Assessment of Lifestyle pattern and Expanded Disability status scale (EDSS) in women with Multiple Sclerosis

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ABSTRACT

The autoimmune disorder "Multiple Sclerosis" (MS) is a disease that affects the central nervous system and causes demyelination. Women are more affected. Despite growing research, there is limited understanding of the impact of nutrition and lifestyle on MS progression in India. Women with MS (30) from Multiple Sclerosis Society of India (Chennai Chapter) participated in the study. The purpose of this inspection was to study the lifestyle and its effect on "Expanded Disability Status Scale" (EDSS). Data were collected on dietary intake, physical activity levels, MS symptoms, and EDSS scores, focusing on factors such as stress, sleep disturbances, and disability levels. Participants had a mean age of 34.5±9.3 years, with disease onset at 26.8±8.04 years. Most of them were sedentary and overweight (mean BMI: 27.1±5.9 kg/m²), with 46.6% showing gain in weight after MS onset. A significant portion (93.3%) was breastfed during childhood, and 90% were not offspring of consanguineous marriages. Sleep disturbances were prevalent, with 60% reporting difficulty falling asleep. Chronic stress was the most common relapse trigger (73.3%), and 66.6% were on disease-modifying drugs. The EDSS scores showed that 33.3% were moderately disabled, and 13.3% had severe disability. An important positive connection between the time-span of MS and EDSS was noticed, indicating that longer disease duration is strongly associated with greater disability. This study suggests that women with MS in India face significant challenges in terms of lifestyle, which can contribute to increased disability. Both nutritional education and lifestyle modifications can positively impact symptoms and should be integrated into MS care.

INTRODUCTION

Multiple sclerosis (MS) is brain and spinal cord disorder that can damage the myelin and axons. At first, the inflammation stayed for a little then demyelination began, that was characterized by neurological symptoms (Compston and Coles, 2008). MS treatment is high-cost value and ranks second after Heart Failure(HF) in medical field, with an estimated cost of $8528 to $54,244 per patient (Adelman et al., 2013).

The disease is common in individuals between the ages of 20 to 50 years. Females suffer more than men with a ratio of 3:1(Staff et al., 2009). It develops in the brain and spinal cord areas to lead the development of a wide range of clinical manifestations. Vision, sensory and speech problems, tremor, bladder and bowel problems, these are some common symptoms of the disease.

MS is an infrequent problem in Asian regions with prevalence rate of 1 and 20 per 100,000. The MS is mostly seen in South Asia and Japan, between 5 and 20 per 100,000. The number of MS patients in India is increasing and the mean age of onset in all the studies was 27-29 year (Bhatia et al., 2015).

It is seen in most patients that the disease grows fast, identified by continuous accumulation of neurological deficits (Fitzner and Simons, 2010). The disease continues as relapsing-remitting MS (RRMS) and is characterized by episodes of acute exacerbations, followed by partial or complete recovery of the deficits in patients. Approximately 70% of the RRMS patients after a period of 10-19 years, subsequently develop secondary progressive MS (SPMS) (Fitzner and Simons, 2010).

The biology of MS is not specified clearly and is considered as a complex multi causal disease. Inflammation is the initial stage of damage in the nervous system, Studies have suggested that genetic, environmental or infectious agents can influence the onset of MS (Loma and Heyman, 2011). Environmental issues like exposure to sunlight, season of birth, obesity, lack of physical

activity, gut micro biome, vitamin D deficiency smoking and poor lifestyle are known to be risk factors for MS (Milo and Kahana, 2010).

Although nutrition and lifestyle play an important role in the etiology of MS, association between diet and the MS are still not clear. A study was conducted to show the comparison between the dietary pattern of patients with MS and healthy controls. The results indicated the pervasiveness of MS increased in patients whose food course was high in animal fats, mostly in meat products, sugars and hydrogenated fats, and low in fruits and vegetables, whole grains.

A low diet in high-fat dairy products and high diet in whole grains, soy, fruits, vegetables and fish was contrarily related to the risk of MS (Jahromi et al., 2012).

The unpredictable nature of MS and the eventually occurring disability need to care at a high level that often exceeds abilities and family resources. Without appropriate management of the disease, people with MS might be at a serious risk for clinical deterioration, injury, inadequate nutrition and hydration (Minden et al., 2004). This study is conducted to understand the lifestyle pattern of individuals affected with MS in India and its association with disability status.

METHODOLOGY

Considering the rarity of multiple sclerosis and the challenges in identifying suitable participants, the study included 30 women diagnosed with MS who were registered with the MS Society of India, Chennai Chapter and those who reported at the center were included for this descriptive cross-sectional study. Participants in the sample were chosen by convenience sampling.

