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A PATIENT-CENTERED ETHNOGRAPHIC INTERVIEW AND MEASUREMENT OF INTELLIGIBILITY IN SPASTIC-ATAxic DYSARTHRIA FOR PEOPLE WITH MULTIPLE SCLEROSIS

by

COURTNEY LEPPEK

THESIS

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

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MASTER OF ARTS

2020

MAJOR: SPEECH LANGUAGE PATHOLOGY

Approved By:

_______________________________________
Advisor Date
DEDICATION

This thesis is dedicated to my Mother whose own strength has ignited my own courage and passion to rise above and pave my own path. In addition, to every individual with Multiple Sclerosis, always remember this condition is a speed bump, not a roadblock.
ACKNOWLEDGEMENTS

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CHAPTER 1 INTRODUCTION

Multiple Sclerosis (MS) is an autoimmune condition that affects approximately 2.3 million people world-wide. Recent studies have tripled the estimated number of people living with MS in the United States (e.g. From 350,000 to approximately 913,925). MS is caused by T-Cells in the brain and spinal cord attacking the myelin coating on the axons in these vital areas. Demyelination of these sensitive areas causes a variety of symptoms that are unique and unpredictable from individual to individual. The most common associated symptoms include fatigue, gait difficulties, numbness or tingling in the face body or extremities, spasticity, weakness, vision problems, vertigo, bladder problems, sexual problems, bowel problems, pain, emotional changes, cognitive changes, and depression. Many MS patients may also experience fewer common symptoms such as: swallowing problems, tremors, seizures, breathing problems, itching, headache, hearing loss, and speech problems. Additionally, MS comes in three different types: relapsing remitting (e.g. development of new lesions cause exacerbation of old of development of new symptoms), secondary progression (e.g. no new lesions develop, yet symptoms continually worsen), and primary progressive (e.g. one exacerbation with symptoms continually worsening).

This study focused on analyzing the speech problems that result from demyelination in speech specific areas in the brain and improving the ways that speech language diagnosis to be done. Dysarthria speech problems are prevalent in approximately 40%- 50 percent of people with MS with three types of dysarthria: spastic, ataxic or mixed. Differential diagnosis of these three types of dysarthria depends on the severity and location of neurological lesions, which can occur in the white matter of the upper motor neuron or cerebellum. Therefore, the specific speech, voice, and accompanying physical signs are reflected by the location of these lesions. Mixed dysarthria is the most common in MS because multiple neurological systems are typically affected by the
condition (Miller, 2008; Darley, Aronson, & Brown, 1969a, 1969b, 1975). Due to this, dysarthria in MS potentially accompanied by the underlying symptoms such as, spasticity, weakness, tremor and ataxia which can be complicated by fatigue. The following review of the literature is divided into three key sections: Characteristics of Spastic-Ataxic Dysarthria in Individuals with Multiple Sclerosis, Diagnostic Factors and Associated Quality of Life in Individuals with Multiple Sclerosis, and Quality of Life in Individuals with Multiple Sclerosis and Communication Disorders.
CHAPTER 2 LITERATURE REVIEW

Characteristics of Spastic-Ataxic Dysarthria in Individuals with Multiple Sclerosis

To understand the effect of dysarthria diagnosis on an individual, it is vital to first understand what dysarthria is and the wide variety of diagnoses that can result from the diverse nature of its neurological lesions. Dysarthria, a group of neurogenic speech disorders characterized by "abnormalities in the strength, speed, range, steadiness, tone, or accuracy of movements required for breathing, phonatory, resonatory, articulatory, or prosodic aspects of speech production" (Duffy, 2013, p. 4). These abnormalities are due to one or more sensorimotor problems—including weakness or paralysis, incoordination, involuntary movements, or excessive, reduced, or variable muscle tone (Duffy, 2013). Duffy (2013) further describes that dysarthria can adversely affect intelligibility of speech or how natural one’s speech sounds, like many disorders dysarthria potentially can affect both naturalness and intelligibility. Additionally, Duffy notes that intelligibility can be normal in some speakers with dysarthria. Like many other communication disorders, dysarthria potentially can co-occur with other neurogenic communication disorders such as disorders of language, cognition, and swallowing. The predominant framework for differentially diagnosing dysarthria is based on a perceptual method of classification (Darley, Aronson, & Brown, 1969a, 1969b, 1975). The method proposed by Darley, Aronson, and Brown (1969a, 1969b, 1975) relies primarily on the auditory perceptual attributes of speech or the aspect of speech that are identified auditorily. These aspects of dysarthria diagnosis further point to the underlying pathophysiology which created a differential diagnosis of dysarthria. The observed auditory perceptual attributes are then used to characterize the type of dysarthria, once combined with the pathophysiological information, underlying neurologic illnesses may be identified. The major types of dysarthria identified by perceptual attributes and associated loci of pathophysiology
(Duffy, 2013) are listed as follows: Flaccid (i.e. disorders of the lower motor neuron system and/or muscle), Spastic (i.e. bilateral disorders of the upper motor neuron system), Ataxic (i.e. disorders of the cerebellar control circuit), Hypokinetic (i.e. disorders of the basal ganglia control circuit), Hyperkinetic (i.e. disorders of the basal ganglia control circuit), Unilateral upper motor neuron (i.e. unilateral disorders of the upper motor neuron system), Mixed (i.e. various combinations of dysarthria types (e.g. spastic-ataxic; flaccid-spastic), and Undetermined (i.e. perceptual features indicate a case of dysarthria but do not clearly fit into any of the identified dysarthria types).

Spastic-Ataxic Dysarthria, known as a mixed dysarthria, is associated with neurologic damages to the upper motor neuron system and cerebellar control circuit. Darley et al. (1972) was one of the first studies to describe and quantify spastic-ataxia dysarthria in MS patients. The common speech disorders observed in these individuals included impaired loudness control and increased harshness. Less frequently speech disorders were articulation errors, restricted use of vocal variations for emphasis, poor pitch control, hypernasality, inappropriate pitch level, and breathiness. Contrary to previous research, "scanning speech" was not a prominent characteristic in the participants in Darley’s study (1972). “Scanning speech” was defined as those spoken words or syllables which were broken-up into separate syllables with noticeable pauses and varying forces. Despite not observing scanning speech, the study suggested that these individuals’ speech disorders were not solely attributable to cerebellar involvement, but resulting from motor system dysfunctions (Darley, Brown, & Goldstein, 1972). As previously mentioned, these earlier findings were later contradicted. Fitzgerald et al. (1987) analyzed the speech of 23 MS patients who were administered with a battery of tests to determine the type, frequency and severity of their speech and language problems. Deficits were found in all aspects of speech production, including respiration, phonation, prosody, articulation, and resonance. Observed speech deficits were most
often mild in severity. The most influential factor in intelligibility of speech was the precision of
consonant production. The consonant production impairments were found to be strongly
associated with cerebellum dysfunctions in MS patients with spastic-ataxic dysarthria.
Insufficient respiratory support also impaired speech intelligibility for all participants, particularly
affecting in their vocal quality, volume control and clarity of speech articulation (Fitzgerald,
Murdoch, & Chenery, 1987). These observed characteristics were perceived not only as “scanning
speech”, mentioned in previous research, but also showing deficits in speech prosody and
respiration. In the study by Hartelius, Buder, & Strand (1997), the researchers developed a new
approach to describe the long-term phonatory instability of speakers with MS when compared to
persons with typical speech within normal limits. This study used three measures for analyzing the
speech instabilities in individuals with MS: a) coefficients of variation, b) magnitude-based
analysis of spectral energy, and c) frequency-based analysis of spectral components. All measures
showed significant differences in speech intelligibility between individuals with MS and healthy
adults according to a linear discriminant analysis based on the spectral cues (Hartelius, Buder,
& Strand, 1997). Results of their study furthered our understanding of communication disorders
in people with MS because mild cases of MS were observed in most of previous studies (Darley
et al., 1972; FitzGerald, Murdoch & Chenery, 1987). Hartelius, Buder, & Strand’s study in 1997
paved the way for numerous studies on MS and associated communication disorders.

According to Darley, Brown, & Goldstein (1972), Spastic-Ataxic Dysarthria was
characterized as a mixed type of dysarthria for 40-45 percent of individuals with MS.
Subsequently, several studies investigated the correlations of the degree of severity for each speech
impairments in Spastic-Ataxic Dysarthria in comparison to the associated anatomical locations of
lesion(s), types of disease progression, and severity of neurological involvement (Darley et al., 1972; FitzGerald, Murdoch & Chenery, 1987).

Besides focusing on defining Spastic-Ataxic Dysarthria, current research was also interested in investigation of the effect of MS dysarthria on the voice, speech production and motor speech characteristics. One of the most commonly observed vocal deficits in MS was dysphonia. Dogan et al. (2007) evaluated the voice quality in patients with MS through a multidimensional set of procedures composed of video laryngo-stroboscopic examination, acoustic analysis, and subjective measurements (e.g. Grade, Roughness, Breathiness, Asthenia, and Strain scale and Voice Handicap Index). Results of their study showed significant quantitative analyses of acoustic parameters such as: fundamental frequency, jitter percent, shimmer percent, soft phonation index, and noise to harmonics ratio; while, stroboscopic examination only revealed 40% MS patients with a “posterior chink” in the glottal closure showing higher soft phonation index values. Through vigorous quantitative acoustic analysis, results of this study showed that most of the MS patients had dysphonia due to weakness in their voice and that MS speech showed impairments in acoustic parameters including fundamental frequency, soft phonatory index, and jitter values (Dogan et al., 2007).

