ORIGINAL ARTICLE

SLEEP QUALITY IN PEOPLE WITH MULTIPLE SCLEROSIS

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Highlights: (1) Individuals with MS may experience sleep disorders. (2) Pharmacological and nonpharmacological strategies are implemented to improve sleep. (3) Sleep hygiene and integrative practices contribute to better sleep among people with MS.

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ABSTRACT

Introduction: Multiple sclerosis is a chronic neurological autoimmune condition marked by damage to the myelin sheath, resulting in impaired transmission of nerve impulses and a wide range of symptoms, including sleep disorders. Objectives: to assess sleep quality in people with MS according to the parameters established by the Mini Sleep Questionnaire and based on the participants' own perceptions. Method: quantitative, qualitative, descriptive, and exploratory research conducted in a virtual environment. Data collection took place between March and April 2023 through the following instruments: 1) Sociodemographic and clinical characterization; 2) Mini Sleep Questionnaire; 3) Guiding questions. Quantitative data were analyzed and presented descriptively, while qualitative data were examined through Thematic Analysis. Results: A total of 56 people with multiple sclerosis participated, mostly women, white, between 18 and 39 years old. Most reported relapsing-remitting multiple sclerosis, with up to five years since diagnosis, and were undergoing pharmacological treatment. The most frequent symptoms included tingling, weakness, walking difficulties, and urinary or intestinal dysfunction. Forty-seven participants presented sleep-related difficulties, among whom 7 had mild sleep difficulty, 7 moderate, and 33 severe sleep difficulty. Three thematic categories were identified: “Sleep quality as perceived by people with multiple sclerosis”; “Pharmacological strategies related to sleep quality adopted by people with multiple sclerosis”; and “Nonpharmacological strategies related to sleep quality adopted by people with multiple sclerosis”. Conclusion: People with multiple sclerosis exhibit sleep disturbances and employ strategies aimed at improving sleep quality.

Keywords: Multiple Sclerosis; Nervous System Diseases; Sleep; Sleep Quality; Health Strategies

INTRODUCTION

Multiple sclerosis (MS) is a rare, chronic, neurological autoimmune condition that arises when lymphocytes and monocytes infiltrate the central nervous system (CNS), attacking the myelin sheath, the protective layer of neurons. When this layer is damaged, nerve impulse transmission fails, which affects the brain, cerebellum, and spinal cord[1].

Worldwide, an estimated 2.8 million people live with MS, representing a prevalence of 35.9 cases per 100,000 persons, and every five minutes one person is diagnosed with the disease. Globally, women are affected at least twice as often as men, with some locations showing ratios higher than 4:1[2].

This condition manifests in distinct clinical forms, with the most common being relapsing-remitting multiple sclerosis (RRMS), which affects up to 85% of people with MS and is characterized by periods of neurological dysfunction, with sudden onset of symptoms lasting more than 24 hours (relapses) alternating with stages of clinical stability and absence of new neurological manifestations[3].

MS symptoms vary widely depending on the affected CNS regions and may include visual disturbances, hemiparesis, paresthesia, paraparesis, dysesthesia, urinary and/or fecal sphincter dysfunction, gait ataxia, cognitive deficits, fatigue, and emotional lability, among others[4].

Among disease manifestations, sleep disorders stand out. Although they are underexplored in clinical practice, they may affect more than 50% of people with MS[5]. These disorders include insomnia, sleep-related breathing disorders, restless legs syndrome, and narcolepsy, all of which may result in fatigue[6]. The occurrence of such disorders is associated with the location of neurological lesions. For example, lesions in the hypothalamus and brainstem can impair the maintenance of the sleep-wake cycle and cause respiratory interruptions during sleep; lesions in the dorsal pontine tegmentum and spinal cord may lead to REM sleep behavior disorders or sleep-related breathing disorders; infratemporal lesions in the cerebellum, brainstem, and spinal cord are related to periodic limb movement disorder and restless legs syndrome[7].

Sleep is a physiological state that plays a vital role in health and well-being since various processes occurring during this period contribute to brain activity and recovery,

cognition, memory, and emotional control, which are particularly important for people with MS[7]. Furthermore, sleep quality involves sleeping sufficiently, regularly, and without interruption[8].

