

Review Article

Multiple sclerosis and occupations: a scoping review

Esclerose múltipla e ocupações: uma revisão de escopo

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Abstract

Introduction: Multiple sclerosis is an autoimmune disease that affects the central nervous system and causes multiple symptoms in the physical, cognitive, sensory, psychosocial, and occupational dimensions. **Objective:** This study aimed to map the repercussions of multiple sclerosis on occupations in different treatment environments. **Methodology:** A scope review was carried out considering original scientific articles published in the last five years comprising January 2017 - December 2022 **Results:** The analysis of the 14 included studies shows reduced relationships between occupations in health and occupational involvement of people with Multiple Sclerosis, mainly in Activities of Daily Living and Instrumental Activities of Daily Living. The results gave rise to the category Repercussions of Multiple Sclerosis on the Daily Activities of People Living with Multiple Sclerosis. **Conclusion:** It was possible to identify that the studies that investigated the occupations of people with Multiple Sclerosis report limitations regarding engagement in daily life and that they need more depth and investigation in different occupations.

Keywords: Activities of Daily Living, Multiple Sclerosis, Occupational Therapy.

<u>Resumo</u>

Introdução: A Esclerose Múltipla é uma doença autoimune que afeta o Sistema Nervoso Central, que cursa com múltiplos sintomas nas dimensões físicas, cognitivas, sensoriais, psicossociais e ocupacionais. Objetivo: Este estudo teve o objetivo de mapear as repercussões da Esclerose Múltipla nas ocupações e atividades de vida diária de pessoas que vivem com Esclerose Múltipla. Metodologia: Foi realizada uma revisão de escopo considerando artigos científicos originais publicados entre janeiro de 2017 e dezembro de 2022. Resultados: A análise dos 14 estudos incluídos apresenta poucas relações entre as ocupações na saúde e o envolvimento ocupacional da pessoa com Esclerose Múltipla, principalmente, em Atividades de Vida Diária e Atividades Instrumentais de Vida Diária. Os resultados originaram a categoria Repercussões da

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Esclerose Múltipla nas Atividades Diárias da Pessoa que vive com Esclerose Múltipla. **Conclusão:** Foi possível identificar que os estudos que investigaram as ocupações das pessoas com Esclerose Múltipla relatam limitações quanto ao engajamento no cotidiano e carecem de mais aprofundamento e investigação em diferentes ocupações.

Palavras-chave: Atividades Cotidianas, Esclerose Múltipla, Terapia Ocupacional.

Introduction

Multiple Sclerosis (MS) is a demyelinating disease of the Central Nervous System (CNS) that has both autoimmune and degenerative components. The cause of MS is still unknown; however, there are studies suggesting that herpesviruses or retroviruses may trigger an autoimmune reaction that leads to inflammation, causing the destruction of myelin in various areas of the CNS (Associação Brasileira de Esclerose Múltipla, 2020). This disease commonly affects individuals in the prime of their productive lives, with the onset of symptoms typically occurring between the ages of 20 and 40. The symptoms of the disease can be multiple and complex, appearing depending on the areas of the CNS that are most affected. Sensory symptoms may include sensations of pain, burning, paresthesias, visual disturbances, partial blindness, blurred vision, and loss of central vision. Additionally, vertigo may occur. Motor symptoms may include difficulty walking and maintaining balance, difficulty coordinating eye movements, sphincter control issues, and tremors. Psychological, neurological, and cognitive symptoms may include depression, mood swings, difficulty controlling emotions, such as laughing or crying, reduced reaction time, quick visual information processing, learning, and memory (Cabeça et al., 2018; Abou et al., 2024; Allataifeh et al., 2020).

Due to causing long-term permanent neurological disability, MS is considered one of the common causes of disability among young adults (Lexell et al., 2006), including difficulties in performing daily occupations. Occupations refer to any activity or task necessary for the management of self-care (e.g., eating, dressing), productivity (e.g., school, work, household chores), or leisure activities (World Federation of Occupational Therapists, 2012; Romero-Ayuso, 2010), and occur over time in different contexts, carrying goals, meanings, and utility for individuals.

