: (1) identified themselves as Hispanic/Latino; (2) were 18 years old or older; (3) were diagnosed with a relapsing form of MS; (4) had an EDSS score of less or equal to 8; (5) were able to log on to the patient portal; (6) had a smartphone or home internet access; and (7) were interested in participating. The reason for excluding patients with an EDSS higher than 8 was that those patients had advanced disability levels and were restricted to bed most of the

day. The sample size was projected to be a minimum of 50% of participants from the 30 that met the inclusion criteria. However, due to the clinic's unexpected closure due to severe weather, only 8 participants were included in the QI initiative.

Intervention

Project Team

The project team included a family nurse practitioner, Multiple Sclerosis Certified Nurse (MSCN), who acted as the PD, a PT case manager, and a medical assistant. The PD created six educational videos, three in English and three in Spanish, performed EDSS exams, initiated the PT/OT referrals, administered the baseline and final MSSM-R to participants, and sent the emails to patients with the link to view educational videos. The medical assistant sent referrals, scheduled follow-ups, scanned care plans and updates into the EMR, and faxed additional information, including patients' demographics, to the PT case manager. The PT case manager kept direct contact with all the PT clinics and collected care plans for the PD to review and sign. The PT case manager also gave patients unable to afford PT services the link for virtual PT exercises from the *Above MS* website (Above MS, 2021) to practice at home.

Action Plan

One week before the project implementation, I held a meeting for all staff to introduce the project's goal and staff responsibilities to carry out the project. The PD conducted a review of current patient medical records to determine eligible patients and contacted patients via telephone to explain the QI initiative and determine if they were interested in participating. If interested, the PD informed the MA to schedule a face-to-face visit for the patient. During the first visit, the PD collected all demographic data not available in the EMR and performed an EDSS exam. At the end of the visit, the PD gave the patient instructions on how to complete the

MSSM-R and allowed time for its completion. The PD collected the baseline MSSM-R, scored it, and added the result to the data collection excel spreadsheet.

The PD created a total of six videos. The same three topics were translated from English to Spanish. The PD sent to participants via email or text the link of three short educational videos of approximately fifteen-minute each in one-week intervals. The PD provided these educational sessions with options of face-to-face meetings after their initial and follow-up visits in the clinic, a telehealth visit, or via a secure video hosting website that has the analytics to track video traffic called secure.vidyard.com. The topics covered were: What is Multiple Sclerosis? Que es Esclerosis Múltiple? Eating Well, Comiendo Bien, and What is a Relapse? Que es una Recaída? The MAs received training for initiating the PT and OT referrals with the assistance of the PT case manager. The PT case manager ensured that the PT evaluation and care plan was initiated and sent to the PD for signature. The PT case manager gave biweekly updates to PD. The PD reviewed the care plans, approved them by signature, and the MA scanned it into the EMR. New care plans and updates were shared between specialties via fax and scanned into EMR. For a visual representation of the timeline of this QI project, refer to Figure 2.

Implementation

The participants were recruited between February 1 through 5, 2021, and scheduled for the first visit. Changes were made to the QI timeline due to unexpected barriers encountered. The initial recruitment included 13 participants, but three dropped out due to the Covid-19 pandemic. Also, the QI initiative was reduced from twelve to eight weeks after being faced with rescheduling all the patients for the initial visit because of the unexpected closure of the neurology clinic due to a week of inclement weather. The unexpected weather in Texas affected providers' and participants' internet services, so virtual visits were also unavailable. One

participant was seen via telemedicine for the initial visit due to the increased disability state and the long-travel distance of 248 miles between his residence and the clinic.

The initial plan evolved from simultaneously coordinating the referrals to PT/OT and delivering the educational sessions to dividing the intervention into two phases. The first phase was concentrated on the PT/OT referrals, followed by the second phase of delivering one educational video weekly for participants to watch. Having the videos in a website delivered directly to the participants' email was essential for the success of the QI initiative's education program. The website www.vidyard.com is a secure website that helped with traffic tracking of persons who watched the video and even tracked the percentage of each video seen. The coordination of PT/OT consumed more time than anticipated due to insurance barriers, including high copays for patients. A virtual option for PT was introduced to assist patients unable to afford the copay associated with inpatient PT/OT visits. The virtual exercise and fitness program given to patients to practice from home was from the *Above MS* website (Above MS, 2021); this is a virtual community offering education and healthy lifestyle information for people with MS. The contributors were experts in the field, fitness instructors, and occupational therapists. After the intervention was over, most of the patients verbally reported an improvement in their understanding of MS as a disease and their confidence in adopting healthy lifestyle changes.