Based on these considerations, this study aims to assess sleep quality in people with MS according to the parameters established by the Mini Sleep Questionnaire and the participants' own perceptions.

METHODS

This quantitative and qualitative, descriptive, and exploratory study was conducted in a virtual setting. The participants were reached through virtual groups and communities on the social media platforms Facebook, Instagram, and WhatsApp, where the participating researcher disseminated study information and invitations.

The study participants were individuals with MS who met the following eligibility criteria: self-reported age equal to or greater than 18 years and a diagnosis of MS. Data collection took place between March and April 2023 through a digital instrument created using Google Forms, which comprised three sections: 1) sociodemographic and clinical characterization form developed by the authors; 2) the Mini Sleep Questionnaire, developed by Zomer et al. (1985)[9] for screening sleep disorders, whose Portuguese version was published by Gorestein, Tavares, and Aloe (2000)[10] and validated by Falavigna et al. (2011), demonstrating internal consistency of 0.77. The questionnaire includes items on hypersomnia and insomnia, scored on a seven-point Likert scale ranging from 1 (never) to 7 (always). The final score is classified into four levels: good sleep quality (10–24 points), mild sleep difficulty (25–27 points), moderate sleep difficulty (28–30 points), and severe sleep difficulty (≥31 points)[11]; 3) the open-ended questions "In your perception, how is your sleep quality?" and "Do you use any measure or strategy that contributes to improving your sleep quality?", also developed by the authors.

The digital form contained an introductory section intended to explain the study objectives and procedures, collect each participant's personal email address, and present the Informed Consent Form (ICF). Upon agreement, a "next" key on the page directed participants to a section containing the eligibility criteria for verification, followed by three sections that

respectively covered the sociodemographic and clinical characterization, the Mini Sleep Questionnaire, and the open-ended questions. After completing the form, the ICF and a copy of the participant's responses were automatically sent to the provided email address.

Data from the digital form were organized in a Microsoft® Excel spreadsheet. Information related to the sociodemographic and clinical characterization and the Mini Sleep Questionnaire was presented descriptively. Qualitative data from the open-ended questions were analyzed using Content Analysis, following Bardin's Thematic Analysis approach[12]. This method relies on a set of systematic and objective procedures for message content description, enabling the inference of knowledge regarding the conditions under which messages are produced and received.

In this approach, the theme represents the unit of meaning that naturally emerges from the analyzed text, based on statements about specific subjects. The thematic analysis comprised three stages. The first, pre-analysis, involved organizing and systematizing collected data and ideas while highlighting key aspects necessary to understand the research focus. The second, material exploration, comprised analytical description of the data, emphasizing the most relevant parts, coding, and categorization of textual content. This step transformed raw data into themes by segmenting the text into recording units. The third stage, results treatment, categorization, and interpretation, encompassed the processing and interpretation of results to deepen understanding of the studied topic and to determine which interview excerpts could be interpreted according to the established analytical axes[12].

The study complied with ethical standards governing research involving human participants. The research project was submitted to and approved by the Research Ethics Committee (CEP) of the Federal University of Alfenas (UNIFAL-MG), under opinion no. 5.880.369.

To ensure anonymity, participants were identified using alphanumeric combinations, where the letter P refers to the participant, followed by Arabic numerals corresponding to the sequence in which the form was completed.

RESULTS

A total of 56 people with MS participated in the study. Most were women (100%), white (66.1%), aged between 18 and 39 years (62.5%), with higher education (41.1%), married (46.4%), without children (60.7%), and engaged in paid work (57.1%), as shown in Table 1.

