



Influence of Social Isolation Measures Due to COVID-19 on Quality of Life of People with Multiple Sclerosis

Alice ED^{1*}, Mauricio OB², Carlos Bandeira MM³ and Talita DS⁴

¹Department of Medicine, University of Sao Paulo, Brazil

²Department of Arts, Sciences and Humanities, University of Sao Paulo, Brazil

³Department of Arts, Sciences and Humanities, University of Sao Paulo, Brazil

⁴Department of Medicine, University City of Sao Paulo, Brazil

Research Article

Volume 6 Special Issue 1

Received Date: June 14, 2022

Published Date: June 30, 2022

DOI: 10.23880/eij-16000S1-020

***Corresponding author:** Alice Estevo Dias, Department of Medicine, University of Sao Paulo/SP, Brazil, Av. Indianópolis 2752, Sao Paulo/SP, Brazil, Zip code: 04164-003, Tel:+55 11 5087-6050-99988-8279; Email: alice.estevo@abem.org.br

Abstract

Background: People with Multiple Sclerosis (MS) are more susceptible to worsening in the course of COVID-19. Strict isolation is necessary to minimize the risk of infection.

Objective: To analyze the influence of social isolation measures on quality of life of people with MS during the COVID-19 pandemic period.

Methods: 41 people with MS participated (22 Relapsing-Remitting, 14 Primary Progressive, 5 Secondary Progressive), 25 females and 16 males, aged between 18 and 70 years, EDSS from 0 to 8.5. All of them answered a structured questionnaire generated by "Google Forms" containing 10 questions about the perception in communicative and mental domains.

Results: According to the domains: Communicative: difficulty in verbal communication (n= 13/32%), change in activity and communicative frequency (n= 31/76%), with reduced face-to-face communication, and increased use of video calls by cell phone. Mental: vulnerability (n= 20/49%), sadness (n= 27/66%), concern/fear (n= 31/75%), and impact on quality of life (n= 33/80%), with the support of family/friends, leisure, and religiosity.

Conclusions: The majority of respondents in this cross-sectional study revealed a moderate to severe impact on quality of life in all domains. In the face of uncertainties, MS specialists must adapt to monitoring for complications in the spheres of psychology and speech therapy, as well as adopt rehabilitation options applicable to the moment.

Keywords: SARS-CoV-2; COVID-19; Multiple Sclerosis; Quality of life and telerehabilitation

Introduction

Unlike the general population, the course of COVID-19 in Multiple Sclerosis (MS) patients is modified by a number of factors; the chronic disease is often associated with a number of other health complications and the chronic immunomodulatory treatment associated with immunosuppressive effects at various levels of the immune system and the cytokine network. In milder COVID-19 cases, the exacerbation of MS may be only temporary but the risk of relapse or progression of the disease is not negligible. The long-term and systematic modification of the immune response by DMD drugs, immunosuppressants, or corticosteroids is another significant factor. The result can be completely different and often complicated courses of the COVID-19 infection [1]. Furthermore, viral infections may contribute to MS exacerbation and relapses as an environmental factor in genetically predisposed individuals [2,3].

This is the reason why prevention is recommended through social isolation, including changes in activities of daily living, such as social practices, work and medical appointments and multi professional rehabilitation.

Social isolation and loneliness are significant predictors of mortality [4-6], and they are associated with poorer physical and mental health [7]. For instance, is associated with lower self-rated physical health [8], lower health-related quality of life and health status [9], poorer cardiovascular and mental health and greater vulnerability to dementia [10,11]. Social isolation has long been associated with adverse effects consequences for physical and mental health and, even before the COVID-19 pandemic, there was little evidence of its impact on health [12,13]. The purpose of this study was to evaluate the influence of social isolation measures on the quality of life of a group of people with MS during a period of the COVID-19 pandemic.

Methods

Study Design and Sample

A cross-sectional study was used to examine the behavior and perception of people with MS about how they were affected by social isolation implemented to contain COVID-19 infection.

Participants

Participants were recruited from the Brazilian Multiple Sclerosis Association, where they received multidisciplinary

care. Participant recruitment was from September to December 2020. All had a neurologist confirmed diagnosis of MS in all subtypes, according to the McDonald 2017 criteria and, signed the Informed Consent Form and Clarified to participate in the study.

Procedures

A structured questionnaire was developed specially for this study and questions were asked about: 1) Personal data of the participants, such as socioeconomic and socio demographic profile (gender, age, place and type of residence, education, number of people living in the place, assistance of people in the home, access to treatment/rehabilitation/therapies, diagnosis for COVID-19, maintenance or not of isolation) and, current health status; 2) Self-report of impact on quality of life and perception of the effect of social isolation in the communicative (D1) and mental (D2) domains. Data were collected from an online questionnaire, generated using Google Forms, containing 10 objective and closed questions developed by professionals in Speech therapy and Psychology, areas recognized as essential for the recovery of MS signs and symptoms. A three-point scale was used to identify the impact of social isolation in the analyzed domains, in which 0 meant "nothing"; 1, "little"; and 2, "very". The protocol was sent to participants with MS by WhatsApp.