Measurement Tools

The Multiple Sclerosis Self-Management-Revised scale (MSSM-R) included in Appendix C was the selected measuring tool to evaluate patient MS knowledge and self-management skills. The MSSM-R is currently the only available tool developed specifically to address self-management among individuals with MS. It is a reliable tool with a Cronbach's $\alpha = 0.85$ (Ghahari et al., 2014). Ghahari et al. (2014) evaluated the criterion, test-retest reliability,

and face validity of the MSSM before revision. There was no statistical difference between Time 1 and Time 2, suggesting satisfactory test-retest reliability (Ghahari et al., 2014). The mean score was 3.31, suggesting moderate face validity of the MSSM from the perspective of people with MS (Ghahari et al., 2014). The scale is based on a 0 to 100 scale in which higher scores indicate a higher degree of self-management. It consists of 24 questions, and the answers are based on a scale of 1 through 5 where 1 means “I completely disagree,” and 5 is “I completely agree.” The scores for questions 21, 23, and 24 had to be reversed before scoring the final result. The questions included in the MSSM-R address issues regarding healthcare provider (HCP) relationship and communication, treatment adherence and barriers, social and family support, MS knowledge and information, and health maintenance behavior (Bishop & Frain, 2011). One example of the questions included to assess MS knowledge and information is, “I feel like I understand what MS is.” An example of a question addressing HCP relationship and communication is, “My medical provider is very willing to answer all of my questions.” Questions such as “I am confident I need to take my medication to be healthy” focus on treatment adherence and barriers. Other statements such as “I feel I have a lot of emotional support from my friends and family,” address social and family support, and “I avoid getting overheated when possible” are included to address health maintenance behavior.

Data Collection

A week before starting the project and having a list of the participants willing to participate in the QI initiative, the PD collected demographics available from the EMR. Demographic data included the patient's: years since diagnosis, age, gender, marital status, race, monthly household income, the highest level of education achieved, employment status, cigarette smoking habit, number of days exercising per week, and last PT/OT referral. PD collected

weekly data on videos seen by patients. The baseline EDSS, documentation of educational sessions provided, and baseline and final MSSM-R were also collected by PD. In addition, the PD collected biweekly data on the presence of a PT and OT referral, care plan, and any updates. Please refer to the timeline in Figure 2 for a visual diagram of the estimated time it took to conduct each component of this project, from IRB approval to disseminating results.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) version 26 software was used to analyze the QI data. Descriptive statistics were used to summarize the demographics and clinical characteristics of the patients with MS. These characteristics included years since diagnosis, age, gender, marital status, race, monthly household income, the highest level of education achieved, employment status, cigarette smoking habit, number of days exercising per week, and last PT/OT referral. A table was used to display the results (Table 2).

The first aim of this QI initiative was to improve self-management knowledge and skills through a series of bilingual educational sessions. To determine if specific Aim 1 was met, pre- and post-intervention MSSM-R scores were compared using the paired t-test to determine if there was a significant improvement after the educational modules. In addition, the number of videos viewed by each patient was reported on a bar chart.

The second aim was to improve the clinic's coordination and individualization of physical and occupational therapy referrals. To determine if specific Aim 2 was met, the percentage of eligible patients who received PT/OT referrals, individualized care plan, updates, and completion of the EDSS was reported. The alpha level for all statistical tests in the analysis was $p < .05$.

RESULTS

Characteristics of Demographic Data

The sample consisted of 8 participants. The eight participants identified as Hispanic or Latino, and their ages ranged from 31 to 65 ($M = 49.1$, $SD = 12.9$). Year since diagnosis ranged from 2 to 28 years ($M = 14.1$, $SD = 9.7$). The last PT/OT referral ranged from one year to more than ten years. As expected in MS populations, there were more women (62.5%) than men (37.5%). Their mean baseline MSSM-R was 80.7. For more specific demographics, refer to Table 2. The large effect size of the intervention supports this type of delivery of MS self-management education can be effective in helping Latino MS patients to understand and better manage their MS symptoms.

Outcomes

There was a significant improvement from pre-education MSSM-R scores ($M = 80.7$, $SD = 7.7$) to post-education scores ($M = 94.7$, $SD = 3.6$; $t(7) = 5.600$, $p = .001$, $d = 1.97$). A bar chart representation of videos viewed per patient is presented in Figure 3. All participants viewed all three educational videos except for one participant who only saw one video.

Seven out of the eight patients had their baseline EDSS completed (88.8% EDSS completion), as shown in Figure 4. In addition, Figure 5 represented the 50% of the participants who had PT/OT referrals, individualized care plans completed, and updates received and scanned in the patient's EMR. The four participants who did not receive PT/OT face to face received a link via email for virtual PT tailored for MS patients.