In addition to dysarthria, dysphonia was also observed in MS patients. Arnett et al. (2008) evaluated how the oral motor articulation speech problems of individuals with MS contributed to neuropsychological task performance and group differences on tasks relevant to cognitive dysfunction in MS. Some neuropsychological tasks used in this study required rapid oral motor response. The study conducted by Arnett et al. (2008) did not show significant differences between the MS group and the control group. The only interesting finding was that group differences in fatigue and depression only observed as rapid oral motor speed was required (Arnett et al., 2008).
Similarly, Rusz et al. (2018) observed the interaction of primary and secondary symptoms of MS during oral motor speech production. This study emphasized on the importance of quantitative measurement and its correlation with neurological lesions associated with MS. This study concluded that automated speech analyses may provide valuable biomarkers of disease progression in MS as dysarthria could represent the early onset of MS development and underlying pyramidal-cerebellar pathophysiology (Rusz et al., 2018).

While some studies analyzed the interaction of MS symptoms with speech, the other recent research examined acoustic variation and phoneme structure of speech sampling for dysarthric speech. Kuo and Tiaden (2016) conducted a study to examine acoustic variations in passages read out loud by speakers with dysarthria and healthy speakers. The dysarthric speakers were compared to healthy speakers on several acoustic variables such as: measures of global speech timing (e.g., articulation rate, pause characteristics), vocal intensity (e.g., mean sound pressure level and intensity modulation), and segmental articulation (i.e., utterance-level second formant interquartile range, F2 IQR) (Kuo, & Tjaden, 2016). Results from this study suggested that acoustic variation during passage reading should be included in MS diagnosis processes.

Likewise, the effects of phoneme structure on intelligibility also should be considered when analyzing and collecting speech samples with dysarthric patients. Rosen, Goozée, & Murdoch, (2008) evaluated hypotheses based on these effects on intelligibility by showing the extreme F2 movement (e.g. in diphthong production) when compared to typical F2 movement (Rosen, Goozée, & Murdoch, 2008; Catteno et al., 2014). The severity of dysarthria speech depended on the size and loci of neurological lesions and could potentially become more severe due to depression and fatigue (Arnett et al., 2008), as well as self-perception of vocal changes (Dogan et al., 2007).
In conclusion, Spastic-Ataxic Dysarthria in MS is highly variable, and can develop at any point in the disease’s progression. The current diagnostic protocol includes a variety of quantitative measures, both informal (e.g. speech samples, oral facial examinations, or rating scales to note the presence of the various Spastic-Ataxic Dysarthria qualities in the individual’s speech) and formal standard assessments (e.g. Revised Robertson Profile, Assessment of Intelligibility in Dysarthric Speech, Frenchay Dysarthria Assessment, etc.) to diagnosis and develop treat goals for Spastic-Ataxic Dysarthria. As stated by Duffy (2013) and Lowit & Kent (2010) the goals of these dysarthria assessments are to: 1) describe perceptual characteristics of the individual's speech and relevant physiologic findings 2) describe speech subsystems affected (i.e., articulation, phonation, respiration, resonance, and prosody) and the severity of impairment for each 3) identify other systems and processes that may be affected (e.g., swallowing, language, cognition); and 4) assess the impact of the dysarthria on speech intelligibility and naturalness, communicative efficiency and effectiveness, and participation. While Duffy (2013) centered around discovering and identifying impairments in body structure and function, in addition to including underlying strengths and weaknesses in speech production and verbal/nonverbal communication, current research reflects the need to use a qualitative assessment to support these quantitative measurements. The impact of dysarthria will be determined by several factors summarized further by Piacentini et al. (2014) stating that quality of life assessments should include several factors first revolving around the individual's limitations in their ability to actively participate in various aspects of life. These limitations center around communication, interpersonal interactions, self-care, or learning. Second Piacentini et al. (2014) stated that environmental and personal factors, serve as both limitations and aid in the development of these individual’s ability to engage in successful communication and participate in life. Thirdly, Piacentini et al. (2014) outlines the
significant impact that communication impairments can pose on quality of life and functional limitations in respect to the person’s role in society prior to the development of the communication disorder. Additionally, this include the impact these changes have of the person’s community. Although the quality of life in the Dysarthric Speaker is frequently used as the qualitative measurement in Spastic-Ataxic Dysarthria Assessment, this measure does not capture all the important factors that may define the experience that people with MS have.

**Diagnostic Factors and Associated Quality of Life in People with Multiple Sclerosis**

Though MS is one of the leading causes of nontraumatic neurological disability in young adults in both Europe and United States. Several factors are known about the diagnosis process the first is that uncertainty regarding the condition’s evolution diagnosis disclosure a difficult process. One study aimed to investigate patients’ global perspective towards the communication they received when being diagnosed with MS (Meissina, et al., 2015). The study 150 patients recently diagnosed with Clinically isolated syndrome (CIS) which according to the study is one example of the way MS potentially progresses. CIS describes the first incident of neurologic symptoms caused by inflammation or demyelination (i.e. loss of the myelin that covers the nerve cells) in the central nervous system (CNS)) and lasting a minimum of 24 hours, often CIS do not reoccur, however if symptoms present again lasting a minimum of 24 hours, the diagnosis is often changed to MS. The study consisted of 86 individuals who fulfilled the diagnostic criteria for MS and 64 fulfilled the diagnostic criteria for CIS. These individuals completed a 17-item questionnaire assessing factors influencing their satisfaction during their diagnosis with the information provided at the individuals time of diagnosis. Most individuals completing the survey cited that diagnosis disclosure took place in a private setting and in most cases (87.3%) the disclosure took a span of less than 30 minutes. Furthermore, many of the individual surveyed (75%) felt moderately or
highly satisfied with the information provided to them at this time. Meissina, et al. (2015) concluded the degree of satisfaction in the individuals surveyed seemed significantly related to patients’ younger age, an increased time dedicated to disclosing the diagnosis, a CIS diagnosis, information tailored to the individual, and an adequate emotional support system. It is important to note that study reported that most patients reported a good degree of satisfaction about the communication of MS or CIS diagnosis (Meissina, et al., 2015). A fruitful relationship between patient and neurologist is essential to obtain a better acceptance of the disease, patients’ compliance with chronic treatments and to improve patients’ quality of life (Meissina et al., 2015). However, a second study conducted by Hepworth and Harrison (2004) used mixed qualitative and quantitative methods to study the information needs of people with MS in the UK. Focus groups involving 103 People with MS who discussed their significant experiences. Questionnaires were sent to 4100 People with MS (approximately 5 percent of the MS population at the time) and 2030 responded. Similar to what Meissina, et al. concluded several years later, Hepworth and Harrison also noted information provision provided to individual at diagnosis was found to have improved dramatically over the last seven years. This improvement is noted among respondents to who had been diagnosed in the last five years, 71 percent thought they had received enough information at diagnosis. Of the total surveyed population, 43 percent thought they had not received adequate information at diagnosis. Though these information provisions were found to be inconsistent, although centers noted for an increased interest in the gaining and further understanding patient perspective. One of the main conclusions Hepworth and Harrison is there a considerable scope for improving provisions of information to people with MS. The results of these research studies further indicate the importance of health care professionals providing guidance, in terms of
information provisions, for service providers in the health and social services as well as other voluntary organizations and public information providers.

Though, the inconsistent scale to which information was provided could center around appropriate information being both hard to find and use, and that it was not available when and where they wished to access it. Thought information was provided inconsistently individuals surveyed cited the most common problematic situation was the diagnostic process itself. Hepworth and Harrison (2004) learned the diagnosis process was responsible for the greatest number of negative experiences amongst the people with MS involved in the focus groups. Of the people attending the focus groups, 49 per cent mentioned the negative experience they had when they were given their diagnosis. Only eight people were happy with the way they were given their diagnosis. Consultants and other health care professionals were criticized in several ways, including a lack of knowledge about MS, a lack of support, poor attitude, and no provision of information. Furthermore, continuing the ideal that someone with MS should be a person, and not just as a person with MS, who is likely to want to take an active role in life. Information should be provided to help achieve this goal. Enabling people to participate actively in life (as a result of access to information and increased knowledge about the condition), whether in the home, workplace or elsewhere, has been shown to have a positive impact on their self-esteem and general wellbeing (Hepworth & Harrison, 2004; Yorkson, 2001). This may seem self-evident. It is, however, easy for service and information providers to focus on the condition and the information specific to that condition rather than seeing the Person with MS in the broader light. As a result, health care professionals may underestimate the importance of information provisions and fail to provide information that helps the Person with MS really engage and participate in life in addition to gaining an understand of possible symptoms and progression of symptoms. The focus group
showed that being provided with these types of information meant a great deal to the Person with MS and their state of mind in obvious ways, such as mobility and control, but perhaps more importantly in being prepared for the uncertain future with MS such as the effects of aging or even how to fulfilling a parental role would look with MS. Furthermore, information provisions need to be targeted at three communities. These three communities are: people with MS, the general public (including the family, friends and colleagues) and state and voluntary service providers. The public would need general information about MS and living with MS and the support available. This would help them to understand the condition and provide necessary support. Also the sensitive time of diagnosis the information provided to the individuals must be written in way which is easy to both read, understand, and further encourage a development of a positive support system. Similarly, service providers would need general information about MS, and the help and information that are available. The latter would help them to direct People with MS to informational and practical support. Service providers, including health and social care professionals and support groups, would probably benefit from training in the information needs of people with MS and how these might be satisfied. Service providers must be aware of the diverse nature of MS from case to case and how the condition may change over time, and that informed support is required over an extended period. Health professionals involved in diagnosis also need training in how to provide information at diagnosis in a supportive and sensitive fashion. This is particularly important because it was clear that people varied dramatically in their desire to have information (Hepworth & Harrison, 2004).