Inclusion Criteria

Women aged 18 to 50, diagnosed with MS and enrolled with the Multiple Sclerosis Society of India (MSSI) Chennai Chapter, were included in the study, willingness to participate in the study.

Exclusion criteria

Severely disabled subjects (EDSS score of >6) were excluded. Pregnant women can be affected by MS but they were was excluded from this study. The Multiple Sclerosis Society of India (MSSI) Chennai Chapter granted authorization for the study to begin after the Institutional Independent Ethics Committee approved the protocol. Nutritional, anthropometric, lifestyle and EDSS assessment that would be performed were explained to the participants. Consent was acquired in writing. Furthermore, the socio demographic data, including age, sex, family type, medical history, and other facts, were gathered using a semi-structured, pre-designed program.

Anthropometric measurements:

A wall-mounted measuring tape was used to measure height (in centimeters), without shoes, to the closest 0.1 cm. Similarly, a portable and digital measuring scale was used to measure body weight (in kg). Body weight (kg) divided by height (m^2) squared yielded the body mass index (BMI). Using a flexible, non-stretchable measuring tape wrapped around the navel, the waist circumference was measured and recorded to the closest 0.1 cm.

Lifestyle assessment

An interview schedule was planned to gather information on socio-demographic profile, medical history and lifestyle factors like stress , sleep and physical activity.

EDSS assessment

The "Expanded Disability Status Scale" (EDSS) is the most widely used assessment tool in MS. The EDSS is a clinical scale that ranges from 0-10. The EDSS scores were assessed by a certified Neurologist.

Statistical Analysis

The "Statistical Package for Social Sciences" (SPSS) software, version 21.0, was used to analyze the data. While mean and standard deviation were utilized for continuous variables, descriptive statistics like frequency and percentage, were used for categorical variables.

Results

Multiple Sclerosis (MS) is a disease that harms women and typically strikes individuals at a younger age. Since women often serve as the primary caregivers in society, the impact of a debilitating condition like MS on this group needs urgent attention and intervention.

Table 1. Demographic and Anthropometric Details of the Subjects

Parameter	Category	Number	Percent (%)
Total Subjects	Age Range (15-50 yrs)	30	-
	Mean Age ± S.D.	-	34.5 ± 9.3
Family Type	Nuclear Family	21	70.0
	Joint Family	9	30.0
Marital Status	Single	10	33.3
	Married	18	60.0
	Divorced	2	6.6
	Widowed	-	-
Mother's Age at Subject's Birth	Below 18	5	16.6
	18-25	17	56.6
	26-30	8	26.6
	More than 30	-	-
Breastfeeding Status	Yes	28	93.3
	No	2	6.6

Consanguineous Marriage (Parental)	Yes	3	10.0
	No	27	90.0
BMI (Body Mass Index)	Mean BMI (kg/m^2) ± S.D.	-	27.1 ± 5.9

Only female subjects diagnosed with multiple sclerosis were included in the study and the age group of the subjects ranged from 15 to 50 years. Age range and mean age of the subjects are presented in table 1.Most of them (70%) are from nuclear family and the remaining 30 per cent belonged to joint family. Being women of the house, the subjects need to manage their family life in addition to their health condition. Majority of the subjects were married (60%), while 33.3 per cent were single and 6.6 per cent were divorced. Since MS affects young adults, it can have an impact on the relationship of the individuals, adjustment issues and coping with symptoms of MS is not only challenging for the person affected with the disease but also for her spouse.

It can be observed that the age of the mother of majority of the subjects (56.6%) was 18-25 years and the remaining 26.6 and 16.6 per cent had the age of their mother as 26-30 years and below 18 years, respectively of the subjects (93.3%) were breastfed during their childhood, whereas, only 6.6 per cent of the subjects were not breastfed. Most of them (90%) were not the offspring of a consanguineous marriage, whereas, only 10 per cent were offspring of a consanguineous marriage. The body weight of the subjects was 65.7±15.9 kg and mean BMI was 27.1±5.9 kg/m^2.

