

## **Long term follow-up of Cervical Dystonia Patients treated with Botulinum Toxin A – Prof. Dr. A.O. Ceballos-Baumann and Dr. P. Haussermann**

Botulinum toxin (BTX) is nowadays regarded as first choice therapy for cervical dystonia and blepharospasm. It has dramatically improved the quality of life of many patients with focal and segmental dystonias. BTX was introduced in the early 1980s as treatment for focal dystonia. Most studies, however, provided only short term follow-up ranging from months to two years and data on the long term condition of dystonia patients originally treated with BTX is very rare. In cervical dystonia and blepharospasm roughly 75% of patients initially improve, and a response is generally seen within the first week which lasts an average of 12 weeks. Long-term efficacy and safety of BTX is an important question for patients and health care providers.

In this paper we present a summary of a study on 100 patients with cervical dystonia, who started injections with BTX type A 10-12 years ago. Our aim was to evaluate the adherence to the BTX-therapy and establish the reasons for discontinuation of BTX treatment.

100 patients, who received their initial BTX-injections between 1988 and 1992 were either interviewed, when attending a reinjection appointment or contacted by telephone, if they were no longer treated at our clinic. General practitioners, health insurers or local authorities were also asked for assistance in the case of those patients who could not be contacted by phone. Patients still receiving BTX were re-examined and those, who claimed it had no effect or had lost the initial treatment effect with BTX, were re-evaluated.

Six patients could not be contacted and four patients had died in the meantime. Of the remaining 90 patients, 57 are still being treated with BTX (63%) - 32 of them at the initial treatment centre and 25 in other neurological departments. These 25 patients still on BTX in other centres were contacted by telephone.

Before BTX treatment was initiated, 89/100 patients had tried other therapies: Pharmacotherapy was used in 64/100 patients, psychotherapy in 29 /100, surgery (mainly selective neurectomy) in 6/100, physiotherapy in 58/100 and alternative medicine such as acupuncture in 57/100 patients.

Of the 33 patients who stopped taking BTX-injections, 16 remained without further treatment and 17 tried other treatment approaches (pharmacotherapy 8/17, physiotherapy 9/17 and alternative medicine 4/17). Of the 33 patients who stopped BTX-therapy 18 dropped out after only one injection; subsequently, another 15 patients choose not to receive additional injections. Immunoresistance (loss of benefit, due to development of antibodies against BTX) was a problem in three patients. However, the main reason to abstain from further injections were side-effects of the BTX-therapy and travel inconveniences.

Although 34 of the patients reported some sort of adverse reactions on at least one treatment visit, most of these were transient and not severe. The most common adverse reactions reported were weakness of neck muscles (13 patients), mild swallowing difficulties for solid food (12 patients) and general weakness (5 patients). Side effects led eleven patients to discontinue BTX. It is of great interest that six patients with cervical dystonia had spontaneous and lasting improvement. It is difficult to ascertain whether BTX itself influences the natural development of cervical dystonia.

Of further interest is the fact that 18 patients stopped BTX injections after the first treatment session. This may be more compared to other studies on the short term effects of BTX. However, when our 100 patients got their first BTX treatment (Botox, Dysport, - BTX Type B - Neurobloc was not available at that time)), it was still regarded as experimental and had no approval by the German health authorities. This may have prompted more reservation towards BTX and explain the relatively high discontinuation rate after the first treatment session.

To summarise, BTX type A is a safe and effective treatment, leading to sustained relief from symptoms of cervical dystonia. In a parallel study on 100 patients with blepharospasm the results were almost identical. Approximately 70% of patients continued with BTX over more than 10 years and still gained meaningful benefit of BTX-injections.

In conclusion, at least more than 60% patients with common forms of dystonia such a torticollis and blepharospasm still continue with the BTX therapy after more than 10 years.

*Prof. Dr. Andres. O. Ceballos-Baumann is a leading neurologist at the Neurological Clinic in Munich and member of the EDF Medical Advisory Board.*