With several studies noting the quality of life implications in the MS diagnostic process, Edwards, Barlow and Turner (2008) sought to investigate the pre-diagnosis period. During this period, whilst symptoms are being investigated and the cause is uncertain, can be particularly
stressful, and in some cases, symptoms may not be indicative of MS; practitioners may suspect other causes, for example, psychogenic explanations. Some doctors avoid telling a patient that he or she has MS in the belief that ‘ignorance is bliss’. In such cases, the individual being diagnosed often expresses anger and disappointment towards the medical profession when an MS diagnosis is eventually confirmed (Edwards, Barlow & Turner, 2008). During the pre-diagnosis period, people must live with illness without legitimacy. Without health practitioner providing a confirmed diagnosis, patients are often misunderstood by others; having a label for symptoms results in a reduction in stress and improves relationships. In fact, in most participants (n=15) in Edwards’, Barlow’s, and Turner’s study, had waited a long time for a diagnosis, or a diagnosis had been entered in their patient records, but the individual had not been informed of the diagnosis of MS. Of the seven participants diagnosed within the last five years, three had difficulty obtaining a diagnosis. This study highlights the impact that doctor–patient communication at the point of diagnosis has on people with MS and the way in which participants sought to make sense of and understand their diagnosis. Improving the way in which doctors break bad news to people with MS is important and warrants further study. It was apparent that some participants did not wish to discuss their treatment with health professionals who they perceived to be ill-informed. This has implications for future disease management. Feelings of uncertainty and anxiety associated with unpredictable, chronic illness may be decreased by improving patients’ knowledge of the disease. Confirming previous and future studies, it is important that patients being diagnosed with MS receive adequate information about their condition and its treatment from the point of diagnosis onwards. Providing information in a variety of formats (e.g. verbal, written) and on more than one occasion may assist with the individual’s expression that they did not receive adequate information at their diagnosis (Hepworth & Harrison, 2004; Edwards, Barlow and Turner, 2008; Meissina, et
These studies suggest huge implication for people with MS later in life. Some participants discussed having difficulty disclosing their MS diagnosis as they fear causing distress to loved ones and fear negative reactions from others. These results accord with past MS research suggesting that people with MS demonstrated disability by using crutches, for example, and felt that this helped them to feel in control by signaling that something was wrong, whilst others disclosed their MS to new acquaintances in order to avoid being viewed as ‘drunk’. People with MS often express they are torn between disclser or concealment of their MS diagnosis in order to counteract devaluing social interactions (Hepworth & Harrison, 2004). The distrust in healthcare professional before a diagnosis of MS mixed effects on individuals in the MS community while some have positive experiences with and complete access to medical treatment; others have felt that they had been denied access to treatments whereas others were satisfied with treatment received. Similar to previous and future studies Edwards, Barlow, and Turner (2008) conclude, MS is poorly understood by the medical and nursing professionals alike; patients may be given an unrealistic picture of what to expect in the future and this may contribute to feelings of dissatisfaction with treatment. Furthermore, this lack of understanding from Health Care Professionals has been shown to contribute to an individual quality of life. Soundy, et al. (2016) reported upon these factors analyzing the considerable impact on an individual’s quality of life, affecting a variety of aspects including ability to continue life roles, to work or undertake leisure activities. In addition to these interpersonal and psychological factors, MS also has a large financial burden associated with the condition. Direct medical costs in the US are identified as above $10 billion each year, and in the UK this has been reported as an average of £8397 per patient, each 6 months, with costs rising with increasing disability. However, impairments often impact on their ability to communicate. This is important as the experience of MS is influenced by how well
individuals can participate and interact in their own environment. Furthermore, health care professional’s interaction with patients and the involved communication utilized in these interactions are important features that impact the experience of living with the illness, further affecting individuals’ sense of identity, feelings and attitudes (Soundy, et al., 2016). Similar to Meissina, et al. (2015) the evidence provided by Soundy et al. (2016) only identified broad needs for individuals who are undergoing the diagnosis process for MS to be provided with adequate information provisions however this is difficult to translate into clinical practice and does not consider the factors which influence interactions between professional and patient. Soundy, et al. (2016) took this a step further concluding, patients may perceive limited value in asking a question if they believe Healthcare Professionals’ to be ill-informed. In contrast, several relational aspects of the Healthcare Professional-patient interaction, focused on the unprofessional delivery of information (e.g., use of a casual or patronizing manner, dismissing the patient’s experience, or implying the patient’s problems were psychological), influencing the patients’ willingness to ask questions. The study also discussed other demographic factors that can impact on the Healthcare Professional-patient interaction include, the age group (older adults can be more accepting of paternalistic care), ethnic background (for example a greater power imbalance was identified by African American men), level of education and differences between the demographics of the interviewer and interviewee. Finally, the study remarked on the settings where the interactions take place, (e.g. a lack of privacy or too much noise) can inhibit interaction and patient engagement. In order to promote the best care for patients with MS and according to the perception of patients with MS good Healthcare professional-patient interaction should be responsive, informative within the limits of science, able to identify symptoms and problems, able to arrange follow up care and be supportive. In order to be responsive, Healthcare Professionals need to
understand the common information requirements of patients, they also need be aware of the variation in readiness to ask questions and varying needs of patients. Information giving should be tailored by the Healthcare Professional’s to the patient’s needs and readiness, doing this will help meet the needs of patients (Hepworth & Harrison, 2004; Edwards, Barlow and Turner, 2008; Meissina, et al., 2015; Soundy, et al., 2016).

Quality of Life in Individuals with Multiple Sclerosis and Communication Disorders

MS, though typically known for its physical symptoms such as walking difficulties and numbness and tingling, the condition is also known for cognitive alterations and effects on one’s quality of life. One of the only qualitative studies conducted on Quality of Life and MS, examined satisfaction with communicative participation as reported by adults with multiple MS (Baylor et al., 2007). Participants were asked to discuss their satisfaction with their communication in a variety of situations in a semi-structured interview. From there the researchers derived several themes that were cohesive across the sample, such as: comfort (e.g. ease and confidence), success of the outcome (e.g. function is achieved, and a connection is made) and personal meaning of participation (e.g. personal preferences, comparison with past conversations, and thinking about one's own communication). However, these participants did not talk about frequency of communication activities as a key part of their satisfaction (Baylor et al., 2007; Catteno et al., 2014). Overall, this study again demonstrated a further need to identify customized intervention targets and treatment outcome measurements. With that, it also demonstrated a greater need for more qualitative studies to further analyze quality of life and MS. While this Baylor et al. (2007)’s qualitative approach further reveals a need to tailor assessment, intervention, and treatment outcome measures to each individual case of MS, other studies focus on quantifying quality of life and MS. Amato et al. (2001) analyzed quality of life and its main clinical and demographical
determinants in patients who had been diagnosed with MS for an average of 12.4 years. The study used the MSQOL-54 inventory, a disease-specific instrument. The study determined, “depression, fatigue and disability level were confirmed to be significant and independent predictors of quality of life” (Amato et al., 2001). Overall, the study argued that quality of life instruments should be used to help to provide a broader measure of the disease impact and to develop a care program that fits the individual patient's needs comparable to the results of Baylor et al. (2007).

While few studies were found that focused on quality of life and MS as well as on Spastic-Ataxic Dysarthria and dysarthria-related quality of life. One analysis focused on the relations between duration of disease, severity, and general quality of life with patients with multiple sclerosis. It was determined that dysarthria-related quality of life is compromised in patients with MS, furthermore the diagnosis of dysarthria in this population was demonstrated as a secondary measure in both clinical practice and research for people with MS. Other commonly used measures and general quality of life tools do not seem to capture this aspect of the disease. More studies are needed to analyze the impact of other variables (e.g., social support, work status) on dysarthria related quality of life. Nonetheless, dysarthria-related quality of life should be considered as a supplementary outcome measure in clinical practice and in descriptive efficacy and outcome research in patients with MS (Catteno et al., 2014). It has been shown that Spastic-Ataxic Dysarthria is particularly difficult to treat due to spontaneous recovery and the typical ebb and flow of the disease through periods of exacerbation and remission. These studies on quality of life and MS could reflect the frustrations and anxieties felt by people with MS, furthermore, denoting the necessity for individualized intervention programs that address the underlying thoughts and feelings of people with MS. However, currently there are not MS specific Quality of Life
Assessments, and often the current quality of life assessments neglect to analyze key aspects and individualized symptoms that can influence an individual with MS in unique ways.

Consequently, one earlier study (Yorkson, 2001) sought to examine an insider’s perspective on communication in MS. Qualitative research methods were used because they are designed to provide a systematic way of exploring complex issues, such as communication, that cannot be separated from the context in which they occur. The study used seven participants, all of whom had mild communication impairments, described their everyday experiences of communication and the impact of MS on these experiences. Three vital themes and 8 subthemes were derived via inductive analysis of verbatim transcripts included: watching the communication changes, it’s about participating in my life, and communicating is unpredictable. The first theme, watching the communication changes, included life is not what it was, and acknowledging the change in communication as subthemes. The participants gave clear insights about their experiences in a variety of communicative situations. Even those with the mildest communication impairments appeared to be intensely aware of these changes. The second theme, it’s about participating in my life, included participation is important, communicative participation has changed, and communicative participation is limited by many factors as subthemes. These individual’s concerns about communication focused mainly on issues of participation. This communicative participation involved many factors such as playing the roles, doing the things one wants to do, and communication within the context of one’s everyday life. This made one important conclusion: Participation Is Important to this population. In fact, participation by the informants took many forms, including working, volunteering, taking part in educational programs, and maintaining friendships. Even more so, continued participation in the face of MS was important to the participants of this study. The final theme, communication is unpredictable,
included the subthemes communication problems are variable, people treat you differently, and old strategies fail. In addition to limitations in communicative participation, participants indicated that communication was no longer as they had learned to expect it. This unpredictability made it difficult to anticipate or prepare for communicative interactions. Participants spoke of unpredictability that did not relate to the long-term course of the disease but rather to issues of day-to-day variability of communication, being treated differently by people, and the fact that old strategies for communication no longer worked well (Yorkson, 2001).

Yorkson (2001) in addition to later study’s (Baylor et al., 2007, Catteno et al., 2014) defines what is needed in a MS specific quality of life measurement. These articles conclude People with MS need a specific quality of life assessment that provides the individuals perspective on several vital fronts. The first would examine the changes in communication across the disease’s progression—accounting for potential changes across the evolution of the disease, and individual experiences with the disease. The second would examine the individual’s perceptions of their ability to participate—do they feel they are missing opportunities to participate and how do they individual’s likelihood to participate vary across settings (e.g. at work, at home, or in a noisy environment like a restaurant). The third would center around if the individual feels their importance of their participation being met.

