Well-being and disease severity of multiple sclerosis patients following a physical activity program

Bem-estar e gravidade da doença de pacientes com esclerose múltipla seguindo um programa de atividade física

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Abstract

Introduction: Multiple sclerosis (MS) is a chronic disease of the central nervous system that mainly affects young adults, promoting a great impact on functionality. Fatigue is a very common symptom, associated with multiple impairments in sensitivity, muscle activity, neuromotor control, balance, cognition and problem-solving ability. MS leads to strong functional restrictions, particularly in the context of daily living activities, as well as in patient participation. **Objective:** To understand the implications of a self-regulation program in the perception of well-being and mental health in MS patients. **Methods:** A set of exercises was implemented for use in daily activities, supported by different studies with MS patients. Patients were asked to classify the severity of their disease and to use the Mental Health Inventory (MHI-38), at the beginning (time A) and at the end (time B) of the self-regulation program. We used the Statistical Package for the Social Sciences (SPSS) version 25. A non-parametric statistical hypothesis test (Wilcoxon test) was used to analyze the variables. **Results:** The mean age was 44 years old, with patients between the ages of 20 and 58. 58.3% were women, 37.5% were currently married, 67% were retired and the mean level of education was 12.5 years. The correlation between the perception of disease severity and psychological well-being before the self-regulation program ($r = 0.26$, $p < 0.05$) and after the intervention ($r = 0.37$, $p < 0.01$) suggests a low to moderate correlation. **Conclusion:** The implementation of the self-regulatory model, through the promotion of physical activity in patients with MS, had a positive impact of clinical rehabilitation, well-being, and perception of disease severity of these people.

Keywords: Multiple sclerosis. Self-regulation. Physical activity.

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Resumo

Introdução: *A esclerose múltipla (EM) é uma doença crônica do sistema nervoso central que afeta principalmente adultos jovens, promovendo um grande impacto na funcionalidade. A fadiga é um sintoma muito comum, associado a múltiplas deficiências na sensibilidade, atividade muscular, controle neuromotor, equilíbrio, cognição e capacidade de resolução de problemas. A EM leva a fortes restrições funcionais, principalmente no contexto das atividades de vida diária, bem como na participação do paciente.* ***Objetivo:*** *Compreender as implicações de um programa de autorregulação na percepção de bem-estar e saúde mental em pacientes com EM.* ***Métodos:*** *Um conjunto de exercícios foi implementado para uso nas atividades diárias, apoiado por diferentes estudos com pacientes com EM. Solicitou-se aos pacientes que classificassem a gravidade de sua doença e que utilizassem o Inventário de Saúde Mental (MHI-38), no início (tempo A) e no final (tempo B) do programa de autorregulação. Utilizou-se o Statistical Package for the Social Sciences (SPSS) versão 25. Um teste de hipótese estatística não paramétrica (teste de Wilcoxon) foi utilizado para analisar as variáveis.* ***Resultados:*** *A média de idade foi de 44 anos, com pacientes entre 20 e 58 anos. 58,3% eram mulheres, 37,5% eram casados, 67% eram aposentados e a escolaridade média era de 12,5 anos. A correlação entre a percepção da gravidade da doença e o bem-estar psicológico antes do programa de autorregulação (r = 0,26, p < 0,05) e após a intervenção (r = 0,37, p < 0,01) sugere uma correlação baixa a moderada.* ***Conclusão:*** *A implantação do modelo autorregulatório, por meio da promoção de atividade física em pacientes com EM, teve impacto positivo na reabilitação clínica, bem-estar e percepção da gravidade da doença dessas pessoas.*

Palavras-chave: *Esclerose múltipla. Autorregulação. Atividade física.*

Introduction

Multiple sclerosis (MS) is a chronic disease of the central nervous system, with no cure and unknown causes, that affects more often young adults at the beginning of their career and their personal development.[1,2] With initial diagnosis between 20 and 40 years old, MS has direct implications for the functionality of these individuals, as well as the financial involvement in health care and rehabilitation.[3]

Fatigue is a very common symptom, associated with multiple impairments in sensitivity, muscle activity, neuromotor control, balance, cognition and problem-solving ability. MS leads to strong functional restrictions, particularly in the context of daily living activities, as well as in patient participation.[4,5]

Outbreaks of this disease can occur either as progressive (primary, secondary), progressive relapsing, or relapsing remitting. When the disease is progressive primary, the progression occurs from the beginning without previous recurrences. In the secondary progressive type, the progression follows an initial relapsing and remitting phase of the disease. In the remitting-recurrent type, there are outbreaks, and in this case, there was a rapid expansion in the treatments available. These types of multiple sclerosis have implications for decision-making in treatments and rehabilitation.[6-9]

