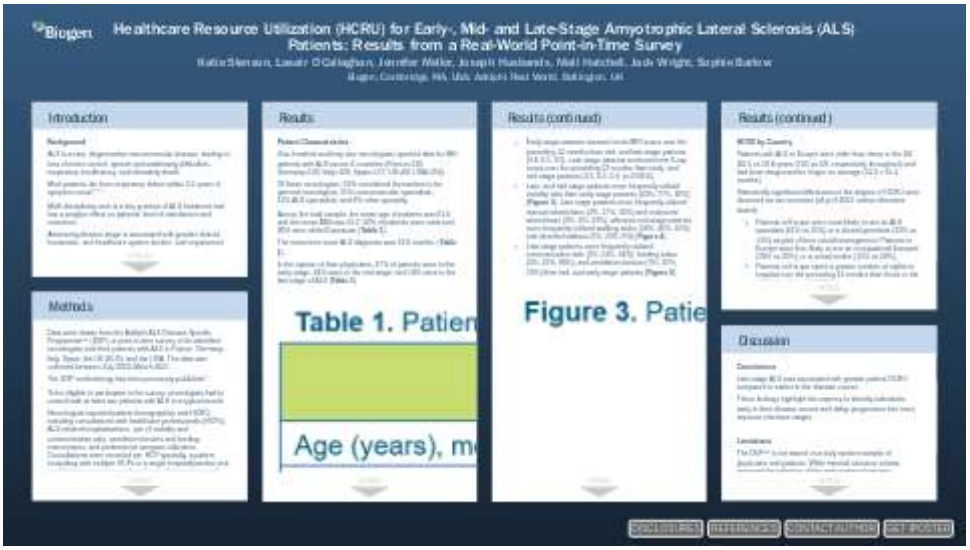
Healthcare Resource Utilization (HCRU) for Early-, Mid- and Late-Stage Amyotrophic Lateral Sclerosis (ALS) Patients: Results from a Real-World Point-in-Time Survey



Katie Stenson, Lasair O'Callaghan, Jennifer Mellor, Joseph Husbands, Niall Hatchell, Jack Wright, Sophie Barlow

Biogen, Cambridge, MA, USA; Adelphi Real World, Bollington, UK

PRESENTED AT:

Virtual Poster Sponsor: PHAR

VIRTUAL ISPOR 2021

INTRODUCTION

Background

ALS is a rare, degenerative neuromuscular disease, leading to loss of motor control, speech and swallowing difficulties, respiratory insufficiency, and ultimately death[1].

Most patients die from respiratory failure within 3-5 years of symptom onset[2,3,4].

Multi-disciplinary care is a key premise of ALS treatment and has a positive effect on patients' level of satisfaction and outcomes[5].

Advancing disease stage is associated with greater clinical, humanistic, and healthcare system burden, and requirement for assistive devices[6].

Objective

This study assessed the degree of healthcare resource utilization (HCRU) in early-, mid-, and late- stage patients with amyotrophic lateral sclerosis (ALS).

METHODS

Data were drawn from the Adelphi ALS Disease Specific Programme™ (DSP), a point-in-time survey of de-identified neurologists and their patients with ALS in France, Germany, Italy, Spain, the UK (EU5), and the USA. The data was collected between July 2020–March 2021.

The DSP methodology has been previously published[7].

To be eligible to participate in the survey, neurologists had to consult with at least two patients with ALS in a typical month.

Neurologists reported patient demographics and HCRU, including consultations with healthcare professionals (HCPs), ALS-related hospitalizations, use of mobility and communicative aids, ventilation devices and feeding interventions, and professional caregiver utilization. Consultations were recorded per HCP specialty, a patient consulting with multiple HCPs in a single hospital/practice visit would accrue a greater number of consultations as a result.

Neurologists identified whether patients were in the early-, mid-, or late-stage of ALS, according to their clinical judgement.

Comparisons across the three disease stages were conducted using analysis of variance (ANOVA) and chi-squared tests. Additional pairwise comparisons between disease stages and markets were conducted using chi-squared, Fisher's exact, and t-tests with Bonferroni corrections.

