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Impact of Multiple Sclerosis on Participation

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Abbreviations

- MS** Multiple Sclerosis
- APPM** Activities and Participation Profile related to Mobility
- EDSS** Expanded Disability Status Scale
- MFIS** Modified Fatigue Impact Scale
- YSD** Years since diagnosis
- FIM** Functional Independence Measure

Abstract

Multiple sclerosis (MS) is a neurological chronic disease that affects around 2.5 million people world-wide and causes pain, mobility difficulties and cognitive losses that may have impact on patient's well-being. This study's objective is to evaluate and clarify the impact of multiple sclerosis on daily life situations, fatigue and independence.

Methods: The sample included 42 patients, 24 women and 18 men and with a minimum of 22 years of age, a maximum of 64 years and a mean age of 45 years. Inclusion criteria was having MS diagnosis for more than 2 years, being able to read and write Portuguese and the absence of traumatic, orthopedic, rheumatic, vascular pathologies or others which affects mobility or other functional or structural neurological comorbidities.

To measure the level of participation it was used the Activities and Participation Profile related to Mobility (APPM) questionnaire, to measure the disease stage it was used the Expanded Disability Status Scale (EDSS). These were the two scales mainly used in this study. The Functional Independence Measure was used to assess the degree of independence and the Modified Fatigue Impact Scale was used to evaluate fatigue impact. Regarding the distribution of the different variables, either parametric or non-parametric tests were used.

Results: There was no statistical evidence for age or gender's effect on EDSS, APPM or fatigue; There was a significant positive correlation and prediction of EDSS on APPM; There was a significant negative correlation between EDSS and Functional Independence Measure score.

Conclusions: The results shown that EDSS predicts participation levels and that the more advanced disease stage the less is patients' independence is. This study also concluded that the stage of MS disease is more relevant than the years of disease with respect to the

prediction of participation levels. This study also showed that there is no effect of gender on the advance of the disease stage or participation levels.

Keywords: Multiple Sclerosis; Fatigue; Participation; Activities and Participation Profile related to Mobility; Functional Independence Measure;

Introduction

Multiple sclerosis (MS) is a chronic disease that affects the central nervous system (CNS). MS affects the myelin sheath that cover, protects and nourishes CNS nerve axon's fibers. There are, still unknown, autoimmune inflammatory processes that destroy myelin sheath which results in loss of axons in the CNS and causes neurologic signs and symptoms. It is known that MS affects around 2.5 million people around the world, mainly in the United States and European countries [1].

The symptoms can vary in frequency, severity and regional distribution. Most of the symptoms cause pain, mobility difficulties and even cognitive losses. Fatigue affects 70% of the patients diagnosed with MS and muscle spasms, muscle stiffness, tingling, weakness, paralysis and urinary urgency are some of the most reported complaints [1].

MS causes cognitive functions losses and physical handicap on patients, who live decades with this disease [2].

Expanded Disability Status Scale (EDSS) is widely used to quantify disability in multiple sclerosis and used to assessment of patients with MS [3].

These clinical manifestations interfere on patients' quality of life and therefor as one of the most intrusive illnesses, MS affects the participation in life's roles and quality of life [4].

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) defines participation as the involvement of an individual in a real-life situation. Participation is dependent on the ability and capacity to learn, to experiment, to focus, to execute tasks, to deal with stress and many other valences such as mobility, self-care and other daily life activities [5].

MS is one of the most disabling diseases considering its progressive symptoms and the way that pain and fatigue can affect patients' availability to deal with daily tasks and play their role in society [4].

This study intends to clarify and objectify the impact of MS and its complications in participation. It is important to clarify the impact of this illness on daily tasks as it is a disease that affects a wide range of population's age and its symptoms are highly suggestive of interfering with patients' well-being and participation. It is also important to explain the outcomes of this disease considering the years of disease and the gender. The quality of life of patients may also depend on the impact of the disease on the patient's independence. The more enlightened we are the better will be the social and psychomotor rehabilitation and health care.

