



Pilares



Informação



4.712 seguidores
no Instagram



26.793 curtidas
no Facebook



Mais de **1 milhão**
de visitas no site



Maior hub de
blogueiros do Brasil



5 ANOS



Mais de **50 palestras** ministradas



Mais de **300 eventos** participados



Mais de **100 milhões** de pessoas alcançadas nas redes sociais



5º Prêmio CÂMARA ESPANHOLA de **SUSTENTABILIDADE**



Políticas Públicas



Acolhimento

+5 mi

de pessoas alcançadas

+3 mil

mensagens respondidas
por mês



Redes Sociais

*Dados de 2018



432 mil
Interações

64,8 mi
pessoas alcançadas

147,7 mi
de enjamento

910
Posts

510 mil
Visitas site



Pesquisa

847

pessoas com EM
reponderam sobre
a sua situação
empregatícia



XXXVI CONGRESSO MÉDICO
UNIVERSITÁRIO DA FMUSP
COMU
2017

actrimS
AMERICAS COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

**Panels
Awards
Clinical**

Publicação na Revista Neurology

Employability situation in patients diagnosed with multiple sclerosis #384

Denis Bernardi Bichueti¹, Carolina Martines Estrutti¹, Gustavo San Martin Elexpe Cardoso², Enedina Maria Lobato de Oliveira¹
1: Disciplina de Neurologia - Universidade Federal de São Paulo. 2: AME (Amigos Múltiplos pela Esclerose)
email: bichueti@unifesp.br



OBJECTIVES

- Evaluate the employment status of Brazilian patients with multiple sclerosis (MS) and its evolution along the disease course
- Evaluate the influence of age of onset, time to diagnosis and disease duration on the employment status

METHODS

- Cross sectional study
- Electronic survey including 12 questions about demographic, social and occupational status at the moment of diagnosis and present day
- The survey was made available for the patients admitted to a patient committed organization Amigos Múltiplos pela Esclerose (AME), <https://amigosmultiplos.org.br> by e-mail and social media advertisement

RESULTS

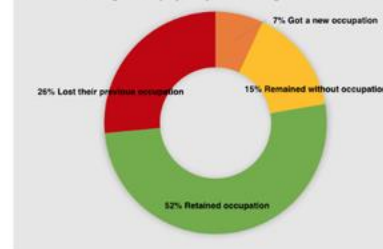
- 847 answered the questionnaire from the 5 Brazilian geopolitical regions
 - 41 excluded duplicated answers
 - 2 excluded: 1 denied and 1 did not have MS
- 804 subjects analyzed
 - Female: 673 (84%); Male: 131 (16%)
 - 50% single, 41% married, 7% divorced and 1% widowed;
 - 67% had a college degree, 29% had finished high school, 2% had graduated from elementary school and 1% hadn't finished elementary school;
 - 94% had a professional occupation contributing to the family income at least once in their lives; 82% of them were employed at the time of diagnosis but only 62% are currently employed
- Analysis was performed on the 94% (753 patients) that were employed once in lifetime
 - Median age of onset and current age are 27.8 and 35.5 years; median time to diagnosis and disease duration are 1.0 and 6.0 years
 - Evaluation of employment status through disease course disclosed that 52% retained and 26% lost their occupation, 6% became employed and 15% remained unemployed
 - 75% considered that MS had major influence against maintaining/obtaining a remunerated activity
 - Longer time to diagnosis, longer disease duration and older age were the only MS related factors associated with being unemployed for the 753 patients that ever had a remunerated activity
 - Holding an university degree was positively associated to employment status
 - There was no difference among the 5 Brazilian geopolitical regions nor between genders

753 patients with MS that were employed once in lifetime Clinical and demographic data

	Unemployed today 288 (38%)	Employed today 465 (62%)	P value for never being employed ^a
Age of onset (years)	27.5 (21.6-34.0)	27.9 (23-33.8)	0.4411
Age of diagnosis (years)	31.0 (24.5-38.3)	30 (25.8-30.5)	0.4918
Time to diagnosis (years)	1 (0-5)	1 (0-3)	<0.0001
Current Age (years)	36.8 (30.6-43.8)	34.8 (30-40.4)	0.0223
Disease Duration (years)	7 (4-13)	6 (0-11)	<0.0001

Data is presented as median (IQR) and P^a analyzed by Mann-Whitney test

Changes in employability status during the disease course



DISCUSSION / CONCLUSIONS

- This survey discloses that the rates of unemployment nearly doubles during disease course, and only 62% of persons with MS in their productive years are employed
- This is an important information considering that the unemployment rate among the economically active population in Brazil for the last trimester of 2017 was 12% (<https://www.bps.gov.br>), vs 38% of persons with MS. Moreover, this is a young population were 2/3 hold a college degree
- The evaluation of employment status through the disease's course disclosed a dynamic change within these patients regarding being or not being employed, which means that the MS-employment relationship along disease course is more complex than simply retaining or losing one's remunerated activity
- Longer time to diagnosis, longer disease duration and older age were associate with being unemployed for the 753 patients that ever had a remunerated activity. Longer time to diagnosis can imply treatment delay, which is known to increase disability. Furthermore, older patients might have higher disability or not have been offered early and aggressive treatment, as these protocols were not available at the time they were diagnosed. These concepts still needs further evaluation, but it is possible that early and continuous treatment, which is known to preserve neurologic function, might influence employment status
- Knowing the rate of unemployment and the factors associated to it can help understand the costs of MS in Brazil and also to implement public and private measures that focus on patients being more productive and less dependent of social benefits, thus gaining personal autonomy and reducing disease's indirect costs
- Further evaluation of these hypothesis and data is needed to fully comprehend disease's cost in Brazil