RESULTS

Patient Characteristics

One-hundred and forty-two neurologists reported data for 880 patients with ALS across 6 countries (France=130; Germany=120; Italy=129; Spain=157; UK=88; USA=256).

Of these neurologists, 53% considered themselves to be general neurologists, 31% neuromuscular specialists, 13% ALS specialists, and 4% other specialty.

Across the total sample, the mean age of patients was 61.6 and the mean BMI was 24.2. 62% of patients were male and 90% were white/Caucasian (**Table 1**).

The mean time since ALS diagnosis was 19.0 months. (**Table 1**).

In the opinion of their physicians, 37% of patients were in the early-stage, 44% were in the mid-stage, and 19% were in the late-stage of ALS (**Table 1**).

Table 1. Patient characteristics

	All patients (N=880)
Age (years), mean (SD)	61.7 (11.1)
Sex, male n (%)	554 (61.8)
BMI, mean (SD)	24.2 (3.2)
Ethnicity, white/Caucasian n (%)	793 (90.2)
ALS current stage, n (%)	
Early	323 (36.7)
Mid	389 (44.2)
Late	168 (19.1)
Total number of comorbidities, mean (SD)	1.6 (1.5)
Most common comorbidities, n (%)	
Hypertension	380 (43.2)
Depression	199 (22.6)
Anxiety	158 (18.0)
	(n=854)
Time since ALS diagnosis (months), mean (SD)	19.4 (22.1)

HCRU by Disease Stage

Patients with ALS at later stages were older (59.6, 62.0, 65.2 years; early-, mid-, late-stage, respectively throughout) and had longer time since diagnosis (13.0, 20.1, 30.2 months) (**Table 2**).

Table 2. Patient characteristics by disease stage

	Early-stage (N=323)	Mid-stage (N=389)	Late-stage (N=168)	p-value
Age (years), mean (SD)	59.6 (11.1)	62.0 (10.6)	65.2 (11.2)	<0.0001*
Sex, male n (%)	204 (63.1)	236 (60.7)	104 (61.9)	0.7929**
BMI, mean (SD)	24.5 (2.9)	24.2 (3.0)	23.4 (4.0)	0.0016*
Total number of comorbidities, mean (SD)	1.5 (1.5)	1.6 (1.4)	1.8 (1.6)	0.0608*
Ethnicity, white/Caucasian n (%)	288 (89.4)	353 (90.7)	152 (90.4)	0.8370**
	(n=315)	*(n=377)*	*(n=162)*	
Time since ALS diagnosis (months), mean (SD)	13.0 (19.3)	20.1 (18.2)	30.2 (29.8)	<0.0001*

* p-value calculated using ANOVA ** p-value calculated using chi-squared tests *** p-value calculated using T tests

Statistically significant differences in the degree of HCRU were observed across disease stages (all $p<0.0001$ unless otherwise stated).

- Late-stage patients attended a greater number of ALS-related HCP consultations over the preceding 12 months in both the US and Europe, respectively (12.0, 15.8, 26.0) (**Figure 1**). Late-stage patients were more likely than mid- and early-stage patients to see

several HCP specialties as part of their overall management, including pulmonologists (26%, 43%, 64%), respiratory therapists (11%, 16%, 35%), dieticians (13%, 16%, 33%), physical therapists (51%, 63%, 71%), and speech and language therapists (22%, 41%, 46%).

- Late-stage patients experienced a greater number of ALS-related hospitalizations over the preceding 12 months (0.2, 0.4, 0.8) (**Figure 2**) and spent a greater number of nights in hospital overall (0.4, 0.8, 3.2). Late-stage patients were also more likely to have been admitted via the ER (4%, 14%, 34%), to have spent time in ICU (0%, 2%, 10%), and to have required assisted ventilation (1%, 7%, 25%) during hospitalization.