Objectives

This study's purpose is to evaluate and clarify the impact of multiple sclerosis on daily life situations, fatigue and independence.

This investigation tries to give answer to questions such as "In which gender MS seems to have a higher impact on fatigue?"; "Which fatigue dimension is more involved?"; "What is the relation between MS stage and participation and mobility?" and "Which domain of Modified Fatigue Impact Scale (MFIS) [6] seems to be more affected in MS?". To give answer to the questions previously raised the hypotheses referred below were formulated:

- a) Gender and / or age are determinant factors for:
 - i. Modified Fatigue Impact Scale (MFIS) Cognitive and / or Physical domains score.
 - ii. Activities and participation profile related to mobility (APPM) [7].
- b) EDSS level correlates positively with APPM and affects it.

- c) Years since diagnosis (YSD) correlates positively with APPM and affects it.
- d) EDSS score correlates negatively Functional Independence Measure (FIM) [8] instrument score.

Methods

a) Participants

There were surveyed 42 patients diagnosed with MS, among which 24 were female and 18 were male. 38,1% were employed and half of the sample were retired. The patient's age ranged between 22 and 74 years and the mean age was 44,71 years with a standard deviation of 13,87.

The years since diagnosis varied from 2 to 33 years and the EDSS score minimum was 0 while the maximum was 7,5.

The sample composition complied with these inclusion criteria: subjects aged between 18 and 75 years, able to read, write and understand Portuguese. MS diagnosed for more than 2 years, followed in Neurology department of CHUC.

Exclusion criteria included traumatic, orthopedic, rheumatic, vascular pathologies, other pathologies that affects mobility, or other functional or structural comorbidities.

b) Inquiry procedure

The used questionnaires were filled by the researcher during a clinical interview about all the scales, after the specialty consultation in Neurology department of CHUC. Every patient filled the informed consent after reading it carefully and declared their consent authorizing the use of the answers on this study. This study meets the norms imposed by Ethics Committee of the University of Coimbra.

c) Measures

Personal characteristics such as age, gender and professional situation were registered in a proper socio-demographic survey.

Clinical records such as years of MS illness were reported by the patients themselves. The assessment of the level of severity of MS was done by each patient responsible neurologist, using EDSS (Attachment 1). This scale, that ranges from 0 (no disability) to 10 (maximum disability), is widely used to evaluate MS related disability and it was developed by Kurtzke [3].

To measure the activities and participation profile related to mobility (APPM) (Attachment 2) it was used a questionnaire, that was validated for the Portuguese population by Martins [7], and consists in 18 questions related to daily activities and, for each of them, the patient is invited to graduate the degree of difficulty that he feels about them. The difficulty degrees used ranged from 0 to 4 (0 – no difficulty (no difficulty); 1 – slight difficulty (little difficulty); 2 - moderate difficulty (some difficulty); 3 - severe difficulty (severe difficulty); and 4 - complete difficulty (unable to perform)).

The Modified Fatigue Impact Scale (MFIS) scale (Attachment 3) was used to evaluate the fatigue level of participants. It was used the Portuguese validated version of the MFIS, validated by Gomes [6], and it is composed of a total of 21 items, divided in two domains – cognitive domain (1-5, 11, 12, 15, 16, 18 and 19 items) and physical domain (6-10, 13, 14, 17, 20 and 21 items).

To evaluate the functional independence of the participants, before the diagnosis and at the date of the survey, it was used the FIM (Attachment 4) scale that evaluates the independence in 6 main domains (Self-care, Sphincter Control, Transfers, Locomotion, Communication and Social Cognition) through a total of 18 items [8]. The levels of

independence, in each item, range from 1 to 7, where 1 and 2 score correspond to complete dependence, 3 to 5 modified dependence and 6 and 7 independence or only device-dependence status. Participants are asked about their dependence status in each item and give answers about their needs before the diagnosis and their needs by the moment of the survey.

d) Statistical procedures

The data treatment and statistical analysis was performed on IBM SPSS Statistics 22[®] software for Windows.