DISCUSSION

This QI initiative achieved its overall goal. Participants improved self-management skills through patient-centered education and care coordination. The significant increase of mean MSSM-R survey scores from pre- to post-intervention suggests the effectiveness of bilingual

education and patient-centered care coordination in this QI initiative. Before this project, the patients at the neurology outpatient clinic were not receiving education on their disease. Also, PT/OT referrals were sent, but no care plan or updates were scanned in the EMR until weeks after these referrals were done, or patients never got the referral, and providers would find out until the next follow-up visit. Patients did not have an EDSS exam to have a baseline and assess for any disability progression.

The significant improvements in MS knowledge and self-management reflect the impact of the intervention. Also, the enthusiasm from participants involved in the project and the high participation in watching the videos demonstrated that this QI initiative was an effective intervention in the clinic. As anticipated, the bilingual, readily available, easy to access educational videos were a successful method of implementing patient education due to the current lack of specific provider time allotted to patient education. Also, virtual learning facilitated the barrier of traveling since many of the patients with MS travel long distances to be seen in the neurology outpatient clinic. The plan was to send the link to the educational videos to the patients via email by the end of their initial visit.

The goal of completing 75% of EDSS exams was met with only one participant not completing the EDSS due to several factors, including high disability and a long-distance trip to the clinic. The process of having an annual EDSS on file for each patient with MS was instituted as a standard of care process in this neurology clinic. The new process aligned with the American Academy of Neurology (2015) MS guidelines which encouraged clinicians to have an annual EDSS for patients with MS to help offer timely interventions, thereby reducing MS progression. The 75% goal of patients receiving PT/OT referral was partially achieved. Only 50% of the patients agreed to have PT/OT referral, and these were accomplished with

individualized care plans and updates as needed. The process of monitoring the referrals changed. We encouraged the patients to update us once they started their PT/OT evaluation. We made sooner follow-up visits to make sure the referral went well and if there was a need for another referral to continue with more PT/OT. After the PT/OT referral or virtual PT was done, the patients reported more enthusiasm in adding an exercise routine to their daily routine. After viewing the “Eating Well” educational video, some participants started looking closely at their eating habits and, on their follow-up visit, asked for advice on how to improve them.

Relation to Literature

While the rationale for providing self-management skills interventions for people with a lifelong disease such as MS is acknowledged as extremely important, the self-management literature regarding MS is limited. This QI initiative is consistent with a previous study by Hemmatpoor et al. (2018), demonstrating a significant improvement ($p < .001$) in the self-management scores after educational sessions through a lecture, discussion, question and answer, and a video projector. Similar to this QI initiative, Ehde et al. (2015) had clinically meaningful benefits improving self-management intervention for fatigue, pain, depression in adults with MS by using technology to deliver the educational intervention. Waltrip et al. (2021) findings highlighted the importance of HCPs being proactive in providing education in patients with MS regarding relapse management. Based on the importance of patients distinguishing the difference between their daily symptoms and an MS relapse, this QI initiative included a video explaining a relapse.

Clinical Implications

Bilingual educational videos and patient-centered care coordination appear to be effective in improving self-management skills among adult Latino patients with MS. Based on this

project, to be successful, future QI projects on self-management of MS for Latino patients should require bilingual education on disease-related knowledge and implementing strategies to empower patients to become informed individuals fully involved in their health care. Based on this project, it is prospective to promote self-management skills and use similar intervention in other chronic conditions where education is needed. Poureslami et al. (2016) found that culturally sensitive education can improve self-management skills in other populations. Delivering the education in the patients' primary language is ideal for addressing the language barrier. Having the educational videos to deliver the education should help accommodate possible encountered barriers such as transportation. Participants should have options of where they can access the educational sessions. Participants showed a significant improvement in health maintenance behaviors and HCP relationships and communication. The care coordination of their PT/OT increased their confidence to continue improving their gait difficulties. The individualization of these services was significant to these patients. For instance, one of these patients was wheelchair-bounded and received PT/OT to strengthen his upper extremities. He had MS for 25 years and still worked part-time, helping others with disabilities. The next PDSA cycle was planned to add other educational topics, continue with bilingual delivery of the topics, continue using the virtual platform to deliver the education, and deliver PT/OT exercises for all patients to continue with PT exercises at home.

The barrier of insurance regarding PT/OT referrals was unexpected. For the next PDSA cycle, the plan was to determine the copayment amount for PT/OT before ordering the referral. Also, adding the virtual PT/OT was included as an option. After the project was done, other providers in the clinic started scheduling patients for the EDSS evaluation. The addition of more patients coming, especially to have their annual disability examination besides their routine

follow-ups, increased the financial revenue for the clinic. The EDSS visit was a 45 -minute visit and was charged as an annual exam. Having approximately 3000 patients with the diagnosis of MS, the revenue of these visits was a great help to cover the clinic overhead spending.