Summary
Overall, Multiple sclerosis produces neurological impairments that are variable in duration, severity and quality. Speech is frequently impaired, resulting in decreased communication skills and quality of life. This Mixed Qualitative and Quantitative Study is designed to investigate the underlying thoughts and feelings that accompany people with Multiple Sclerosis and communication disorders, specifically Spastic-Ataxic Dysarthria. The purpose for
conducting this research is to provide Speech-Language Pathologists with a better understanding that Multiple Sclerosis is a multi-faceted condition that has both internal and external implications for speech and to provide this population with improved considerations of quality of life assessment measures that focus on diagnosing the whole person and not typical symptoms.

**Research Questions**

a. In what ways do people with Multiple Sclerosis describe their speech?

b. In what ways do people with Multiple Sclerosis describe living with this condition?

c. In what ways do people with Multiple Sclerosis self-evaluate their speech sample compared to how a student clinician evaluates the speech sample?

d. In what ways do the intelligibility measurements of people with Multiple Sclerosis compare to the theme(s) present in their interviews?
CHAPTER 3 METHODS

Mixed Methods – Concurrent Nested Design

In order to answer the above research questions, this study will use a mixed methods approach to consider the research questions from both a qualitative and quantitative perspective. Tashakkori and Teddlie (2003) have provided three reasons why mixed designs are beneficial in behavioral research and applicable to the present study. First, mixed designs can answer research questions that a solely qualitative or quantitative approach cannot. Second, they allow researchers to obtain and make sense of participants’ views, which may be quite diverse and are, in and of themselves, subjective and not based on an absolute truth. Finally, stronger and better inferences can be made when methodologies are combined. This study used a Concurrent Nested Design, which implied the priority given to the qualitative data collected. Because everyone’s experience with MS is unique, it is vital to gain a broader perspective on how each person’s journey with MS affects their communication and therapy track progression. However, a purely qualitative approach could not provide intelligibility measurements and perceptual rating on MS speech. Therefore, it is important to include quantitative methods in analyses of these case studies.

Qualitative Component

The qualitative measures were conducted last through an ethnographic interview with the participants in which they discussed their individual journey with MS. This will be achieved through asking a variety of questions. The interview will start with questions about the diagnosis process, such as how long their diagnosis process lasted, how they were told they were diagnosed, if they felt the healthcare professional was knowledgeable about MS, and whether they feel they were provided with enough information on MS and how the condition progresses. The next questions centered around what symptom specific changes the person experiences as a result of
MS, such as “how those symptoms impact their speech?”, “what strategies they use to communicate”, and “how those strategies have changed as the condition progressed and how they felt about watching the changes in their communication. The interview was concluded with their self-description of negative and positive outcomes resulting from their condition, communication changes that have affected their ability to participate in life, individual’s feeling about unpredictable communication and progression of the condition, and the advice they could give to people who were newly diagnosed with MS (see Appendix A). The interview was developed with assistance from a variety of speech-language pathologist from various perspective. Additionally, these interview questions were designed to encourage the participant to share relevant experiences that have shaped the individual’s personal journey with MS. Therefore, during the interview, though these questions were structured in a specific way participants were encouraged to share any details they felt molded their journey with MS.

Following each participant’s ethnographic interview, the participants responses were analyzed utilizing an adaption Boyatzis (1998), Kvale (1996), Patton (2015), and Seidman (2006). First verbatim transcriptions were completed for both interviews. Second, each participant’s responses were read carefully to ensure understanding of each participant’s individual journey with Multiple Sclerosis. Third, for each interview transcript, the transcripts were analyzed through inductive analysis; that is, meaningful milestones of the participants’ journeys were extracted from the transcriptions to create an outline that encompassed vital aspects of the ethnographic interview (Boyatzis, 1998; Seidman, 2006). The outlines then yielded themes (Boyatzis, 1998) that detail each participants’ experience with MS, which were personalized to their MS course. The participant’s individual themes were then combined into gross thematic categories. In order protect participant confidentiality, all identifying information was removed from each transcript; this
included information such as names, locales, dates, and anything that could link to the identity of the participant. In addition, pseudonyms are used for each participant.

**Quantitative Component**

The quantitative portion of this study was collected using a variety of measurements, which was supported by current literature (Wallin, et. al, 2019). The first a speech-language sample was collected by instructing individuals to read Caterpillar passage. After the participants read the passage they were asked to rank their own speech based in several categories (e.g. comfortableness, understandability to themselves, understandability to an unfamiliar listener, their feelings on their vocal quality, such as breathy, hoarse, etc.), and other hallmarks of Spastic-Ataxic Dysarthria (e.g. frequency of pauses, difficulty to initiate speech, articulation, smoothness of speech). The speech-language sample was then analyzed by a graduate student clinician. The graduate student listened to the speech language sample and then provided a ranking for the individual in the same categories listed above. Diadochokinetic rates were also collected for each participant using one trial of each of the diadochokinetic tasks (e.g. /pʌ/, /tʌ/, /kʌ/, /bʌ/, /dʌ/, and /ɡʌ/ and /bʌdʌɡʌ/ and /pʌtʌkʌ/ in addition to written instructions and supplemental models when needed. The participants were instructed to “take a deep breath and say the syllable the first syllable as quickly and evenly as possible for approximately 10 seconds, until requested to stop” by the investigator. The investigator repeated these instructions for each additional syllable target, and combined targets. The consonant-vowel combinations were selected due to their frequent use in clinical speech assessments for the evaluation of three major articulatory organs: lung, tongue tip and tongue dorsum, in addition to relatively low cognitive burden. Next the Revised Robertson Dysarthria Profile was administered. The assessment measures the interaction of respiration, phonation, articulation, and an examination of the Oral Facial Mechanism in both structure and
function. The Revised Robertson Dysarthria Profile was chosen as it is easily accessed and provides a complete analysis of the various aspects of Dysarthria. The assessment was given according to the instructions. A hearing screening and Mini Mental Status Examination were also administered to each participant to ensure no interactions between cognition, and hearing.

**Participants**

Participants were recruited from local support groups in Michigan. Each support group was contacted and asked to distribute a flyer to the members of support group, and then members called to schedule a time to come to the Communication Sciences and Disorders department. The recruitment process yielded two participants; both were age 62 with Secondary Progressive MS. Both participants met the inclusion/exclusion criterion included a) proof of Multiple Sclerosis Diagnosis, b) proof of spastic-ataxic dysarthria, c) no other neurological impairments, d) a passed hearing screening and e) between the ages of 18-65. Proof of Multiple Sclerosis and Spastic-Ataxic Dysarthria were provided to the investigator at the data collection session via a doctor’s note confirming MS diagnosis and Spastic-Ataxic Dysarthria. Both participants took the note home following the data collection session. Even though each participant is a case study, results were also be compared across diagnosis process, progression of symptoms, and speed of diagnosis. The entire data collection session took between one and a half and two hours to complete and during the data collection an intake form was used to obtain age and document start and end time of tasks. Scoring was conducted by members of the research team. For each participant, a speech-language sample, diadochokinetic rates, a patient self-rating scale, a speech intelligibility measurement, and a formal assessment were collected to confirm the results of the informal assessments. During the second half of the session, a qualitative ethnographic interview was conducted.
**Research Design**

The research materials required were centered around the need to provide qualitative and quantitative data that captures the multifaceted nature of MS and the uniqueness of individual experience. The study also required a calibrated audiometer to screen the participants hearing to eliminate hearing loss as the cause of speech disorders. As previously stated, this is a Mixed-Methods Concurrent Nested Design, which was conducted within the Communication Sciences and Disorders at Wayne State University. Data collection included a video recording of the participant’s interview (i.e. See Appendix A), a measurement of speech intelligibility which was conducted utilizing the Revised Robertson Dysarthria Profile and diadochokinetic rates of “PaTaKa” and “BaDaGa” (i.e. See Appendix B), a speech language sample collected with the Caterpillar Passage, and Diadokinetic Rates (i.e. See Appendix C), and rating scale for participants and raters (i.e. See Appendix D).

**Study Protocol**

Two participants were recruited who were qualified for participant inclusion/exclusion criteria for this study. They were asked to participate in this research study on a voluntary base. For each research participant, a signed inform consent was obtained before interview and data collection. During the interview, the participants were asked about their individual journey with Multiple Sclerosis, and the impact on their life. The participant also read the testing materials in order to evaluate how clear his/her speech is. Study protocols of this research are outlined as follows:

1) Research participants reviewed information sheet which provided an introduction of the study. Then the participants were provided the HIPPA summary form which they then
signed. Then they were given a hearing screen, and the Mini Mental Status Examination to rule out any interactions from hearing or cognition.

2) Research participants took part in an interview, read a paragraph passage out loud after which they completed a survey stating how they felt about their speech, and participated in a measurement of speech clarity. The interview process was audio and video recorded throughout the process.

3) Research participants were asked to attend a 2-hour session. The interview took approximately 40-50 minutes. The reading passage, speech samples and rating took about 15 minutes. The speech clarity measurement took approximately 20-30 minutes.

4) Research participants were asked questions about their journey with MS, symptoms, their experiences, how those symptoms have affected their speech, Multiple Sclerosis’s negative impacts, and its positive impacts on their life. They did not have to answer questions that made them feel uncomfortable.

5) Participants’ audio and video recordings were only to be reviewed by members of the research team, in the Communication Sciences and Disorders department. Their recordings were not be shared outside of the research team, in the Communication Sciences and Disorders department, and were deleted once the research study had concluded.

