

ARTIGO ORIGINAL/ORIGINAL ARTICLE

A Hidden Burden: The Impact of Medication Collection in Hospital Pharmacies in Multiple Sclerosis and Migraine Patients

Barreira Oculta: O Impacto da Recolha de Medicação em Farmácia Hospitalar nos Doentes com Esclerose Múltipla e Enxaqueca

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Abstract

Introduction: Besides dosage, monitoring, and adverse effects, difficulties in accessing treatment contribute to the overall burden associated with medication. Collecting multiple sclerosis (MS) and migraine medications from Hospital Pharmacy Services (HPS) improves adherence, but the distance from home and the time-consuming process may negatively affect patients' lives. We aimed to evaluate the impact of collecting MS/migraine therapy from HPS.

Methods: This was a single-centre, observational, cross-sectional study based on an anonymous online questionnaire. The questionnaire included data on treatment collection, satisfaction with treatment [Patient Global Impression of Change (PGIC)], and disability scales (MSIS-29 for MS; MIDAS for migraine). Adults with MS/migraine who had been collecting medication from HPs for more than 3 months were included. Descriptive statistics were performed using SPSS®.

Results: Among 145 participants (MS = 108; migraine = 37), 64.8% were women, with a median age of 48 years. The average scale scores were PGIC: 5/7; MSIS-29: 42.0%; MIDAS: 21/90. 85.5% of patients collected their medication themselves; however, 34.5% of those responsible for collection frequently or very frequently missed work to do so. On average, patients spent 1.1 hours ($\sigma = 1.0$) to reach the hospital (mean distance: 16.1 km, $\sigma = 13.4$) and a mean of 1.1 hours ($\sigma = 0.6$) waiting at the HPS. The estimated annual time spent (ATS) on medication collection was 13.5 hours/year ($\sigma = 12.4$). Waiting time at the HP was a predictor of satisfaction with the collection method, which had a median score of 3 (1 = strongly disagree, 5 = strongly agree), negatively correlating with ATS ($p < 0.001$, $R^2 = 0.7$ and 0.9). Most participants (73.1%) preferred collecting their medication from a community pharmacy.

Conclusion: For patients with MS and migraine, optimizing the hospital or community medication dispensing process could imply a significant improvement in their quality of life.

Resumo

Introdução: Além da posologia, monitorização e efeitos adversos, as dificuldades no acesso à terapêutica fazem parte do impacto associado à medicação. A recolha da terapêutica da esclerose múltipla (EM) e da enxaqueca em Farmácia Hospitalar (FH) promove a adesão, mas a distância ao domicílio e morosidade do processo po-

derão influenciar negativamente a vida dos doentes. O nosso objetivo foi avaliar o impacto do levantamento de terapêutica para EM/enxaqueca na FH.

Métodos: Estudo unicêntrico, observacional, transversal, baseado no preenchimento de questionário *online*, anónimo, incluindo dados da recolha da terapêutica, escalas de satisfação com o tratamento [percepção global de mudança (PGIC)] e de incapacidade (MSIS-29, EM; MIDAS, enxaqueca). Foram incluídos adultos com EM/enxaqueca sob terapêutica de recolha em FH, há mais de 3 meses. Estatística descritiva realizada com SPSS®.

Resultados: Em 145 participantes (EM = 108; enxaqueca = 37), 64,8% eram mulheres, com idade mediana de 48. Pontuações médias nas escalas: PGIC 5/7; MSIS-29 42,0%; MIDAS: 21/90. Em 85,5%, os doentes recolhem a sua medicação; contudo, 34,5% dos responsáveis pela recolha faltam frequentemente/muito frequentemente ao emprego para tal. Em média, demoram 1,1 h ($\sigma = 1,0$) até chegarem ao hospital (distância média 16,1 km, $\sigma = 13,4$) e 1,1 h na FH ($\sigma = 0,6$). Estima-se um tempo gasto anualmente (TGA) com o levantamento da medicação de 13,5 horas/ano ($\sigma = 12,4$). O tempo de espera na FH foi preditor do nível de satisfação com o método de recolha, que, em mediana, foi de 3 (1 = nada de acordo, 5 = totalmente de acordo), correlacionando-se negativamente com o TGA ($p < 0,001$, $R^2 = 0,7$ e $0,9$). A maioria dos participantes (73,1%) preferia recolher a medicação numa farmácia comunitária.