Figure 1. Total number of HCP consultations in the past 12 months (*p<0.0001)

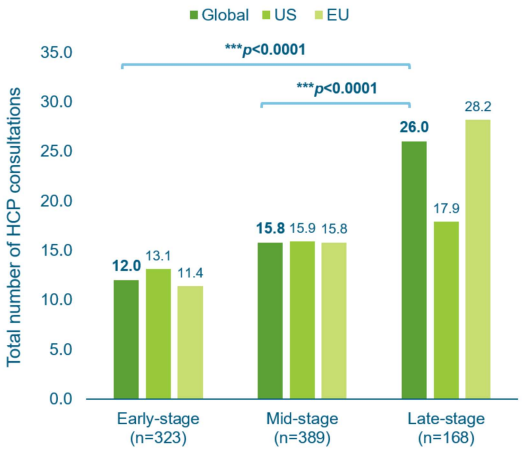
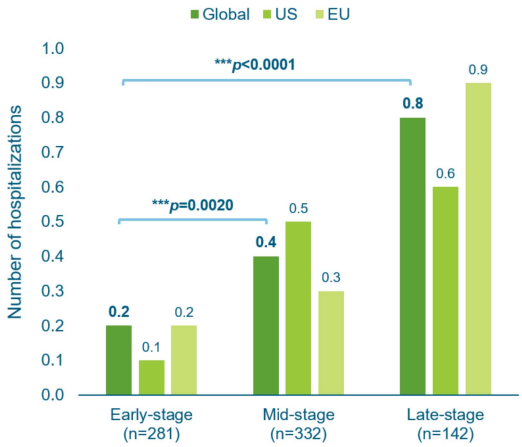


Figure 2. Total number of ALS-related hospitalizations in the past 12 months (*p<0.0001)



* p-value calculated using ANOVA ** p-value calculated using chi-squared tests *** p-value calculated using T tests

RESULTS (CONTINUED)

- Early-stage patients received more MRI scans over the preceding 12 months than mid- and late-stage patients (0.8, 0.5, 0.5). Late-stage patients received more X-ray scans over the preceding 12 months than early- and mid-stage patients (0.2, 0.2, 0.4; p=0.0016).
- Late- and mid-stage patients more frequently utilized mobility aids than early-stage patients (40%, 77%, 80%) (**Figure 3**). Late-stage patients more frequently utilized manual wheelchairs (2%, 17%, 35%) and motorized wheelchairs (0%, 6%, 33%), whereas mid-stage patients more frequently utilized walking sticks (36%, 46%, 10%) and wheeled walkers (3%, 22%, 8%) (**Figure 4**).
- Late-stage patients more frequently utilized communicative aids (5%, 24%, 54%), feeding tubes (2%, 12%, 68%), and ventilation devices (5%, 32%, 74%) than mid- and early-stage patients (**Figure 3**).

