BACKGROUND

- Management strategies for adult spasticity include physical and pharmacological therapies, as well as surgery in selected cases.1
- Botulinum toxin type A (BoNT-A) is a recommended pharmacological option for patients with spasticity and its anti-spastic effects have been demonstrated in stroke and central nervous system lesions.4,5 multiple sclerosis (MS) and cerebral palsy.6,7 However, the impact of BoNT-A treatment on the daily lives of real-world patients with spasticity has not been studied widely.9 Carency®, an online social media platform for people with chronic conditions, was used to survey patients and caregivers of patients with spasticity who were receiving BoNT-A treatment.

OBJECTIVE

- To understand the burden of BoNT-A treatment from the patient perspective, in terms of impact on activities of daily living and quality of life.

METHODS

Study design

- An online, cross-sectional survey conducted between 30 November 2017 and 28 February 2018 via the Carency® platform.
- Emails were sent to patients and caregivers from France, Germany, Italy, Spain, the UK and the USA inviting them to complete the online questionnaire.

Inclusion criteria

- Eligible participants were aged ≥18 years old and were either patients self-described as having spasticity and who had received BoNT-A treatment for ≥1 year, or caregivers of such patients.
- Spasticity had to be as a result of MS, traumatic brain injury, spinal cord injury, cerebral palsy, brain tumour or spastic paraplegia.

Assessments/analysis

- The questionnaire (presented in the local language) comprised multiple-choice questions and Likert scale and free-text responses.
- The following domains were assessed: number of BoNT-A injections; time since diagnosis; duration of caregiving; burden, costs and benefits of BoNT-A treatment; and life improvements associated with BoNT-A treatment.
- For caregivers, some questions related to their patient, whereas others related to their experience as a caregiver.

Statistical analyses

- Descriptive analyses are presented.

RESULTS

Participants

- In total, 615 participants were included in the analysis (427 patients and 188 caregivers).

Baseline characteristics for patients and caregivers are presented in Table 1.

- Most patients (553) were receiving onabotulinumtoxinA as their current BoNT-A treatment, followed by 38% receiving incobotulinumtoxinA and 11% receiving abobotulinumtoxinA (Table 3).
- Mean time since diagnosis was 8.1 years, compared with a mean time of 4.6 years between diagnosis and treatment initiation.

BoNT-A treatment behaviour

- Mean number of BoNT-A injections reported was 4.4 injections per year (4.3 injections for patients only) and was consistent across conditions and BoNT-A formulations.
- The mean number of injections ranged from 2.8 per year for brain tumour to 5.8 per year for traumatic brain injury.
- The mean number of injections per year was 4.5 for onabotulinumtoxinA, 4.6 for abobotulinumtoxinA and 4.8 for incobotulinumtoxinA.
- Overall, 26% of patients reported receiving 6 injections per year.
- Number of injections per year increased in line with number of difficulties patients reported in activities of daily living (Figure 3).

- For most patients (352/427, 83%), the next treatment date was scheduled immediately after they received their BoNT-A injection.
- In 63% (235/370), injection intervals were always the same, and this was sometimes as arranged at a result of spasticity symptoms.
- The remaining 5% (133/359) would have liked earlier retreatment, but this was not possible.
- Needle-based scheduling seemed to depend on number of injections per year (Figure 2).

- Most patients (375/427, 87%) reported that treatment goals of BoNT-A injections were discussed with doctors.

Impact of BoNT-A treatment

- Issues with or concerns about BoNT-A injections

• The main issues with and concerns about BoNT-A injections reported by patients related to side effects (40% of respondents), efficacy (32%) and treatment administration (18%).

Burden of BoNT-A injections

• At least, 70% of patients reported problems with receiving BoNT-A treatment.

- The most problematic issues were fear of injections (324/427, 76%), frequency of injections (325/427, 78%) and availability of timely appointments (339/427, 79%).

Cost of BoNT-A injections

- At the time of each BoNT-A injection costs were incurred by 77% (330/427) of patients.

- Both the reported costs associated with each BoNT-A injection were >€100 in 57% (285/503) of patients.

- Transportation costs and parking fees were the most frequent types of costs.

Beneﬁts of BoNT-A injections

- BoNT-A treatment resulted in improvements in overall satisfaction with life as reported by 92% of patients (Figure 3).

- For the individual domains, improvements were reported for 81 to 94% of patients (Figure 3).

