Prior Authorization & Treatment Delays
National Survey Results on How Federal Requirements Impact Access to Botulinum Toxins

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Even the most well intended policies can have unexpected consequences.

People using botulinum toxins, and the health care providers who treat them, are discovering this truth firsthand due to a Centers for Medicare and Medicaid Services requirement that impacts treatment.

A national survey of nearly 300 patients and health care providers throughout the United States explores how the agency’s requirement for prior authorization before each botulinum toxin treatment is limiting access, creating treatment delays and causing patients to struggle unnecessarily.

The survey was conducted October-December 2020 by The Headache & Migraine Policy Forum in partnership with the Movement Disorders Policy Coalition and the Alliance for Patient Access.
The Centers for Medicare & Medicaid Services Policy

The agency’s requirement comes in response to the steadily growing popularity of botulinum toxins in recent years.

Patients, providers and advocates see increased use of the injectable medications as evidence that diagnostics and treatment options have improved. Increased use of treatment suggests that fewer people are struggling with untreated migraine disease and movement disorders. The Centers for Medicare and Medicaid Services, on the other hand, interpreted the increase as evidence that people were misusing the medication for non-medical, cosmetic purposes. To curb the potential for fraud, the agency began requiring prior authorization before every individual injection.

The agency understandably wants to make the best use of limited health care dollars. But data shows the policy is having the unintended consequence of limiting treatment for patients who need it.

About Botulinum Toxin Treatment

Innovation has spurred new treatment options in recent decades, increasing patients’ hope for an improved quality of life. One such treatment is a botulinum toxin, a biologic medication injected by a health care provider to quell migraine symptoms.

In addition to treating migraine disease, the medication is also used for certain movement disorders, such as dystonia and spasticity, where the body moves or jerks involuntarily. The injection helps relax the muscles, allowing patients to move around more freely while experiencing fewer symptoms. Botulinum toxins are the first-line treatment for cervical dystonia, making them a critical option for people living with the disease.
Key Findings: Patients’ Input

Patients’ survey responses indicated that they are experiencing delays and disruptions to care as a result of the new prior authorization policy.

Patients reported:

- **54%** they had to seek additional visits with their provider
- **29%** they were forced to postpone appointments
- **56%** their condition worsened waiting for therapy

“It creates more work for everyone involved and more suffering for us as patients.”

“My treatment was postponed approximately 2 months and has caused a relapse that will take a long time to recover from.”

“I just live in pain.”

“This new rule causes unnecessary suffering for those of us with chronic migraine.”
Key Findings: Health Care Providers’ Input

Health care providers reported that the new prior authorization rule can be detrimental to patients’ health.

Health care providers reported that:

- **78%** patients who benefit from botulinum toxin injections can’t access them with the new rule.
- **82%** patients have experienced additional headache days or movement challenges waiting for treatment.
- **65%** patients are going to the emergency room because they can’t receive timely treatment.

“Patients are unable to obtain the treatment they require.”

“Patients who have benefited for years are suddenly cut off.”

“It has caused countless patients to become hopeless, angry and socially crippled.”
Health care providers’ survey responses also showed how the Centers for Medicare and Medicaid Services requirement was creating staffing and logistical problems in their clinics.

Survey findings suggest that challenges related to the prior authorization requirement impact clinics of all sizes. Some health care providers reported having one-20 injectors at their clinics, while some providers at larger institutions had well over 100.

61% of providers reported needing an additional 3-15 hours to fill out paperwork.

11% of providers reported needing more than 30 hours to complete the prior authorizations.

69% of providers reported having a backlog of appointments due to this new rule.

“My staff is overwhelmed and demoralized.”

“It’s a huge hassle and bad for patient care.”
Conclusion

Policies have consequences, sometimes unintended ones. National survey results confirm that:

- **Patients** who would otherwise benefit from botulinum toxin treatment are instead facing treatment delays and avoidable, painful symptoms. Their quality of life is diminishing, and they’re losing valuable time making additional visits to their health care provider.

- **Health care providers** are finding it more difficult to provide medically necessary treatment for their patients and to run their clinics efficiently. They are watching both their patients and their staff struggle unnecessarily.

- **The health care system**, meanwhile, is absorbing the added costs inherent in administrative red tape, along with the expense of avoidable ER visits from patients who can no longer control their disease.

To encourage access to treatment for people living with migraine disease, movement disorders and other conditions treated by botulinum toxins, policymakers should consider re-examining the prior authorization requirement in light of its unintended consequences.

Demographics

**Survey Respondents**
- 51% Patients
- 49% Providers

**Providers by Practice Type**
- 59% Academic specialty practice
- 8% Academic general neurology practice
- 23% Private practice specialist
- 10% Private practice general neurology
- 2% Private practice primary care
The Headache & Migraine Policy Forum advances public policies and practices that promote accelerated innovation and improved treatments for persons living with headache disorders and migraine disease.

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