Implication for Future QI Projects

These findings have some relevance for future QI projects and clinical practice for the patient's promotion of self-care management. Because of the minimal number of studies and QI projects with effective interventions to reduce ethnic and racial disparities, this QI may have significant implications for the self-management of Latinos with MS.

Limitations

There are limitations to this QI initiative. One of the main limitations of this project was the small sample size, largely due to the ongoing Covid-19 pandemic, which affected the recruitment process. Many of the patients with MS were on immunosuppressive drugs and were taking extra precautions with quarantine guidelines such as avoiding unnecessary trips out of their homes. Most of them were still not vaccinated, so they did not want to participate in a project that might have required them to come to the clinic. Most of the patients were postponing any extra treatments such as referrals to PT because they were scared to become infected with the Covid-19 virus. Another limitation was the location of the clinic. The outpatient neurology clinic was located in the North part of the city, so patients coming from the southern areas of Texas usually pass the two other MS clinics before arriving at this location.

Conclusions

In this particular QI initiative project, the significant improvements in MS knowledge and self-management reflect the impact of the intervention. All the providers in the clinic embraced the project because patients were able to learn about their disease in between their visits and

actively participate in decision-making. In addition, providers could see PT/OT evaluations, care plans, and updates soon after these were done, and this enhanced communication between these specialties.

Also, the enthusiasm from participants involved in the project and the high participation in watching the videos demonstrated that this QI initiative was a positive intervention in the clinic. As anticipated, the bilingual, readily available, easy to access educational videos were a successful method of implementing patient education due to the current lack of specific provider time allotted to patient education. Also, virtual learning facilitated the barrier of traveling since many of the patients with MS travel long distances to be seen in the neurology outpatient clinic. The plan was to send the link to the educational videos to the patients via email by the end of their visit. The barrier of insurance regarding PT/OT referrals was unexpected.

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Appendix A: Determination of Not Human Subjects Research

Activities meeting the DHHS definition of research or the FDA definition of clinical investigation and involve human subjects are subject to IRB review and approval.

On 12-22-2020, the Office of Research Compliance reviewed the project below and determined that the proposed activity does not meet the FDA definition of a clinical investigation or DHHS definition of research:

Type of Review:	Not Human Subjects Determination
IRB ID:	TAMU-CC-IRB-2020-11-05
Project Lead:	Kyoung Eun Lee
Title:	Patient-Centered Education and Care Coordination to Improve Self-Management Skills in Latinos with Multiple Sclerosis
Rationale:	The project will not develop or contribute generalizable knowledge

Therefore, this project does not require IRB review. You may proceed with this project.
Limits to this determination:

1. This determination applies only to the activities described in the documents reviewed. Any planned changes require submission to the IRB to ensure that the research continues to meet criteria for a non-human subject research determination.
2. This project may NOT be referenced as “IRB approved.”

The following statement can be included in the manuscript: “This project was reviewed and determined to not meet the criteria for human subjects research by the Texas A&M University - Corpus Christi Institutional Review Board.”

Appendix B: Facility Support Letter

Neurology Center of San Antonio

Boss ◊ Bahamon ◊ Castro ◊ Clements

August 31, 2020

Dear Dr. Baldwin,

The purpose of this letter is to provide Anna Castro, a Doctor of Nursing Practice student at Texas A&M University College of Nursing and Health Sciences, support in conducting a quality improvement project at the Neurology Center of San Antonio. The project, Personalized Care Planning for Latino Adults with Multiple Sclerosis, to Increase Self-Management Skills.

The purpose of this project is to improve patients' self-care management skills. The Neurology Center of San Antonio was selected for this project because it has a high population of Latino patients with multiple sclerosis. Anna Castro is employed at this institution and has an interest in improving care at this facility.

I, Virginia Vazquez, manager at the Neurology Center of San Antonio, do hereby fully support Anna Castro in the conduct of this quality improvement project Personalized care Planning in Latino adults with Multiple Sclerosis to increase self-management skills, at the Neurology Center of San Antonio.

I also approve Anna Castro to access protected health information (PHI) for purposes of conducting this quality improvement project. She has signed a HIPAA release form.