The analysis started by verifying the normal distribution of all the variables used to conclude what statistical tests would be adequate considering the collected data. It was used the Kolmogorov-Smirnov for the whole sample (n=42) and Shapiro-Wilk distribution test was used to test subgroup normality (by gender), because gender samples n was less than 30.

It was used the non-parametric Mann-Whitney test to compare gender's effect (two independent variables) and used the non-parametric Kruskal-Wallis test to examine the age effect.

To inspect the correlation between EDSS or YSD on APPM it was used the non-parametric test rho (p) of Spearman as neither EDSS or YSD samples were following normal distribution. In this test the strength of the correlation was classified according to this scale: correlation between zero and 0.19 is considered very weak; between 0.20 and 0.39 is considered weak; between 0.40 and 0.59 is considered moderate; between 0.60 and 0.79 is considered strong; and between 0.80 and 1 is considered very strong.

To test the effect of EDSS or YSD on APPM it was used the Regression test and Pestana and Gameiro [9] assumption were taken into account: linearity, homoscedasticity, autocorrelation (Durbin-Watson test) and residuals normality.

Results

The normality test for age, participation, years since diagnosis, modified fatigue impact scale each domain's score and EDSS results are shown on Table 1. results shown that the sample didn't follow a normal distribution for YSD, FIM and EDSS variables as $p < 0,05$.

Table 1 Kolmogorov-Smirnov's normality test results for the whole sample. (Df: Degrees of freedom; Sig.: Statistical significance)

Variable	Statistic	Df	Sig.
Age	0,082	42	0,200
APPM	0,133	42	0,061
YSD	0,142	42	0,033
MFIS Cognitive domain	0,080	42	0,200
MFIS Physical domain	0,081	42	0,200
EDSS	0,262	42	0,000
FIM	0,298	42	0,000

The results of table 2 show that the variable APPM didn't follow a normal distribution for the female sample, the variable Years since diagnosis didn't follow a normal distribution for the female sample, the variable MFIS Physical domain (MFISPD) didn't follow a normal distribution for the male sample and either male and female samples of

EDSS variable don't follow a normal distribution ($p < 0,05$). Considering these results, the analysis using these variables was done with non-parametric tests.

Table 2 Results of Shapiro-Wilk normality test according to the gender. (Df: Degrees of freedom; Sig.: Statistical significance)

Variable	Gender	Statistic	Df	Sig.
Age	Male	0,948	18	0,390
	Female	0,952	24	0,301
APPM	Male	0,916	18	0,111
	Female	0,813	24	0,000
YSD	Male	0,925	18	0,162
	Female	0,888	24	0,012
MFIS Cognitive domain	Male	0,918	18	0,119
	Female	0,962	24	0,478
MFIS Physical domain	Male	0,894	18	0,045
	Female	0,972	24	0,710
EDSS	Male	0,808	18	0,002
	Female	0,808	24	0,000

Table 3 shows descriptive values for different variables displayed according to the gender. For MFIS Cognitive domain (MFISCD) and APPM, female sample had higher mean which means that female gender may tend to have higher cognitive fatigue and higher difficulties on participation. For physical fatigue the male sample had a higher mean. Although for all these three variables the gender effect wasn't statistically significant as shown by the Mann-Whitney test results ($p > 0.05$).

Table 3 Descriptive values for different variables according to the gender and gender's effect on them.

