

Psychology and Neurology in Multiple Sclerosis: A Preliminary Study for Patients' Perspective in Puerto Rico

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Background: Up to half of MS patients experience depression at some point during the disease. Depression is often overlooked and untreated given the symptom's comorbidity with MS. Studies have demonstrated that depression in MS can negatively impact neurocognitive functions exacerbating the cognitive impact.

Objective: To explore MS patients' attitudes about mental health to identify possible reasons for lack of mental health treatment.

Methods: A non-experimental, transversal design of an exploratory type was utilized. A total of 80 participants were recruited with a non-probabilistic sample at Fundación de Esclerosis Múltiple de Puerto Rico. Participants were 21 to 65 years old.

Results: A total of 26.3% (n=21) were male and 73.7% (n=59) female; 23.8% (n=19) reported psychological treatment and 31.3% (n=25) reported a diagnosis of depression at some point after the MS diagnosis. A total of 57.5% (n=46) indicated not receiving information from their neurologist about the influence of MS in their mental health and 75% (n=60) said they would visit a psychologist/psychiatrist to positively impact their mental health.

Conclusion: Most MS participants agreed that mental health was of importance and would visit a mental health specialist. Psychoeducation, patient-physician relationship, centered care and integration between specialist are important roles in the overall treatment for MS and depression.

Keywords:

Multiple-sclerosis, depression, psychology, neurology, attitudes

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Introduction

Multiple sclerosis (MS) is an unpredictable chronic central nervous system disorder characterized by damage to the brain and spinal cord¹. According to the Atlas of the Multiple Sclerosis International Federation², more than 2.3 million people in the world experience this disorder. In the Western World, MS is the utmost prevalent non-traumatic basis of neurological disability in young and middle-aged adults³. In Puerto Rico, it is estimated that 7.1/100,000 females and 2.9/100,000 males experience MS, representing a higher incidence when compared to other countries in the Caribbean and Latin American⁴. This condition is mostly characterized by symptoms that affect mobility, vision, fatigue, cognitive functions, bladder/bowel function, and sensory and motor functions⁵. According to research, it has been found that more than half of MS patients will experience neuropsychiatric symptoms little after the onset of the disease, and depression is the most prevalent⁶. Currently, there is no cure for MS, however, there are medical treatments that prevent the progression and exacerbations of symptoms, modifying the disease expression⁷. Even though depression is the most prevalent mental disorder in MS, it is frequently not addressed or undetected by their health professionals and consequently not treated by mental health professionals, consequently depriving MS patients of optimal treatment for their conditions⁸⁻¹⁰.

MS risks factors vary from exposure to tobacco smoke and organic solvents, unhealthy diet, Epstein-Barr virus (EBV) infection, obesity in adolescence, low levels of vitamin D and genetic features¹¹. Psychosocial risk factors such as non-adaptive coping and deficient social support have been identified to contribute to depression in MS patients¹². Additional risk factors like changes in the brain structure, immunological reactions and inflammatory pathways, as well as alcohol dependence and smoking¹³, have also been considered as possible causes for developing depression in MS. One of the largest investigations assessing depression prevalence in MS, found a total of 33.9% MS patients who presented some level of depressive symptoms¹⁴ and other studies and analysis have found similar results with up to 50% of incidence^{15,16}. This suggests a high incidence

of depression in MS. Literature shows that cognitive fatigue and depression are correlated with lower information processing speed, executive functioning, attention, motor functions, memory¹⁷ and speed of mental process¹⁸. Which could suggest depression has an impact in neurocognitive functions, and consequently, in quality of life¹⁹.

In mental health, specialists continue to discover diverse evidence-based models and approaches of therapy that could aid MS patients. An integrated treatment plan as well as psychoeducation, have been proven to be one of the interventions of most benefit for MS patients due to a reduced number of relapses and enhancement in quality of life²⁰. For instance, the Cognitive Behavioral Therapy, Mindfulness-based psychological interventions and Acceptance and Commitment Therapy have been researched to be an effective treatment to decrease depression in the MS population²¹⁻²³. Benefits such as overcoming challenges of daily life, promoting resilience, and reducing distress related to this medical condition are one of the benefits from these interventions²⁴ (Simpson et al., 2014). Likewise, they have been shown to be successful treatments for working with different neuropsychological aspects of MS patients²⁰. However, literature is still debating and exploring why the comorbidity of these conditions is said to be undertreated or under-diagnosed.