Sincerely,

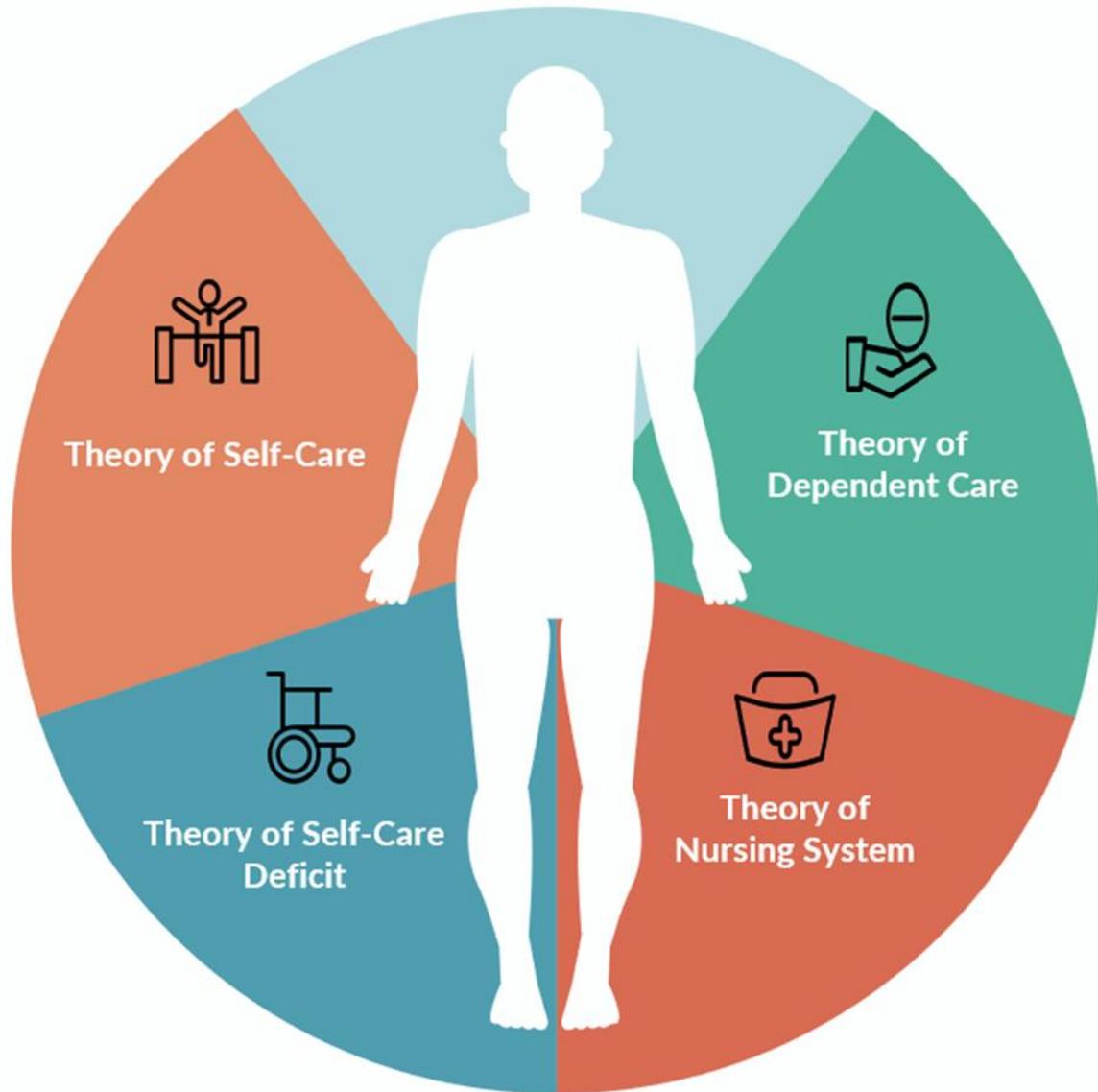

Virginia Vazquez

Appendix C: Multiple Sclerosis Self-Management Scale-Revised

	I Disagree Completely	I Disagree Somewhat	I Neither Agree nor Disagree	I Agree Somewhat	I Agree Completely
1. I feel like I understand what MS is.	1	2	3	4	5
2. I seek out information about my MS.	1	2	3	4	5
3. Since I was diagnosed with MS I have learned very much about it.	1	2	3	4	5
4. I have a good understanding of why I take my medications and what they are supposed to do.	1	2	3	4	5
5. I try to take a break when I feel myself getting tired.	1	2	3	4	5
6. I feel I have a lot of emotional support from my friends or family.	1	2	3	4	5
7. I make sure I eat regular meals.	1	2	3	4	5
8. I get enough sleep.	1	2	3	4	5
9. My medical provider is very willing to answer all my questions.	1	2	3	4	5
10. My immediate family is very supportive of me in handling my condition.	1	2	3	4	5
11. Most decisions in my life I make on my own (or with my partner).	1	2	3	4	5
12. I am comfortable discussing my questions with my health care provider.	1	2	3	4	5
13. I have friends who are supportive of me in handling my condition.	1	2	3	4	5
14. I talk to my doctor about the side effects from my medications.	1	2	3	4	5
15. I am confident I need to take my medication to be healthy.	1	2	3	4	5
16. I feel like I am involved in decisions about my treatment.	1	2	3	4	5
17. Taking my medication is a routine part of my regular activities (like brushing my teeth).	1	2	3	4	5
18. I have confidence in the treatment approach of my medical provider.	1	2	3	4	5
19. I avoid getting overheated when possible.	1	2	3	4	5
20. My doctor and I have very good communication about my condition.	1	2	3	4	5
21. Side effects make it very difficult for me to take my medications as I should.	1	2	3	4	5
22. I don't even think about it; taking my medication is just a habit now.	1	2	3	4	5
23. Sometimes I still forget to take my medication.	1	2	3	4	5
24. I feel like taking my medication is a trial run; I might decide to stop.	1	2	3	4	5
25. I take Vitamin D on the daily basis.	1	2	3	4	5