Variable	Gender	Mean	Minimum	Maximum	p	Gender's effect (i)
MFIS Cognitive domain	Male	14,39	3	38	0,500	Absent
	Female	15,75	1	34		
MFIS Physical domain	Male	23,33	13	40	0,684	Absent
	Female	21,67	2	40		
APPM	Male	27,06	0	65	0,274	Absent
	Female	23	0	63		

(i) Mann-Whitney test for independent sample (Non-parametric test)

Table 4 shows the age's effect on MFISCD, MFISPD and Participation. The non-parametric test Kruskal-Wallis for independent samples revealed that there wasn't effect of age ($p > 0,05$).

Table 4 Age's effect.

Variable	P	Age's effect (i)
MFIS Cognitive domain	0,229	Absent
MFIS Physical domain	0,379	Absent
Participation	0,251	Absent

(i) Kruskal-Wallis for independent samples – Non-parametric test

Table 5 shows the correlation between different variables related to the stage of the disease and the participation levels. Between EDSS and APPM there is a very strong correlation ($p = 0,822$) and between YSD and APPM there is a moderate correlation ($p = 0,522$).

Table 5 p values of correlation between variables resulting of the non-parametric tho (p) of Spearman test.

Variable	Spearman test	APPM
EDSS	Correlation coefficient (correlation strength)	0,822 (very strong)
	Bilateral significance	0,000
YSD	Correlation coefficient (correlation strength)	0,522 (moderate)
	Bilateral significance	0,000

Table 6 shows the linear regression test results in which EDSS and YSD were the independent variable and APPM was the dependent variable. The results, considering that n=42 and APPM has a normal distribution shown that regression statistic value (R) is higher for EDSS than for YSD. Homoscedasticity was ensured for both EDSS and YSD and there was independence between the residues. We accepted the hypothesis that both independent variables have effect on APPM ($p < 0,05$).

Table 6 Regression test for APPM results with coefficients, ANOVA and Durbin-Watson results. Sig.: statistical significance.

	R	R ²	Standardized Coefficients (Beta)	t	Sig. (i)	Durbin-Watson
EDSS	0,907	0,822	0,907	13,613	0,000	1,501
YSD	0,543	0,295	0,543	4,090	0,000	1,877

(i) ANOVA

Table 7 shows the correlation between EDSS and FIM total score. There is a very strong negative correlation ($p = -0,869$) between EDSS and FIM.

Table 7 p values of correlation between EDSS and FIM total score resulting of the non-parametric tho (p) of Spearman test

Variable	Spearman test	FIM
EDSS	Correlation coefficient (correlation strength)	-0,867 (very strong)
	Bilateral significance	0,000

Discussion

The determination of Gender's effect on each MFIS domain and / or on Participation (APPM) shown that there was no statistical evidence to affirm that gender is determinant for any of these variables.

Although age is related to more diseases severity and diminished physiological reserve, there was no statistical significance to support the hypothesis that each MFIS domain or Participation (APPM) might be affected by age.

Another objective of this study was to evaluate the correlation between EDSS or YSD with APPM score. The results showed that there was a higher correlation between EDSS and APPM than between YSD and APPM score. These results may mean that, even it isn't the only cause, EDSS score, that is related with the stage of MS disease, is highly related with lower levels of participation. Having in mind that YSD had a lower correlation with APPM than EDSS had it is fair to say that EDSS has a more important role on MS impact on APPM.

With the regression test values we could affirm that, with an R^2 value of 0,822, EDSS predicts APPM and explain 82,2% of APPM's variance. With a R^2 value of 0,295 we concluded that YSD predicts APPM but only explain 29,5% of APPM's variance. With

this we may conclude that EDSS's values affects more the level of participation of patients than YSD and as the higher EDSS, higher APPM then EDSS higher scores imply loss of participation and changes in daily routines and therefore decrease in quality of life. We can also conclude that the stage of MS disease is more relevant than the years of disease with respect to the prediction of participation levels.

With this study we also wanted to examine the correlation between EDSS and FIM. There was a very strong negative correlation between EDSS and FIM. With this data we concluded that the more advanced is MS then there is less independence in domains such as locomotion and sphincter control.