Conclusão: Para os doentes com EM e enxaqueca, uma otimização do processo de dispensa hospitalar ou na comunidade da sua medicação poderá traduzir-se numa melhoria significativa na sua qualidade de vida.

Introduction

Multiple sclerosis (MS) affects around 2.9 million people globally and typically starts in the early years of working life.¹ MS can limit patients' autonomy, especially in mobility and employment. MS is estimated to be associated with an indirect cost (i.e., not related to medication) of 22.1 billion US dollars in the United States.² Early and effective disease-modifying treatment (DMT) is essential to improve prognosis.¹

Migraine is the second leading cause of disability worldwide, and it is also associated with a significant socioeconomic impact.³ Calcitonin gene-related peptide (CGRP) monoclonal antibodies (MAbs) reduce migraine impact on work productivity and performance.⁴

Beyond dosage and side effects, difficulty accessing medication adds to the treatment burden. In Portugal, as in other countries, MS DMTs and CGRP MAbs are typically dispensed at Hospital Pharmaceutical Services. Although patients may theoretically choose any public hospital, this flexibility is often limited by practical barriers such as distance, travel time and institutional processes.

Frequent contact with Hospital Pharmaceutical Services (HPS) may benefit patients, especially when ac-

cess to pharmaceutical health professionals is possible. However, limited human resources for quick care, insufficient medication storage, and the distance to the hospital may lead to a significant time spent accessing ambulatory treatment. Understanding the implications of medication collection from hospital pharmacies is crucial for identifying logistical deficiencies and developing solutions in the distribution chain. Our study aimed to characterize the medication collection burden experienced by patients with MS or migraine followed in the Neurology department, concerning time, logistical difficulties and economic implications. Secondly, we aimed to evaluate patients' satisfaction with the collection method, as well as its predictors and implications.

Material and Methods

This was a unicentric Portuguese cross-sectional observational study, based on an anonymous survey sent to patients by email. Adult patients who collected DMT for MS or MAbs for migraine in the HPS for more than three months were invited to participate. Patients who received treatment on the hospital's day unit (or those who received short courses of treatment) were

not included in this study. Other exclusion criteria were being medicated simultaneously with DMT for MS and MAbs for migraine, having a language barrier or cognitive impairment that hinders survey consent or its understanding, illiteracy, or not having an email address. The study survey included: demographic, clinical (on MS and migraine, respectively) and medication collection data; patient-reported outcome measures (PROMs) – a treatment satisfaction scale (Patient Global Impression of Change Scale - PGICS), and disability scales (Multiple Sclerosis Impact Scale [MSIS-29] in MS; Migraine Disability Assessment [MIDAS] in migraine). Some of the questions were non-mandatory. Scales were Likert-like.

The primary outcome was quantifying the time spent annually (TSA) on medication collection. This was calculated for each patient according to the time spent trav-

elling and waiting in the HPS (hours), multiplied by the number of required medication collections per year. It did not consider the time spent looking for parking or the journey after collecting medication. Secondary outcomes were defined as the relation between the burden with medication collection and treatment satisfaction and adherence, and the identification of demographic and collection-related factors that might impact this burden.