Table 2: Medical history and Clinical Profile of the participants

Parameter	Category	Number	Percent / Mean ± SD
Mean Age of Onset	—		26.8 ± 8.0 years
Duration of Disease (years)	0-5	12	40.0%
	6-10	12	40.0%
	11-20	4	13.3%
	More than 20	2	6.6%
First Symptom at Onset	Vision problem	13	43.3%
	Numbness in specific body area	13	43.3%
	Gait difficulties	3	10.0%
	Loss of taste sensation	1	3.3%
Number of Relapses	0-5	16	53.3%
	6-10	5	16.6%
	11-20	1	3.3%
	More than 20	8	26.6%
Triggers	Stress	22	73.3%
	Environmental factors (heat and cold)	17	56.6%
	Food	2	6.6%
Medications and Uses	Rebif, Copaxone, Tysabri – Disease- modifying drugs	20	66.6%
	Steroids – Immunosuppressive drugs	5	16.6%
	Tablets for BP and diabetes – Co- morbid management	1	3.3%
	None	4	13.3%

From table 2, we can infer that the mean age of onset of MS in the subjects was 26.8±8.04 yrs. Majority of the subjects had the duration of the disease from 0-5 years (40%) and 5-10 years (40%). Only 13.3 per cent have the disease from 10-20 years and 6.6 per cent for more than 20 years. The majority of the subjects had vision problems (43.3%) like double vision, blurring of vision during their onset, and 43.3 per cent had numbness in specific body areas, like limbs, hands and face as their first symptom. Around 10 per cent had gait difficulties like imbalance and in coordination as their first symptom and only 3.3 per cent of the subject had loss of taste sensation. Most of them (53.3%) had 0-5 relapses, 16.6 per cent had 6-10 relapses, 3.3 per cent had 11-20 and 26.6 per cent had more than 20 relapses after the onset of MS.

It could be inferred that the most common trigger for relapses in patients was stress (73.3%). Environmental conditions like extreme heat or cold was the second most common trigger (56.6%) and food (6.6%) were the least common trigger for patients. It could be observed that most of the subjects were on disease modifying drugs (66.6%) to prevent relapses as they were in the initial stage of the disease (RRMS). Around 6.6 per cent were on immunosuppressive treatment and were prescribed steroids that were cost effective for the subjects who could not afford disease modifying drugs for their treatment.

Table 3: Lifestyle pattern of the participants

Category	Variable	Number	Percent
Type of Physical Activity	Zumba	1	3.3
	Brisk Walking	3	10.0
	Meditation	2	6.6
Duration of Physical Activity	Less than 30 minutes	3	50.0
	30 minutes	2	33.3
	1 hour	1	16.6
	More than 1 hour	-	-
Daily Stress Level	Very High	7	23.3
	High	4	13.3
	Moderate	16	53.3
	Low	3	10.0
	No Stress	-	-
Common Stressors	Work/Education	7	23.3
	Family	9	30.0
	Financial	2	6.6
	Health	12	40.0
	Social	-	-
Sleep Pattern (Insomnia)	Yes	18	60.0
	No	12	40.0

From table 3, it could be inferred that majority of the subjects (10%) engaged in brisk walking, while 6.6 per cent did meditation and 3.3 per cent performed Zumba. Around 80 per cent did not engage in any kind of physical activity. Patients were not able to perform vigorous forms of exercise due to fatigue and pain and opted for walking. Most of the subjects (50%) involved in regular physical activity for less than 30 minutes, as fatigue was a major symptom. Around 33.3% involved in regular physical activity for a duration of 30 minutes and only 16.6% involved in regular physical activity for 1 hour. Majority of the subjects (53.3%) had moderate stress, while 23.3 per cent and 13.3 per cent had very high and high stress, respectively. Only a few (10%) had low stress. For most of the subjects (40%) , their health was a main stressor as MS is a devastating disease that suddenly attacks the young adults and hinders their future goals, due to which subjects are prone to depression and stress. Most of them (60%) had problem in falling asleep while 40 per cent had refreshing and sound sleep.

Table 4: Percentage distribution of subjects based on their EDSS scores and disability

EDSS score	Level of disability	Number	Per cent
0-3	Mild disability	16	53.3
3.5-5.5	Moderate disability	10	33.3
6-9.5	Severe disability	4	13.3

From table 4, it is displaying that majority of the subjects were disabled mildly, whereas, 33.3 % were moderately disabled and 13.3% were severely disabled.

Table 5: Correlation of Various Variables with EDSS Score in Participants with Multiple Sclerosis

S. No	Variables Compared	r value	t value	Level of Significance	Mean ± SD (Variable 1) / (EDSS)
1	Duration of MS vs EDSS	0.588	3.88	p < 0.001	7.97 ± 7.76 / 3.25 ± 2.11
2	Weight vs EDSS	-0.468	-2.89	p < 0.01	65.53 ± 16.03 (kg) / 3.25 ± 2.11 (EDSS)
3	Relapse vs EDSS	0.305	1.70	NS	1.97 ± 1.38 / 3.25 ± 2.11 (EDSS)
4	Sleep vs EDSS	0.229	1.27	NS	0.60 ± 0.50 / 3.25 ± 2.11 (EDSS)
5	Stress vs EDSS	-0.130	-0.70	NS	2.50 ± 0.97 / 3.25 ± 2.11 (EDSS)

From table 5, it is seen that a statistically positive correlation is there between disease duration and EDSS whereas a moderate, negative correlation was observed between body weight and EDSS Score.