Table 1 – Distribution of participants according to sociodemographic characteristics. Alfenas, MG, Brazil, 2023

Sociodemographic characterization	**n**	**%**
Gender		
Female	56	100.00
Race or ethnicity		
White	37	66.07
Mixed race	16	28.57
Other	3	5.35
Age		
18 to 39 years	35	62.50
40 to 59 years	18	32.14
70 years or older	3	5.35
Education		
Up to high school	15	26.78
Higher education or postgraduate	41	73.21
Marital status		
Single	25	44.64
Married	26	46.42
Other	5	8.92
Children		
Yes	22	39.28
Paid work		
Yes	32	57.14
Clinical characterization	**n**	**%**
Relapsing-remitting multiple sclerosis	47	83.92
Primary progressive multiple sclerosis	1	1.78
Secondary progressive multiple sclerosis	3	5.35

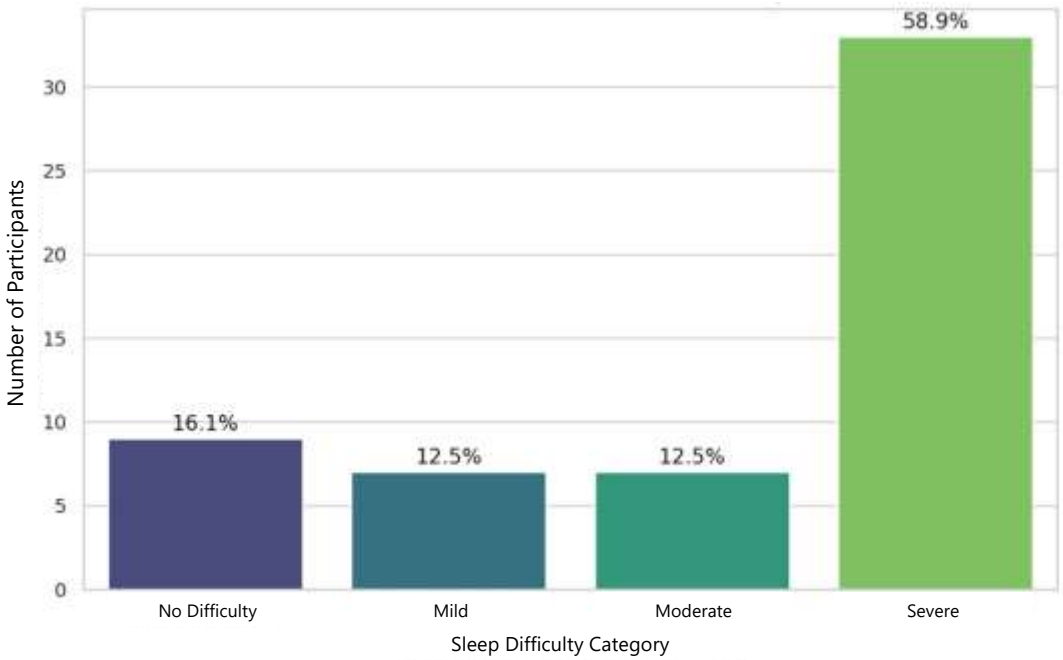
Do not know	5	8.92
Time since diagnosis		
Up to 5 years	30	53.57
6 to 10 years	12	21.42
More than 10 years	14	25.00
Pharmacological treatment		
Interferon beta 1a (Avonex, Rebif)	2	3.57
Interferon beta 1b (Betaferon)	2	3.57
Glatiramer acetate (Copaxone)	4	7.14
Fingolimod (Gilenya)	5	8.92
Teriflunomide (Aubagio)	2	3.57
Dimethyl fumarate (Tecfedera)	8	14.28
Natalizumab (Tysabri)	18	32.14
Other	15	26.78
Nonpharmacological treatment		
Yes	16	28.57

Source: Author (2023).

In relation to clinical characterization, most participants reported RRMS (83.9%) with a diagnosis period of up to five years (53.57%). All were under pharmacological treatment, and only 16 participants (28.6%) used some form of nonpharmacological treatment, as shown in Table 2.

The most frequent symptoms were tingling sensation (78.3%), followed by weakness in both legs (48.2%), walking difficulty (39.3%), and urinary or intestinal dysfunction (39.3%). Participants also reported burning pain sensation (35.7%), double vision (33.9%), and paralysis on one side of the body (14.3%). Most (73.2%) indicated experiencing more than one symptom.

Among all, 47 participants (83.9%) presented sleep-related difficulties, of whom 7 (12.5%) reported mild sleep difficulty, 7 (12.5%) moderate, and 33 (58.9%) severe, as illustrated in Graph 1.