Figure 3. Patient utilization of functional/supportive aids as a result of ALS

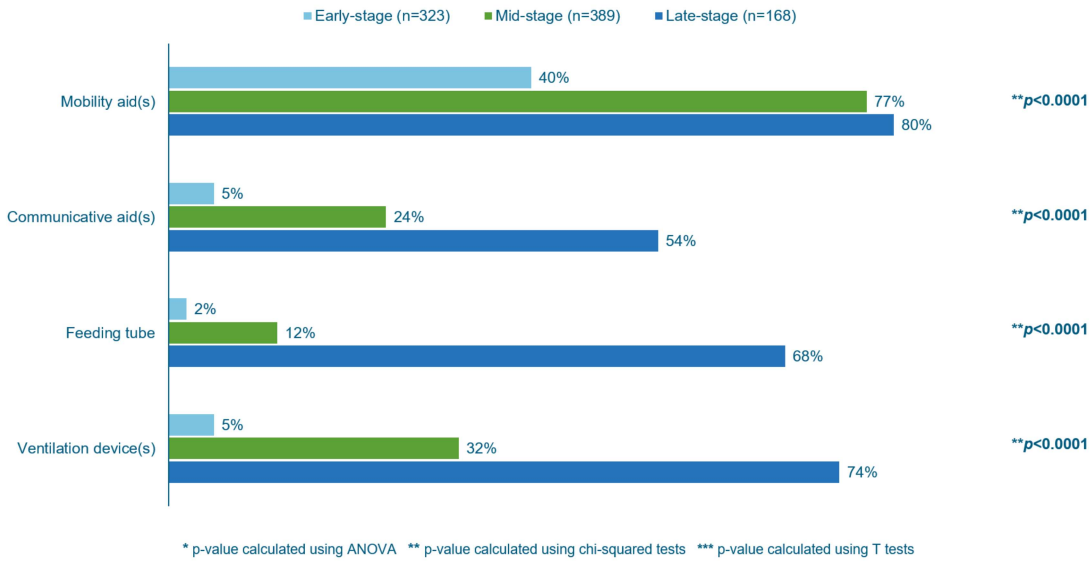
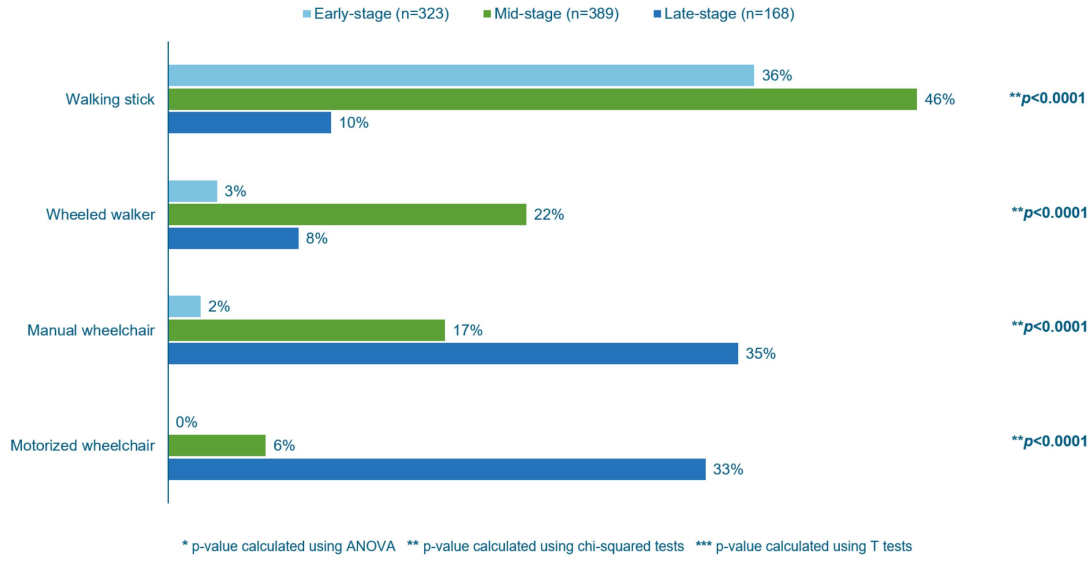
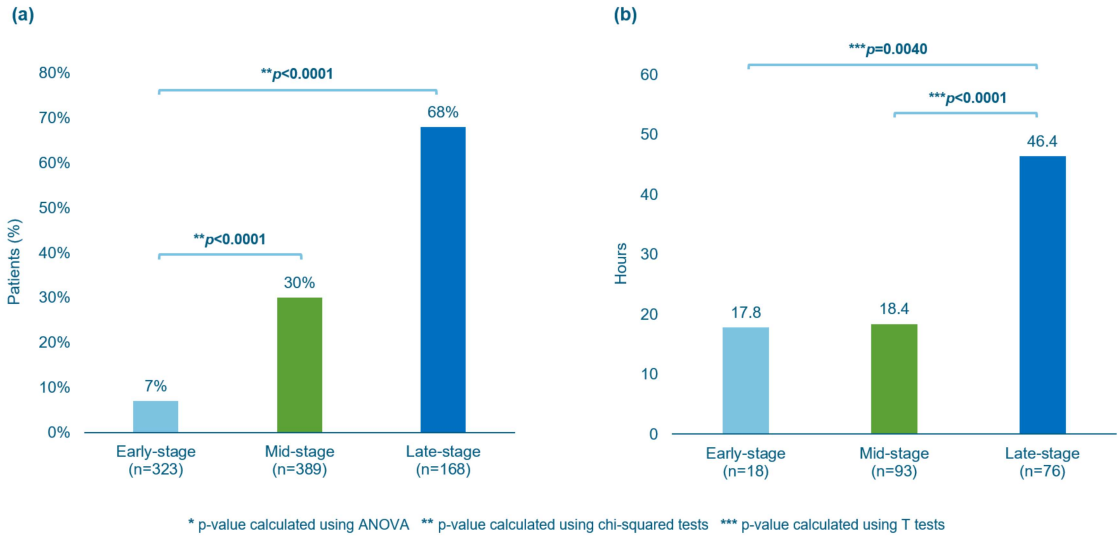