These results may be important for the patients, families and caregivers coping strategies and understanding either the limitations that the disease may bring and its worsening trend. Society may also be aware of MS impact on participation and independence to be regardful for some patients needs and to develop inclusive strategies.

Limitations of this study and advice for further studies

In this study there was collected data from a total of 42 subjects which can be relatively small regarding MS prevalence both in Portugal and worldwide so some of the conclusions must be carefully generalized to the population.

Using these four measures (EDSS, APPM, FIM and MFIS), we analyzed variables related to disease stage, participation profile, independence and fatigue impact but there may be other domains that either are affect by MS or affects MS's course that we haven't tested. Some of the variables samples were not following a normal distribution, even though our sample's size was 42, and because of that we had to use non-parametric tests that aren't so statistically strong as parametric tests.

In this study the patients were contacted only one time and it would be better to have FIM data for different moments and compare the evolution of FIM domains score.

Giving the purpose of this study we hadn't collected more details about MS disease in each patient, such as MS type, number/recent outbreaks and current pharmacological therapy.

Future studies should have in mind the type of the MS disease and try to give answers about the impact of the different therapies on participation and patients physical and cognitive well-being.

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Attachments

1. Expanded Disability Status Scale (EDSS)

ESCALA EXPANDIDA DO ESTADO DE INCAPACIDADE - EDSS

A Escala Expandida do Estado de Incapacidade de Kurtzke (EDSS) é um método de qualificar as incapacidades ocorridas durante a evolução da esclerose múltipla ao longo do tempo. A escala EDSS quantifica as incapacidades em oito sistema funcionais (SF) ***.

ESCORE EDSS

Escore	Características	Escore Total
0	Exame neurológico normal (todos os SF grau 0; cerebral, grau 1 aceitável)	
1,0	Sem incapacidade (1 SF grau 1)	
1,5	Sem incapacidade (2 SF grau 1)	
2,0	Incapacidade mínima em 1 SF (1 SF grau 2, outros grau 0 ou 1)	
2,5	Incapacidade mínima em 2 SF (2 SF grau 2, outros grau 0 ou 1)	
3,0	Incapacidade moderada em 1 SF (1 SF grau 3, outros grau 0 ou 1) ou incapacidade discreta em 3 ou 4 SF (3/4 SF grau 2, outros grau 0 ou 1). Deambulando plenamente.	
3,5	Deambulação plena, com incapacidade moderada em 1SF (1 SF grau 3) e 1 ou 2 SF grau 2; ou 2SF grau 3; ou 5 SF grau 2 (outros 0 ou 1)	
4,0	Deambulação plena, até 500 m sem ajuda ou descanso (1 SF grau 4, outros 0 ou 1)	
4,5	Deambulação plena, até 300 m sem ajuda ou descanso. Com alguma limitação da atividade ou requer assistência mínima (1 SF grau 4, outros 0 ou 1)	
5,0	Deambulação até 200 m sem ajuda ou descanso. Limitação nas atividades diárias (equivalentes são 1 SF grau 5, outros 0 ou 1; ou combinação de graus menores excedendo o escore 4.0)	
5,5	Deambulação até 100 m sem ajuda ou descanso. Incapacidade impedindo atividades plenas diárias (equivalentes são 1SF grau 5, outros 0 ou 1; ou combinações de graus menores excedendo o escore 4.0)	
6,0	Assistência intermitente ou com auxílio unilateral constante de bengala, muleta ou suporte (equivalentes são mais que 2 SF graus 3+)	
6,5	Assistência bilateral (equivalentes são mais que 2 SF graus 3+)	
7,0	Não anda 5 m mesmo com ajuda. Restrito a cadeira de rodas. Transfere da cadeira para cama (equivalentes são combinações com mais que 1 SF 4+, ou piramidal grau 5 isoladamente)	
7,5	Consegue apenas dar poucos passos. Restrito á cadeira de rodas. Necessita ajuda para transferir-se (equivalentes são combinações com mais que 1 SF grau 4+)	