**Data Analysis Procedure**

The qualitative results of this study was analyzed through descriptive analysis of participants answers during the ethnographic interview to deduce similar themes from each of the interviews. While the quantitative results were analyzed through: a) the participant’s self-rating of hallmarks of Spastic-Ataxic Dysarthria during the Caterpillar passage, b) intelligibility was
measured through the participant’s scores on the Revised Robertson Dysarthria profile, in addition to the precision and clarity of their articulatory movements during diadochokinetic rates, c) objective acoustic measurements and analysis obtained from the speech language sample. To ensure the reliable results an inter-rater reliability system was used to evaluate patients' speech production rating the level of severity in dysarthric speech present in the participant’s speech-language sample.
CHAPTER 4 RESULTS

Qualitative Results

Two participants were successfully recruited for this study, each having a unique experience with their MS diagnosis, progression of symptoms, and overall interactions with the disease. Throughout the document, the participants are referred to by the pseudonyms Mia and Jane. Three main thematic categories emerged from the data analyses: 1) Living with MS is What You Make of It, 2) Communication Impacts My Whole Life, and 3) Communication and MS is Misunderstood. Pseudo-names are used in the following sections to identify participants.

“Mia” Interview Summary

All Mia’s life she noticed that things were always harder for her, but she remarked that she led, and continues to lead, a great life. Always classifying herself as a hard worker, she worked two jobs, and was single mom—no matter the circumstances she maintained a positive outlook.

Her first symptoms were numbness on one side of her body and a heaviness in her left leg, and the onset was sudden one morning. However, at the time she was extremely physically active and attributed these symptoms to a 10-mile hike she has taken a few days prior. But by the end of the day she struggled to get up and down the stairs due to how heavy her foot felt. Thinking she had hurt her back or fearing something worse had happened, she sought out her chiropractor who was a tenant at her workplace.

After Mia described her symptoms and expressing worries that she had pinched a nerve or even had a stroke. Her chiropractor told her not to panic but he thought that she should go see a neurologist. That night she spent hours googling her symptoms, concluding that it could be either a brain tumor or Multiple Sclerosis (MS).
The next day she saw her primary care physician for the first time in four years. At this time, she was not told much or provided with any information, nor was MS mentioned. The only things she was told was her neurologist was sending her for an MRI of her brain and that she needed to get into a neurologist right away.

After the MRI of her brain Mia was able to get into the neurologist, who ordered a second MRI but this time of the spine and brain. Mia was still not given an official diagnosis until after the second MRI came back and at this time, she was told she had MS. At this moment Mia felt relieved as she has lost a sister to brain cancer two years prior. In this moment she remembers telling herself that she could do this. With plans to keep up her active lifestyle, and she would not let this diagnosis stop her. That evening Mia was confronted with how severe MS was, when she was unable to complete an easy going walk with her friend.

Since 2012, she hasn’t had any new lesions, yet her condition and symptoms continue to worsen, and her diagnosis shifted to Secondary Progressive MS. She remarked how frustrating it is to go from being able to run upstairs to barely being able to walk up a few steps. Mia discussed at length her experiences with a variety of neurologists throughout her journey with many of her experiences being negative. Dealing with the negative experiences from these professionals who she felt did not prepare her for the condition’s progression, she cited “My neurologist pretty much seemed to only have interest drug you’re on and how many new lesions you have”. Mia advised newly diagnosed individuals and other with MS to stick up for yourself and find the professional you work with best. She paints an analogy about what it is like to live with MS and her need to separate the condition from herself:

“"It’s never bothered me that I have MS...I picture the MS is in a backpack I can’t take off. It’s in the backpack it’s not in me, it’s sort of one of those annoying things, ‘oh I’d like to take this backpack off so bad today.’"
When it comes to her speech, Mia reports that the most influential symptom on her speech is fatigue, citing that her speech becomes more unintelligible as the day progresses. That when her decline in speech occurs, Mia chooses to go to bed and doesn’t like to interact with anyone. Since being diagnosed she has also noticed that people change the way they interact with her, often speaking to her louder, especially when she’s using her scooter. She expresses the changes in the way people communicate is frustrating, however she appreciates those who will go out of their way to show they care.

Overall, Mia has good and bad days with MS she recounts there are several positives that have resulted from her condition. Such as connecting with individuals who also have MS who she’s met through her support group and from her Mindfulness and Yoga for people with MS course, reconnecting with his significant other from high school, and finally she feels that her empathy towards people with disabilities has increased. When it comes to her speech, she wants people to understand, “The biggest piece of advice she can give individuals being diagnosed today is to ‘be your own advocate’ and until someone with MS is able to do this they will not be able to handle this disease.”

“Jane” Interview Summary

Jane first began experiencing symptoms in the mid 1970’s during a retreat she suddenly noticed that the top of her gums was getting numb. Jane recalls thinking, “Crap! Now I’m gonna have go to the dentist something is wrong”. At the dentist office he said everything was fine, but he suggested that she see a neurologist. She has no idea how he knew that. But he did, so she followed up with a neurologist.

Jane discussed how the neurologist was incredible and an accurate diagnosis was made immediately, which was unheard of at the time of the Jane’s diagnosis. However, though her
diagnosis was made quickly, Jane did not know she was diagnosed with MS at the time of her diagnosis as her neurologist only disclosed the diagnosis to her parents. And her parents felt at Jane’s youthful age of 15 that learning about her diagnosis would be detrimental as they did not want her to stop participating in activities, so they chose not to tell her about her diagnosis. Jane’s diagnosis was revealed to her when her brother’s friend began to exhibit similar symptoms. While her parents were preparing to visit family for a vacation, her brother confronted their parents about the possibility that the symptoms Jane had been experiencing could be MS. Their parents told him that it was MS, and Jane’s brother told them if they did not tell the Jane about her diagnosis by the time they go back from California, then he would. And after much back and forth discussion it was decided that they would tell her when they returned from California, because she deserved to know what was going on.

However, while her parents were visiting family Jane discovered a book on her Mother’s nightstand about the Swank Diet for MS. Her brother told her about the book, and she thought that if it is what he said it is, then she was going to learn everything she could about it and gobbled the book up. When her parents returned home, she told them, “I know it’s MS that I probably have and instead of working toward a certain goal separately we can work together”, and the rest is history. When Jane finally had her suspicions of her diagnosis confirmed at 17 years old, she was furious, but in hindsight she understands why her parents made the choice not to tell her. “When I grew older and wiser”.

Jane strived to not let MS stop her from enjoying her life, starting when she graduated high school and her and her friend started their own business to fund a trip around Europe. And despite their families thinking that the pair would not be also to finance the trip, when they graduated, they had raised enough money to visit 6 countries. The participant also achieved her bachelor’s and
master’s degree in social work, with her degrees she conducted a career in which Jane used experiences with MA to better understand and help her clients.

While earning her bachelor’s degree Jane’s symptoms began to progress, as she lost her ability to walk, and her MS diagnosis changed to Secondary Progressive. Later, while she was earning her master’s degree, she began to lose her ability to use her right hand and started the stages of grief all over again. Although this time Jane worked hard to reach acceptance, she began to use humor to find positives in the progression of her condition.

“I remember saying when I went back to get my Masters, by the time I finish my program I was saying, ‘MS? MSW? Hey! We’ve got a perfect marriage here; it’s going work out’”.

Jane discusses at length the life altering affects that changes in her communication had on her life and her ability to participate in it as communication was her tool. Yet she has found several positive outcomes of her diagnosis with one of the best results of her diagnosis was being able to run a MS support group for 35 years and participating in a longitudinal study about MS. She truly believes in inspiring those around her to fight against MS. Jane currently sees a speech pathologist, where she learns strategies to help her speech become less nasal.

**Theme 1: Living with MS is what you make of it**

Both participants discussed what aspects of how living with this life altering neurologic condition has affected their individual journey’s with MS. Yet, MS is often unpredictable in nature with the progression of the disease varying, as Mia stated in her interview:

“The fear of the unknown is worse (of) the worst thing”

With both participant’s MS being a secondary-progressive type, the women understand that their conditions continually worsen with few medications existing to stop the advancement of the disease. Additionally, the advancement of both individual’s symptoms, though unique,
invokes a fear as neither have a way to predict what symptoms they will develop next. This “fear of the unknown” is further revealed as both women reflect on the impacts of the sudden loss of both their mobilities which continue to affect them today. Jane statement of “Dang it, it’s my body, it’s my life” and additional statement from Mia stating “I can’t run and save the day anymore.” further captures the ideal that this condition has the power to change the way someone interacts with the world. People with MS mourn their losses and fear what will come next as MS’s vast array of symptoms can affect nearly every symptom of the body.

Yet, it is vital to consider everyone has an individualist experience with symptoms, the diagnosis process, and treatment of the condition. Though Jane cites a positive experience with her early diagnosis, Mia’s experience is the opposite as she has struggled with living with a condition without legitimacy for nearly 36 years prior to her diagnosis. She expresses the frustration with neurologists as she stated,

“My neurologist pretty much seemed to only have interest (in which) drug you’re on and how many new lesions you have”

Furthermore, Mia discussed that she felt she was not prepared to handle the progression of the condition, that she felt she was on her own. Although the condition poses many uncertainties individuals learn to rise above the unknown and learn to, as Mia advises, “Be your own advocate”. Continuing that until people with MS learn this, they will not be prepared to handle this disease and plan ways to handle their care. She additionally emphases the importance of finding a neurologist that will work with the person.

Despite the individualistic approaches to medical care, both participants discuss the profound impact their MS support groups have had on their lives. Their involvement in these communities further allowed them the focus on their strengths as they continue to live with this
condition. This unexpected result of their diagnosis has provided these participants with a sense of safety and understanding through the uncertain turmoil of the condition allowing them to thrive and develop newfound fortitudes. Jane summarizes this ideal as she states,

“There are many positive outcomes from my MS diagnosis—the environment I was raised in taught me to be a positive with my diagnosis and helping others, and my support group has made all the difference in my attitude with my diagnosis.”