Results

A total of 41 adults with MS were included in this study. Descriptive statistic of the study sample is presented in Table 1. Table 2 shows the responses to the questionnaire.

Characteristics	Value
Gender	
Female	25 (61)
Male	16 (39)
Type of Multiple Sclerosis	
Relapsing-Remitting (RRMS)	22 (54)
Primary progressive (PPMS)	14 (34)
Secondary Progressive (SPMS)	5 (12)
MS duration - mean (sd)	13.66 (9.48)
Age/ Mean (sd)	18-70/49.95 (11.59)
EDSS/Mean (sd)	0-8.5/4.07 (2.47)

Note: Values are presented as number (percentage) for categorical variables and range/mean \pm SD for numerical variables.

Table 1: Demographic characteristics of the participantsa.

Domain	Nothing		Little		Very	
	N	%	N	%	N	%
Communicative						
Has social isolation affected the quality of your communication activities?	10	24	14	34	19	47
Modified your communication frequency?	10	24	12	29	19	47
Do you talk more through communications technologies and less face-to-face?	0	0	2	5	39	95
Do you feel difficulty to pronounce the words?	28	68	9	22	4	10
Do you feel difficulty to produce the voice?	29	71	9	22	3	7
Mental						
Has social isolation affected your quality of life?	8	19	13	32	20	49
Do you feel vulnerable?	20	49	21	51	0	0
Do you feel sad?	14	34	11	27	16	39
Do you feel worried?	10	24	13	32	18	44
On line health care, family, friends, leisure, and religiosity have helped?	2	5	12	29	27	66

Table 2: Influence of isolation measures due to COVID-19 on quality of life.

Discussion

The world has been facing a global public health crisis since coronavirus 2019 disease (COVID-19) emerged as a life-threatening pandemic. With the spread of COVID-19 across the planet, the uncertainty of contracting the highly contagious disease for which there is no known treatment so far, causes insecurity and fear. This resulted in people avoiding public places and face-to-face human interactions. Like most, people with MS are confined to their own homes and implement social distancing as a measure to contain the spread of the infection of SARS-Cov-2.

This social isolation leads to loneliness and boredom, which can have detrimental effects on physical, communicative, and mental well-being. From the point of view of communication, it was observed that people perceived that social isolation has greatly affected the quality of their communicative activities, leading them to a drastic reduction in face-to-face conversations and needing to resort to communication technologies such as social networks, text messages by WhatsApp and mobile video calls, as a way to get around loneliness. Corroborating previous studies on alleviating social isolation [14], this manuscript indicates that some physical information and communication technology (ICT) solutions can help overcome loneliness. Difficulties regarding voice production (phonation) and word pronunciation (articulation of speech sounds), known in combination as dysarthria, were reported by the participants. The literature highlights that approximately 40-50% of people with MS have dysarthria impacting confidence in communication.

According to current research, it is suggested that the COVID-19 pandemic impact can cause mental health problems such as depression, anxiety disorders, panic disorder, stress, emotional changes, sleep disorders, posttraumatic stress symptoms, and suicidal ideation. Recent scientific evidence suggests the occurrence of a psychiatric epidemic simultaneously with the COVID-19 pandemic, requiring a focus by world health institutions [15]. In the period of the pandemic caused by COVID-19, a greater degree of psychological distress (depression, anxiety and stress) was observed in people with multiple sclerosis compared to people in a control group. However, comparing with data prior to the pandemic, no significant increase in psychological distress was observed in two studies, with the exception of worsening sleep quality. The study points out the need for more studies to assess the real psychological impact caused by the pandemic [16]. A study suggests that religiosity and religious coping served as protection for the mental health of the elderly during the COVID-19 pandemic, especially in relation to depression [17].

Research during the COVID-19 pandemic noted that the best coping strategies for dealing with grief and improving mental health were: positive thinking, active coping and social support [18]. Resources involving ICT, especially when mediated by organizations of people with multiple sclerosis, in addition to presenting themselves as a solution in the process of overcoming social isolation, it also supports distance rehabilitation.

Telemedicine, according to the World Health Organization, means the provision of health services when distance is a critical factor. Home rehabilitation with the help

of telemedicine showed promise according to some studies, with increased patient engagement and positive results in rehabilitation. A study showed that telerehabilitation is effective for speech symptoms and may be indicated to patients with limited access to speech therapy centers and technological availability [19]. Other studies evaluated the use of digital tools for neuropsychological rehabilitation in patients with MS. These studies have shown positive contributions from the use of technology both for evaluation and for rehabilitation [20,21]. The findings of this study have relevant implications for the discussion on social isolation among people with MS during the COVID-19 pandemic. The results help the scientific community to accumulate evidence to find future research targets and inform health professionals, as well as being useful in the COVID-19 seasons, where it is extremely important to find solutions to deal with social isolation.

