

Parental Evaluation of Botulinum Toxin Therapy in Children with Cerebral Palsy: A Cross-Sectional Study from Western Libya and Its Clinical Implications

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Abstract

Cerebral palsy (CP) is a common childhood motor disorder caused by non-progressive brain injury or malformation during early development, leading to muscle spasticity and coordination problems. This cross-sectional study aims to evaluate parental satisfaction with botulinum toxin type A (BoNT-A) treatment in children with cerebral palsy, focusing on perceived effectiveness and side effects. The study's objectives include collecting demographic and clinical information, assessing parental knowledge of BoNT-A, evaluating treatment outcomes, monitoring side effects, and measuring overall patient satisfaction. The study involved 75 children aged 1 to 5 years, mostly affected by birth-related oxygen deprivation. Data collected from parents showed significant improvements in muscle tone and daily activities following BoNT-A treatment, with most parents expressing positive satisfaction despite some mild side effects. The findings suggest that BoNT-A is a safe and helpful treatment when combined with rehabilitation therapies. This study highlights the importance of educating parents about BoNT-A treatment and emphasizes the need for careful patient selection and follow-up to achieve optimal results. Increasing awareness among healthcare providers and families can improve treatment experiences for children with cerebral palsy.

Keywords. Cerebral Palsy, Botulinum Toxin, Spasticity, Parental Evaluation, Libya.

Introduction

Cerebral Palsy (CP) is defined as a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain [1]. Spasticity, a motor disorder characterized by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks, is one of the most common and disabling symptoms in children with CP, affecting approximately 70% to 80% of them [2,3]. Ineffectively managed spasticity leads to restricted movement, the development of skeletal deformities, and difficulties in daily care, negatively impacting the quality of life for both the child and the entire family [4].

In recent decades, Botulinum Toxin Type A (BoNT-A) has emerged as a fundamental and effective therapeutic intervention for managing focal spasticity in children with CP [5]. BoNT-A works by inhibiting the release of acetylcholine from presynaptic nerve endings at the neuromuscular junction, leading to temporary and localized muscle paralysis, thereby reducing muscle tone [6]. Clinical studies have demonstrated the efficacy of this treatment in improving the range of motion (ROM), facilitating physiotherapy, enhancing upper and lower limb function, and ultimately improving the child's ability to perform daily activities [7,8]. However, the success of any therapeutic intervention, especially in chronic conditions requiring long-term care like CP, is measured not only by objective clinical outcomes but also by the acceptance, satisfaction, and adherence of the primary caregivers, who are usually the parents [9]. Parental evaluation is a crucial factor because it reflects the treatment's impact on the child's and family's daily lives, encompassing aspects such as ease of care, improved sleep, reduced pain, and the ability to dress, which may be more significant to parents than purely motor metrics [10].

The scientific literature, particularly in the Middle East and North Africa (MENA) region, lacks in-depth studies focusing on parental evaluation of the BoNT-A treatment experience and the influence of cultural and social factors on awareness and acceptance [11]. Spasticity in CP results from damage to the upper motor neuron pathways, leading to a loss of inhibitory control over the spinal cord [12]. This dysfunction causes muscle overactivity and increased resistance to passive movement. BoNT-A is an effective local treatment that directly targets hyperactive muscles. Its unique mechanism of action lies in its ability to cleave the SNAP-25 protein, which is essential for the fusion of acetylcholine-containing vesicles with the presynaptic membrane, thereby preventing neurotransmitter release [6]. The treatment effect typically lasts from 3 to 6 months, the period required for the nerve to regenerate the SNAP-25 protein [13].

Numerous systematic reviews have confirmed the efficacy of Botulinum Toxin Type A (BoNT-A) in enhancing functional outcomes among children with cerebral palsy (CP) [7]. Reported improvements encompass several clinically significant domains. One of the most notable benefits is the enhancement of gait, particularly in cases of equinus deformity that arise from spasticity of the calf muscles [14]. In addition, BoNT-A has been shown to increase passive range of motion (PROM), thereby facilitating the effective use of adjunctive interventions such as casting or orthoses [15]. Another important outcome relates to ease of care, which is highly valued by parents; the reduction in spasticity substantially decreases the challenges associated with routine caregiving activities, including diaper changes, dressing, and bathing [16]. Collectively, these

findings underscore the therapeutic value of BoNT-A in improving both functional mobility and quality of life for children with CP and their families.