Graph 1 - Participants' perception of sleep quality according to Mini Sleep Questionnaire parameters (n = 56). Alfenas, MG, Brazil, 2023.

Source: Prepared by the authors (2023).

Please indicate the number that best describes your answer	Never (1) n(%)	Very rarely (2) n(%)	Rarely (3) n(%)	Sometimes (4) n(%)	Frequently (5) n(%)	Very frequently (6) n(%)	Always (7) n(%)	Total n(%)
1. Do you have difficulty falling asleep at night?	3(5.35)	19(33.93)	9(16.07)	9(16.07)	8(14.29)	3(5.35)	5(8.92)	56(100)
2. Do you wake up in the middle of the night and cannot fall asleep again?	6(10.71)	18(32.14)	9(16.07)	9(16.07)	8(14.29)	3(5.35)	3(5.35)	56(100)
3. Do you take sleeping pills or tranquilizers?	23(41.07)	13(23.21)	9(16.07)	4(7.14)	0(0.00)	0(0.00)	7(12.50)	56(100)
4. Do you sleep during the day? (not counting planned naps or rest)	23(41.07)	14(25.00)	7(12.50)	7(12.50)	2(3.57)	2(3.57)	1(1.78)	56(100)
5. When you wake up in the morning, do you still feel tired?	0(0.00)	9(16.07)	11(19.64)	10(17.85)	10(17.85)	6(10.71)	10(17.85)	56(100)
6. Do you snore at night (as far as you know)?	21(37.50)	13(23.21)	7(12.50)	7(12.50)	1(1.78)	4(7.14)	3(5.35)	56(100)
7. Do you wake up during the night?	3(5.35)	9(16.07)	7(12.50)	8(14.28)	11(19.64)	5(8.92)	13(23.21)	56(100)
8. Do you wake up with a headache?	12(21.42)	15(26.78)	6(10.71)	12(21.42)	5(8.92)	5(8.92)	1(1.78)	56(100)
9. Do you feel tired for no apparent reason?	0(0.00)	8(14.28)	8(14.28)	14(25.00)	7(12.50)	10(17.85)	9(16.07)	56(100)
10. Do you have restless sleep? (frequent position changes or movements of legs/arms)	4(7.14)	9(16.07)	8(14.28)	11(19.64)	10(17.85)	4(7.14)	10(17.85)	56(100)

Table 2 - Distribution of participants' responses to Mini Sleep Questionnaire items (n = 56). Alfenas, MG, Brazil, 2023.

Source: Prepared by the authors.

The items with the highest frequencies of "very frequently," "frequently," and "always" responses were "When you wake up in the morning, do you still feel tired?" (46.42%), "Do you wake up during the night?" (51.78%), "Do you feel tired for no apparent reason?" (46.42%), and "Do you have restless sleep?" (42.81%).

Regarding participants' perception of their sleep, three thematic categories were identified. The first, "Sleep quality as perceived by people with MS," reflects individual perceptions. Some participants described their sleep as satisfactory, as evidenced by the following excerpts:

I consider it a good sleep (P34)

Excellent; I even get annoyed by how well I sleep (laughs). (P35)

Others, while classifying their sleep as "good," reported that emotional conditions or MS-related symptoms affected sleep quality:

Good, but from time to time I wake up frequently at night. (P7)

It is good; sometimes I wake up with pain or burning in my leg, but not every day. (P17)

It depends on daily activities, as well as psychological and stress factors. (P21)

Good, but it could be better. (P50)

Conversely, several reported impaired sleep quality:

Average. I start feeling sleepy around 9 p.m., but usually go to bed at 11 p.m. I wake up at 3 a.m. and try to fall asleep again until 5 a.m. or later, then get up at 6:50 or 7 a.m. (P12)

Some nights I sleep well, others not so much. It varies a lot, but I rarely feel well-rested. (P16)

Poor, because I sleep a lot and always feel tired. (P22)

I alternate between periods of sleepiness and insomnia. (P30)

Because I wake up 3 to 4 times a night to urinate and sometimes take a while to fall asleep again, my sleep quality is poor. (P51)

I do not consider it good; I wake up several times at night to use the bathroom. (P55)