Material and methods

Study design and participants

This research had a non-experimental, transversal design of an exploratory type. The purpose of this study was to explore the attitudes of patients towards mental health treatment and referrals, with the purpose to analyze possible reasons. To obtain a representative sample subjects were calculated to be 116 Puerto Rican MS patients. However, due to limitations a total of 80 participants were recruited and the study was converted into a sample data preliminary investigation. Participants were ages 21 to 65 years old, males and females. The inclusion criteria required participants to have a diagnosis of MS, be older than 21 years old and live in Puerto Rico. The exclusion criteria consisted in participants with other neurological conditions and participants underage or older than 65 years old. The

sample selection was a non-probabilistic sample, due to the transversal origin of the study and was realized with a descriptive approach. Subjects were recruited with at the Fundación de Esclerósis Múltiple de Puerto Rico through orientation regarding the study and voluntary response sampling. The Fundación de Esclerósis Múltiple de Puerto Rico has patients from all over Puerto Rico, and is the biggest and most knows foundation in Puerto Rico regarding MS. It offers education, support groups, activities and help to thousands of MS patients in Puerto Rico.

Instruments

In this research, the following instruments were used: Multiple Sclerosis Patients Sociodemographic Data Sheet, which included questions aimed at knowing the profile of the study participants. Additionally, the survey titled Attitudes towards Mental Health of patients with Multiple Sclerosis was used to explore different aspects of their perception regarding mental health services, in a Likert scale form with the choices of Completely Agree, Agree, Disagree or Completely Disagree. This instrument was created by the three principal researchers in the study and consisted of exploratory questions aimed at MS patients attitudes towards mental health. There were initially 37 questions, but they were reduced to 30 by the three judges in charge of the revision. The questions are aimed to describe and explore the participants' attitudes about receiving mental health, about their perspective towards the need for mental health, about their perspective of their knowledge towards mental health and they're willingness to undergo a mental health treatment. This instrument was uniquely created for this study with the purpose to explore the attitudes from MS patients, due to the absence of instruments directed to this specific population.

Data Analysis

Quantitative data was analyzed by descriptive statistics, using the Statistical Package for the Social Sciences data analysis software (SPSS, IBM Corporation, 2013). Descriptive statistics were used to analyze the participants answers from the instrument. The instrument did not go through a validity or reliability procedure as it was made with the pur-

pose to explore and describe MS patients' attitudes towards mental health treatment.

Procedure

The Institutional Review Board (IRB) authorization was solicited and accepted in Ponce Health Sciences University to carry out the investigation. Once the IRB authorization was obtained the sample data collection was initiated. The orientation process was commenced to recruit the participants in the study at the Fundación de Esclerósis Múltiple de Puerto Rico. The development, information, steps, benefits, and possible risks of the study were explained to the participants. Due to limitations worldwide regarding COVID-19, only 80 participants were recruited for the study. The sociodemographic sheet and the Attitudes towards Mental Health of patients with Multiple Sclerosis instrument were administered through the months of January to March 2020.

Results

A total of 73.7 (n=59) females and 26.3% (n=21) males with the diagnostic of MS were recruited for the study. The ages varied from 21 to 65 years old. The participants were a diverse group of people with MS in terms of marital status, education, socio-economic status, and health and mental health treatment. Of the participants 100% (n=80) were receiving neurological treatment now (see table 1).

Participants were most commonly (n=27) between the ages of 36-45 with a 33.8%. Followed by 30% (n=24) between the ages of 46-55, 27.5% (n=22) between the ages of 56-65 and 8.8% (n=7) between the ages of 21-35. Regarding the participants marital status, the majority was single 42.5% (n=34), 40% (n=32) was married, 1.3% (n=1) was widowed and 16.3% (n=13) was divorced. In highest level of education obtained, 31.3% (n=25) of the participants had a bachelor's degree, following by 26.3% (n=21) master's degree, 21.3% (n=17) high school degree, 17.5% (n=14) associate/certificate degree and 3.8% doctorate degree. In the participants' occupation, the majority was employed 40% (n=32), a total of 36.3% (n=29) had disability pay, 17.5% (n=14) were unemployed and 6.3% (n=5) were retired (see table 1).