According to Salas & Lanas (2019), occupations are activities that people engage in daily, and these performances hold value based on sensory, emotional, motor, cognitive, social, and spiritual experiences. Occupation is a constant movement between what we are, what we do, and what we seek to become, being essential for our health and well-being (Wilcock, 1999).

In this sense, due to the symptoms of MS, occupations can be interfered with, and individuals may have difficulty performing tasks they enjoy or need to do, leading to modifications in their occupational routine (Preissner et al., 2016). People with MS may experience restrictions in participating in activities, the need for adaptations, or abandoning work activities, as well as progressively requiring assistance due to interference in cognition and functionality (Lexell et al., 2006). Cardoso et al. (2024) also highlight modifications, adaptation, transition, and occupational ambivalence based on the diagnosis.

In this context, the aim of this scoping review was to map the impacts on the occupations of individuals with Multiple Sclerosis.

Method

Protocol and registration

This study follows the criteria established in the JBI Scope Review Methodology (Peters et al., 2020). As a requirement to support the search strategy, the research question was prepared using the acronym Population, Concept and Context (PPC), defined: What is known from the literature about the repercussions of Multiple Sclerosis on the occupations and activities of daily life of people who live with Multiple Sclerosis in different treatment settings? The population being: Multiple Sclerosis; the concept: occupation and activities of daily living; and the context: different treatment environments.

Verification of items relevant to the chosen method occurred using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist through the instruments used in the search and selection stages (PRISMA Statement, 2020). The research protocol was registered in the OSF database and can be checked via the registration: 10.17605/OSF.IO/2N7GM. (Cardoso, 2022).

Selection criteria

Population

For this review, studies addressing individuals with Multiple Sclerosis from an occupational perspective were considered.

Concept

To understand Multiple Sclerosis from the perspective of occupation, occupation is defined as the various daily activities that also promote different experiences during the engagement (American Occupational Therapy Association, 2020).

Context

Due to the variability in the clinical presentation, signs, and symptoms of Multiple Sclerosis, this study focused on all contexts of intervention, including hospital, outpatient, and home settings, among others.

Types of source

For this study, original scientific articles published within the last 5 years, between January 2017 and December 2022, were considered, with quantitative, qualitative, or mixed approaches. This was done to identify updated evidence and consider various approaches related to the topic.

Search strategies

After defining the PCC search strategy, two independent researchers conducted searches in the following databases: Virtual Health Library - Regional Portal (BVS), SciElo (SciElo.Org), Lilacs, OTseeker, and PubMed. The following descriptors were used based on the structured vocabulary of the Health Sciences Descriptors (DeCS) and their correspondence in Medical Subject Headings (MeSH): Occupation; Multiple

Sclerosis; Daily Activities, with corresponding terms: *occupation**; ADL; *Activities of Daily Living; Multiple Sclerosis*; MS.

From these descriptors, search formulas were used on the selected platforms: *Occupation** OR ADL OR *activities of daily living* and *multiple sclerosis* OR MS. All articles found through the above search were organized according to the description below to identify duplicates and evaluate their suitability based on the inclusion criteria. In case of disagreement between the two researchers, a discussion meeting with a third author was held.

Data organization

As tools for identification, analysis, and eligibility of the data, three structured forms on the Google Forms platform were used, with items based on the guidelines for systematic reviews from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). Google Forms was used because it allows data to be organized in spreadsheets through Google Sheets, thus providing the researcher with an organized view of the search results.

Form 1 for identification included the following items: Database; Filter (Title and Abstract); and Identified Quantitative Data. Form 2 included: Title; Author; Year; Objective; Reason for Inclusion; and Researcher Observations. Form 3 contained: Title; Authors; Research Design; Year; Objective; Database; and Reason for Inclusion. Articles included in the second analysis were reviewed using Form 3.

Data treatment and exclusion criteria

After the search, all studies that passed through the instruments were organized in a spreadsheet, sorted by search platform, year, title, and study objective. The data were then identified by letter and number and sequenced according to the publication year, from the most recent to the oldest. All studies identified in the search were evaluated by 2 (two) independent reviewers to establish their suitability according to the inclusion criteria for this review. The exclusion criteria for the studies in this review were: not presenting the occupational perspective; full text not available in its entirety; not directly addressing MS; and not using the occupational perspective.