Both individuals strived to find positives in their diagnoses and make the absolute most of their diagnoses. Often with expressions of resiliency, and through various unpredictable and frustrating changes, they seek to share their experiences with the MS communities. The condition has additionally helped them become more empathic as people and filled them with a want to make, as Jane puts it, “Living with this disease I’ll turn into what I’m going to do”.

**Theme 2: Changes in Communication impact my whole life**

MS is a multi-faceted condition that has both internal and external implications for speech, and both individuals discuss the frustrating impact that their changes in speech have had on their quality of life. With Mia stating, “My speech challenges are the most frustrating thing I have to deal with” and Jane expressing “I think losing communication was the most difficult part, because communication is my tool”. These powerful statements reflect on what these individuals want people to understand about communication and MS with research reflecting that these changes in communication often affects people with MS as they that watching the communication changes yields a profound impact from the individuals experience. Furthermore, as each individual experience with MS varies due to the unique nature of the disease, increased reactions to changes in their communication potentially denoted increased severity of Spastic-Ataxic Dysarthria.
This heavily indicates that people with MS opinions, thoughts, and feeling regarding their changes in communication demonstrates an impact on the severity of Spastic-Ataxic Dysarthria. Jane continues this idea as she expresses extreme frustration in her changes in communication:

“I always used to think Whether I was standing up or sitting down, it’s not going to matter as long as I can still talk. And then…. Whoever pulled this on me! What am I supposed to learn from this!”

From the participants’ own expressions of the complex nature of communication disorder and MS conclusions can be drawn regarding the isolating and debilitating nature of the disease, and its profound impact on the individual’s quality of life.

**Theme 3: Communication and MS is misunderstood**

The final themes are focal around the reactions of frustrating nature regarding changes in one’s communication abilities affect an individual’ ability to participate in important activities and engage in interaction with other people. Mia describes several changes she has observed since her diagnosis stating “I’m not drunk. And I don’t necessarily need you to finish my sentences.”, and “My hearing’s okay. No need to talk louder.” With Mia painting a powerful image in her changes in interactions with people, her environment, it can be further concluded these changes additional impact her participation in these essential meaningful activities as her change in communication is often misunderstood by those around her.

Participation is important to many individuals. Participation allows individuals to work, volunteer, take part in educational programs, and maintain friendships. Though as Mia further describes, “When I’m having trouble talking, I don’t want to hang out, I just want to go to bed”. This exhibits loss of the vital aspect of participation due to the unpredictability of communication and MS. This unpredictability made it difficult to anticipate or prepare for communicative interactions, unpredictability that did not relate to the long-term course of the disease but rather to
issues of day-to-day variability of communication. Therefore, Mia opts to withdraw in the moments of uncertainty rather than face misunderstanding from strangers or even close friends and family. However, Jane prefers to utilize a different approach to address the misunderstandings, “Especially with the group I facilitate I talk about it upfront and say, ‘my speech is the most frustrating thing I have deal with’”. This further demonstrates the impact the individual experience with MS has on the individual

**Quantitative Results**

**Hearing/Mini-Mental Status Examination**

Both participants’ hearings were screen at 25 dB across frequencies of 500, 1000, 2000, 4000 Hz in both the left and right ears. Both Mia and Jane passed their hearing screenings. The Mini-Mental Examination was administered to determine if cognitive interactions were present. The Participant Mia scored 28 and Participant Jane scored a 24 which indicated both participants’ cognition abilities were normal.

**Dysarthria Profile (Revised)**

Mia demonstrated mild difficulty across the hallmark Spastic-Ataxic Dysarthria sections (e.g. Respiration, Phonation, DDK, and Articulation). However, this participant’s speech deficits flared up when she became fatigued. Several descriptive factors were made across various tasks that further indicate a case of Spastic-Ataxic Dysarthria: variability in pitch, variability in rate of speech, and inconsistent breath support. In addition, several confirming motor signs were present: right-side facial droop, severe weakness in her left hand, and leg, Mia currently uses an electric scooter for mobility, and bilateral tremor of the tongue. Scores on the Dysarthria Profile are as follows:
Table 1: “Mia” Dysarthria Profile (Revised) Scores

<table>
<thead>
<tr>
<th>Section:</th>
<th>Task Section Average:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I.  Respiration</td>
<td>3.6</td>
</tr>
<tr>
<td>II. Phonation</td>
<td>4.3</td>
</tr>
<tr>
<td>III. Facial Musculature</td>
<td>4.9</td>
</tr>
<tr>
<td>IV.  Diadochokinesis (DDK)</td>
<td>3.4</td>
</tr>
<tr>
<td>V. Articulation</td>
<td>4.5</td>
</tr>
<tr>
<td>VI. Intelligibility/Rate/Prosody</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Jane demonstrated moderate-severe difficulty across the hallmark Spastic-Ataxic Dysarthria sections (e.g. Respiration, Phonation, DDK, and Articulation). Additionally, the participant demonstrated deficits in the areas of facial musculature and intelligibility/rate/prosody, these areas were often influenced by the participant’s discoordination of her tongue, lips, and other oral facial structures, and inconsistent breath support. The oral-facial examination revealed several confirming motor signs: bilateral weakness the lips, tongue, and velum. The tongue tremors at rest and a right facial droop is also observed. The participant was expressive and frequently conveyed emotions through facial expressions. Additional several descriptive factors were made across various tasks/sections that further indicate a case of Spastic-Ataxic Dysarthria. Respiration was shallow at rest and during speech and speed of respiration during speech was slow as frequent breaks in pitch occurred throughout the passage. The participant’s voice was hypernasal, hoarse, weak, and strained at times. Rate of speech slows down at the end of sentences and
phrases due to insufficient breath support. Speech is monotone at times with insufficient stressing during phrases and sentences. The following scored were collected from the Dysarthria Profile (Revised):

Table 2: “Jane” Dysarthria Profile (Revised) Scores

<table>
<thead>
<tr>
<th>Section:</th>
<th>Task Section Average:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Respiration</td>
<td>2.8</td>
</tr>
<tr>
<td>II. Phonation</td>
<td>3.0</td>
</tr>
<tr>
<td>III. Facial Musculature</td>
<td>3.8</td>
</tr>
<tr>
<td>IV. Diadochokinesis (DDK)</td>
<td>2.8</td>
</tr>
<tr>
<td>V. Articulation</td>
<td>2.6</td>
</tr>
<tr>
<td>VI. Intelligibility/Rate/Prosody</td>
<td>2.8</td>
</tr>
</tbody>
</table>

**DDK/Caterpillar Passage/Rating Scale**

After the participants read the passage they were asked to rank their own speech based in several categories (e.g. comfortableness, understandability to themselves, understandability to an unfamiliar listener, their feelings on their vocal quality, such as breathy, hoarse, etc.), and other hallmarks of Spastic-Ataxic Dysarthria (e.g., frequency of pauses, difficulty to initiate speech, articulation, smoothness of speech). Mia noted she felt extremely uncomfortable while reading and she did not think a stranger would be able to fully understand her speech while reading. However, when compared to the rater who noted she appeared neutrally comfortable and produced near clear speech while reading the passage. Overall Mia’s DDK and the caterpillar
passage, rate was again variable with the most difficulty being on /bʌdʌgʌ/, and the participant indicating it was difficult to breathe when producing the DDK. Rating scale results are found below:

Table 3: “Mia” Clinician vs. Self-Ratings

<table>
<thead>
<tr>
<th></th>
<th>Frequency of Strained Facial Expressions</th>
<th>Frequency of Slurred Words</th>
<th>Frequency of Unexpectant Pauses</th>
<th>Overall Understandability Reading Passage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mia</td>
<td>5 (Extremely Uncomfortable)</td>
<td>2 (Rarely)</td>
<td>2 (Rarely)</td>
<td>4 (Less Understood)</td>
</tr>
<tr>
<td>Rater</td>
<td>3 (Neutral)</td>
<td>2 (Rarely)</td>
<td>2 (Rarely)</td>
<td>2 (Nearly Clear Speech)</td>
</tr>
</tbody>
</table>

While Jane’s speech was extremely hyper-nasal, often resulting in distortions and imprecision of both consonant and vowel sounds during DDK for both /pʌtʌkʌ/ and /bʌdʌgʌ/. Consonant distortions and imprecisions were most prevalent in: Alternating Motion Rates (AMR’s) /tʌ/ and /bʌ/ (e.g. consistently produced as /ma/ and Sequential Motion Rate (SMR’s) /bʌdʌgʌ/ with imprecision resulting in production of the voiceless DDK (e.g. /pʌtʌkʌ/). Voice quality sounded strangle/strained throughout DDK and the Caterpillar passage and producing speech over longer utterances amplified both unintelligibility and harsh vocal quality. Patient additionally presented with the following confirming motor Signs: right hand tension, and inability to perform both gross and fine motor movements, right facial droop, and bilateral velum weakness, and utilizing a motorized chair for mobility due to patient inability to no longer ambulate. During the Caterpillar Passage the participant had difficulty tracking through the passage during time 23 Min 51 Sec to 24 Min 34 Sec, examiner found a tongue depressor and moved it line by line to allow the participant to complete the reading.

Once the passage was completed the client was provided the rating scale, on which the participant remarked that sometimes even her husband has difficulty understanding her, however
she ranked that acquaintances and strangers having the most difficulty understanding her speech. The participant rated that she felt neutral in areas of comfortableness, frequency of slurred words, frequency of unexpectant pauses, and overall understandability. The rating from the rater matched for overall comfort reading the passage and overall understandability; however, a higher rating was given on frequency of slurred words, and frequency of unexpectant pauses. This result indicated potential unawareness of the severity of the confirming speech signs of Spastic-Ataxic dysarthria. The ratings are as follows:

Table 4: “Jane” Clinician vs. Self-Ratings

<table>
<thead>
<tr>
<th></th>
<th>Frequency of Strained Facial Expressions</th>
<th>Frequency of Slurred Words</th>
<th>Frequency of Unexpectant Pauses</th>
<th>Overall Understandability Reading Passage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>3 (Neutral)</td>
<td>3.5 (Sometimes)</td>
<td>3 (Sometimes)</td>
<td>3 (60-75% unintelligible)</td>
</tr>
<tr>
<td>Rater</td>
<td>3 (Neutral)</td>
<td>4 (often)</td>
<td>4 (often)</td>
<td>3 (60-75% unintelligible)</td>
</tr>
</tbody>
</table>

Acoustic Analysis

For Participant Mia diadochokinetic rates both AMR’s and SMR’s, and caterpillar passage were analyzed using the Praat Software it was noted that the Mia’s Shimmer was elevated for all values, normally Shimmer is <.5 dB. Shimmer is amplitude instability and is elevated for disorders that interfere with medial-lateral wave propagation and indicated an increased breathy vocal quality. In addition to the high shimmer, the Jitter was elevated for all but two values (e.g. /da/ and /ga/), normally Jitter is between .2 and 1%. Jitter is frequency instability and is elevated for edge abnormalities and disorders that compromise Continuous-Time function. Elevated Jitter additionally represents increased hoarseness in vocal quality. The participant’s percentage of
Voice breaks was additionally elevated with normal values in females <1.997%, Participant MIA’s values ranged from 18.98% to 50.23%.

For Participant Mia’s Temporal Analysis, the Mean Words per second was significantly lower than the typical range 4-28, Mia’s Mean word per second ranging from 1.98-3.34 words per second. These values further indicate a case of Spastic-Ataxic Dysarthria despite the participant’s within functional limits intelligibility. Overall, Participant Mia presents with a Mild Case of Spastic-Ataxic Dysarthria.
Jane’s diadochokinetic rates, both AMR’s and SMR’s, and caterpillar passage reading were analyzed using the Praat Software it was noted that the JANE’s Shimmer was elevated for all values with a range of 1.076 dB to 1.59 dB, normally Shimmer is <.5 dB. Shimmer is amplitude instability and shimmer is frequently elevated for disorders that interfere with medial-lateral wave propagation and indicated an increased breathy vocal quality. In addition to the high shimmer, the Jitter was elevated for all values, ranging from 1.61%-3.59%, normally Jitter is between .2 and 1%. Jitter is frequency instability and is elevated for edge abnormalities and disorders that compromise Continuous-Time function. Elevated Jitter additionally represents increased hoarseness in vocal quality. The participant’s percentage of Voice breaks was additionally elevated with normal values in females <1.997%, Jane’s voice break values ranged from 56.93% to 87.29%.
Jane’s Temporal Analysis, the Mean Words per second was significantly lower than the typical range 4-28, with Jane’s Mean word per second ranging from 1.14-2.55 words per second. These values further indicate a case Severe case of Spastic-Ataxic Dysarthria, evident by the participant’s profound values generated from the Acoustic Analysis.
CHAPTER 5 DISCUSSION

Intelligibility Measurements and Evidence of Spastic-Ataxic Dysarthria

In this study intelligibility measurements and the use of ethnographic interviews were combined to further improve the diagnosis process for individuals with Multiple Sclerosis and Spastic Characteristics of Spastic-Ataxic Dysarthria. These measurements of Intelligibility were reflected in the acoustic analysis and scores generated by the Dysarthria Profile (Revised) for both participants who exhibiting different severities. Despite the variance in severities, both participants with MS demonstrated the hallmarks of Spastic-Ataxic Dysarthria (e.g. impaired loudness control, harsh or hypernasal voice quality, impaired articulation, impaired stress, impaired pitch control and interactions with other primary symptoms). These hallmark features were due to one or more sensorimotor problems—including weakness or paralysis, incoordination, involuntary movements, and excessive, reduced, or variable muscle tone (Duffy, 2013). Additionally, Duffy (2013) stated, Dysarthria can adversely affect intelligibility of speech, naturalness of speech, or both. Spastic-Ataxic Dysarthria in People with MS is difficult to treat due to spontaneous recovery and typical fluctuations between exacerbation and remission (Darley et al, 1972). As previously noted, it is possible for intelligibility to be normal in some individuals with dysarthria. Further noted in the review of the literature, it is possible for dysarthria to co-occur with other neurogenic disorders such as disorder of language, cognition, and swallowing. The predominant framework for differentially diagnosing dysarthria is based on a perceptual method of classification (Darley, Aronson, & Brown, 1969a, 1969b, 1975). As this framework created by Darley, Aronson, and Brown (1969a, 1969b,1975) predominately relies upon auditory perceptual attributes of speech that point to the underlying pathophysiology, however the use of this framework often cases mild of Spastic-Ataxic Dysarthria go undiagnosed.
Both participants Mia and Jane demonstrated the hallmark features of Spastic-Ataxic Dysarthria and both described negative reactions to the changes in their communication. According to a 2019 study by the National Multiple Sclerosis, even though 40-60 percent of people with MS experienced communication disorders, less than 35 percent of individuals were referred for speech evaluation and treatment. In recent years there is an increasing trend in supplement perceptual analyses of dysarthria with acoustic analyses of speech parameters. This advancement in physiological instrumentation for assessment is aimed at improving objectivity in measurement, refining our understanding of dysarthria features specific to MS, and ultimately aiding clinical decision-making and treatment planning (Miller, 2008). Therefore, the Acoustic Analyses of Voice Quality and Temporal Analyses provided a better identification of Spastic-Ataxic Dysarthria through acoustic measurements of abnormal Jitter, Shimmer, % voice breaks, harmonicity, syllable duration, and Mean Words per second.

**Implications of the Diagnostic Process on Quality of Life**

Two individuals’ journeys through MS was investigated in the current study. Both participants discussed starkly different diagnosis processes. Participant Mia, despite have symptoms of MS since she was teenager not receive an official diagnosis of MS until 36 years after the initial onset of her condition. Yet, after Mia received her diagnosis, she did not feel her healthcare professionals prepared properly to handle her diagnosis, nor provided her adequate information regarding the potential progression of the condition. At the time when Jane was diagnosed immediately after the onset of her symptoms, she felt that her healthcare professional provided adequate information and prepared her well to handle the potential progression of the condition. Such a variation in these diagnosis and treatment processes could greatly impact the individual’s reactions to their symptoms, particularly as their communication changes.
When participants were asked to rate their speech following the Speech Language sample collection, Mia demonstrated a hypersensitivity to her speech while Jane demonstrated a lack of insight into her deficits. These differences in awareness could highlight unique experiences with the participants’ individual diagnosis process. For Mia it took several years to receive a confirming diagnosis, which contrasted from Jane’s early diagnosis which gave her additional time to process and accept the diagnosis. Meanwhile Mia lived with illness without legitimacy. Without health practitioner providing a confirmed diagnosis, patients are often misunderstood by others. It is important to have a label for symptoms results which gives a reduction in stress and improves relationships (Edwards, Barlow & Turner, 2008). Additionally, Jane was provided with adequate information on MS at the time of her diagnosis, while Mia was not. Provisions of information at the time of diagnosis enable people to participate actively in life (as a result of access to information and increased knowledge about the condition), whether in the home, workplace or elsewhere, has been shown to have a positive impact on their self-esteem and general wellbeing (Hepworth & Harrison, 2004; Yorkson, 2001). Further research should center around further exploration into the onset of diagnosis and effects of adequate information given on an individual with MS’s reaction to diagnosis and later awareness into deficits related to MS symptoms.

**Impacts of Communication Disorders on Quality of Life**

Both participants demonstrated individual and variable responses in their ethnographic interviews. The variability in these responses directly correlates with the unique nature of Multiple Sclerosis with no two experiences with the condition or development of symptoms holding similarities. The use of Ethnographic interviewing demonstrated increased diagnostic benefits as participants expressed their unique journey’s with MS, and the impact of their changes in communication on the quality of life. Furthermore, the use of ethnographic interviewing
supplemented the current gap in research as the interview provided an open communication allowing the participant to discuss the impact of other variables (e.g., social support, work status) on dysarthria related quality of life.

Both participants expressed that their changes in communication have vastly impacted their quality of life as reflected in the developed themes from their ethnographic interviews. However, the themes generated from the participant’s interview mirror the themes generated in Yorkson (2001) as both participants in the current study also cited that the most impactful aspects of their communication disorders were watching as communication changes, participating in my life, and communicating can be unpredictable.

However, this study still indicated that Spastic-Ataxic Dysarthria in People with MS is particularly difficult to treat due to spontaneous recovery and the typical ebb and flow of the disease through periods of exacerbation and remission. Consistent with previous literature, the current investigation on MS and diagnosis of associated communication disorders concluded that both individual participants experienced frustrations and anxieties, further denoting the necessity for individualized diagnostic procedures, treatment, and potential need to integrate counseling therapy. A patient-centered intervention program that addresses the underlying thoughts and feelings of people with MS regarding changes in their communication and the individual’s reactions to those changes would provide diagnosis and treatment on a case-by-case basis. Currently, there are no MS specific Quality of Life Assessments. Current quality of life assessments, which are adapted from other non-specific quality of life assessments often neglect to analyze key elements and individualized symptoms that can properly describe an individual with MS in unique ways. To appropriately assess the impact of MS and its associated
communication disorders on an individual’s quality of life, ethnographic interview procedures should be utilized analyze each person’s experience with MS.

