MS patients' perception of the effects of PR-fampridine on walking disorders and daily life: results from an observational study conducted via an online patient community

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Conclusions

- Most MS patients reported improvements since the start of PR-fampridine treatment for their walking impairment. The most significant results following the prescription were improved walking ability that allowed walking without focusing, increased walking distance and less fatigue, particularly for patients with lower EDSS (4-5).
- Among patients using walking aids, such as a cane or access ramp, about half reported less need or an easier use of these devices.
- About half of patients report a gain in autonomy, mainly when walking outside of their home and in moving about at home.
- When patients report an increase in autonomy while taking PR-fampridine, these gains were sustained over time, regardless of treatment duration.
- These benefits are linked to a positive impact in patients' quality of life, mainly in their social and family life.
- Although improvements were greater for patients with RRMS, patients with PPMS and SPMS, who have access to less therapeutics possibilities, have also experienced benefits from PR-fampridine.

Introduction

- Multiple Sclerosis (MS) is a neurodegenerative disease frequently causing walking impairment[1].
- Prolonged-release PR-fampridine (dalfampridine extended-release in US) is approved for the improvement of gait function in MS patients with walking disability (Expanded Disability Status Scale 4-7).
- Fampridine targets the underlying neurological causes of MS walking impairment through modification of neurotransmission in the CNS[2] and can be used in patients with any subtype of MS.

Objectives

The study aims at observing how patients' daily life evolved following the prescription of PR-fampridine.

Methods

Carenity.com

- CARENITY is an international online patient community devoted to people with chronic diseases.
- It allows patients and caregivers to share their experiences, to access medical information and to participate in online surveys, generating real-world patient insights.

Survey

- An online questionnaire was submitted to the members of the Carenity French MS community.
- The questionnaire had been proofread by one MS patient with walking disabilities.
- The questionnaire was self-reported, including clinical data such as EDSS level.

Inclusion criteria

- MS patients with EDSS between 4 and 7, currently receiving PR-fampridine.

Online survey data collection

- From January to February 2018.

Results

Respondents' profile

- 62 MS patients answered the questionnaire.
- ♀ 68% ♂ 32% Mean age : 52.7 y.o

18-30 y.o	31-40 y.o	41-50 y.o	51-60 y.o	61-70 y.o	70+ y.o
2%	2%	37%	39%	19%	2%

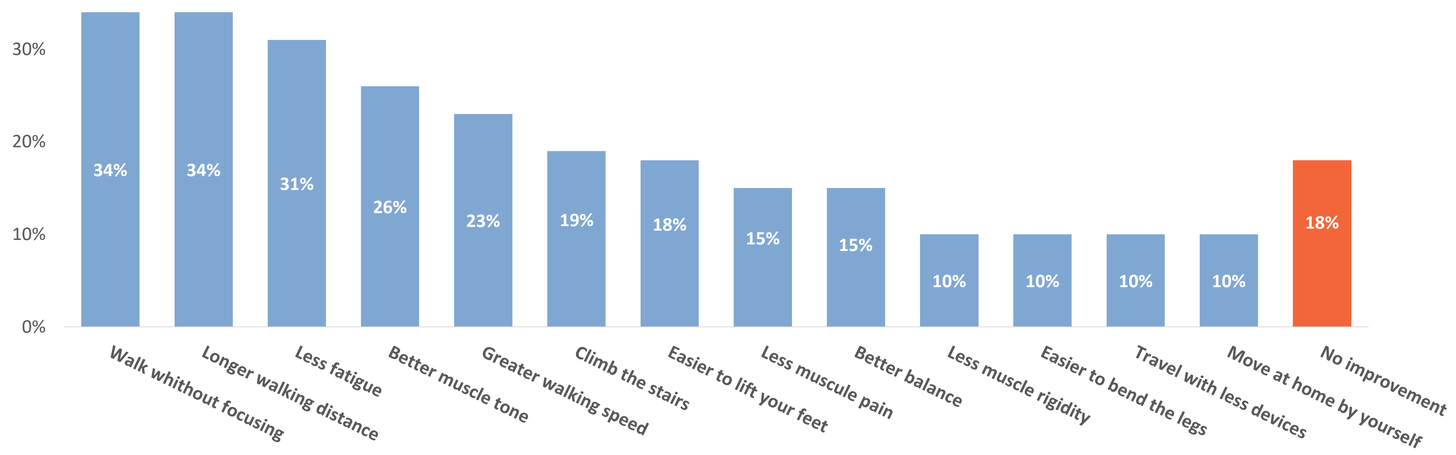
Secondary progressive MS	Relapsing-remitting MS	Primary progressive MS	Do not know
50%	27%	19%	3%

- 48% had an EDSS of 4 or 5 and 52% of 6 or 7.
- 36% had been taking PR-fampridine for less than 2 years and 35% for more than 4 years.