Demographic and collection-related data were presented descriptively, with absolute numbers, percentages, mean/median values and standard deviation (SD)/interquartile range (IQR). The relation between variables was assessed with Chi-Square/Mann-Whitney U tests. A multivariate analysis was also performed to determine burden-related factors. A *p*-value of <0.05 was considered statistically significant. Statistical analysis

Table 1. Demographic characterization (N = 145)

	Total (N = 145)	MS (N = 108)	Migraine (N = 37)	p-value
Sex (Female, N, %)	94; 64.8%	62; 57.4%	32; 86.5%	0.001 § a
Age (median, IQR)	48 years old IQR 39.0-55.0	47 years old IQR 37.0-55.0	50 years old IQR 40.5-44.5	0.059
Higher Degree of Education (N, %)	74; 51.0%	52; 48.1%	22; 59.5%	0.235
Employment (N, %)	116; 80.0%	85; 78.7%	31; 84.6%	0.313
Time since diagnosis* (years, N, %)	NA	10 years IQR 5.0-17.0	1-5 years: 1; 2.7% 5-10 years: 9; 24.3% 10-20 years: 13; 35.1% 20-30 years: 7; 18.9% >30 years: 7; 18.9%	NA
Phenotype (N, %)	NA	RRMS: 76; 70.4% PPMS: 4; 3.7% SPMS: 2; 1.9% CIS: 1; 0.9%	NA	NA
Treatment (N, %)	NA	Teriflunomide: 39; 36.1% Dimethyl fumarate: 23; 21.3% Interferon-beta formulations: 19; 17.6% Fingolimod: 13; 12.0% Ofatumumab: 7; 6.5% Glatiramer acetate: 5; 4.6% Siponimod: 2; 1.9%	Galcanzumab: 23; 62.2% Erenumab: 14; 37.8%	NA
Disability Scale Scores (median, IQR)	NA	MSIS-29: 42.0% IQR 36.0-60.0	MIDAS: 21.0 IQR 11.0-50.0	NA
PGICS Score (median, IQR)	5.0 ("Moderately better, with a slight but significant improvement") IQR 2.0-6.0	4.0 ("With some improvement, but no significant change") IQR 2.0-6.0	6.0 ("Better, with a change that was real and useful") IQR 4.0-7.0	0.001 § b

CIS - clinically isolated syndrome; NA - not applicable; PPMS - primary progressive MS; SPMS - secondary progressive MS; RRMS - relapse-remitting MS; PGICS - Patient Global Impression of Change Scale.

* Time since diagnosis was asked differently for MS and migraine patients, as time since a migraine diagnosis is more difficult to report by patients according to the authors' expertise. As such, for migraine patients, this item was asked with different categories: "1-5 years", "5-10 years", "10-20 years", "20-30 years", ">30 years".

§ Statistically significant = *p* < 0.05; a Chi-square test; b Mann-Whitney U test

was performed with SPSS®. This study adhered to the relevant STROBE checklist. This study was approved by the hospital's ethical committee (registration identification number 044/2024). Patients' informed consent was required before answering the questionnaire.

Results

One hundred and forty-five patients replied to the survey (response rate 54.7%, 265 surveys sent), 108 with MS and 37 with migraine. The full demographic and clinical characterization can be found in **Table 1**. Global satisfaction with treatment was significantly higher in migraine (median PGICS of 6.0/7.0 vs 4.0/7.0 for MS).

Medication collection data is described in **Table 2**. The mean travel time to the hospital (TTH) to collect medication was 1.1 ± 1.0 hours. The estimated average distance to the hospital was 16.1 ± 13.4 km. TTH was not significantly correlated with distance to the hospital but differed substantially between each means of transportation. Within the HPS, the mean waiting time reported was 1.1 ± 0.6 hours, which was higher in migraine group (1.4 ± 0.6 vs 1.0 ± 0.6). Patients who chose priority access ($N=22$, 15.2%) waited significantly less time (0.5 ± 0.4 hours vs 1.2 ± 0.6 hours, $U=388$, $p<0.001$),

but the number of patients who opted for priority access did not differ between the two pathologies. Medication was provided on average for 2.4 ± 0.8 months, for longer periods in MS (2.7 ± 0.7 months vs 1.5 ± 0.5).