Figure 1

Orem's Self-Care Deficit Theory of Nursing



Note. Created Based on the description by Taylor & Renpenning (2011) of Dorothea Orem's Self-Care Deficit Nursing Theory

Figure 2

Timeline of Quality Initiative Project

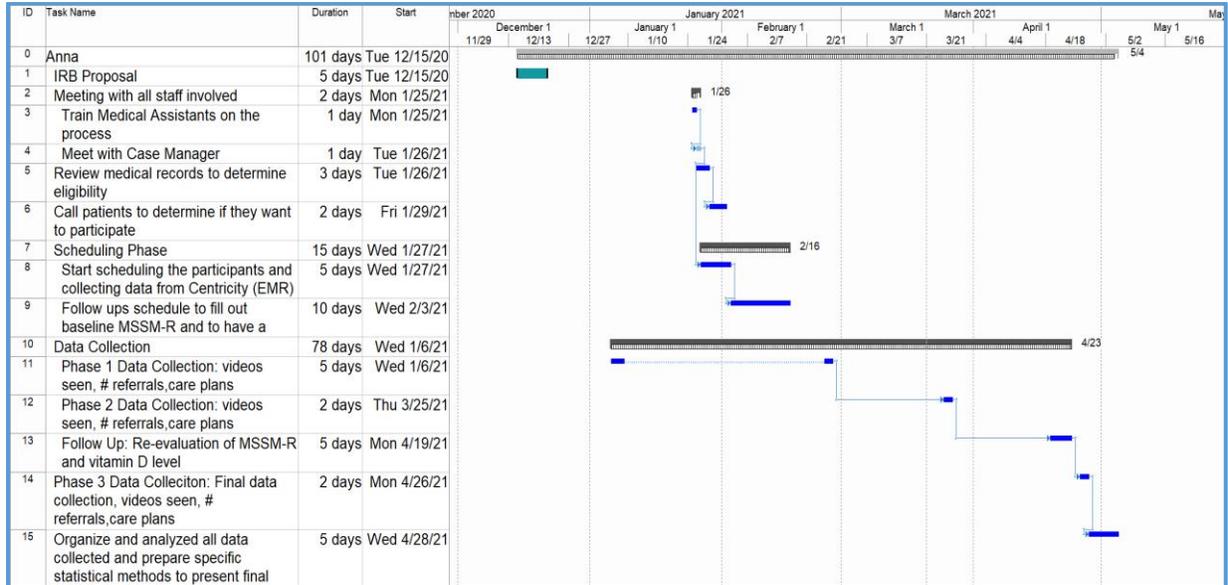


Figure 3

Total Videos Viewed per Participant

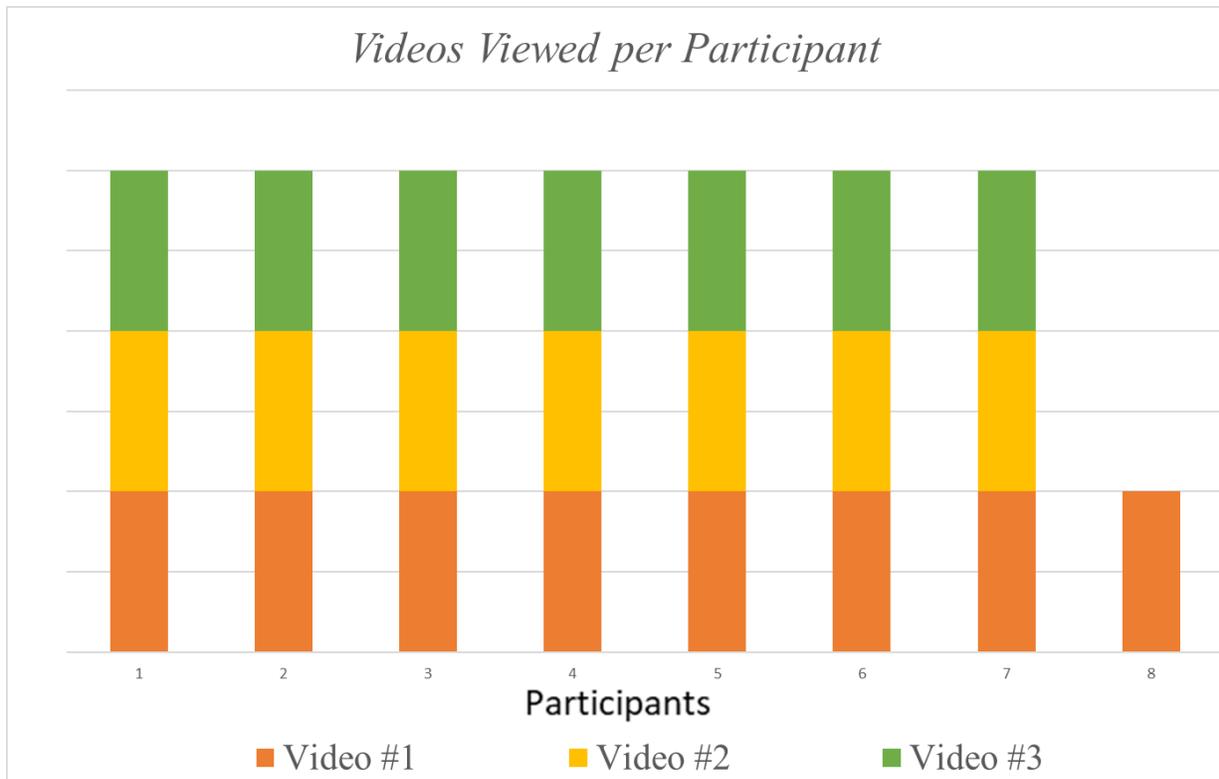


Figure 4

EDSS Pre and Post Intervention

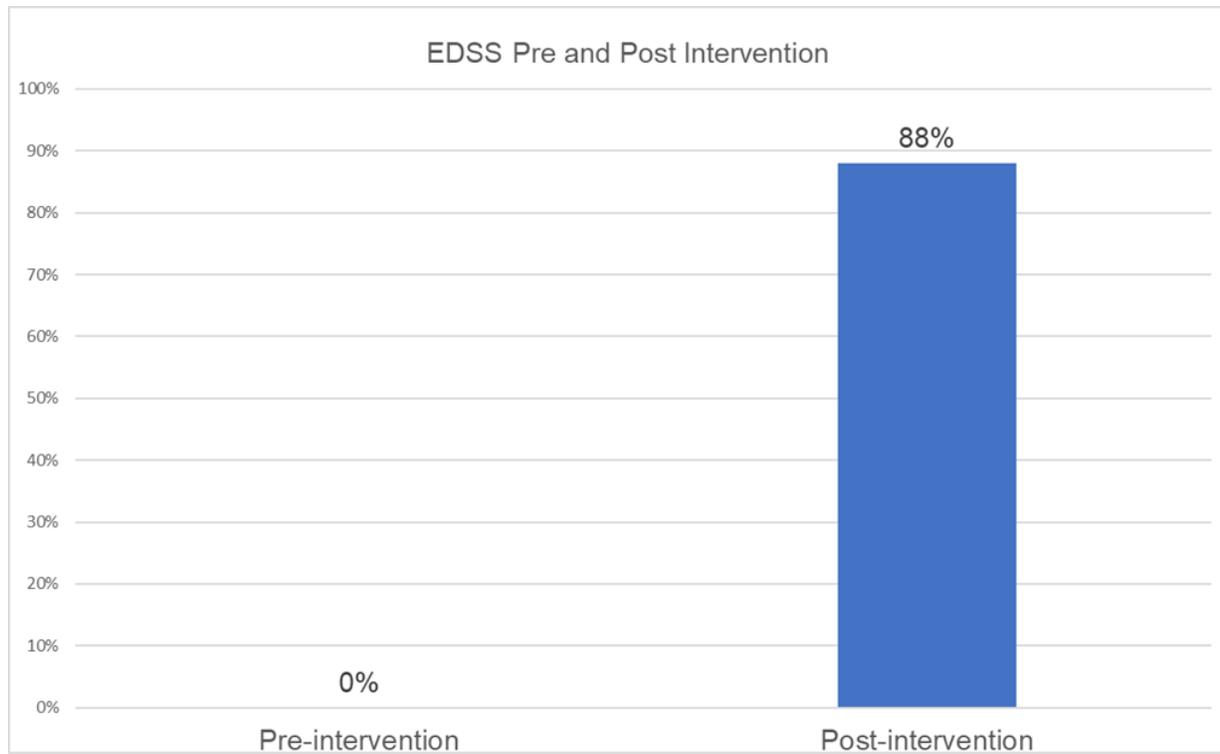


Figure 5

Pre and Post Intervention PT/OT Referrals, Care plan, and Updates

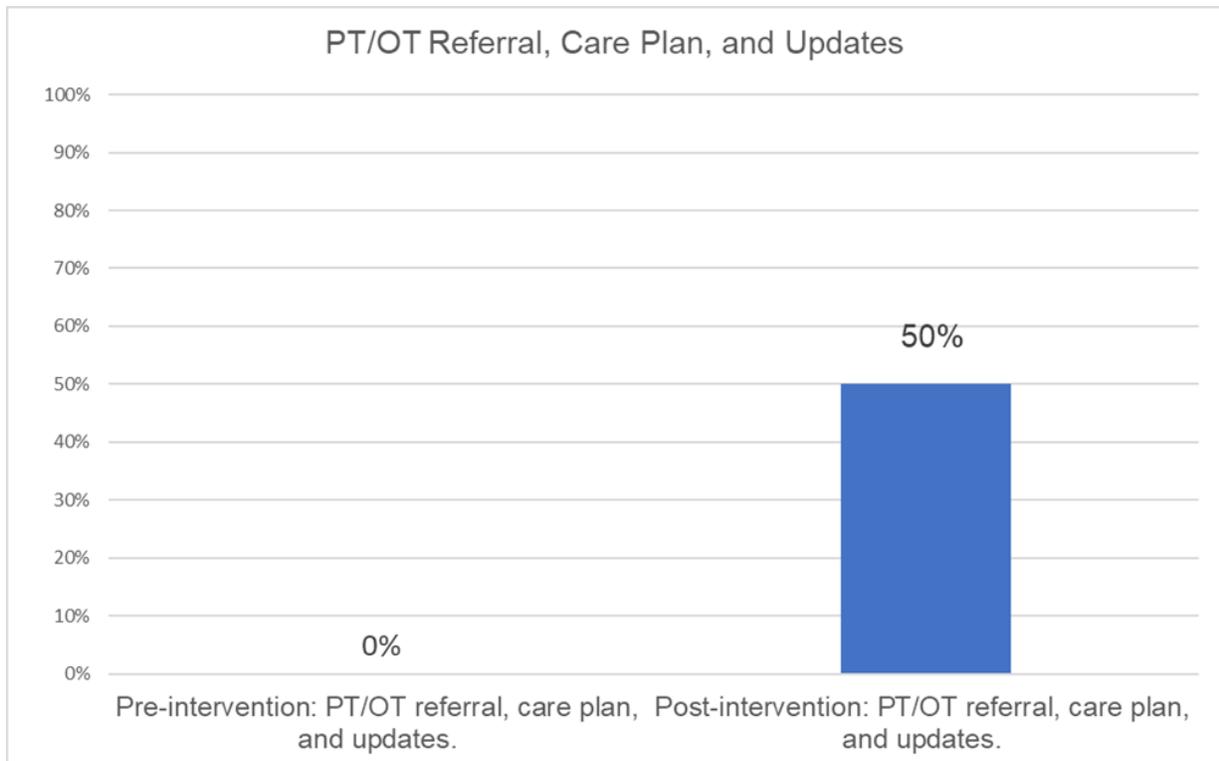


Table 1

Risk Assessment

Risk	Impact	Contermeasure	Resources	Barriers