Parental evaluation of treatment outcomes is vital, as it focuses on Patient-Reported Outcomes (PROs) that traditional clinical measures may not capture [9]. A study by Symons et al. (2006) showed that parents generally consider BoNT-A treatment acceptable for spasticity management and observe improvement in specific functional goals [4]. A qualitative study also indicated that parents particularly value the improvement in the child's and family's quality of life, including reduced pain and improved social interaction [10]. However, the treatment experience can be accompanied by anxiety, particularly concerning the injection procedure and potential side effects [13]. Therefore, a deep understanding of parental knowledge and awareness levels is crucial to ensure treatment adherence and achieve optimal outcomes. Clinical consensus agrees that BoNT-A injections must be part of a comprehensive, multidisciplinary treatment program [12]. Physiotherapy and functional training post-injection are considered essential to maximize the benefit of temporary spasticity relief [7]. Once muscle tone is reduced, the opportunity arises to strengthen antagonist muscles and improve motor patterns through intensive exercises [5]. Recent reviews have confirmed that combining BoNT-A with rehabilitative interventions leads to greater functional improvements compared to monotherapy [7].

Studies on CP and its management in the Middle East and North Africa (MENA) region are relatively scarce compared to Western literature [11]. However, available data suggest that the prevalence of CP in Arabic-speaking countries is approximately 1.8 per 1,000 live births [3]. This region often faces unique challenges related to healthcare resources, the availability of specialized centers, and cultural and social factors that may influence treatment awareness and adherence. Therefore, a study like the one conducted in Libya provides valuable local data that can guide public health programs in the region. The objectives of this study are centered on examining parental perspectives and clinical practices related to the use of Botulinum Toxin Type A (BoNT-A) in pediatric care.

Methods

Study Design

This cross-sectional, offline national survey was conducted to obtain exact and reliable data. The questionnaire included structured questions to identify the knowledge of the effectiveness and side effects of BoNT-A in children with cerebral palsy. The study was conducted in western Libya between December 2024 and May 2025. It consists of 75 cerebral palsy cases that had BoNT-A injections as part of their treatment.

Survey Development and Validation

The study included 32 questions divided into four parts. The first part is demographic data and Information about the child's information (11 questions), the second part is information explained by health care providers regarding the injection (6 questions), the third part is post-injection information (5 questions), and the last part is about the side effects that occur after 2-4 weeks after injection (10 questions). This approach allowed for a comprehensive evaluation of parental satisfaction and clinical factors related to BoNT-A treatment efficacy and side effects.

Data Analysis

To evaluate the results of this study, descriptive statistics have been used to analyze the data and test the hypotheses using Statistical Packages for Social Sciences (SPSS V. 27), which include: Frequency Tables and chi-square test.

Results

Data from 75 parents of children with CP receiving BoNT-A treatment were analyzed. The demographic profile of the participants revealed a relatively stable family environment and a high educational background among the parents. The results indicate that the majority of parents (96%) were literate, with over 60% having a bachelor's degree or higher. This high educational level is a significant factor in understanding treatment complexities.

Table 1. Distribution of Parental Marital Status

Marital Status	Count (n)	Percentage (%)
Lives with both parents	59	78.7
Lives with mother only	10	13.3
Lives with father only	6	8.0

Table 2. Parental Educational Level

Educational Level	Count (n)	Percentage (%)
Higher education	28	37.3
Intermediate education	27	36.0
Bachelor's degree	17	22.7
Illiterate	3	4.0

The clinical profile of the children showed a high prevalence of spasticity-related motor dysfunction (90.7%). The high utilization of physiotherapy (86.7%) before starting BoNT-A treatment aligns with integrated management protocols.

Table 3. Use of Concomitant Interventions Before BoNT-A

Intervention	Yes (%)	No (%)
Physiotherapy	86.7	13.3
Other Medications (e.g., Baclofen)	52.0	48.0

The study evaluated the quality of communication between healthcare providers and parents. While awareness of general safety was exceptionally high (94.7%), significant gaps were found regarding the active ingredient and specific side effects. Statistical analysis showed a significant correlation between parental education and knowledge of adverse effects ($\chi^2 = 7.053$, $p = .008$).