Escore	Características	Escore Total
8,0	Restrito ao leito, mas pode ficar fora da cama. Retém funções de autocuidado; bom uso dos braços (equivalentes são combinações de vários SF grau 4+)	
8,5	Restrito ao leito constantemente. Retém algumas funções de autocuidade e dos braços (equivalentes são combinações de vários SF grau 4+)	
9	Paciente incapacitado no leito. Pode comunicar, não come, não deglute (equivalentes é a maioria de SF grau 4+)	
9,5	Paciente totalmente incapacitado no leito. Não comunica, não come, não deglute (equivalentes são quase todos de SF grau 4+)	
10	Morte por esclerose múltipla	
TOTAL		

*** SISTEMA FUNCIONAIS (SF) PARA A ESCALA EXPANDIDA DO ESTADO DE INCAPACIDADE

Funções Piramidais

0. Normal
1. Sinais anormais sem incapacidade motora
2. Incapacidade mínima
3. Discreta ou moderada paraparesia ou hemiparesia; monoparesia grave
4. Paraparesia ou hemiparesia acentuada; quadriparesia moderada; ou monoplegia
5. Paraplegia, hemiplegia ou acentuada quadriparesia
6. Quadriplegia
- V. Desconhecido

Funções Cerebelares

0. Normal
1. Sinais anormais sem incapacidade
2. Ataxia discreta em qualquer membro
3. Ataxia moderada do tronco ou de membros
4. Incapaz de realizar movimentos coordenados devido á ataxia
- V. Desconhecido

Funções do Tronco Cerebral

0. Normal
1. Somente sinais anormais
2. Nistagmo moderado ou outra incapacidade leve
3. Nistagmo grave, acentuada paresia extraocular ou incapacidade moderada de outros cranianos
4. Disartria acentuada ou outra incapacidade acentuada
5. Incapacidade de deglutir ou falar
- V. Desconhecido

Funções Sensitivas

0. Normal
1. Diminuição de sensibilidade ou estereognosia em 1-2 membros
2. Diminuição discreta de tato ou dor, ou da sensibilidade posicional, e/ou diminuição moderada da vibratória ou estereognosia em 1-2 membros; ou diminuição somente da vibratória em 3-4membros

3. Diminuição moderada de tato ou dor, ou posicional, e/ou perda da vibratória em 1-2 membros; ou diminuição discreta de tato ou dor, e/ou diminuição moderada de toda propriocepção em 3-4 membros
4. Diminuição acentuada de tato ou dor, ou perda da propriocepção em 1-2 membros, ou diminuição moderada de tato ou dor e/ou diminuição acentuada da propriocepção em mais de 2 membros
5. Perda da sensibilidade de 1-2 membros; ou moderada da diminuição de tato ou dor e/ou perda da propriocepção na maior parte do corpo abaixo da cabeça
- V. Desconhecido

Funções Vesicais

0. Normal
1. Sintomas urinários sem incontinência
2. Incontinência {ou igual uma vez por semana
3. Incontinência }ou igual uma vez por semana
4. Incontinência diária ou mais que 1 vez por dia
5. Caracterização contínua
6. Grau para bexiga e grau 5 para disfunção retal
- V. Desconhecido

Funções intestinais

0. Normal
1. < obstipação diária e sem incontinência
2. Obstipação diária sem incontinência
3. Obstipação < uma vez por semana
4. Incontinência > uma vez por semana mas não diária
5. Sem controle de esfíncter retal
6. Grau 5 para bexiga e grau 5 para disfunção retal
- V. Desconhecido