CONCLUSIONS

- Patients with spasticity experience a diverse range of challenges associated with BoNT-A treatment, including injection frequency, having to take time off from work for treatment, fear of injections, appointment availability, and costs associated with treatment.

- Despite these challenges, patients reported large improvements in many areas of their lives and overall satisfaction with life following BoNT-A treatment.

References

7. www.carenity.co.uk.

Disclosures

- The authors have no conflicts of interest to disclose.

Medical writing support

- The authors thank Li-Jane Chau, BS Phm, and Germaine Hanson-Wilkinson, MSc of Watermark Medical for providing medical writing and editorial support, which was sponsored by Ipsen in accordance with Good Publication Practice guidelines.

Acknowledgements

The authors thank all patients and caregivers involved in the study, as well as the care teams, investigators and research staff at participating institutions.

Table 1. Baseline characteristics of all participants (N=615).

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Patients (n=427)</th>
<th>Caregivers (n=188)</th>
<th>Caregivers (n=188)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex, n (%)</td>
<td>Male 206 (49)</td>
<td>Female 220 (51)</td>
<td>Male 84 (45)</td>
</tr>
<tr>
<td></td>
<td>Female 221 (51)</td>
<td></td>
<td>Female 104 (55)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (95% CI), years</td>
<td>5.1 (4.3–6.0)</td>
<td>5.1 (4.3–6.0)</td>
<td>5.1 (4.3–6.0)</td>
</tr>
<tr>
<td>Duration of caregiving, n (%)</td>
<td>1–3 years 22 (5)</td>
<td>1–3 years 30 (16)</td>
<td>1–3 years 10 (5)</td>
</tr>
<tr>
<td></td>
<td>1–3 years 30 (16)</td>
<td></td>
<td>1–3 years 10 (5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (95% CI), years</td>
<td>4.7 (4.0–5.4)</td>
<td>4.7 (4.0–5.4)</td>
<td>4.7 (4.0–5.4)</td>
</tr>
<tr>
<td>Time since patient diagnosis, n (%)</td>
<td>1–3 years 244 (57)</td>
<td>1–3 years 103 (55)</td>
<td>1–3 years 244 (57)</td>
</tr>
<tr>
<td></td>
<td>1–3 years 244 (57)</td>
<td></td>
<td>1–3 years 103 (55)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (95% CI), years</td>
<td>4.0 (3.5–4.5)</td>
<td>4.0 (3.5–4.5)</td>
<td>4.0 (3.5–4.5)</td>
</tr>
<tr>
<td>Date of patient’s first BoNT-A injection, n (%)</td>
<td>1–3 years 224 (52)</td>
<td>1–3 years 105 (55)</td>
<td>1–3 years 224 (52)</td>
</tr>
<tr>
<td></td>
<td>1–3 years 224 (52)</td>
<td></td>
<td>1–3 years 105 (55)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (95% CI), years</td>
<td>4.0 (3.5–4.5)</td>
<td>4.0 (3.5–4.5)</td>
<td>4.0 (3.5–4.5)</td>
</tr>
<tr>
<td>BoNT-A treatment received by patient, n (%)</td>
<td>OnabotulinumtoxinA 338 (91)</td>
<td>OnabotulinumtoxinA 109 (58)</td>
<td>OnabotulinumtoxinA 338 (91)</td>
</tr>
<tr>
<td></td>
<td>AbobotulinumtoxinA 109 (58)</td>
<td></td>
<td>AbobotulinumtoxinA 109 (58)</td>
</tr>
<tr>
<td></td>
<td>Other 1 (0.3%)</td>
<td>Other 1 (0.3%)</td>
<td>Other 1 (0.3%)</td>
</tr>
<tr>
<td></td>
<td>Don’t know 3 (0.9%)</td>
<td>Don’t know 3 (0.9%)</td>
<td>Don’t know 3 (0.9%)</td>
</tr>
</tbody>
</table>

Figure 1. Number of difficulties in activities of daily living according to number of BoNT-A injections received, as reported by patients (n=427).

Figure 2. Planning of next treatment date according to number of BoNT-A injections received, as reported by patients (n=427).

Figure 3. Improvement in daily activities following BoNT-A injections, as reported by patients (n=427).

This study was sponsored by Ipsen.

Presented at TOINS 2019 | Copenhagen, Denmark | 18–19 January 2019