DISCUSSION

This study draws attention on the lifestyle pattern and its association with disability status in MS patients. This is one of the few studies to focus on lifestyle and its association with disability status of MS patients in India.

Women in nuclear families need to take care of their family as well as their health which can create stress for MS patients. Though women living in joint family have other members to help them, MS disease can significantly impact on humans, influencing their wellbeing and quality of life. Often, this creates stress for families as well as the person affected with the disease (Ucelli, 2014). Women with MS are at a 6-fold increase in the risk of divorce. The distress between relations can lead to a poorer prognosis and management of illness if not addressed properly (Tompkins et al., 2013).

According to studies, there was no association of MS risk with the age of the mother or father at birth (Bager et al., 2006). Breastfeeding is protective against autoimmunity. The impact of breastfeeding as an infant upon future risk of MS remains unclear. The absence of breastfeeding during infancy has an association with an increased risk of pediatric form of MS (Brenton et al., 2017). The duration of this illness is crucial in the treatment of MS and the treatment also depends on disease progression, disability score (EDSS) and the type of MS. Nutritional management also varies based on the duration of the disease. The greater the duration, the greater might be the worsening and the subjects could have severe malnutrition, swallowing difficulties, gait difficulties and the line of nutritional management can considerably vary.

Relapses are common in relapsing remitting type of MS and as the duration of the disease increases the number of relapses also increase and the disease could then progress to progressive type of MS. Number of relapses are important to determine the amount of neurological damage or disability. Triggers in MS patients could lead to relapses or flare up or appearance of the old symptoms, hence it is very important to avoid triggers in MS patients. Multiple sclerosis patients go through a lot of stressful situations in their life ranging from their health to financial issues (Mohr et al., 2004).

Around 80 per cent did not engage in any kind of physical activity. Patients were not able to perform vigorous forms of exercise due to fatigue and pain and opted for walking. Subjects who had gait problems, vision problems and who had difficulty in walking engaged in meditation and relaxation exercise that could also relieve stress. Subjects who had a higher EDSS score were not able to do any kind of exercise due to their disability, but participants with mild and moderate EDSS scores should be encouraged to exercise to prevent further progression and subjects who were involved in regular physical activity had lower disability irrespective of the duration of their disease.

MS is a devastating disease that suddenly attacks the young adults and hinders their future goals, due to which subjects are prone to depression and stress. Moreover, the various symptoms of MS, onset of relapses, family issues arising due to their health condition can also cause stress in the subjects. Common sleep issues in MS patients include insomnia, nocturnal movement disorders, sleep apnea, and rapid eye movement sleep behavior disorder. (Fleming and Pollak, 2005).

The study indicates that as the duration of the disease increases, the level of disability tends to rise. This aligns with the progressive nature of MS, where accumulation of neurological damage over time contributes to worsening physical ability. The longer an individual lives with MS, the greater likelihood of experiencing more pronounced impairments in mobility and daily activities, as reflected in higher EDSS scores. A moderate but significant negative correlation was discovered between body weight and EDSS scores. The correlation indicates that individuals with lower body weight are at a risk of higher disability levels. It indicates that higher disability levels in MS lead to reduced physical activity, muscle wasting, and unintentional weight loss. Moreover, weight loss may also indicate disease severity or poor nutritional status in more

debilitated individuals. This association highlights the need for a comprehensive approach in MS care.

CONCLUSION

This study highlights the challenges faced by women living with multiple sclerosis in India. It clearly shows that as the disease progresses over time, the level of disability also increases, which reflects the natural course of MS. Interestingly, women with lower body weight were found to have higher disability levels, possibly due to muscle weakness, loss of mobility, or poor nutritional intake. Many participants reported high stress levels and difficulty sleeping, yet very few engaged in regular physical activity due to the symptoms of MS like fatigue or pain. These patterns emphasizes the need for early intervention and a more well-rounded approach to care. Addressing not just the physical symptoms, but also lifestyle factors like stress, sleep quality, diet, and activity levels can improve the quality of life in women with Multiple sclerosis.

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