Data analysis

The data were analyzed using a quantitative-qualitative approach. Quantitative data were analyzed and presented in numbers and tables, while qualitative data, including concepts and definitions that address the research question in the given context, were organized into an analysis category following the content analysis method (Bardin, 2011).

The analysis followed the processes of content analysis, which include pre-analysis, material exploration, and result treatment (Bardin, 2011). Pre-analysis is the stage when researchers conduct a general review of the data; in this study, this stage occurred after the application of Instrument 3, which provided the studies to be included.

The material exploration phase involves the analysis of the materials (Bardin, 2011). In this study, after obtaining the results, which were the included articles, the exploration involved reading the data, analyzing the concepts, and understanding how the findings could answer the research question. During this exploration phase, researchers also used notes as a tool to assist in constructing the units of analysis.

Result treatment is the stage when the data are processed, inferences are made, materials are interpreted, and information is extracted (Bardin, 2011). In this study, after the data were organized in the spreadsheet, it was possible to analyze the objectives, concepts, and information from each study in more detail, and thus organize the results and analysis categories, which will be presented in the following sections.

Results

After applying the search formula on the selected platforms, a total of 3950 articles were identified, of which, by analyzing the title and abstract, 27 studies were included, which were read in full to analyze eligibility for the present study. At this stage, 13 studies were removed for the following reasons: duplicates (n = 4), not presenting the occupational perspective (n = 7), not available in full (n = 1), not addressing MS directly and not using the occupational perspective (n = 1). Thus, 14 studies met the research criteria and were included. Figure 1 presents the flowchart that contains the identification, analysis, eligibility and inclusion process.



Figure 1. Data search flowchart. Source: Authors, based on PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only.

According to the results, it was possible to identify that the majority of studies (n=9) investigated and/or analyzed the impacts of MS on Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL), whether through qualitative, quantitative or mixed study. Those who did not focus on the occupations analyzed (ADL and IADL) set out to investigate issues such as social participation (n=1), contextual factors that make daily activities difficult (n=1), perception of care (n=2) and development of a cognitive intervention program for people with MS (n=1). Table 1 presents the organization of the results with information on the reference and objective of the selected studies.

Table 1. Selected Studies.

Reference	Objective
Karhula, M. E., Kanelisto, K., Hämäläinen, P., Ruutiainen, J., Era, P., Häkkinen, A., & Salminen, A L. (2022). Self-reported reasons for changes in performance of daily activities during a 2-year multidisciplinary multiple sclerosis rehabilitation. International Journal of MS Care, 24(3), 110-116.	The study investigated whether individuals with severe and moderate disability would achieve the main objective of rehabilitation, which is improved performance and satisfaction with daily activities, as measured by the Canadian Occupational Performance Measure (COPM).
Franco, R. C., Curib, H. T., Andrade, L. F., & Ferretti, E. C. (2022). Compreensão das dificuldades e dos fatores contextuais nas atividades cotidianas de pessoas com esclerose múltipla: um estudo piloto. Cadernos Brasileiros de Terapia Ocupacional, 30, 1-15.	Understand the difficulties and contextual factors (environmental and personal) that affect the daily activities of people with MS.
Goverover, Y., Chen, M. H., Botticello, A., Voelbel, G. T., Kim, G., DeLuca, J., & Genova, H. M. (2022). Relationships between changes in daily occupations and health-related quality of life in persons with multiple sclerosis during the COVID-19 pandemic. Multiple Sclerosis and Related Disorders, 57, 1-7.	Explore the impact of mandatory lockdown and social distancing policies on engagement in daily occupations for individuals with multiple sclerosis (MS) and able-bodied adults.
Jansa, J., Ferdinand, S., Milo, M., Løyning, I. G., Huilla, T., Kallmayer, L., Ilsbroukx, S., Filló, N., Raats, J., Jakobson, J., & Kos, D. (2022). Performance of Activities of daily living in people with multiple sclerosis. Multiple Sclerosis and Related Disorders, 57, 103342.	This study aims to systematically investigate ADL performance using the Assessment of Motor and Process Skills (AMPS) in people with MS (PMS) across all disease types and within the Kurtzke Expanded Disability Status Scale (EDSS) of 1 .0 to 8.0.
Jaramillo Buitrago, J., & Pérez Parra, J. E. (2021). Fatigue and functional independence in people with multiple sclerosis. Salud Uninorte, 37(1), 67-83.	Establish the relationship between functional independence in activities of daily living in people with multiple sclerosis.
Yazgan, Y. Z., Tarakcı, E., Gungor, F., & Kurtuncu, M. (2021). Understanding the impact of cognitive impairment and disease severity on activities of daily living in MS patients with different disability levels. Clinical Neurology and Neurosurgery, 200, 106398.	The study investigates the impact of cognitive impairment and disease severity on ADL in MS patients with different levels of disability.
Homayuni, A., Abedini, S., Hosseini, Z., Etemadifar, M., & Ghanbarnejad, A. (2021). Explaining the facilitators of	