Table 1. Descriptive MS Subjects Sociodemographic Data

		N	%
Variables			
Gender	Male	21	26.3
	Female	59	73.7
Age	21-35	7	8.8
	36-45	27	33.8
	46-55	24	30
	56-65	22	27.5
Marital Status	Single	34	42.5
	Married	32	40
	Widow	1	1.3
	Divorced	13	16.3
Education	Highschool	17	21.3
	Associate	14	17.5
	Bachelor	25	31.3
	Master	21	26.3
	Doctorate	3	3.8
Occupation	Employed	32	40
	Unemployed	14	17.5
	Disability	29	36.3
	Retired	5	6.3

Note: MS= multiple sclerosis, n= number of participants
Table 1 represents the distributions of sociodemographic data of the participants.

A total of 57.5% (n=46) responded they did not received information from their neurologist about the influence of multiple sclerosis on their mental health and vice versa. A total of 42.5% (n=34) reported having received psychiatric treatment at some point after receiving the diagnostic of MS and 26.2% (n=21) reported receiving present psychiatric treatment. A total of 30% (n=24) indicated receiving psychological treatment at some point after receiving the diagnostic of MS and 23.8% (n=19) indicated that they received present psychological treatment (see table 2).

A total of 31.3% (n=25) reported having a current diagnosis of depression given by a mental health professional and 13.8% (n=11) responded having a diagnosis of anxiety given by a mental health

Table 2. Neurological and Mental Health Treatment

		N	%
Variables			
MS and Mental Health Information	Yes	34	42.5
	No	46	57.5
Psychiatric Tx.	Yes	34	42.5
	No	46	57.5
Present Psychiatric Tx.	Yes	21	26.2
	No	59	73.8
Psychological Tx.	Yes	24	30
	No	56	70
Present Psychological Tx.	Yes	19	23.8
	No	61	76.2
Depression Dx.	Yes	25	31.3
	No	55	68.7
Anxiety Dx.	Yes	11	13.8
	No	69	86.2
Past Depression	Yes	27	33.8
	No	53	66.2
Mental Health Precautions	Hobby	29	36.3
	Exercise	28	35
	Meditation	5	6.3
	Spirituality	8	10
	Family Support	10	12.5

Note: MS= multiple sclerosis, Tx= treatment, Dx= diagnosis
Table 2 represents the demographic information regarding health and mental health.

professional. Regarding past depression diagnosed by a health or mental health professional in the past 33.8% (n=27) indicated a positive history of depression. Concerning mental health precaution care, the majority of participants 36.3% (n=29) reported that they used a hobby to care for their mental health, following by exercise 35% (n=28), family support

12.5% (n=10), spirituality 10% (n=8) and meditation 6.3% (n=5) (see table 2).

Regarding the instrument Attitudes towards Mental Health of patients with Multiple Sclerosis, a total of 85% agreed with the statement *I think that the mind, like any part of my body, can get sick*. Similarly, a total of 76.2% agreed with the statement *My mental health influences my behavior*. A total of 92.4% agreed with *Mental health is necessary to live a healthy life* showing a positive perspective regarding mental health. Regarding being aware of how the condition of Multiple Sclerosis could affect mental health 83.7% agreed with the statement. Concerning who is responsible for their mental health, a total of 87.4% agreed with the statement *I consider myself responsible for taking care of my mental health*. However, in the statement indicating they considered their physician and health professionals responsible for taking care of their mental health a total of 45% agreed.

A total of 81.2% agreed that they would consider going to therapy to treat a mental illness or develop themselves as a person. Which could implicate a positive perspective towards mental health treatment. In statement *I think that chronic sadness is a normal symptom of mental health* a total of 37.5% agreed. In statement *I believe depression cannot influence my condition of Multiple Sclerosis* the majority of patients 34.7% agreed. Regarding the statement of *Mental health services are unnecessary* a total of 18.6 % agreed. Conversely, a total of 76.2% agreed that the good mental health of society contributes to empathy. Regarding the care for their mental health and its prevention for damage to physical health a total of 60% agreed.

In statement *Mental health care is a routinely part of my health* a total of 58.8% agreed. Which implicates some preventive measures are implemented in their care. A total of 93.7% agreed that mental health is just as important as physical health the majority of patients. Implicating a positive and significant view towards mental health. In statement *I think my condition of Multiple Sclerosis has an impact on how I feel psychologically* a total of 72.4% agreed. Regarding visiting a mental health professional as a part of their routine for the condition of MS a total of 56.2% agreed. In statement *I believe I can positively impact my condition of Multiple*

Sclerosis with the help of a psychologists or psychiatrist the majority of patients a total of 72.4% agreed, which could suggest a positive view towards mental health.