Research has shown that many patients with MS have notable decreases in quality of life (QOL) as well a low perception of QOL with disease progression.[10,11] These studies advocate the promotion of physical activity (PA) as a way to improve QOL and its perception. Other studies show that there is a correlation between the physical component of PA and QOL. They also conclude that these results do not occur only in the physical but also in the mental dimension.[12-15]

People with MS who are more active appear to have a behavior that facilitates greater adherence and involvement in promoting greater PA.[16-18]

Self-regulatory models have been used to promote PA in people with MS.[19-21] Self-regulation (SR) can be defined as an iterative process of goal orientation that requires the reflexive implementation of various mechanisms of change and maintenance that aim at specific tasks and temporal results. The SR model follows three procedural steps: in the 1st phase, individuals define personal goals; in the 2nd, they actively seek the objectives; in the 3rd, they seek both the achievement and maintenance of the desired objectives.[19-22]

This study aims to determine whether a program of educational intervention based on SR for the promotion of physical activity (IPPA), considering the perception of disease severity, contributes to improve psychological well-being in MS patients.

Methods

This is a prospective cohort study with a consecutive sample of MS patients. Evaluation 1 took place in the first session of the SR program (time A), and evaluation 2 at the end of the program (time B).

The educational program was applied in 30 patients divided into three groups. It was an inclusion criterion to have the diagnosis of MS for more than one year. The sessions were performed once a week, for 90 minutes, over a period of seven weeks. At each session the group discussed a theme related to physical activity limitations as well as potential strategies to minimize these disabilities. After that, a set of exercises was implemented to be used in the activities of daily living, according to studies developed with MS patients.

The self-regulation program aims to empower people to take responsibility for their own well-being by taking control over the factors that influence their health.

Participants

The socio-demographic characteristics of the 30 participants are shown in Table 1. They had a mean age of 44 years old, distributed between 20 and 58 years old. Fifty-eight point three percent (58.3%) were women, 37.5% were currently married, 67% were retirees, and the average level of schooling was 12.5 years.

Material

The Mental Health Inventory - 38 (MHI – 38) is a self-report tool designed to measure general psychological distress and well-being. It was developed as part of the National Health Insurance Study[23] and has been studied extensively in a variety of populations. The full-length MHI consists of 38 items in which the respondent uses a 6-point Likert-style response, generating subscales. According to mental health model, there are two components of mental health, positive and negative: psychological well-being, with 14 items in two dimensions (general positive affect and emotional ties), and psychological distress, with 24 items in three dimensions (anxiety, depression and loss of behavioral/emotional control).

In the present study we used the 14 items of the positive component of the model, psychological well-being. Generally, it has been expressed as a broad construct with numerous cognitive and affective components such as life satisfaction, positive and negative emotions, pleasure, contentment, and congruence between anticipated and attained life aims. Lower score express higher well-being.

Table 1 - Characteristics of sample (n = 30)

Variables	%	M	SD
Gender			
Female	58. 3		
Male	41.7		
Age		44. 7	10.7
Years of education		12. 5	5.7
Marital status			
Married	37.5		
Single	29. 2		
Divorced	25.0		
Widower	8.3		
Prefessional activity			
Work full-time	25.0		
Retired	66.7		
Unemplyed	8.3		
Who lives with			
Wife/husband	12.5		
Spouse/child	25.0		
Parents	45.8		
Alone	16.7		
Has difficulty in moving home			
Yes	41.7		
No	50.0		
Sometimes	8.3		
What aids to walk			
Cane	50.0		
Crutches	16.6		
Wheelchair	33.3		
Has difficulty in walking away from home			
Yes	58.3		
No	29.2		
Sometimes	12.5		
What aids to walk			
Cane	33.3		
Crutches	25.0		
Wheelchair	20.8		
Years of diagnosis		9.8	6.7

Note: M = mean; SD = standard deviation.

Perception of disease

One of the questions is: "Please rate the severity of your illness ". The answer is quoted in a 1-11 numerical scale; and used the domain of psychological well-being, the MHI[23], at the beginning (time A) and at the end (time B) of the self-regulation program. We inspected the reliability with Cronbach´s alpha, and the validity with helath and self-referent measures (like self-efficacy and self-concept). Results showed reliability measures above .80, and moderate correlation with comparison measures.

Program intervention

The sample included 30 individuals in three intervention groups: two groups in facilities belonging to the Portuguese Society of Multiple Sclerosis (in Lisbon and Porto), and a third group in the Physical Medicine and Rehabilitation Department of Centro Hospitalar e Universitário de Coimbra (CHUC). The procedures recommended by Helsinki Declaration were followed.

