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West Syndrome- From the SLP lens: A Case Series

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ABSTRACT

West syndrome is a rare epileptic encephalopathy of infancy marked by infantile spasms, hypsarrhythmia, and developmental delay. Children with this condition often present with feeding and communication difficulties, requiring multidisciplinary management. The present case series describes children diagnosed with West syndrome, presenting with an associated feeding disorder. