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Analyzing Language Dysfunctions in Patients of Motor Neuron Disease and Their Psycho-Emotional Problems: A Case Study

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Abstract

Language dysfunctions and psycho-emotional problems in patients with motor neuron disease have been an underexplored area in the Pakistani context. MND patients face certain challenges based on their language, communication and psycho-emotional health that are disregarded in the context of Pakistan. This study aims to use a case study approach to investigate the language dysfunctions and psycho-emotional problems that MND patients face. This research focuses on analyzing the nature and extent of language dysfunctions and psycho-emotional problems in MND patients through the data collected from the patient and the caregivers. For data collection through observation and the caregivers' semi-structured interviews, the consent of the patient and his caregivers was taken. This data was recorded in the form of field notes which were subsequently transcribed to form textual data and identify the patterns and themes. The findings indicate that there are significant challenges that MND patients face at different phases from producing sounds in words to the formation of sentences and experiencing short and long pauses followed by muteness. Besides, it has also been found that the gradual loss of language and communicative abilities not only affects the psycho-emotional health of the patient but also the caregiver. The study contributes to the research on MND in Pakistan and draws the attention of researchers and healthcare providers to the dire need for their targeted intervention to improve patient care and support systems. The insights from this research can inform rehabilitation strategies and caregiver training programs, ultimately improving the quality of life for patients and fostering better support systems.

Introduction

Language is regarded as a dominant means of human communication shaping our identity, interaction and emotional release. In Pakistan, language dysfunctions caused by motor neuron disease amongst MND patients have not been explored as they should have been, so these areas remained underexplored creating a gap. This study investigates the specific language and communication barriers an MND patient faces. A set of neuromuscular diseases—Motor Neuron Disease (MND) results in progressive disability by affecting the upper and/or lower motor neurons. There are two forms of MND: Amyotrophic lateral sclerosis (ALS) and Primary lateral sclerosis (PLS) both involve upper motor neuron degeneration, which, for some individuals, can also accompany extra-motor changes in cognitive, behavioral, and/or emotional functioning. With piqued interest in cognitive subtypes, the characterization of the cognitive profile of MND continues to evolve (Garcia-Willingham, 2019). It is also known as Amyotrophic Lateral Sclerosis (ALS), a progressive neurodegenerative disorder that primarily affects the parts of the nervous system responsible for controlling voluntary muscle movements. The disease causes extensive damage to various components of the nervous system, including the motor areas of the cerebral cortex, the brainstem (such as the nucleus of the hypoglossal nerve), and the anterior horn cells of the spinal cord. This widespread neural impairment results in significant motor dysfunction and progressive disability (Abe, Fujimura, & Toyooka, 1993). The progressive damage to the upper motor neurons in MND results in symptoms like muscle tension in both limbs, which is called “Spastic paraparesis” in medical terms, whereas the problem with lower motor neurons leads to muscle contraction.

However, the explicit disclosure and distribution of the symptoms may be based on the specific areas and extent of damage within the nervous system. For instance, bulbar MND primarily affects the muscles associated with breathing and swallowing, resulting in symptoms like dysphagia (difficulty in swallowing) and dysarthria (difficulty in speaking). These variations in symptom presentation depend on the location and severity of the neuronal damage (Bak & Hodges, 1997).

This article aims to use a case study to uncover the specific language dysfunctions that are experienced by MND patients and the impact of these dysfunctions on their communicative abilities. This case study is based on a woman XYZ who was a school teacher and famous for her teaching and communicative skills. She was closely related to the researcher, so the researcher had a living experience of witnessing the language atrophy of the patient while suffering from motor neuron disease. The existing literature on motor neuron disease and its impact on cognitive and linguistic abilities underscores the importance of conducting an in-depth investigation to better understand the complexities of language dysfunctions in MND patients.

Language Processing and Human Brain

The neurobiological knowledge of language has considerably increased over the past few decades. Language is such a designed system that has different levels of language skills including the recognition of sounds and sound patterns, letters in words, words, using grammar and constructing meaningful sentences while using all of them. Language abilities are generally divided into two functions: comprehension and production which may depend on associative networks like the “frontal and temporal lobes” but may not depend on only these networks (Hickok & Poeppel, 2007). The human brain comprises the right and left hemispheres, and different regions in them have been identified supporting specific functions of language. There are findings that support how different regions of the brain are connected to one another and how they work. The left side of the brain has a temporal and inferior frontal area along with other areas, but this area especially helps in understanding the syntax, whereas for drawing/understanding the meaning of the utterance(s), both sides of the brain work collaboratively by making use of the connections between temporal and frontal areas. The electrophysiological data show that within these brain networks, there comes the basic sentence structure first and then the grammar and meaning. The network on the right side of the brain handles the prosody (rhythm and intonation) in spoken language. This is the process that has a clear signal that can be detected through brain activity measurements. There is a study that has been conducted on patients suffering from lesions in the corpus callosum. This study has revealed that the “posterior portion” of this structure plays a crucial role when the syntactic and prosodic information interact during language processing.

Almost every study based on the brain for language processing reveals that at least there is one function-related activation in the left perisylvian cortex, which involves the temporal, frontal, prefrontal, and parietal cortices. The specific function of the perisylvian cortex is based on functional imaging studies that investigate different aspects of language processing, such as phonology, syntax, and semantics. As far as spoken language comprehension is concerned, it begins with the acoustic-phonological analysis of the speech input, and the basic neural regions that support this preliminary stage are the auditory cortex and other areas around it (Friederici, 2011). Friederici (2011) further finds different parts of the brain that support language production, like the left inferior gyrus that lies in Broaca’s area, plays a vital role in sentence production. Similarly, the supplementary motor area helps and supports the motor planning involved in speech production. Another area of Broaca that is called the left posterior lobe helps and supports syntactic processing: sentence structure and grammar. The posterior temporal lobes help in processing the words, their meaning, and structures of the meaning, whereas the anterior temporal lobes are involved in words and their meaning along with their syntactic structures in sentences. As speech sounds are the lifeblood of communication, the auditory cortex is involved in processing speech sounds and their integration with syllables.

Significance of Study

While studying the impact of motor neuron disease on language comprehension and production, it is important to understand the language deficit so that appropriate care and therapy may be provided to the sufferers. Baka and Hodges (2003) identified language dysfunction as one of the salient symptoms in some MND patients. Therefore, if the language of MND patients is studied/monitored carefully, it will not only help the caregivers diagnose the problems at an early stage but also devise personalized strategies to communicate so that communication of the sufferer may remain functional. This continuous and careful monitoring will also address some interesting theoretical queries about the production/representation of language and the underlying concepts in the brain. There are more than 80% of MND patients who face speech problems. These speech problems are also called dysarthria. There is a considerable increase in dysarthria as the disease progresses (www.rcslt.org).

Dysarthria, a condition in which the sufferer suffers from slow, slurred, and unclear speech with reduced speech intelligibility, is a motor disorder of speech that highlights two main abnormalities: articulation of speech and intelligibility of speech. With this problem comes some other problems like slow speaking rhythm, pronouncing the words correctly, and losing control over speech volume. These problems make it difficult for the listeners to understand what such patients say. Understanding the nature of dysarthria in amyotrophic lateral sclerosis (ALS) is essential because the loss of communication stops patients from taking part in many activities that may reduce their quality of life and lead them to social isolation. The main purpose of dysarthria management in ALS patients is to optimize effective communication so that the communication may remain there as long as it can. There are several fields of study such as physiology, pathology, speech therapy, and neurology in which information about dysarthria in ALS is published (Tomik & Guilof, 2010).

MND patients have been observed through studies making efforts to communicate and thinking that poses barriers in deciding on their personal healthcare. It has also been found that people living with MND, their caregivers or healthcare professionals, found it hard to maintain a level of communication with them. The quality and accuracy of verbal communication are compromised which leads to anxiety.

Statement of the Problem

An ability to communicate effectively is integral for getting quality health care but unfortunately, the maintenance of effective communication goes unnoticed by health care professionals or caregivers. Therefore, the health care providers to MND patients should adapt and adopt such strategies that may accommodate the communication needs of the patients (Paynter, Mathers, Gregory, Vogel, & Cruice, 2022). Cobble (1998) noticed that language processing in sufferers of MND has not been deeply studied, but only general cognition has been touched upon. He conducted a study with nine MND patients who were tested through various language assessment tools and subsequently, their performance was compared with the performance of nine other individuals who did not have MND. The results showed that some of the MND patients had language impairment. However, there was a mild language deficit that only appeared when formal testing was employed. The patients with MND appeared to have problems with naming and spelling, showing their understanding of the complex tasks and certain other tasks that entailed the meaning of words or sentences. The present case study aims to understand the communicative problems of a patient suffering from Motor Neuron Disease. The study is based on first-hand primary data that would have wide practical implications.

Research Methodology

In this study, the case study method has been employed to uncover the language dysfunctions faced by MND patients. The subject of the study was a school teacher renowned for her teaching and communication skills. She was closely related to the researcher, so the researcher is a first-hand source of information who witnessed how the language of the subject gradually started to be dysfunctional in different phases of MND disease.

The case study method is one of the forms of qualitative research. The case study research helps to identify a topic that might be explored in a natural setting for in-depth analysis of the information collected through multiple sources (Hancock & Algozzine, 2006). There are three types of case study methods: exploratory, explanatory and descriptive case study. In this study, the descriptive case study method has been used because Hancock and Algozzine (2006) claim that the comprehensive description of the targeted phenomenon within its context can only be presented with the use of the descriptive case study method. Therefore, the researcher selected this method to develop a deeper understanding of his subject's linguistic and communication challenges and contribute to the theoretical frameworks, existing literature available on MND, approaches to addressing the linguistic and communication challenges of MND patients and the needful steps to be taken to introduce the programs for the rehabilitation of MND patients.

Background Information of the Patient

The subject in this study, a 58-year-old female, was a devoted high school teacher, specializing in Mathematics and Physics. She had a very demanding professional career and lifestyle. Despite teaching in school, she also taught coaching classes in the evenings. However, she never missed her regular walk in the evening. She did not have any medical history except high blood pressure, and she was on medication for high BP. As far as the diet is concerned, she was a balanced diet-conscious person who always preferred home-cooked foods without being overly rich in spices and fats. Before the beginning of MND, she did not have any indication(s) of any serious health issues.

Before the clinical diagnosis and confirmation of the MND disease, the immediate family members noticed that she walked unsteadily slightly which increased over time. Besides the unsteady walk, they also noticed slurred speech which was mild in the beginning but increased lately. The patient was taken to a family physician who suspected the negative effect of an unnoticed mild stroke but for further examination, he referred her to a neurologist. After a thorough examination and getting the history of the patient, certain tests were advised: MRI (Magnetic Resonance Imaging), EEG (Electroencephalogram) and EMG (Electromyography). Having received the results of the tests, the respective doctor declared that she was suffering from motor neuron disease and told the family that MND was an incurable disease; however, the process of deterioration of muscles could be slowed down by medication. He also shared that the life expectancy with MND was only four years.

Data Collection

The patient was closely related to the researcher so there were no formal protocols required to visit the patient. However, the research intent was shared with the immediate family members who did not show any reservations or apprehension. Therefore, the patient was visited every week for three months to collect data.

Observations and semi-structured interviews with immediate family members were used as tools to collect data and record in the form of field notes. These tools helped in developing deeper insight into not only the physical, behavioural and emotional realities of the patient but also the caregivers.

Data Analysis

The collected data was analyzed for coding and categorizing, leading towards the thematic analysis of the content. For analysis of the data, the data was broken down into linguistic, communicative, physical, behavioural and emotional challenges of the MND patient and then the communicative, behavioural, emotional and social challenges faced by the family members/caregivers. Moreover, the role of the family in supporting the patient in physical mobility, emotional well-being and keeping the patient's spirit high was also seen and analyzed critically and set apart from other things.

Language Dysfunctions and Communication Barriers in MND

Language dysfunctions and communication barriers are marked effects of MND amongst the patients suffering from this disease. The findings of the data revealed that the patient in this study encountered language and communication challenges, which were among the most salient early observations. These challenges were observed by the family members and the victim, who shared these unexpected experiences with the immediate family. It was noticed that she not only started to have problems with speech production while teaching but also with her writing skills. In the beginning, the writing speed became slow and after a few months, her hand was shaky while writing on the board and notebooks of the students. Moreover, she was unable to keep the pressure on her pen which resulted in fainted words or letters and sometimes overly dark.

As far as speech is concerned, her speech was also becoming slow, slurred and unclear. The speech problems began with prolonged sounds and difficulty in pronouncing the words correctly. With these language and communication challenges, it was also noticed as if she was struggling to produce the correct sounds and words like "Pani (water)" "Ghar (House)", "Gari (Car)", "Kapray (clothes)", "Khana (food)", "Baat (talk)", " Takia (pillow)" and many other words like these. In an effort to pronounce the sound or words correctly, the victim tried to repeat the words so that she might be understood correctly. Sometimes she skipped some sounds within words like "Khana" and only "aaaana", "Paani" and only "aaani". The family members repeated the words to confirm whether she meant them and then responded to her. It was also noticed that she was struggling with finding an appropriate word to express herself. She was not seen as having any problem in listening and understanding whatever was communicated to her. However, she was facing problems in

This issue was identified as an extra burden on the patient to communicate immaculately which added to her suffering and mental torture. This was not only a challenge for the MND victim but also the caregivers. Despite having difficulty in understanding and interpreting the speech of the patient, the family members handled the situation with love and care and said the same word or matching word for the patient's convenience. She confirmed the caregivers' word(s) by nodding. In this way, she was given confidence for clear communication. It was also found that language and communication dysfunctions ultimately resulted in muteness disassociated her from her active social life and participation in everyday activities.

Physical Challenges in MND

The physical challenges in motor neuron disease appeared to be one of the significant challenges in this case study. The data collected informed the researcher that the patient under observation started to feel that she was having problems in writing and holding the pen that developed an understanding of something wrong with the strength in her hand that was hampering the movement while writing on the blackboard and the notebooks of the students. She was like an untiring personality but started to get tired quickly. It further added to the mental shock when an unsteady walk was noticed by herself, colleagues and family members. It was observed that she was losing balance while walking and this unsteady walk turned into immobility rapidly. However, at the beginning of the unsteady walk, she was provided with help by family members to save her from the risk of falls and further physical injuries to add to the distress of the patient. Subsequently, a wheelchair was arranged for her and now she could visit the doctor in a wheelchair with a family member. As the problem increased, she was observed unable to move her hands to take meals, manage saliva dripping down from mouth and move from one side to another in bed. All these conditions underscored the necessity of continuous help and support of the caregivers.

Behavioural, Psycho-Emotional and Social Challenges in MND

Motor neuron disease not only affects the language and physical mobility of the patients but also causes behavioural, emotional and social challenges for the victims to undergo. The family reported that the subject in this study was shocked by these sudden changes in her body which changed her behaviour. She was a lively lady before the onset of this disease but was seen as extremely upset and irritated. She was also seen losing confidence while communicating with others and avoided involving herself in conversation. During clinical examinations and tests, she was hopeful but when the doctor disclosed that MND was an incurable disease, she was not ready to accept that and subsequently started to be seen as depressed and losing hope as the days passed. The family also shared that she used to get irritated when she failed to communicate what she wanted to. With MND the case in this study became bed-ridden and confined to one room. She was isolated from her social network, which was difficult for her to accept as she was a sociable person. This isolation added to her emotional pain. This unsociability not only affected the psycho-emotional and social life of the patient but also the caregivers who were her immediate family members. Attending to the patient and spending most of the time was the top priority of the family members. All these problems were not only the problems of the patient, but the family was also facing anxiety, depression, and hopelessness. However, the family members served and attended to her as one of their primary responsibilities and never got irritated over her behaviour or reactions but with one another when somebody was unavailable to look after her. They shared that they knew she was passing through a psycho-emotional crisis but that was a similar crisis for them.

Ethical Consideration

Ethical considerations are thought to be the backbone or the most important part of the research. Considering the ethical considerations in this study, the research shared the objectives of the research with the victim of MND and the family members who were the caregivers. They were made aware of the benefit of this study at the broader level to other MND patients, caregivers and health professionals. The potential participants in this study were also given confidence that their names and other identities would remain confidential and would never be disclosed to anyone at any level. Having received the consent of the research participants, the data collection process started and after every session, the data was transcribed from notes to the text and shared with the participants for confirmation. Upon the confirmation of the participants, the data was recorded formally with the satisfaction that there is no subjective element involved in the data.

Discussion

This study is mainly focusing on investigating the language dysfunctions and psycho-emotional problems of motor neuron disease patients. The findings of the study have revealed that MND patients face different types of language dysfunctions which begin with a realization that their ability to speak is not supporting them to communicate as fluently as it was before and gradually leading them towards delayed utterances, feeble sounds, short and long pauses and ultimately finding it difficult to speak or communicate and subsequently substituted by mutism. The existing literature fortifies the findings that there are two different observations in MND regarding language: language change(s) and language impairment. Language change(s) in MND patients is overlooked or not given due consideration, whereas speech impairment(s) gains more attention. Patients' verbal communication starts to reduce leading to mutism, which is one of the frequently highlighted symptoms in literature.

The findings drawn from data also showed that the initial language dysfunctions ultimately result in mutism which is also termed "speechlessness" (van Bogaert, 1925) or "inability to speak" in the available literature (Ziegler, 1930). This symptom of mutism/speechlessness/inability to speak is one of the early signs that the patient is going to suffer from dysarthria, which is a condition in which the muscles of the patient get weak, and it becomes difficult for him/her to speak. In addition, these symptom(s) cannot be associated with difficulty in producing language verbal language, but there can be some other neurological or linguistic problems. Apart from verbal language production, there is another area: the written language of the mute patients that should be addressed by the researchers but except for finding "spelling errors," nothing significant has yet been reported. This is also one of the gaps in this area of research (Ferrer, Roig, Espino, Peiro, & Guiu, 1991). Other than that, other noteworthy areas that have yet to be paid heed and reported are the non-verbal counterparts like echopraxia (involuntary imitation), stereotypical expressions, echolalia (repetition of words, phrases, and sentences) of MND patients (Deymeer, Smith, DeGirolami, & Drachman, 1989; Mitsuyama & Takamiya, 1979; Neary et al., 1990, Constantinidis, 1987; Meyer, 1929).

In this study, the subject was not seen having any trouble understanding the language of the caregivers. Still, another observation is that MND patients face difficulty in understanding language, and this difficulty is tacked to problems with abstract thinking/general dementia rather than syntactic limitations (Neary et al., 1990; Peavy, Herzog, Rubin, & Mesulam, 1992). However, in this case study, the patient could easily understand when the caregivers or visitors said something. It was also found out that she had a good memory because she could recognize his siblings and other relatives which means she did not have dementia.

Moreover, there is "Semantic Paraphasias" (speech errors where a person substitutes a word with another that has a related meaning, even though it's incorrect in the context) that is also one of those evident aphasic symptoms that have also been rarely addressed (Gentileschi, Sperber, & Spinnler, 1999; Neary et al., 1990). However, in this case study the subject was not seen substituting the words and using them in the wrong context rather she was seen struggling with producing the correct sounds of the word but was unable to pronounce the words that started with “P, B, G, K” and in later stages skipped the initial sounds.