The TSA was 13.5 ± 12.4 hours, which was higher in the migraine group (21.5 ± 16.7 vs 10.7 ± 9.0 hours). In a multivariate linear analysis for TSA ($R^2 = 0.90$, $p < 0.001$), including variables correlated with this outcome in univariate analysis, the TTH ($\beta = 0.59$), waiting time in HPS ($\beta = 0.26$), and the dispensing period in months ($\beta = -0.44$) remained significant negative predictors of TSA, reflecting the fact that longer dispensing intervals reduce the number of annual trips and, consequently, the total time burden. In the same multivariate linear analysis, disease, means of transportation, distance to the hospital and priority access did not predict TSA.

In most cases (85.5%, $N = 124$), the patients collect their own medication. Employment and satisfaction outcomes were assessed using Likert-like items (1 = strongly disagree; 5 = strongly agree), with higher scores reflecting greater agreement with each statement. In 34.5% of the cases, the person collecting medication must ask for a work leave often or very often (score 4 or 5 on a Likert scale).

Table 2. Medication Collection Burden ($N = 145$)

	Total ($N = 145$)	MS ($N = 108$)	Migraine ($N = 37$)	p-value
Travel Time to the Hospital (Mean $\pm$ SD, hours)	1.1 ± 1.0	1.1 ± 0.9	1.1 ± 1.0	0.181
Mean of transport x Time (N, %, Mean $\pm$ SD, hours)				0.044 § a
Bus		15, 10.3%: 1.8 ± 1.5		
Own transport		121, 83.4%: 1.0 ± 1.0		
Ride-hailing Services		3, 2.1%: 0.6 ± 0.4		
Someone else		6, 4.1%: 1.1 ± 0.8		
Distance (Mean $\pm$ SD, Km)	16.1 ± 13.4	16.3 ± 14.5	15.4 ± 9.8	0.604
Medication collection (N, %)				0.202
Done by the patient	124, 85.5%	90, 83.3%	34, 91.9%	
Done by family members	18, 12.4%	15, 13.9%	3, 8.1%	
Done by non-family members	3, 2.4%	3, 2.8%	0.0%	
Waiting Time in HPS (Mean $\pm$ SD, hours)	1.1 ± 0.6	1.4 ± 0.6	1.0 ± 0.6	<0.001 § a
Preference for Priority Access (N, %)	22, 15.2%	17, 15.7%	5, 13.5%	0.744
Treatment Dispensing Duration (Mean $\pm$ SD, months)	2.4 ± 0.8	2.7 ± 0.7	1.5 ± 0.5	<0.001 § a
Time Spent Annually (Mean $\pm$ SD, hours)	13.5 ± 12.4	10.7 ± 9.0	21.5 ± 16.7	<0.001 § a

HPS - hospital pharmaceutical services; NA - not applicable.

§ statistically significant = $p < 0.05$; a Mann-Whitney U test

Table 3. Influence of medication collection on employment and satisfaction with collection scores

	Total	MS	Migraine	p-value
Medication collection and employment impact *	N = 87	N = 67	N = 20	
Asking for work leave to collect medication from HPS has negative consequences on my employment (or on the employment of the person who collects my medication).	3.0 IQR 2.0-4.5	3.0 IQR 2.0-4.0	4.0 IQR 3.0-5.0	0.159
My employer (or the employer of the person who collects my medication) understands the need for a work leave to collect medication.	4.0 IQR 3.0-5.0	4.0 IQR 3.0-5.0	3.5 IQR 3.0-5.0	0.274
I might lose my job (or the person who collects my medication might lose theirs) because of my medication collection.	1.0 IQR 1.0-2.5	1.0 IQR 1.0-3.0	1.0 IQR 1.0-2.25	0.823
Satisfaction with collection	N = 145	N = 108	N = 37	p-value
I am globally satisfied with the way I collect my medication.	3.0 IQR 2.0-3.0	3.0 IQR 2.0-4.0	2.0 IQR 1.0-3.0	0.001 § ^a
I would rather collect my medication in a CP.	5.0 IQR 4.0-5.0	5.0 IQR 3.0-5.0	5.0 IQR 5.0-5.0	0.168
I would rather receive my medication at home.	4.0 IQR 3.0-5.0	3.0 IQR 3.0-5.0	4.0 IQR 3.0-5.0	0.317
I would prefer that my medication be given in sufficient amount for more months.	5.0 IQR 4.0-5.0	5.0 IQR 3.0-5.0	4.0 IQR 3.0-5.0	0.028 § ^a
I would prefer to keep medication collection on the HPS but with a longer schedule.	3.0 IQR 1.0-4.0	3.0 IQR 1.0-4.0	2.0 IQR 1.0-4.0	0.118

CP - community pharmacy; HPS - hospital pharmaceutical services.