Each session aimed to develop an important issue for the group related to the promotion of physical exercises in a holistic perspective, which addressed the physical-functional aspects and psychological aspects of social interactions to promote the implementation of strategies to achieve personal goals.

The IPPA session included the first aim to stimulate group discussion about a topic that reflects disability or PA limitations, as well as to discuss strategies to minimize these limitations. The second phase was an exercise session where participants learned and practiced physical exercise activities. In the third phase, pursuing the SR model (first phase: individuals establish personal goals; second phase: they actively pursuit goals; third phase: they try to reach the goals) participants were asked to define and plan individual physical exercise activities and strategies that would be held until the next session.

The physical aspects which were developed in each session through a set of exercises appropriate for this population, following recommendations for MS population. The intervention program is described in Figure 1.

We used the Statistical Package for the Social Sciences (SPSS) version 25. A non-parametric, repeated measures statistical test (Wilcoxon test) was used to analyse changes between initial (Time A) and final (Time B) time. The intervention followed ethical procedures recommended by the Helsinki Declaration.

Therapist Objectives
- To stimulate the group towards collaborative interaction of all participants. - To inform participants about the objectives of the work that will be developed over the next eight weeks, once a week. - To explain the international recommendations - To conceptually organize the activity
Activities Developed
Each session begins with a conversation between the group about a topic related to physical functional limitations. - Approach the strategies used to cope with the limitations using the self-regulatory mode. - Promotion of AR, a biopsychosocial perspective. - Strategies that can be implemented to promote AR, taking into account the personal goals of each patient. - Setting goals to be met until the next session.
Physical Activity
Exercise session (30 m) using the particulars of scientific evidence. 1- Moderate-intensity aerobic exercise. 2 - T raininig resistance with low or moderate intensity. First the large muscle groups, then the small groups. 3 - Exercise flexibility. 4 - Program consists of 4-8 different types of exercises, 1-3 sets, increasing gradually, with rest periods. 5 - At the end short relaxation session (10 m).

Figure 1 - Intervention Program for the Promotion of Physical Activity (IPPA) in multiple sclerosis.

Results

After the IPPA, significant differences were found for psychological well-being when comparing Time A and Time B (Table 2).

For 82.27% of the sample, the positive affect rank is lower or better at the end of the program. For emotional ties, 51% of the sample rank is lower at the end of the program, 24,13% is higher or worse, and for the others is identical. For the psychological well-being (PWB), 89,65% of the sample rank is lower or better after the intervention, and 10.34% is higher or worse than at the beginning of the program. No statistically significant correlations where found between the PWB or its dimensions and age, level of scholarly and years of diagnostic. No statistically significant differences (Mann-Whitney test) in PWB for gender; no statistically significant differences (Kruskal-Wallis test) for marital status, working status, nor for walking aids.

Correlation between the perception of diease severity and PWB before the SR program obtained a result of Rs = 0.40 ($p < 0,05$) and non-significant after the intervention, suggesting that higher positive affect lower perception of disease severity. No statistically significant correlations where found with the number of years of diagnostic.

Table 2 - Comparison of psychological well-being between Time A and Time B after application of the Intervention Program for the Promotion of Physical Activity (IPPA)

Dimensions	IPPA (Md)		IPPA (Range)		Z-score	p
	Time A	Time B	Time A	Time B		
General positive affect	41	39	18-60	21-52	-4.12	< 0,0001
Emotional ties	10	10	3-17	3-15	-1.66	ns
Psychological well-being	51	51	21-76	24-63	-4.24	< 0,0001

Note: ns = non-significant. Data was analyzed using Wilcoxon signed ranks test, repeated measurements.

Discussion

Based on the results of our study, we conclude that the majority are young women, retired and live with parents. These women mostly require auxiliary equipment, including cane moving home or away from home. These results are controversial in the literature on the epidemiology of this disease.[1-5]

Most patients' studies are refurbished, which may suggest a decrease in the PA. Various studies on the evolution of the disease[5] indicate that the labor activity and integration of MS patients in a social environment facilitates the promotion of PA and promotes well-being, therefore the importance of implementing strategies that facilitate PA for these patients every day.

There is extensive scientific research that demonstrates the importance of PA and promotion of well-being in MS patients.[20-22] The same was true for the results obtained through the intervention program IPPA developed in this study. However, one of the constraints in programs promoting PA in patients with MS is the motivation for participation, as well as the implementation of daily trendy strategies to facilitate more active and participatory behaviors. This intervention program was created for this purpose, as a motivational and SR program for the promotion of PA in patients with MS.

Conclusion

The implementation of the SR model through the promotion of PA in patients with MS had a positive impact of clinical rehabilitation, well-being, and perception of disease severity of these people.