Discussion

The objective of this study was to explore and describe MS patients' attitudes towards mental health. According to research, many studies conclude that the rates from depression, suicide and low quality of life can be more present in the MS population⁸⁻¹⁰. The etiology of depression in MS is prone to be multifactorial, including biological, psychological, and social contributing factors²⁵. This is crucial since literature has found that depression and related symptoms can have an impact in the neurocognitive functions of MS patients, which could potentially mean a negative impact in their MS condition²⁶. If MS symptoms related to depression often are not addressed or are undetected and consequently not treated by mental health professionals, this could consequently mean MS patients might not be receiving optimal treatment for their conditions⁸⁻¹⁰. Aspects such as disease comorbidity and intercalation between physical symptoms a depressive symptom can be contributing factors as to why this phenomenon is still unclear. For instance, a study found that physicians, even though asked to explore depression in an MS patients' sample, had difficulties auscultating the diagnostic⁹. Since MS symptoms such as fatigue, sensory and motor problems and cognitive damage could also be present in both depression and MS¹⁷ (Golan et al., 2018), it is possible that this could contribute to under-detection or underlying comorbidity. Furthermore, when addressing depression, it has been studied that the majority of patients do not discuss stress with their health professional²⁷. For instance, some health professionals who attend patients with depression, are often influenced by several conditions such as lack of time, psychosocial factors or perceived efficiency²⁸ which brings the importance of integration and communication between health specialists and mental health providers and assessors. In the United Kingdom a recent qualitative study²⁹ explored the care with mental health problems in medical and surgical wards with nurses and physicians. They qualitative data showed that nurses and physicians stated that there was lack of integration and education regarding mental health patients. According to their

data, one of the nurses explained that medics were afraid to deal with mental health patients. Additionally, one of the participants (nurse) stated that mental health was not part of her duties. The authors concluded that identifying the concerns and challenging factors encountered by the staff they can be better equipped to work in the direction of enhancing the quality of care with this population.

From the sample data most of the MS participants agreed that mental health was important and influential for them, and the majority also agreed that they would visit a mental health specialist if necessary. A total of 33.8% reported having a diagnosis of depression at some point after receiving the diagnosis of MS and of those participants 31.3% reported to have a current diagnosis of depression. These numbers suggest congruency to the numbers found in literature that state that a high MS patients' percentage present depression after being diagnosed with MS^{14,16}. However, additional research is needed to compare these results in a broader scale. Another important finding is that 57.5% of patients reported that they did not receive explanatory information from their neurologists regarding the impact of mental health in MS and vice versa. In MS, it is of great importance for patients to understand their physical symptoms as well as their emotional symptoms, and it is of utmost importance

to know the options available for treatment due to depression's impact in MS³⁰. Additionally, the results showed that patients considered themselves and their attending specialist as responsible for taking care of their mental health. This could implicate that even though they consider themselves accountable for their mental health, they also see their attending specialist as responsible for aiding them in the process.

Even though this study did not reach the initial quantity of sample data, and generalizations cannot be made, these findings bring preliminary data and possible explanations regarding mental health and MS.

In conclusion, integration, communication and a multidisciplinary approach between the neurologists, mental health professionals, providers and the patient, are the key to obtain an optimal impact in the treatment for MS. When these sciences are combined, efficiency and collaboration could be vastly beneficial. The longitudinal assessment and early treatment of symptoms related to MS and depression can be of great help to the quality of life in MS patients³¹. For instance, a patient centered approach, evidence-based and guided interventions could be beneficial to address many of these comorbidities³²⁻³⁵. This could aid both neurologists and patients and may possibly lead to further impact regarding optimal mental health treatment in the long-term course of MS.

Limitations and Future Directions

Due to health and wellbeing of participants and researchers regarding the COVID-19 restrictions, the sample data did not reach the necessary amount to generalize the participants responses. In future directions, the recollection of the remaining sample from both the patients and the neurologists' perspective should be completed to be able to provide a representative measure. Furthermore, exploring the neurocognitive aspects of depression in MS in Puerto Rico would be added to the study to compare findings in literature with cultural inclusion. Additionally, the instrument could be validated with a bigger sample towards the Puerto Rican MS population to expand its assessment and reliability. This could bring specific and cultural essential information regarding the impact on the disease course, and it will help us to promote optimal treatment for these comorbidities in Puerto Rico. Additionally, creating a program directed to the integration and training between neurology and psychology would be beneficial for this foundation.

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Declaration of Interest

The Authors declare that there is no conflict of interest.

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