Table 1. Continued...

Reference	Objective
quality of life in patients with multiple sclerosis: A qualitative study. BMC Neurology, 21(1), 193.	and decreased physical functioning on the personal, professional, and social lives of individuals with multiple sclerosis (MS).
Allataifeh, E., Khalil, H., Almhdawi, K., Al-Shorman, A., Hawamdeh, Z., El-Salem, K., & Bumin, G. (2020). The clinical correlates of participation levels in people with multiple sclerosis. NeuroRehabilitation, 47(2), 153-160.	Identify motor and non-motor factors that are associated with the level of participation in instrumental activities of daily living (IADL), leisure, social and religious activities in people with MS.
Hynes, S. M., & Forwell, S. (2019). A cognitive occupation-based programme for people with multiple sclerosis: a new occupational therapy cognitive rehabilitation intervention. Hong Kong Journal of Occupational Therapy, 32(1), 41-52.	The aim of this research was to explore the views of people with multiple sclerosis and occupational therapists on the program and its potential for implementation in practice.
Oliveira-Kumakura, A. R. de S., Bezutti, L. M., Silva, J. L. G., & Gasparino, R. C. (2019). Functional and self-care capacity of people with multiple sclerosis. Revista Latino-Americana de Enfermagem, 27, 1-11.	To describe the levels of self-care and functionality of patients with multiple sclerosis and determine whether sociodemographic, clinical and functional variables interfere with self-care and/or functionality.
Bravo-González, F., & Álvarez-Roldán, A. (2019). Esclerosis múltiple, pérdida de funcionalidad y género. Elsevier Enhanced Reader, 33(2), 177-184.	Identify the type of support and assistance that patients with multiple sclerosis need to deal with the loss of functionality and show how gender affects the perception of these needs.
Dehghani, A., Khoramkish, M., & Shahsavari Isfahani, S. (2019). Challenges in the daily living activities of patients with multiple sclerosis: a qualitative content analysis. International Journal of Community Based Nursing and Midwifery, 7(3), 201-210.	Explore the challenges of activities of daily living (ADL) for people with MS.
Abdullah, E. J., Badr, H. E., & Manee, F. (2018). MS people's performance and satisfaction with daily occupations: implications for occupational therapy. OTJR (Thorofare, N.J.), 38(1), 28-37.	The objectives of this study were to evaluate the performance and level of satisfaction with daily occupations among people with MS and to explore factors associated with their performance and satisfaction.
Cowan, C. K., Pierson, J. M., & Leggat, S. G. (2020). Psychosocial aspects of the lived experience of multiple sclerosis: personal perspectives. Disability and Rehabilitation, 42(3), 349-359.	Explore participants' personal perspectives: on the psychosocial aspects of living with multiple sclerosis (MS) after inpatient rehabilitation; and about experiences of hospitalization for rehabilitation and discharge home.

Source: Authors, 2023.

Discussion

Through the results of the scoping review, it was possible to gather studies that, through various research designs, investigated the relationship between Occupation and

Multiple Sclerosis (MS). It is also important to highlight that during the research process, one of the descriptors used in the search formula was the term "occupation." However, this descriptor resulted in studies that were not related to the occupational perspective identified as the context of this research, but rather to labor activities and work contexts, without a connection to occupational analysis. The descriptor that best identified studies within the occupational perspective was "Activities of Daily Living" (ADL). This means that, although work is an occupation described in the frameworks used in this study, the articles addressing this theme were not related to occupational therapy or the occupational perspective. Instead, they were written and investigated by other fields of knowledge and other professional categories, and their content did not meet the theoretical framework or the objective of the study.