Funções Visuais

0. Normal
1. Escotoma com acuidade visual (AV) igual ou melhor que 20/30
2. Pior olho com escotoma e AV de 20/30 a 20/59
3. Pior olho com grande escotoma, ou diminuição moderada dos campos, mas com AV de 20/60 a 20/99
4. Pior olho com diminuição acentuada dos campos e AV de 20/100 a 20/200; ou grau 3 com AV do melhor olho igual ao menor que 20/60
5. Pior olho com AV menor que 20/200; ou grau 4 com AV do melhor olho igual ao menor que 20/60
6. Grau 5 com AV do melhor olho igual ou menor que 20/60
- V. Desconhecido

Funções mentais

0. Normal
1. Alterações apenas do humor
2. Diminuição discreta da mentação
3. Diminuição normal da mentação
4. Diminuição acentuada da mentação (moderada síndrome cerebral crônica)
5. Demência ou grave síndrome cerebral crônica
- V. Desconhecido

Outras funções

0. Nenhuma
1. Qualquer outro achado devido à EM
2. Desconhecido

2. Activities and participation profile related to mobility (APPM)

Perfil de Atividades e Participação relacionado com a Mobilidade (PAPM)

Deve responder a todos os itens. Assinale as suas respostas através de um círculo, utilizando a seguinte escala:

- 0 Sem dificuldade (nenhuma dificuldade)
- 1 Dificuldade ligeira (pouca dificuldade)
- 2 Dificuldade moderada (alguma dificuldade)
- 3 Dificuldade severa (bastante dificuldade)
- 4 Dificuldade completa (incapaz de realizar)
- NA Não se aplica

Gradue a dificuldade que sente relativamente a cada uma das atividades que se seguem:

1. Tomar conta das atividades domésticas quotidianas (dentro de casa)	0	1	2	3	4	NA
2. Verificar diariamente a caixa do correio ou despejar o lixo	0	1	2	3	4	NA
3. Visitar familiares e amigos, sempre que desejar	0	1	2	3	4	NA
4. Receber pessoas em sua casa sempre que desejar	0	1	2	3	4	NA
5. Relacionar-se com os seus vizinhos e com a comunidade local, em geral	0	1	2	3	4	NA
6. Zelar pela própria saúde (inclui a toma de medicamentos, ir a consultas, etc.)	0	1	2	3	4	NA
7. Tomar conta de outras pessoas (crianças, idosos ou pessoas dependentes)	0	1	2	3	4	NA
8. Tomar conta de plantas ou animais (se os tiver ou gostasse de ter)	0	1	2	3	4	NA
9. Ir à escola, universidade, ou outra instituição de formação	0	1	2	3	4	NA
10. Manter um emprego remunerado	0	1	2	3	4	NA
11. Gerir as finanças domésticas (fazer compras, pagamentos, etc.)	0	1	2	3	4	NA
12. Conduzir ou usar transportes públicos para se deslocar onde desejar	0	1	2	3	4	NA
13. Ir ao café, ao restaurante, a cerimónias ou a reuniões, etc.	0	1	2	3	4	NA
14. Fazer férias (passar alguns dias fora)	0	1	2	3	4	NA
15. Praticar desporto ou exercício físico (como marcha, ciclismo, natação, etc.)	0	1	2	3	4	NA
16. Ir ao cinema, teatro, concertos, exposições, etc.	0	1	2	3	4	NA
17. Ir à igreja regularmente ou sempre que desejar	0	1	2	3	4	NA
18. Participar em atividades de voluntariado	0	1	2	3	4	NA

3. Modified Fatigue Impact Scale (MFIS)

Escala de Impacto de Fadiga Modificada (MFIS)

Em seguida será apresentado um conjunto de afirmações sobre como a fadiga pode afectar uma pessoa. A fadiga é uma sensação de cansaço físico e perda de energia que muitas pessoas sentem de tempos em tempos. Por favor, leia cada afirmação cuidadosamente e desenhe um círculo em volta do número que melhor indique como a fadiga o tem afectado durante as 4 últimas semanas. Se necessitar de ajuda para marcar as respostas, peça ao entrevistador, indicando o número que melhor corresponde à sua resposta. Por favor, responda a todas as questões. Se não tiver certeza sobre qual a resposta a seleccionar, escolha aquela que estiver mais próxima daquilo que descreve o que tem vindo a sentir. O entrevistador poderá explicar algumas palavras ou frases que não compreenda.