Table 4. Parental Awareness and Knowledge Gaps

Knowledge Area	Aware (%)	Unaware (%)
General Safety of BoNT-A	94.7	5.3
Active Ingredient (Botulinum Toxin)	46.7	53.3
Specific Adverse Effects	58.0	42.0

Initial parental feedback after the injection period (2-4 weeks) was generally positive regarding functional improvements. Regarding adverse effects, the most commonly reported were localized pain at the injection site and temporary muscle weakness, although the majority of parents considered the treatment safe.

Table 5. Parental Evaluation of Post-Injection Improvement

Question	Yes (%)	No (%)
Improvement in the child's condition?	85.3	14.7
Improvement in motor functions?	82.7	17.3

Discussion

The high safety awareness rate of BoNT-A treatment (94.7%) is one of the most significant positive findings of this Libyan cross-sectional study. This indicates broad community acceptance of the therapy, which is vital for the success of any treatment program. This high awareness may be attributed to effective health education efforts by healthcare providers in Western Libya or the accumulated experience of parents sharing positive outcomes. This finding aligns with previous studies confirming that parents generally consider BoNT-A treatment acceptable for spasticity management [4].

Despite the high safety awareness, the study revealed concerning knowledge gaps. The lack of awareness among 53.3% of parents regarding the active ingredient (Botulinum Toxin) and 42.0% regarding specific adverse effects represents a significant challenge. This disparity between general safety awareness and detailed knowledge suggests that communication between the clinician and the patient may be superficial or focused on general reassurance rather than comprehensive education.

Detailed knowledge of potential adverse effects (such as temporary muscle weakness or pain at the injection site) is essential for enabling parents to make informed consent decisions and manage expectations correctly [13]. Furthermore, the statistically significant relationship between education level and knowledge of adverse effects ($p = .008$) necessitates the development of simplified educational materials tailored for parents with varying educational backgrounds, ensuring equity in access to information.

The high rate of physiotherapy uses before BoNT-A (86.7%) underscores parental recognition of the importance of rehabilitative interventions. This finding is consistent with the global clinical consensus that BoNT-A is an adjunctive therapy that must be integrated with intensive physiotherapy [3,7]. The combination of chemical spasticity relief provided by BoNT-A and the active functional training provided by physiotherapy generates a synergistic effect leading to greater and more sustainable functional improvements [5]. The Libyan data suggest that clinical practice in the region adheres to this recommended protocol, enhancing the chances of treatment success.

This study is an important addition to the scarce literature on CP in the MENA region [11]. The fact that the majority of children live with both parents (78.7%) may indicate a strong family support network, a crucial protective factor in managing chronic diseases [9]. The results, indicating that 90.7% of children suffer from spasticity-related motor dysfunction, confirm that spasticity is the predominant clinical symptom in this sample, justifying the treatment strategy employed. Providing local data from Libya contributes to building a regional knowledge base that can help adapt global clinical guidelines to local contexts, including logistical challenges and resource availability.

Strengths and Limitations

The main strength of this study lies in its focus on the parental perspective within a geographical context that is underrepresented in global literature. However, a cross-sectional study cannot establish causality or track long-term outcomes. Furthermore, reliance on parental self-reports may expose the results to recall bias.

Conclusion

The present study underscores both the therapeutic efficacy and the overall parental satisfaction associated with botulinum toxin type A administration in children with cerebral palsy, while simultaneously drawing attention to areas requiring enhanced education and vigilant monitoring to ensure optimal safety and outcomes. The findings indicate that BoNT-A treatment is most frequently administered to young children between the ages of one and five years, predominantly targeting the lower limbs where motor function is significantly impaired. Although parents generally report receiving sufficient information regarding the safety of BoNT-A, their depth of understanding concerning its mechanisms of action and potential side effects remains variable. Physiotherapy emerges as a critical adjunct to treatment, integrated both prior to and following injections, thereby reinforcing the multidisciplinary nature of care. Importantly, most parents perceive BoNT-A therapy as effective and economically appropriate, with minimal regret regarding its use, though many express concern over delays in initiating treatment. While adverse effects are relatively common, they are typically mild; nonetheless, the occurrence of serious complications, such as respiratory difficulties, highlights the necessity for careful clinical observation and ongoing caregiver communication. Collectively, these insights emphasize the importance of early intervention, coordinated multidisciplinary management, and comprehensive parental engagement in maximizing therapeutic benefits for this population.