Note: These were Likert-like items, in which 1 = strongly disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = strongly agree. The presented values are medians and IQR.

* If patients answered that they did have to ask for a work leave (independently of the number of times) on a previous question, they were asked about a possible negative influence on their employment.

§ statistically significant = $p < 0.05$; ^a Mann-Whitney U test

Satisfaction with the collection method median score was 3.0 (IQR = 2.0-3.0), which was higher in the MS group (3.0 vs 2.0, $U = 1216.5$, $p < 0.001$). Both in the MS and migraine groups, the time spent waiting in HPS predicted the degree of satisfaction with the collection method (MS: $\beta = -0.31$, $p = 0.003$; migraine: $\beta = -0.51$, $p = 0.041$). TTH was also a predictor but only in the MS group, albeit with a lesser impact ($\beta = -0.22$, $p = 0.026$). We did not find other predictors. The collection satisfaction score did not correlate with the PGICS score in either pathology. **Fig. 1**

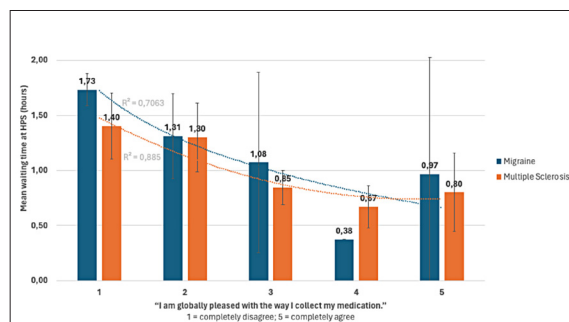


Figure 1. Treatment collection satisfaction scale scores and mean waiting time at HPS with trend line in MS and migraine patients.

shows the variation of the satisfaction score with the mean waiting time in HPS for each disease.

When asked about the possibility of collecting medication in a Community Pharmacy (CP), the median agreement score was 5.0, chosen by 73.1%. On the other hand, the median response was 4.0 when asked whether they would prefer a home-delivery system.

Discussion

In our cohort of mainly young, employed MS and migraine patients, collecting medication from the HPS translated into a mean TSA of 13.5 ± 12.4 hours, which was affected by TTH, waiting time in the HPS and the number of times required for collection per year. On the other hand, the waiting time at the HPS was the main driver of satisfaction felt with the collection method. Asking for work leave to collect medication is frequently required. Most patients (73.1%) would prefer collecting their medication from a CP if possible. Although we observed that the mean waiting time reported was higher in the migraine group, we could not find a definite explanation, since the percentage of patients requiring

priority access was similar; however, some studies could suggest differences in time perception in migraineurs, which could contribute to some difficulty in correctly estimating time spent.⁶

Differences in PGIC score between groups, higher in migraine, might be explained by the different expected effects of treatment in both diseases (mainly relief of present symptoms in migraine versus prevention of future disability in MS).

A 2022 Portuguese study estimated that shifting chronic treatment delivery from hospitals to community settings could save €262.1 per person annually by reducing travel costs and absenteeism, while also improving adherence.⁵ According to 2022 Portugal Bank data, assuming a per worker/hour value of €20, and using the data from our cohort, the annual capital loss with absenteeism related to medication collection in our patients would be €430 for migraine patients and €214 for MS patients. Extrapolating these figures to our centre's population of over 230 MS patients and over 50 migraine patients collecting medication from the HPS, the estimated annual economic loss attributable to absenteeism alone would exceed €49 000 for MS and €21 500 for migraine — a combined total of more than €70 500 per year at a single centre.