The second category, “Pharmacological strategies related to sleep quality used by people with MS,” includes participants who reported using medications to aid sleep, such as anxiolytics and antidepressants, exemplified by the following statements:

I take alprazolam 0.5 mg when I feel tired, but I am too restless to fall asleep. (P12)

I rarely take clonazepam. (P31)

I take sleeping pills. (P36)

I always take tranquilizers. (P53)

The third category, “Nonpharmacological strategies related to sleep quality used by people with MS,” comprised two subcategories: “Use of Integrative and Complementary Practices (ICP) to promote sleep quality in people with MS” and “Sleep hygiene as a strategy to promote sleep quality in people with MS.”

The first subcategory refers to the use of ICPs as nonpharmacological strategies to improve sleep quality. Participants mentioned practices such as meditation, music therapy, aromatherapy, and herbal remedies, as illustrated below:

Guided meditation and relaxation before bedtime. (P5)

Meditation music. (P7)

Herbal medicine. (P9)

Essential oils. (P19)

I usually drink tea at night and play rain sounds to relax and fall asleep (P33)

Aromatherapy (P41)

I drink chamomile tea and soak my foot with calming herbs. (P55)

Ho’oponopono meditation (P56)

In relation to sleep hygiene, included in the second subcategory, participants reported adopting strategies related to diet, environment, and avoidance of electronic or light stimuli, among other behavioral measures aimed at improving sleep quality, as illustrated by the following statements:

> I practice sleep hygiene and maintain proper diet to sleep better (P4)
>
> Sleep hygiene (P6)
>
> [...] sleeping in the darkest place possible, going to the bathroom and drinking water before bedtime, keeping well covered to avoid feeling cold, and reducing cell phone use while lying in bed in the dark (P17)
>
> There are days when I avoid sleeping during the day so I can fall asleep earlier and regulate sleep time; physical activity also helps a lot when I manage to do it. (P21)
>
> Avoiding screens before bedtime, staying away from caffeine in the evening, dark environment. (P50)

DISCUSSION

Among participants, there was a predominance of young women aged up to 40 years with RRMS (83.9%), which is consistent with epidemiological data on MS and with a study indicating RRMS as the most common clinical form, affecting up to 85% of individuals with the disease[2,6]. Among the various symptoms of the condition, the most frequently reported by 78.3% of participants was the sensation of tingling (paresthesia). However, it is known that MS is characterized by the plurality of symptoms associated with the affected regions of the nervous system, with paresthesia being commonly reported and related to spinal cord lesions[4].

Regarding sleep quality, most participants (83.9%) exhibited sleep-related difficulties, which aligns with data in the literature showing that sleep disorders may affect 25 to 54% of patients with MS[13,14].

Concerning items of the Mini Sleep Questionnaire, the highest frequency of responses such as “very often,” “often,” and “always” referred to feeling tired in the morning, waking up

during the night, experiencing unexplained fatigue, and having restless sleep. One study indicates that individuals with longer MS duration tend to have poorer sleep quality, influenced by several factors, including disease progression, relapse frequency, effects of medication, and symptoms of anxiety and depression[15]. Impaired sleep quality may worsen fatigue[14], consistent with findings of this study, in which feeling tired upon waking and without apparent reason stood out among participants' responses.

Sleep-related disorders do not specifically affect individuals with MS, as the literature presents several studies indicating the occurrence of sleep problems also in the general population. Thus, impaired sleep quality was reported in a study conducted with adults from a municipality in the state of São Paulo, which also used the Mini Sleep Questionnaire and found that sleep-related disorders affected 46.7% of participants[16].

Furthermore, a study that assessed sleep quality in the general Brazilian population through the Pittsburgh Sleep Quality Index (PSQI) identified that about 65.5% of participants showed impaired sleep (17), while a study conducted in Iran with individuals with MS, also using the PSQI, showed that 69.1% had poor sleep quality[18].

Poor sleep quality in adults aged 40 years or older is influenced by multiple factors, such as being female and presenting comorbidities like depression, gastritis, ulcer, reflux, and asthma[19].

