The patients' perspective on botulinum neurotoxin A treatment: results of a multinational survey for patients with spasticity

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BACKGROUND

- Management strategies for adult spasticity include physical and pharmacological therapies, as well as surgery in severe or intractable cases.[1]
- Botulinum toxin type A (BoNT-A) is a recommended pharmacological option for patients with spasticity[1] and its anti-spastic effects have been demonstrated in stroke and central nervous system lesions,[2–4] multiple sclerosis (MS)[5] 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.
- Carenity,[8] 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 10 November 2017 and 28 February 2018 via the Carenity[8] 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, stroke, 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; retreatment scheduling, including intervals between injections; discussion of treatment goals; main issues with or concerns about BoNT-A injections; burden, costs and benefits of BoNT-A treatment; and life improvements following 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

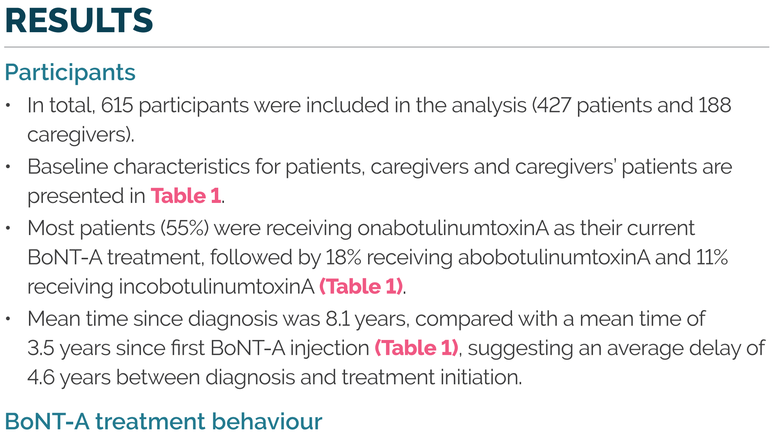
Participants

- In total, 615 participants were included in the analysis (427 patients and 188 caregivers).
- Baseline characteristics for patients, caregivers and caregivers' patients are presented in **Table 1**.
- Most patients (55%) were receiving onabotulinumtoxinA as their current BoNT-A treatment, followed by 18% receiving abobotulinumtoxinA and 11% receiving incobotulinumtoxinA **(Table 1)**.
- Mean time since diagnosis was 8.1 years, compared with a mean time of 3.5 years since first BoNT-A injection **(Table 1)**, suggesting an average delay of 4.6 years between diagnosis and treatment initiation.

BoNT-A treatment behaviour

- Mean number of BoNT-A injections reported was 4.4 per year (n=427, 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, 4.8 for incobotulinumtoxinA and 4.8 for abobotulinumtoxinA.
- 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 1)**.

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



Survey question (Likert-scale response): "*For each of the following items, please assess the level of difficulty you experience/the patient you care for experiences due to your/their spasticity: difficulty to perform daily tasks (e.g. prepare meals, groom yourself, dress…); difficulty to use a computer; difficulty to write; difficulty to walk; difficulty to drive; difficulty to carry something; difficulty to catch something.*"
'Difficulties' were defined as a response of ≥4 to an item (responses scored on a scale of 0 to 10, where 0 was 'no difficulty' and 10 was 'great difficulty').
BoNT-A, botulinum neurotoxin Type A.

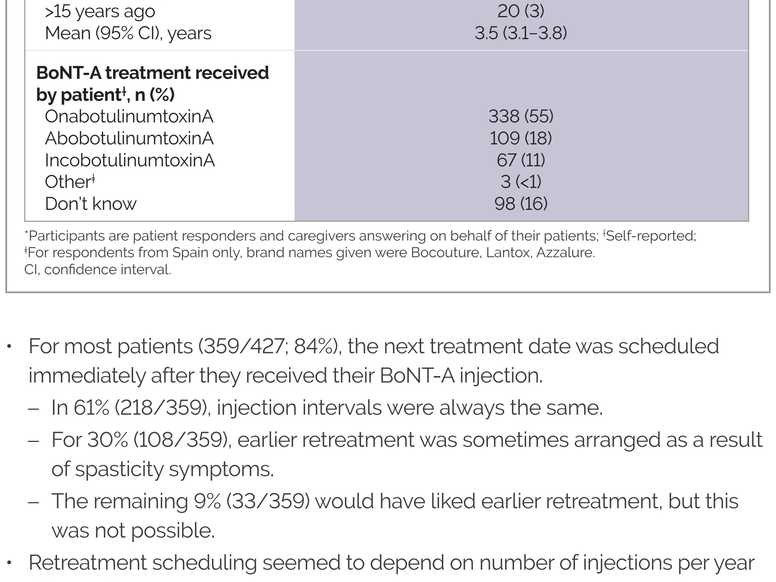
Table 1. Baseline characteristics of all participants (N=615).