Conclusion

This study examined the influence of social isolation measures on quality of life during the COVID-19 pandemic period in a sample of adults with MS. The results provide an initial understanding of the behavior and perception of people with MS about the social isolation imposed by the COVID-19 pandemic. It seems that this condition had a negatively impact on quality of life, as we found that the communicative and mental domains were affected. Therefore, it is necessary that speech therapy and psychology interventions continue, even during social isolation, since MS symptoms are disabling. Current evidence supports that telerehabilitation can be a good tool for care of patients with MS, always with the aim of improving access to care and increasing patient satisfaction. In this sense, it must be emphasized that telerehabilitation for people with MS is and should always be carried out by experts, following the same principles of quality, commitment and safety that guide the conventional care provided to all patients. This study provides the foundation for further intervention development.

Ethical

The ethics committee of the Hospital of Faculty of Medicine Clinics of the University of Sao Paulo approved the study (reference number: 4.513.816), Certificate of Presentation of Ethical Appreciation: 41924921.0.0000.0068, and all research was completed in accordance with the Declaration of Helsinki guidelines for research practice. Informed consent was obtained from all participants

Acknowledgments

The authors acknowledge the Brazilian Association of Multiple Sclerosis for supporting the selection of

participants and disseminating the study. We also thank the people with MS who participated in the survey.

References

1. Mares J, Hartung HP (2020) Multiple sclerosis and COVID-19. *Biomed Pap Med Fac Univ Palacky Olomouc Czech Republ* 164(3): 217-225.
2. Willis M, Robertson N (2020) Multiple sclerosis and the risk of infection: considerations in the threat of the novel coronavirus, COVID-19/SARS-CoV-2. *J Neurol* 267(5): 1567-1569.
3. Amor S, Baker D, Khoury SJ, Schmierer K, Giovannoni G (2020) SARS-CoV-2 and multiple sclerosis: not all immune depleting DMTs are equal or bad. *Ann Neurol* 87(6): 794-797.
4. Steptoe A, Shankar A, Demakakos P, Wardle J (2013) Social isolation, loneliness, and all-cause mortality in older men and women. *Proc Natl Acad Sci U S A* 110(15): 5797-5801.
5. Lunstad JH, Smith TB, Baker M, Harris T, Stephenson D (2015) Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci* 10(2): 227-237.
6. Beller J, Wagner A (2018) Loneliness social isolation, their synergistic interaction, and mortality. *Health Psychol* 37(9): 808-813.
7. (2020) *Social Isolation and Loneliness in Older Adults*. The National Academies Press.
8. Cornwell EY, Waite LJ (2009) Social disconnectedness, perceived isolation, and health among older adults. *J Health Soc Behav* 50(1): 31-48.
9. Hawton A, Green C, Dickens AP, Richards SH, Taylor RS, et al. (2011) The impact of social isolation on the health status and health-related quality of life of older people. *Qual Life Res* 20(1): 57-67.
10. Hunt NL, Bagguley D, Bash K, Turner V, Turnbull S, et al. (2017) An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health* 152: 157-171.
11. Fratiglioni L, Wang H, Ericsson K, Maytan M, Winblad B (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. *Lancet* 355(9212): 1315-1319.
12. Luanaigh CO, Lawlor BA (2008) Loneliness and the health of older people. *Int J Geriatr Psychiatry* 23(12):

- 1213-1221.
13. Courtin E, Knapp M (2017) Social isolation, loneliness and health in old age: a scoping review. *Health Soc Care Community* 25(3): 799-812.
 14. Latikka R, Hernandez R, Lohan ES, Rantala J, Fernandez FN, et al. (2021) Older adult's loneliness, social isolation, and physical information and communication technology in the era of ambient assisted living: a systematic literature review. *J Med Internet Res* 23(12): e28022.
 15. Hossain MM, Tasnim S, Sultana A, Faizah F, Mazumder H, et al. (2020) Epidemiology of mental health problems in COVID-19: a review. *F1000Res* 9: 636.
 16. Altieri M, Capuano R, Bisecco A, d'Ambrosio A, Buonanno D, et al. (2022) The psychological impact of Covid-19 pandemic on people with Multiple Sclerosis: A meta-analysis. *Mult Scler Relat Disord* 61: 103774.
 17. Ghoncheh KA, Liu CH, Lin CY, Saffari M, Griffiths MD, et al. (2021) Fear of COVID-19 and religious coping mediate the associations between religiosity and distress among older adults. *Health Promot Perspect* 11(3): 316-322.
 18. Budimir S, Probst T, Pieh C (2021) Coping strategies and mental health during COVID-19 lockdown. *J Ment Health* 30(2): 156-163.
 19. Dias AE, Limongi JC, Barbosa ER, Hsing WT (2016) Voice telerehabilitation in Parkinson's disease. *Codas* 28(2): 176-181.
 20. Charvet LE, Yang J, Shaw MT, Sherman K, Haider L, et al. (2017) Cognitive function in multiple sclerosis improves with telerehabilitation: Results from a randomized controlled trial. *PLoS One* 12(5): e0177177.
 21. George MF, Holingue CB, Briggs FB, Shao X, Bellesis KH, et al. (2016) Feasibility study for remote assessment of cognitive function in multiple sclerosis. *J Neurol Neuromed* 1(8): 10-18.