Figure 4. Patient utilization of different types of mobility aid(s)



- Late-stage patients more frequently required professional caregiver support as a result of their ALS (7%, 30%, 68%), and those with a professional caregiver also utilized a greater number of hours of care per week (17.8, 18.4, 46.4) (**Figure 5**).

Figure 5. (a) Frequency of professional caregiver utilization (*p<0.0001); **(b)** Total number of professional caregiver hours utilized per week (*p<0.0001)



* p-value calculated using ANOVA ** p-value calculated using chi-squared tests *** p-value calculated using T tests

RESULTS (CONTINUED)

HCRU by Country

Patients with ALS in Europe were older than those in the US (62.5 vs 59.8 years; EU5 vs US, respectively throughout) and had been diagnosed for longer on average (21.0 v 15.4 months).

Statistically significant differences in the degree of HCRU were observed across countries (all $p<0.0001$ unless otherwise stated).

- Patients in Europe were more likely to see an ALS specialist (41% vs 10%) or a clinical geneticist (22% vs 11%) as part of their overall management. Patients in Europe were less likely to see an occupational therapist (29% vs 45%), or a social worker (15% vs 40%).
- Patients in Europe spent a greater number of nights in hospital over the preceding 12 months than those in the US (1.3 vs 0.4; p=0.0002), though there was no significant difference in the number of hospitalizations over the same period (0.4 vs 0.3; $p=0.0601$).
- Patients in Europe received a greater total number of scans over the preceding 12 months than those in the US (1.3 vs 0.9). Scan types recorded included Bone, CT, MRI, PET, SPECT, and X-ray.
- Patients in Europe less frequently utilized communicative aids (21% vs 27%; $p=0.0363$) and therapeutic interventions (45% vs 57%; $p=0.0010$) than those in the US.

DISCUSSION

Conclusions

Late-stage ALS was associated with greater patient HCRU compared to earlier in the disease course.

These findings highlight the urgency to identify individuals early in their disease course and delay progression into more resource intensive stages.

Limitations

The DSP™ is not based on a truly random sample of physicians and patients. While minimal inclusion criteria governed the selection of the participating physicians, participation is influenced by the willingness to complete the survey.

The results are reflective of averages across countries and country-specific results may vary slightly.

Identification of patient disease stage was based on the judgement of the respondent physician and not a formalized diagnostic checklist.

DISCLOSURES

- KS and LOC are employees of Biogen, USA.
- JW, JM, JH, NH, and SB are employees of Adelphi Real World and are under contract with Biogen

REFERENCES

1. Soriani M-H et al. Care management in amyotrophic lateral sclerosis. Rev Neurol (Paris). 2017; 173(5): 288-299.
2. Brown RH, Al-Chalabi A. Amyotrophic Lateral Sclerosis. N Engl J M. 2017; 377(2): 162-172.
3. Al-Chalabi A, Hardiman O. Nat Rev Neurol. 2013; 9(11): 617-628.
4. Bunton-Stasyshyn RK, et al. Neuroscientist. 2015; 21(5): 519-529.
5. Masrori P et al. Amyotrophic Lateral Sclerosis: A clinical review. Eur. J. Neurol. 27(10): 1918-1929.
6. Hardiman O et al. Amyotrophic lateral sclerosis. Nat. Rev. Dis. Primers. 2017; 3, 17071.
7. Anderson P et al. Real-world physician and patient behavior across countries: Disease-Specific Programmes - a means to understand. Curr. Med. Res. Opin.. 2008; 24: 3063-3072.