The results point to the impacts of MS on Daily Activities. ADLs and IADLs are occupations, according to the American Occupational Therapy Association (AOTA) (American Occupational Therapy Association, 2020). However, in addition to these two, the American Occupational Therapy Association (2020) lists other occupations, including: Health management, Rest and sleep, Education, Work, Play/Leisure, and Social participation. This consideration is relevant for understanding that this scoping review reveals that the studies from the five-year period analyzed in this research, which addressed the theme of Occupation and Multiple Sclerosis and followed the proposed methodology, show a tendency to focus on two occupations (ADL and IADL) with a higher frequency (n=9), indicating a possible gap in other occupations.

Given the higher frequency of studies related to ADLs and IADLs, the following discussion will address the category titled "Repercussions of Multiple Sclerosis on the Daily Activities of People Living with Multiple Sclerosis," which was constructed and analyzed based on the selected studies and their full-text reading, with a focus on the objectives.

Repercussions of multiple sclerosis on the daily activities of people living with multiple sclerosis

Daily Activities can be classified as Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are activities aimed at taking care of one's own body and are performed routinely, including bathing, personal hygiene, dressing, eating and swallowing, mobility, personal care, and sexual activity. IADLs are activities that support daily life at home and in the community, including caring for others, caring for pets, child education, communication management, community mobility and driving, financial management, home maintenance, meal preparation and cleaning, religious and spiritual expression, safety and emergency management, and shopping (American Occupational Therapy Association, 2020).

In this context, three studies reviewed presented that the activities most affected in the perception of people with MS were functional mobility, domestic activities, bathing, and eating (Franco et al., 2022; Jaramillo Buitrago & Pérez Parra, 2021; Allataifeh et al., 2020). These impacts are interpreted as negative, as in the study by Jaramillo Buitrago & Pérez Parra (2021), which used the Barthel Index and identified that, in their sample (n=107), the average score in this assessment showed that people with MS had moderate dependence in ADLs.

According to the study by Allataifeh et al. (2020), IADLs are impaired due to body function impairments, such as altered balance, fatigue, and cognitive deficits. In the

study by AAllataifeh et al. (2020), the evaluations used were: Activity Card Sort - Arabic version, Berg Balance Scale, Modified Fatigue Impact Scale, Nine Hole Peg Test, 6-Minute Walk Test, Brief International Cognitive Assessment for Multiple Sclerosis, Stroop test, and Hospital Anxiety and Depression Scale.

Four studies analyzed in this review presented that the impacts on activities occur due to MS symptoms, such as fatigue, and cognitive deficits (Jaramillo Buitrago & Pérez Parra, 2021; Allataifeh et al., 2020; Yazgan et al., 2021; Abdullah et al., 2018). Fatigue made both participation and satisfaction difficult, as it interfered with the speed and completion of daily activities (Jaramillo Buitrago & Pérez Parra, 2021; Allataifeh et al., 2020). Another factor associated with limitations in occupations was cognitive deficits, which interfered more in ADLs and to a greater extent in IADLs (Yazgan et al., 2021; Abdullah et al., 2018). Cognitive function is part of body functions and is considered an essential client factor necessary for performing occupations. Thus, we can understand that MS has interfered with these factors (American Occupational Therapy Association, 2020).

The study by Jansa et al. (2022) showed that the performance of ADLs could be affected at all stages of MS, and this could also be verified by the EDSS score, where the greater the limitations identified by the scale, the greater the difficulties in performing ADLs, as the EDSS tracked the decline in body functions, such as neuro-musculoskeletal functions and those related to motor movement in people with MS.

However, according to the studies included in this review (Oliveira-Kumakura et al., 2019; Dehghani et al., 2019; Abdullah et al., 2018; Cowan et al., 2020), there are subjective factors related to difficulties and limitations in occupational engagement. In this sense, feelings such as uncertainty regarding the course of the disease, fear of disabilities, worsening of the disease, and even coping with social conceptions, such as cultural beliefs about disability and the disease, result in difficulties in ADLs for people with MS (Dehghani et al., 2019).