Authors´ contributions

All authors participated equally in all stages of the study, except for the program implementation that was solely conducted by LP.

References

1. Compston A, Coles A. Multiple Sclerosis. Lancet. 2008;372 (9648):1502-17. DOI

2- Grima DT, Torrance GW, Francis G, Rice G, Rosner AJ, Lafortune L. Cost and health related quality of life consequences of multiple sclerosis. Mult Scler. 2000;6(2):91–8. DOI

3- Evans C, Beland SG, Kulaga S, Wolfson C, Kingwell E, Marriott J, et al. Incidence and prevalence of multiple sclerosis in the Americas: a systematic review. Neuroepidemiology. 2013;40(3):195–210. DOI

4- Henze T. Managing specific symptoms in people with multiple Sclerosis. Int MS J. 2005;12(2):60-8. Full text link

5- Schapiro RT. Managing symptoms of multiple sclerosis. Neurol Clin. 2005; 23(1):177-87. DOI

6- Lublin FD, Reingold SC, Cohen JA, Cutter GR, Sørensen PS, Thompson AJ, et al. Defining the clinical course of multiple sclerosis: the 2013 revisions. Neurology. 2014;83(3):278–86. DOI

7- Ginis KAM, Hicks AL. Considerations for the development of a physical activity guide for Canadians with physical disabilities. Appl Physiol Nutr Metab. 2007; 32(Suppl. 2E):S135–47. DOI

8- Pilutti A, Lelli DA, Paulseth JE, Crome M, Jiang S, Rathbone MP, et al. Effects of 12 weeks of supported treadmill training on functional ability and quality of life in progressive multiple sclerosis: a pilot study. Arch Phys Med Rehabil. 2011;92(1):31-6. DOI

9- Visschredijk MAJ, Uitdehaag BMJ, Klein M, van der Ploeg E, Collette EH, Vleugels L, et al. Value of health-related quality of life to predict disability course in multiple sclerosis. Neurology. 2004;63(11):2046-50. DOI

10- Benedict RHB, Wahling E, Bakshi R, Fishman I, Munschauer F, Zivadinov R, et al. Predicting quality of life in multiple sclerosis: accounting for physical disability, fatigue, mood disorder, personality and behaviour change. J Neurol Sci. 2005;231(1-2):29-34. DOI

11- Howe JAA, Gomperts MA. Aerobic testing and training for persons with multiple sclerosis: a review with clinical recommendations. Physiother Can. 2006;58(4):259–70. DOI

12- Mitchell AJ, Benito-Léon J, González JMM, Rivera-Navarro J. Quality of life and its assessment in multiple sclerosis: integrating physical and psychological components of wellbeing. Lancet Neurol. 2005;4(9):556-66. DOI

13- Dalgas U, Stenager E, Ingemann-Hansen T. Multiple sclerosis and physical exercise: recommendations for the application of resistance, endurance and combined training. Mult Scler. 2008;14(1):35-53. DOI

14- Rietberg MB, Brooks D, Uitdehaag BM, Kwakkel G. Exercise therapy for multiple sclerosis. Cochrane Database Syst Rev. 2005;2005(1):CD003980. DOI

15- White LJ, Dressendorfer RH. Exercise and multiple sclerosis. Sports Med. 2004; 34(15):1077-100. DOI

16- Sangelaji B, Smith CM, Paul L, Sampath KK, Treharne GJ, Hale LA. The effectiveness of behaviour change interventions to increase physical activity participation in people with multiple sclerosis: a systematic review and meta-analysis. Clin Rehabil. 2016;30(6):559–76. DOI

17- Mostert S, Kesselring J. Effects of a short-term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. Mult Scler. 2002;8(2):161–8. DOI

18- Rietberg MB, Brooks D, Uitdehaag BMJ, Kwakkel G. Exercise therapy for multiple sclerosis. Cochrane Database Syst Rev. 2005;2005(1):CD003980. DOI

19- Ford DH, Urban HB. Contemporary models of psychotherapy: a comparative analysis. New York: John Wiley & Sons; 1998. 788 p.

20- Carver CS, Scheier MF. On the self-regulation of behavior. New York: Cambridge University Press; 1998. DOI

21- Maes S, Karoly P. Self-regulation assessment and intervention in physical health and illness: a review. Appl Psychol. 2005;54(2):267–99. DOI

22- Vohs KD, Baumeister RF. Understanding self-regulation: an introduction. In: Baumeister RF, Vohs KD, editors. Handbook of self-regulation. Research, Theory, and Applications. New York: Guilford; 2004. p. 1-9.

23- Veit CT, Ware Jr JE. The structure of psychological distress and well-being in a general population. J Consult Clin Psychol. 1983;51(5):730-42. DOI