Specifically for individuals with MS, in addition to the demyelinating neurological lesions resulting from the disease's pathophysiology, which depending on their location may affect sleep, therapeutic interventions intended to modify the course of the disease and control relapses may also lead to impairments in physiological sleep, resulting in dyssomnias such as hypersomnia or insomnia[7,13].

In relation to the perception of individuals with MS about their sleep quality, some reported satisfactory quality; however, most respondents stated they experienced sleep impairments related to lack of sleep, the sensation of poor sleep, tiredness upon waking, as well as sleep interruptions to urinate, which is consistent with the findings from the application of the Mini Sleep Questionnaire.

Due to the aforementioned impairments, some participants reported using medication to assist sleep. However, it is important to highlight that the use of benzodiazepines, such as

Alprazolam, cited by one participant in this study, should not exceed 12 weeks due to the risk of dependency[20].

Regarding non-pharmacological strategies to assist sleep, respondents reported using ICHP, such as relaxation, guided meditation, calming music or videos, herbal medicines, and aromatherapy. ICHP are therapeutic resources that aim at disease prevention and health recovery, emphasizing attentive listening, the development of the therapeutic bond, and the integration of human beings with the environment and society. They include traditional Chinese medicine, acupuncture, homeopathy, medicinal plants and phytotherapy, art therapy, meditation, music therapy, aromatherapy, and flower therapy[21].

Literature evidence reports improvement in sleep quality with the use of ICHP[22-26]. For instance, meditation, as reported by participants in the study, originates from different cultures and aims to promote relaxation of mind and body, thereby aiding in sleep quality[26]. The use of herbal medicines such as valerian, passionflower, lemon balm, lavender, and California poppy reduces sleep latency and increases both subjective and objective measures of sleep quality[22].

A study conducted with individuals with MS, divided into experimental and control groups, observed significant improvements in sleep quality and overall well-being with the use of music therapy[25]. Another study using aromatherapy, specifically lavender essence, in patients hospitalized in coronary intensive care units with sleep disorders, identified that the application of this ICHP increased sleep quality and reduced patients' anxiety levels[24].

Moreover, participants in the present study also mentioned strategies such as environmental adjustments, dietary and fluid intake before sleeping, regulation of bedtime schedules, and avoidance of electronic devices and screens, which are all related to sleep hygiene.

It is important to clarify that the circadian cycle refers to the rhythm through which the organism alternates between sleep and wake periods, and maintaining this rhythm at regular intervals reflects on physical and mental health, reinforcing the importance of maintaining appropriate sleep hygiene[27].

Sleep hygiene aims to improve sleep through lifestyle changes, such as improving diet, engaging in physical exercise, controlling environmental factors like light, noise, and

temperature, avoiding stimulants and alcohol consumption before bedtime, and relaxing for at least one hour before sleep[28, 29].

Given the above, a study reinforces the relevance of education about sleep hygiene measures, considering that contact with luminous screens, uncomfortable room temperature, and engaging in activities that generate anxiety can result in poor sleep quality[30].

Therefore, health professionals, in their practice, can use educational resources to contribute to the dissemination of information about sleep hygiene and consequently improve individuals' sleep quality[29]. This educational intervention may be particularly relevant in the case of MS, in which sleep-related problems may occur, even though they are rarely addressed in clinical practice[5].

One limitation of this study lies in the fact that virtual data collection enabled access only to individuals familiar with and having access to this environment. Additionally, responses to open-ended questions were often concise, which may be related to the form of communication used in the context of the internet.

CONCLUSION

Based on the results obtained, it is concluded that individuals with MS presented sleep disorders. The occurrence of sleep-related difficulties was evident, particularly the presence of severe sleep disturbance. It was found that although some participants reported good sleep quality, perceptions of impaired sleep quality were predominant. Thus, both pharmacological and non-pharmacological strategies were reported to improve sleep quality, including the use of medication, especially antidepressants, as well as sleep hygiene and the use of ICHP.

Therefore, to design congruent care plans, professionals should identify the health needs of individuals with MS, including the issue of sleep, which, despite its relevance to quality of life, appears to be insufficiently addressed in clinical practice. It is suggested that future studies investigate the influence of sociodemographic and clinical factors on sleep disorders and the impact of specific interventions, including ICHP, on sleep quality.

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