COVID-19 Pandemic.	Impacted the recruitment of participants.	Telemedicine visits were used to mitigate this risk. Also, virtual learning and virtual PT/OT.	Patient instructions over the phone on how to connect to the telemedicine patient portal. Email of educational sessions and virtual link for PT/OT.	Patients might not feel comfortable with face to face visits due to the pandemic.
Difficulty getting PT approved by insurances.	Some health insurances have rules on how much money the patient can spend on PT/OT per year.	Having the virtual PT/OT sessions as an option for patients.	Having the PT case manager knowledgeable about different health care plans and regulations.	Patient not having enough insurance benefits, including funds to use for another PT/OT session. Patient not being able to afford the co-pay.

Table 2*Demographics Characteristics**Demographics Characteristics for Variables of Interest n = 8*

Variable	n (%)
Age	
30-40 years-old	3 (37.5)
41-59 years-old	3 (37.5)
60-70 years-old	2 (25)
Gender	
Female	5 (62.5)
Male	3 (37.5)
Race	
Latino	8 (100)
Employment Status	
Employed	2 (25)
Retired	1 (12.5)
On Permanent Disability	
Yes	5 (62.5)
No	3 (37.5)
Years Since Diagnosis	
Between 1 and 5 years	2 (25)
Between 6 and 15 years	2 (25)
Between 16 and 30 years	4 (50)
Smoker	
Yes	1 (12.5)
No	7 (87.5)
Days of Exercise per Week	
More than 3	0 (0)
Less than 3	3 (37.5)
None	5 (62.5)

Note. Demographics of participants, data generated from SPSS version 26