Another factor related to occupational engagement and functionality was associated with higher socioeconomic and educational profiles. According to Oliveira-Kumakura et al. (2019), these factors acted as protective elements for higher functionality scores and performance in occupations such as ADLs and IADLs.

In addition to the factors already mentioned, unemployment and marriage were issues that influenced low satisfaction with the performance of daily occupations, demonstrating that, beyond clinical factors, social factors are also relevant for occupational engagement and satisfaction (Abdullah et al., 2018). It is believed that these factors may be related to the family's financial obligations and healthcare needs.

In this scenario of multiple limitations in functionality and occupational involvement and participation, some strategies appeared in the literature as effective in rehabilitating and maintaining the health of people with MS. Assistive Technologies (AT) were considered facilitators during daily activities, especially for individuals with mobility-related limitations (Franco et al., 2022).

Investment in programs aimed at the cognitive rehabilitation of people with MS was evaluated as timely and relevant to the needs of people with MS (Hynes & Forwell, 2019). This is because cognitive aspects were considered by people with MS as a factor limiting their engagement in occupations (Yazgan et al., 2021; Allataifeh et al., 2020; Abdullah et al., 2018).

Thus, it is important to highlight that the experience of people with MS can be marked by challenges and limitations regarding their daily occupations. Bravo-González & Álvarez-Roldán (2019) emphasize that healthcare for people with MS needs to be comprehensive, with a focus on caregivers, as the limitations and difficulties are experienced jointly by these individuals.

The study by Cowan et al. (2020) also highlights the lived experience of people with MS and considers the negative impacts of physical and mental fatigue, the desire to maximize independence in daily living activities, minimize dependence on others, and perceptions of loss as important aspects that must be considered when defining rehabilitation strategies for people with MS.

Therefore, the impacts of MS on daily activities are related to the physical demands and symptoms expected in the course of the disease, such as fatigue, cognitive deficits, and mobility difficulties, as well as psychoemotional and social aspects, such as fear of disability and unemployment. Furthermore, care and rehabilitation for better occupational participation are influenced by relevant factors such as higher levels of education and financial status, participation in cognitive rehabilitation programs, and comprehensive care with a focus on the caregiver.

Final Considerations

Through this review, it was possible to identify, in the literature analyzed and through the methodology used in this research, that a large portion of the studies focused on investigating ADLs and IADLs, which leads us to consider that there is still much to be explored regarding the population with MS in the field of occupations. Thus, we consider that the initial objective was achieved, and the results highlight the focus of the literature on MS studies from an occupational perspective, gathering data on the factors related to the repercussions of the pathology on the occupations and ADLs of people living with MS, which include physical, cognitive, psychoemotional, and social factors, as well as relevant treatment strategies.

The analysis of the data was sensitive to reflecting on the relationship between occupations and health and occupational engagement. By categorizing the studies according to the frequency of the topic, we concluded, through various methods and the analysis of different samples, that people with MS have reduced occupational participation, especially in ADLs and IADLs. This factor leads us to question whether, because they are basic activities, ADLs and IADLs are the most frequent complaints, while other activities, such as leisure and religious activities, may no longer be seen as priorities by these individuals.

Therefore, we consider that the present research serves as a potential foundation for scholars in the field of occupation and MS, as it brings together recent studies on the topic. Additionally, it presents the potential of having multiple researchers involved in the search and analysis for inclusion and exclusion.

In this context, based on the results and up until the completion of this research, it was also identified that only one study is of Brazilian origin, pointing to the need for more national research investigating the occupational aspects of people with MS.

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Author's Contributions

Jeice Sobrinho Cardoso contributed to the conception of the work, data collection and analysis, writing and review of the final work. Israel Fernandes de França Cunha, Viviane Magno Borges contributed to the collection and organization of data, Marcelo Marques Cardoso and Natáli Valim Oliver Bento-Torres contributed to the critical review of the content and method. Airle Miranda de Souza contributed to the review of the work. Victor Augusto Cavaleiro Corrêa contributed to the guidance, data analysis, writing and review of the content. All authors approved the final version of the text.

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