In the case of multilingual patients, it has been noted that they lose their ability to use language because they lack detailed explanation (Wilkstrom, Paetau, Palo, Sulkava, & Haltia, 1982) which was true to my case in this study. However, in some of the patients, severe forms of motor aphasia have been observed (Mitsuyama, 1984; Tsuchiya et al., 2000).

It was also found that the rapid loss of speech and physical movement and social disconnection have deeper psychological and emotional effects on the MND patients and their caregivers resulting in depression, disappointment and hopelessness. The existing literature matches with the findings related to psycho-emotional challenges when Hughes et al (2005) state that the rapid decline in physical conditions of the patient not only affects the psycho-emotional health of the patient but also the family members. Another finding was very much related to psycho-emotional issue and that was the change in social life seen turning into confinement for not only the patient but also the caregiver because their social landscape also changed. Supporting the finding Brott et al (2007) confirm that as the condition of MND patients progresses, they start to lose their social contact and their involvement in social activities. Thomas (2004) also claims that the inability to move constructs a barrier between society and MND patients which has psycho-emotional effects on the patient.

Conclusion

This study highlights that MND patients face multidimensional challenges ranging from their language dysfunctions, physical immobility and psycho-emotional crisis. The findings show that the patients’ language dysfunction begins with slurred speech which entails so many other issues in the later stage like prolonged sounds, difficulty in uttering the correct word or sounds, and problems with the specific initial sounds of words like “P, B, T, K”. The ultimate end of language dysfunctions is muteness when the patient becomes unable to speak. There are physical and emotional reasons that contribute to muteness. The physical changes include an inability to walk steadily, move hand(s) freely even take meals and ultimately seek help from the caregivers to turn from one side of the bed to another give rise to psycho-emotional problems. The patient starts to remain stressed as if finding this condition difficult to accept. The study also highlights that it is not only the patient who faces this crisis, but the family also undergoes physical, social and psycho-emotional crises. The study has further highlighted that there is a dire need to provide awareness to caregivers about MND patients' management and to the MND patients as well for facing the challenges.

Limitations of the Study

The study has offered a deeper understanding of motor neuron disease; however, its results can not be generalized because this is a case study in which a single case has been involved. In terms of research methodology, the data was collected only through observations and semi-structured interviews which made this study qualitative whereas if quantitative data were also involved the findings could have been different. Besides, this study is narrowed in geographical terms. The results may vary on another socio-cultural and socio-economic landscape.

Contribution

This study contributes to the understanding of motor neuron disease and the challenges faced by both patients and family members. Moreover, the findings of the study draw the attention of the respective health professionals towards a dire need to introduce a program in which the caregivers may be given training about how to communicate with MND patients through communication aids and keep their psycho-emotional health intact.

Research Implications

The study implies that future researchers should delve deeper into this area of research to explore the challenges of MND patients in different sociocultural and linguistic contexts so that the literature on this topic may be enriched by fostering interdisciplinary research involving linguistics, psychology and health sciences.

The findings of the study further create a need to draw the authorities' attention to introducing an awareness program among people about the early signs of MND and timely intervention of healthcare providers, family and caregivers. There is also a need to establish rehabilitation centres offering help and support to the sufferer and the family members as well because both undergo trauma and need psycho-emotional support. Moreover, introducing training centres for caregivers should be the consideration of the policymakers. The caregivers' training in communicating with MND patients and similarly the patients' training to communicate with caregivers effectively and appropriately will lessen the burden of linguistic, physical and psycho-emotional trauma.

The findings also draw the attention of the local community and organizations that work for human welfare especially the handicapped to play their role and step forward to save MND patients and their families from social disconnection and plan recreational activities for them to take a sigh of relief from the dominant trauma.

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