Conflict of interest. Nil

References

1. Graham HK, Rosenbaum P, Paneth N, Dan B, Lin JP, Damiano DL, et al. Cerebral palsy: the definition and classification of a complex condition. *Nat Rev Neurol*. 2016 Jul;12(7):415-25.
2. Shamsoddini A, Hollisaz MT, Hafezi R. Management of spasticity in children with cerebral palsy. *Iran J Child Neurol*. 2014 Autumn;8(4):1-10.
3. Atia A, Abogrein A, Alssoghaier M, Akroush M, Alsagheer M. Birth Incidence of Cerebral Palsy in Tripoli, Libya: A Population-Based Study. *Khalij-Libya J Dent Med Res*. 2021;5(1):1-5.
4. Symons FJ, Rivard PF, Nugent AC, Tervo RC. Parent evaluation of spasticity treatment in cerebral palsy using botulinum toxin type A. *Arch Phys Med Rehabil*. 2006 Dec;87(12):1618-23.
5. Multani I, Manji J, Hastings-Ison T, Khot A, Graham K. Botulinum toxin in the management of children with cerebral palsy. *Paediatr Neurol*. 2019 Aug;97:3-11.
6. Schroeder AS, Ertl-Wagner B, Britsch S, Schröder JM, Nikolin S, Weis J, et al. Muscle biopsy substantiates long-term MRI alterations one year after a single dose of botulinum toxin injected into the lateral gastrocnemius muscle of healthy volunteers. *Mov Disord*. 2009 Aug 15;24(10):1494-503.
7. Ke M, Wang Y, Chen L. Efficacy of botulinum toxin combined with rehabilitation in children with cerebral palsy: A randomized controlled trial. *Clin Rehabil*. 2024 Jan;38(1):1-10.
8. Lin YC, Chang KH, Lin CY, Wu YY, Wang CH, Chen CL. Evaluating functional outcomes of botulinum toxin type A injection combined with occupational therapy in children with spastic hemiplegic cerebral palsy. *PLoS One*. 2015 Nov 24;10(11):e0142769.
9. Nguyen L, Di Rezze B, Mesterman R, Gorter JW. Effects of botulinum toxin treatment in nonambulatory children and adolescents with cerebral palsy: understanding parents' perspectives. *J Child Neurol*. 2018 Sep;33(10):651-8.
10. Lorin K, Forsberg A. Treatment with botulinum toxin in children with cerebral palsy: a qualitative study of parents' experiences. *Child Care Health Dev*. 2016 Nov;42(6):883-90.
11. Ashqar MMI, Raj NB, Misbach S, Alghamdi MA, Alghamdi AA. Reduction in spasticity following postural management using proper wheelchairs in children with spastic cerebral palsy in Saudi Arabia. *Ann Saudi Med*. 2021 Jul-Aug;41(4):254-60.
12. Sharma A, Gupta P, Khanna D. Physical exercises in combination with botulinum toxin in treating children with cerebral palsy: a literature review. *Cureus*. 2022 Dec;14(12):e32798.
13. Sæther R, Jeglinsky-Kankainen I, Salminen AL. Between anxiety and adaptation: children's and parents' experiences with botulinum toxin treatment in cerebral palsy. *J Clin Med*. 2025 Apr 30;14(9):3164.
14. Thorley M, Lannin N, Cusick A, Novak I, Boyd R. Evaluation of the effects of botulinum toxin A injections when used in non-ambulant children with cerebral palsy. *Dev Med Child Neurol*. 2012 Oct;54(10):912-8.
15. Vidal X, Morral A, Costa L, Tur M. Radial extracorporeal shock wave therapy (rESWT) versus botulinum toxin type A in the treatment of spasticity of the lower limbs in children with cerebral palsy. *J Pediatr Orthop*. 2020 Jul;40(6):e305-10.
16. American Academy of Pediatrics. Safety of botulinum toxin type A for children with cerebral palsy. *Pediatrics*. 2015 Nov;136(5):895-900.