DISCLOSURES

Denis Bichueti has received sponsorship/training from Bayer Health Care, Biogen Inc., Merck, Sanofi-Sandoz, TEVA and Novartis and had travel expenses to scientific meetings sponsored by Bayer Health Care, Biogen Inc., Merck and Novartis.
Carolina Martines Estrutti was granted a scientific research scholarship from FAPESP.
Gustavo San Martin Elexpe Cardoso was employed as research fellow at the Instituto de Física de São Carlos, Universidade de São Carlos.
Enedina Maria Lobato de Oliveira has received support from FAPESP, Biogen Inc., Sanofi-Sandoz and Novartis. She is grant from Biogen, consulting services from Merck, Sanofi-Sandoz.

Received 11/12/2017, accepted for publication 01/09/2018. This study was registered at ClinicalTrials.gov (NCT03701818). This study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Boards of the participating institutions. The authors have nothing to disclose. All authors contributed equally and significantly to the study. All authors approved the final version of the manuscript. Manuscript received 11/12/2017; accepted for publication 01/09/2018. This study was registered at ClinicalTrials.gov (NCT03701818). This study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Boards of the participating institutions. The authors have nothing to disclose. All authors contributed equally and significantly to the study. All authors approved the final version of the manuscript.



Pesquisa

O simples fato de alguém receber e informar o diagnóstico de EM aumenta em 3,3 vezes a chance de perder o emprego, e as taxas de desemprego em pessoas com EM variam de 30 a 43% com média de tempo de doença de 11 a 19 anos.



Pesquisa

As taxas de desocupação nesta amostra de pacientes com EM são muito maiores que na população brasileira geral, e praticamente dobram após o início da doença.

Menos de dois terços das pessoas com EM, em seus anos produtivos e com alto grau de instrução, possuíam uma ocupação com renda no momento da pesquisa.



-
- Somos seres sociais e, na idade adulta, nosso principal local de troca social é o trabalho.
 - A manutenção de pessoas com uma doença crônica como a EM no mercado de trabalho pode contribuir para aumento de sua autonomia e redução de consumo de recursos sociais.



Perguntas Frequentes

- Eu posso trabalhar?
- Como faço pra me aposentar?
- Como trabalhar tendo EM?



ESCLEROSE MÚLTIPLA E O TRABALHO

www.amigosmultiplos.org.br



Sumário

Introdução	pg.04
Capítulo 1 Renda, tempo e vida social	pg.05
Capítulo 2 Contar ou não contar?	pg.09
Capítulo 3 Saúde, dinheiro e mudanças	pg.14
Capítulo 4 O meu caso	pg.17
Capítulo 5 Adaptações e versos	pg.22
Capítulo 6 Trabalhando em casa	pg.29
Sobre o autor	pg.34

Introdução

Em nossa sociedade o trabalho é considerado ao mesmo tempo um castigo e uma libertação. Se por um lado, pode parecer um fardo a se carregar dia após dia unicamente em troca de um salário, pode ser aquilo que nos proporciona contentamento e satisfação. É ótimo sentir aquela sensação de dever cumprido e de terminar um trabalho avaliado positivamente pelos outros e por nós mesmos. Mas em nossa sociedade, além de todas as conquistas que pode fornecer e necessidades que possa suprir, trabalhar constitui um capital moral, que avalia positivamente quem está empregado e desabona quem não exerce uma atividade.

Dessa forma, o trabalho para quem tem EM pode ser uma questão em aberto e que dificilmente possibilita respostas definitivas e universais. O tema já foi muito abordado por nossos blogueiros, aqui na AME ou em seus blogs pessoais, nos proporcionando uma diversidade de relatos, experiências e reflexões sobre o assunto. A minha intenção original era tratar o tema em um único texto, mas devido ao tamanho que a coisa estava tomando resolvi dividi-lo em outras partes. Assim, tentei organizar de uma maneira menos formal, tratando o assunto não como um problema a ser solucionado, mas como uma situação em que se reconhece a tensão entre esses dois elementos e que não encerra a questão, mas mantém uma tensão saudável e fundamental entre Trabalho e Esclerose Múltipla.



OLHAR PERDIDO, MARIANO?
APOSTO QUE ESTÁ SONHANDO
COM LOCAIS ABERTOS
DE NOVO...



SE O MUNDO ESTÁ EM REDE,
POR QUE NÃO PODEMOS
TRABALHAR EM CASA,
ÂNGELO?



PORQUE A TECNOLOGIA
É DO SÉCULO XXI, MAS A
IDEOLOGIA É DO SÉCULO XIX.





Obrigadx!

bruna@amigosmultiplos.org.br
(51) 9.9388-3435

www.amigosmultiplos.org.br