**Clinical Implications and Future Directions**

The outcomes of this study showed the urgent need to make changes about the Dysarthria diagnosis for People with MS and Communication Disorders as customizations are warranted to reflect each individual experience with the condition. A client-centered assessment containing both qualitative and quantitative assessments would help the individuals and those whom providing care to these individuals better understand how to create a nurturing environment for patients with MS. As predicted, each participant had their own personal story to tell, which influenced their experience with MS and opinions of their symptoms. This is apparent through comparisons with perceptual ratings and intelligibility measurements. As both participants’ ratings were different from the student clinician’s ratings which suggested a lack of awareness of symptoms in Jane and the hyper-awareness of symptoms in Mia. Both participants demonstrated hallmarks of Spastic-Ataxic dysarthria outlined by Duffy (2013). Furthermore, both participants divulged in their ethnographic interviews that MS had a variety of impacts on the ways they participate in conversation and interact with others. These interviews showed the impact of dysarthric speech on MS individual’s thoughts and feelings. It is in an urgent need to recruit more participants and expand beyond these two case studies. This future expansion of the current study potentially will have positive social impacts on the MS Community by improving the MS diagnostic protocols for individual’s with MS and associated communication disorders. The current study encouraged individuals with MS to share their stories and to seek speech language and counseling services despite the relapsing and remitting nature of this disorder.
Limitations

There were several limitations identified in this study. Only two participants were recruited which limits the gross comparisons and lacks a complete representation of the MS population. Additionally, the sample size lack variability as the participants are from the similar ethnic backgrounds, sex, and the sample lack inclusion of other MS types (e.g., Relapsing Remitting and Primary Progressive). Finally, the study was limited by timing as further data collection and recruitment would have greatly increase the creditability of the study.
APPENDIX A: INTERVIEW QUESTIONS

1. Tell me about how you were diagnosed with MS.
   a. How long was diagnosis process?
   b. How were told you had Multiple Sclerosis?

2. Tell me about the Healthcare Professional who diagnosed you.
   a. Do you feel they feel were knowledgeable about MS?
   b. When you were diagnosed what kind of information were you provided with?

3. Describe how your Healthcare Professional discussed the possible progressions of MS.
   a. In what ways do you feel you were prepared to handle your diagnosis?
   b. In what ways do you feel you weren’t prepared to handle your diagnosis?

4. Describe how you first started noticing the changes in your speech? Was the onset sudden or did it occur gradually?
   a. How do you think Multiple Sclerosis (MS) has affected your speech through the progression of the condition?

5. In what ways have these changes in your speech impacted your life?
   a. How do these changes in your speech make you feel?

6. Describe the symptoms you experience because of your MS
   a. Possible Symptoms (Circle Described Symptoms):
      i. Fatigue
      ii. Numbness or Tingling
      iii. Spasticity
      iv. Weakness
      v. Pain
vi. Cognitive Changes
vii. Emotional Changes
viii. Swallowing Problems
ix. Tremor
x. Seizures
xi. Breathing Problems
xii. Headache
xiii. Hearing Loss

7. Among these described symptoms, which one do you feel affect your speech?
   a. Questions for each symptom questions (Questions will only be asked about the
      symptoms the individual has identified in question 6 as impacting their speech):
         i. How has Fatigue affected your speech?
         ii. How had Numbness or Tingling affected your speech?
         iii. How has Spasticity affected your speech?
         iv. How has paralysis affected your speech?
         v. How has Weakness affected your speech?
         vi. How has Pain affected your speech?
         vii. How have Cognitive Changes affected your speech?
         viii. How have Emotional Changes affected your speech?
         ix. How have Swallowing Problems affected your speech?
         x. How has Tremor affected your speech?
         xi. How have Seizures affected your speech?
         xii. How have Breathing Problems affected your speech?
xiii. How have Headaches affected your speech?

xiv. How has Hearing Loss affected your speech?

8. Describe how this affected the way your move your mouth, tongue, jaw, and lips (i.e. speech coordination).
   a. Additional Questions
      i. Do you frequently pause during speech? If yes, tell me more.
      ii. Do you have any paralysis in your face or neck due to your MS? If yes, tell me more.
      iii. Do you experience involuntary movement due to your MS? If yes, tell me more.
      iv. Do you experience any discoordination when trying to speak because of your MS? If yes, tell me more.
      v. How do these make you feel?

9. In what ways has your ability to participate in communication changed since being diagnosed with MS?
   a. Have you noticed changes in the way you communicate with people since your diagnosis? Please Describe.
   b. Have you noticed changes in the way people communicate with you since your diagnosis? Please describe.
      i. Do feel you are repeating statements more since your diagnosis?
      ii. How have you coped with these changes? Are there strategies you use to avoid having to repeat yourself?
      iii. How does this affect your interactions with people?
iv. Do you feel yourself avoiding social interactions?

10. Have you noticed changes in other areas besides speech, such as anxiety, or depression?

(Additional Questions can be formulated depending on the individual’s responses)

a. Tell me more about the anxiety you experience because of your MS diagnosis.

b. Tell me more about the depression you experience because of your MS diagnosis.

11. Are there any positive improvements or aspect in your life because of MS? Please Describe.

(Additional Questions can be formulated depending on the individual’s responses)

a. Tell me more about what your MS diagnosis has taught you about yourself.

b. Tell me about how adaptable you have become since being diagnosed with MS.

c. Tell me about how resilient you have become because of your MS.

d. Are there any other positive results that have resulted from your MS diagnosis?

12. As you have navigated your journey with MS, how have aspects of your life been impacted by changes in your communication?

a. In what ways has acknowledging these communication changes been challenging?

b. Currently, what is the greatest challenge you are experiencing in your communication changes?

c. What was the great challenge in your communication changes earlier in the onset of MS?

13. What do you want people to understand about this communication disorder?

14. Tell me, what advice would you give to people who are being diagnosed with MS today?

15. In what ways would you want your story to empower those individual
APPENDIX B: SPEECH LANGUAGE SAMPLE AND DIADOCHOKINETIC RATES

1. Read the following passage out loud. After reading the passage you will be asked to complete a rating scale on how you felt while reading the passage.

THE CATERPILLAR


2. Say each sound individually for 10 seconds, then say them together repeatedly for 10 seconds as clearly and as fast as you can:
• SAY “PA” (FOR 10 SECONDS)
• SAY “TA” (FOR 10 SECONDS)
• SAY “KA” (FOR 10 SECONDS)
• SAY “PA-TA-KA” (REPEATEDLY FOR 10 SECONDS AS CLEARLY AND AS FAST AS YOU CAN)

• SAY “BA” (FOR 10 SECONDS)
• SAY “DA” (FOR 10 SECONDS)
• SAY “GA” (FOR 10 SECONDS)
• SAY “BA-DA-GA” REPEATEDLY FOR 10 SECONDS AS CLEARLY AND AS FAST AS YOU CAN)
APPENDIX C: PARTICIPANT AND RATER SURVEYS

Survey for the Participants:

These questions relate to how understandable you feel your speech overall is:

What do you think your family, friends, and partners understanding of your speech in conversation is? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)
1 2 3 4 5 6 7 8 9 10

What do you think coworkers and doctors understanding of your speech in conversation is? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)
1 2 3 4 5 6 7 8 9 10

What do you think acquaintances and strangers understanding of your speech in conversation is? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)
1 2 3 4 5 6 7 8 9 10

These questions relate to the passage you just read:

Rate how comfortable you felt reading this passage: (1= Extremely Comfortable, 2= comfortable, 3=Neutral, 4= uncomfortable, 5= extremely uncomfortable):
1 2 3 4 5

Rate how often you felt you slurred your words while the reading the passage: (1= Never 2= Rarely 3=Sometimes 4=often 5=frequently):
1 2 3 4 5

Rate how often you felt you paused unexpectedly while the reading the passage: (1= Never 2= Rarely 3=Sometimes 4=often 5=frequently):
1 2 3 4 5
Rate how you feel your overall understandability to a stranger listening to you read this passage would be: (1= clear speech 5=Not able to be understood):

1  2  3  4  5

Survey for the Rater:

These questions relate to how understandable you feel their speech overall is:

Do you think their speech would be understandable to familiar listeners (e.g. friends, family, significant others)? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)

1  2  3  4  5  6  7  8  9  10

Do you think their speech would be understandable to fewer familiar listeners (e.g. coworkers and doctors)? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)

1  2  3  4  5  6  7  8  9  10

Do you think their speech would be understandable to unfamiliar listeners (e.g. acquaintances and strangers)? Please rate on a scale of 1-10. Please circle 1: (1=Not able to be understood 10= clear speech)

1  2  3  4  5  6  7  8  9  10

These questions relate to the passage you just read:

Rate how comfortable do you think they felt reading this passage: (1= Extremely Comfortable, 2= comfortable, 3=Neutral, 4= uncomfortable, 5= extremely uncomfortable):

1  2  3  4  5
Rate how often do you feel they slurred their words while the reading the passage: (1= Never 2= Rarely 3=Sometimes 4=often 5=frequently):

1 2 3 4 5

Rate how often you feel they paused unexpectantly while the reading the passage: (1= Never 2= Rarely 3=Sometimes 4=often 5=frequently):

1 2 3 4 5

Rate how you feel their overall understandability would be a stranger listening to you read this passage would be: (1= clear speech 5=Not able to be understood):

1 2 3 4 5
REFERENCES


Multiple sclerosis (MS) produces neurological impairments that are variable in duration and severity, and that are unique to each case of MS. In addition to variability of symptoms, the length of the MS diagnostic process often affects quality of life. In this mixed qualitative and quantitative study, we used ethnographic interviews to investigate the underlying thoughts and feelings of two very different individuals with MS and Spastic-Ataxic Dysarthria. The results contribute to the understanding of MS as a multi-faceted condition that has implications that are both internal and external to the person with MS. Further, the results reflect the clinical value of improved quality of life assessment measures that focus on diagnosing the whole person and not surface level symptoms.
AUTOBIOGRAPHICAL STATEMENT

My name is Courtney Leppek. I was born on September 8, 1995, in Sturgis, Michigan. My parents are Dawn and Dru Leppek, and I have one sibling, Dru Joseph. I completed my undergraduate degree at Central Michigan University in Communication Sciences and Disorders and attended my master’s program at Wayne State University. Pursuing a career in Speech-Language Pathology stems from my firm belief that every individual is entitled to compassion and empathy. I, myself was diagnosed with Multiple Sclerosis at age fifteen, and though it has challenged me, my condition has also inspired me to combine my passion for Speech-Language Pathology and my firsthand experiences with MS to create research for the MS community.