Parameter	Patients (n=427)	Caregivers' patients (n=188)	Caregivers (N=188)
Sex, n (%)			
Male	216 (51)	84 (45)	84 (45)
Female	206 (48)	104 (55)	104 (55)
Transgender	5 (1)	0 (0)	0 (0)
Age, n (%)			
18–30 years	72 (17)	24 (13)	49 (26)
31–40 years	127 (30)	15 (8)	63 (34)
41–50 years	134 (31)	25 (13)	45 (24)
51–60 years	66 (15)	35 (19)	25 (13)
>60 years	28 (7)	89 (47)	6 (3)
Mean (95% CI), years	41.7 (40.6–42.8)	57.4 (54.6–60.1)	38.6 (36.9–40.2)
Duration of caregiving, n (%)			
<1 year	–	–	11 (6)
1–3 years	–	–	64 (34)
3–5 years	–	–	46 (24)
5–10 years	–	–	45 (24)
10–15 years	–	–	6 (3)
>15 years	–	–	16 (9)
Mean (95% CI), years	–	–	4.9 (4.1–5.7)
Parameter	**All participants***		
Cause of patient spasticity, n (%)			
Multiple sclerosis	256 (42)		
Stroke	122 (20)		
Spastic paraplegia	61 (10)		
Spinal cord injury	60 (10)		
Cerebral palsy	50 (8)		
Traumatic brain injury	48 (7)		
Brain tumour	18 (3)		
Time since patient diagnosis, n (%)			
<3 years	184 (30)		
3–5 years	103 (17)		
5–10 years	136 (22)		
10–15 years	64 (10)		
>15 years	104 (17)		
Not specified	24 (4)		
Mean (95% CI), years	8.1 (7.4–8.9)		
Date of patient's first BoNT-A injection, n (%)			
<2 years ago	271 (44)		
2–5 years ago	186 (30)		
5–10 years ago	101 (16)		
10–15 years ago	37 (6)		
>15 years ago	20 (3)		
Mean (95% CI), years	3.5 (3.1–3.8)		
BoNT-A treatment received by patient†, n (%)			
OnabotulinumtoxinA	338 (55)		
AbobotulinumtoxinA	109 (18)		
IncobotulinumtoxinA	67 (11)		
Other‡	3 (<1)		
Don't know	98 (16)		

*Participants are patient responders and caregivers answering on behalf of their patients; †Self-reported; ‡For respondents from Spain only, brand names given were Bocouture, Lantox, Azzalure.
CI, confidence interval.

- For most patients (359/427; 84%), the next treatment date was scheduled immediately after they received their BoNT-A injection.
  - In 61% (218/359), injection intervals were always the same.
  - For 30% (108/359), earlier retreatment was sometimes arranged as a result of spasticity symptoms.
  - The remaining 9% (33/359) would have liked earlier retreatment, but this was not possible.
- Retreatment scheduling seemed to depend on number of injections per year **(Figure 2)**.
- Most patients (371/427; 87%) reported that treatment goals of BoNT-A injections were discussed with doctors.

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



Survey question (multiple-choice and numeric response): "*Do you plan the next treatment date immediately after you get your injections of Botulinum Toxin A with your doctor?*"; "*On average, how many Botulinum Toxin A treatments do you receive per year?*"
BoNT-A, botulinum neurotoxin Type A.

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 (22%) and treatment administration (18%).

Burden of BoNT-A injections

- At least 79% of patients reported problems with receiving BoNT-A treatment.
  - The most problematic issues were fear of injections (312/427 patients; 73%), costs of getting injections (324/427; 76%), frequency of injections (335/427; 78%) and availability of timely appointments (339/427; 79%).

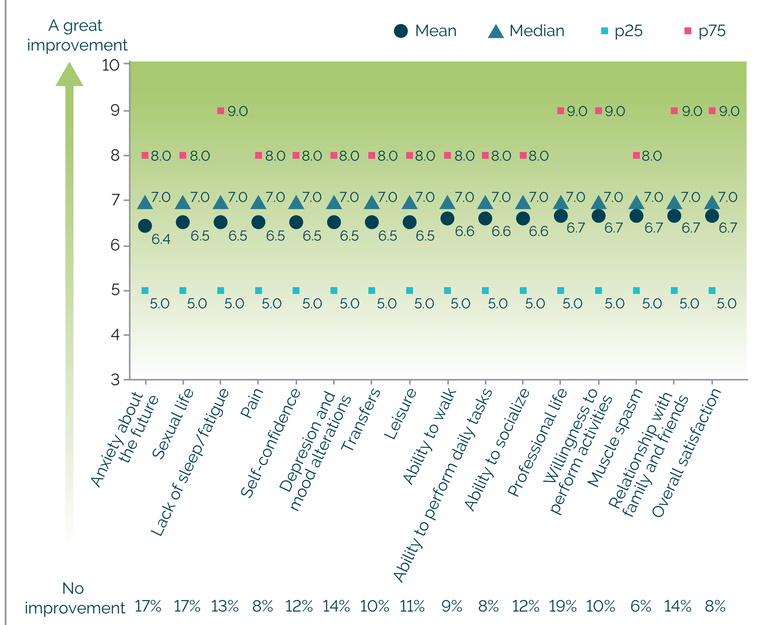
Cost of BoNT-A injections

- At the time of each BoNT-A injection, costs were incurred by 77% (330/427) of patients.
  - The reported costs associated with each BoNT-A injection were >€100 in 57% (188/330) 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)**.

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



Survey question (Likert-scale response): "*Please assess to what extent your current botulinum toxin A injections improve your life.*"
Improvement was rated on a scale of 0–10, where 0 was 'no improvement' and 10 was 'a great improvement'.
BoNT-A, botulinum neurotoxin Type A.

CONCLUSIONS

- Patients with spasticity experience a diverse range of challenges associated 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.

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