Improvement of patients' daily life after start of PR-fampridine treatment

- 82% of patients noticed improvements regarding walking abilities and fatigue (Figure 1).
- For the areas listed in Figure 1, improvements were greater for patients with lower EDSS (4-5) and RRMS forms of the disease:
  - 87% of patients reported improvement with EDSS 4 or 5 and 78% with EDSS 6 or 7. Moreover, patients with EDSS 4 or 5 reported more areas of improvement than patients with EDSS 6 or 7 (mean number of areas = 3.1 versus 2.0).
  - 94% of patients with RRMS experienced improvements versus 84% with SPMS, and 58% with PPMS.
- 49% of patients linked PR-fampridine to a positive impact on their quality of life.

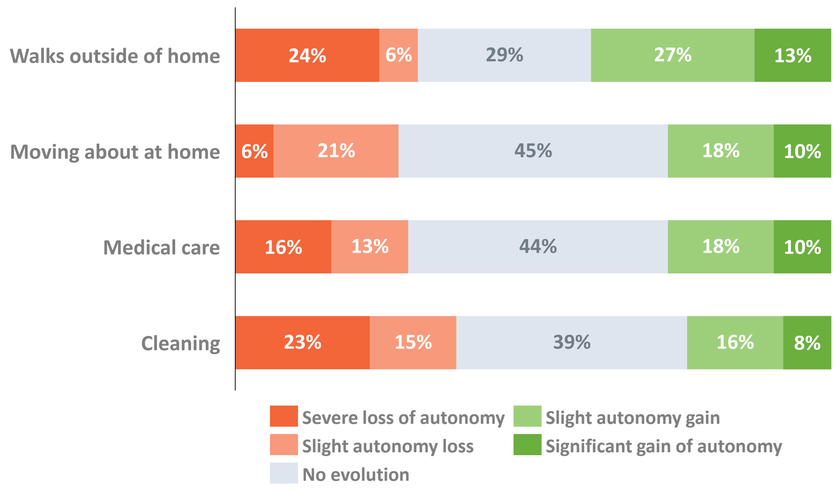
Figure 1. Improvements reported since starting treatment with PR-fampridine



	Professional life	Social life	Family life	Everyday mood	Self-esteem	Family and friends	Financial impact	Overall quality of life
Improvement	29%	45%	45%	42%	41%	33%	17%	49%
No evolution	44%	23%	27%	24%	30%	32%	45%	15%
Deterioration	27%	32%	28%	34%	29%	35%	38%	36%

Table 1. Evolution of patients' quality of life since starting treatment with PR-fampridine

Figure 2. Evolution of patients' daily activities since starting treatment with PR-fampridine



Have been taking PR-fampridine for...	Autonomy gain	No autonomy gain
Less than 2 years n=22	55%	45%
Between 2 and 4 years n=18	50%	50%
More than 4 years n=22	59%	41%

Table 2. Evolution of patients' daily activities since starting treatment with PR-fampridine

	Total n=62			EDSS 4 et 5 n=30			EDSS 6 et 7 n=32		
	Easier to use	*Less used*	*No evolution*	*Easier to use*	*Less used*	*No evolution*	*Easier to use*	*Less used*	*No evolution*
Cane n=46	30%	17%	52%	27%	32%	41%	33%	4%	63%
Access ramp n=31	32%	19%	48%	29%	14%	57%	35%	24%	41%
Grab bar n=27	37%	22%	41%	36%	18%	45%	38%	25%	38%
Manual wheelchair n=21	38%	33%	29%	0%	0%	100%	42%	37%	21%
Crutch n=25	36%	20%	44%	0%	67%	33%	47%	5%	47%
Splint n=19	42%	21%	37%	0%	60%	40%	57%	7%	36%
Walker n=14	50%	14%	36%	25%	50%	25%	60%	0%	40%
Medical scooter n=9	33%	33%	33%	100%	0%	0%	25%	38%	38%

For each walking aid, the shaded green shows the highest percentage between "easier to use" and "less used".

Table 3. Evolution of the use of walking aids since starting treatment with PR-fampridine

References 1. WHO. 2008. Atlas: Multiple Sclerosis Resources in the world 2008; 2. GOODMAN AD *et al*. *Lancet*. 2009; 373(9665):732-738. **Disclosures** OS, KJ: employees of Biogen. OW: employee of Carenity. **Acknowledgments** This study was sponsored by Biogen (Paris la Défense, France). Writing and editorial support for the preparation of this poster was provided by Else Care (Paris, France): funding was provided by Biogen..

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