Several strategies could mitigate the identified burden. First, dispensing medication through community pharmacies (which was the preferred option in 73.1%) could substantially reduce travel time and associated costs, as previously demonstrated in the Portuguese context during the COVID-19 pandemic. Second, extending the medication dispensing period, particularly for stable MS patients, who already receive medication for a longer average duration (2.7 months) compared to migraine patients (1.5 months), would reduce the number of annual trips and, consequently, the TSA and absenteeism. Third, expanding home delivery systems could benefit patients with greater disability or those living further from the hospital. Finally, promoting the use of priority access at the HPS, currently used by only 15.2% of patients despite being associated with significantly shorter waiting times (0.5 vs 1.2 hours), could improve satisfaction with the collection process without requiring structural changes.

This study has several limitations. Its unicentric design limits the generalizability of the findings to other hospital settings or geographic regions. The online sur-

vey methodology may have introduced a selection bias, potentially underrepresenting patients with lower digital literacy or without email access. The return journey from the hospital was also not included in the TSA calculation, which is therefore likely an underestimate of the true time burden. Besides, the subjective nature of self-reported waiting times may be subject to recall bias and may be particularly susceptible to distortion in migraine patients, given documented differences in time perception in this population. The time since migraine diagnosis was collected in categories rather than as a continuous variable, which precludes direct comparison with MS patients and may limit precision in subgroup analyses. Finally, the absence of a validated general quality-of-life scale prevents broader conclusions about the overall impact of medication collection on patients' wellbeing beyond the outcomes specifically measured.

Conclusion

Treatment access barriers, such as the need for collection from the HPS in some settings, must be considered as a treatment burden related to some of the newest and more efficient drugs. Optimizing the medication dispensing process, whether within the hospital setting or through community-based alternatives, could meaningfully reduce the time burden and associated economic losses for patients with MS and migraine. ■

Previous Presentations

This is an original work, and it is not under review elsewhere. Part of its contents were presented at:

- ECTRIMS Congress 2024 (abstract available: Moniz Dionísio J, Henriques M, Costa T, et al. A Hidden Burden: the impact of medication collection in hospital pharmacies in Multiple Sclerosis and Migraine patients. *Multiple Sclerosis Journal*. 2024; 30: (3S) 681–1137. doi: 10.1177/13524585241269221)
- Reunião da Primavera do Grupo de Estudos de Esclerose Múltipla 2024
- Reunião da Primavera da Sociedade Portuguesa de Cefaleias
- 18th European Headache Congress (abstract available: Henriques M, Moniz Dionísio J, Ascensão Pinheiro T, Antão D, Rêgo A, Delgado S, et al. A hidden burden – the impact of medication collection in hospital pharmacies in multiple sclerosis and migraine patients. Abstracts from the 18th European

Headache Congress (EHC): Rotterdam, The Netherlands. 4-7 December 2024. J Headache Pain. 2025; 26:P315. doi: 10.1186/s10194-025-02062-8.

Data Availability

Free and informed consent to participate in the study was obtained from patients. The data that support the findings of this study are available upon request from the authors.

Contributorship Statement / Declaração de Contribuição

JMD, MS, EP, LL, SM, MS, SDA and AR: Conception and design of the study.

JMD, MH, TAP and DA: Acquisition and analysis of data.

JMD, MS; EP and LL: Drafting a significant portion of the manuscript or figures.

All authors approved the final version of the manuscript for publication and assume responsibility for all aspects of the work, ensuring the accuracy and integrity of the data presented.

JMD, MS, EP, LL, SM, MS, SDA e AR: Concepção e planeamento do estudo.

JMD, MH, TAP e DA: Recolha e análise de dados.

JMD, MS, EP e LL: Elaboração de uma parte significativa do manuscrito ou das figuras.

Todos os autores aprovaram a versão final do manuscrito para publicação e assumem responsabilidade por todos os aspetos do trabalho, garantindo a exatidão e a integridade dos dados apresentados.

Responsabilidades Éticas

Conflitos de Interesse: Os autores declaram a inexistência de conflitos de interesse na realização do presente trabalho.

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