Por causa da minha fadiga durante as 4 últimas semanas....

	Nunca	Raramente	Algumas vezes	Muitas vezes	Quase sempre
1. Eu tenho estado menos alerta.	0	1	2	3	4
2. Eu tenho tido dificuldades em manter a atenção por períodos longos.	0	1	2	3	4
3. Eu tenho sido incapaz de pensar claramente.	0	1	2	3	4
4. Eu tenho andado desastrado e descoordenado.	0	1	2	3	4
5. Eu tenho andado esquecido.	0	1	2	3	4
6. Eu tenho tido necessidade de moderar nas minhas actividades físicas.	0	1	2	3	4

7. Eu tenho estado menos motivado para fazer qualquer coisa que exija esforço físico.	0	1	2	3	4
8. Eu tenho estado menos motivado para participar em actividades sociais.	0	1	2	3	4
9. Eu tenho estado limitado na minha capacidade para fazer coisas fora de casa.	0	1	2	3	4
10. Eu tenho tido dificuldades em manter o esforço físico por períodos longos.	0	1	2	3	4
11. Eu tenho tido dificuldades em tomar decisões	0	1	2	3	4
12. Eu tenho estado menos motivado para fazer qualquer coisa que exija esforço mental.	0	1	2	3	4
13. Os meus músculos têm estado fracos.	0	1	2	3	4
14. Eu tenho estado fisicamente desconfortável.	0	1	2	3	4
<p>Por causa da minha fadiga durante as <u>4 últimas semanas</u>....</p>					
	Nunca	Raramente	Algumas vezes	Muitas vezes	Quase sempre
15. Eu tenho tido dificuldades em terminar tarefas que exijam esforço mental.	0	1	2	3	4
16. Eu tenho tido dificuldades em organizar os meus pensamentos quando estou a fazer coisas em casa ou no trabalho.	0	1	2	3	4
17. Eu tenho estado menos capaz de completar tarefas que exijam esforço físico.	0	1	2	3	4

18. O meu pensamento tem estado mais lento.	0	1	2	3	4
19. Eu tenho tido dificuldades de concentração.	0	1	2	3	4
20. Eu tenho limitado as minhas actividades físicas.	0	1	2	3	4
21. Eu tenho tido necessidade de descansar mais frequentemente ou por períodos mais longos.	0	1	2	3	4

4. Functional Independence Measure (FIM)

Escala de Medida de Independência Funcional (MIF)

NÍVEIS	7 Independência completa (em segurança, em tempo normal) 6 Independência modificada (dispositivo)	SEM AJUDA
	Dependência modificada 5 Supervisão 4 Ajuda mínima (indivíduo > 75%) 3 Ajuda moderada (indivíduo > 50%) Dependência completa 2 Ajuda máxima (indivíduo > 25%) 1 Ajuda total (indivíduo < 25%)	AJUDA
MESES OU ANOS		

AUTO-CUIDADOS

A. Alimentação			
B. Higiene pessoal			
C. Banho			
D. Vestir metade superior			
E. Vestir metade inferior			
F. Utilização da sanita			

CONTROLO DOS ESFÍNCTERES

G. Bexiga			
H. Intestino			

MOBILIDADE

I. Leito, Cadeira, Cadeira de Rodas			
J. Sanita			
K. Banheira, Duche			

LOCOMOÇÃO

L. Marcha/Cadeira de Rodas			
M. Escadas			

COMUNICAÇÃO

N. Compreensão			
O. Expressão			

CONSCIÊNCIA DO MUNDO EXTERIOR

P. Interação social			
Q. Resolução dos problemas			
R. Memória			

TOTAL

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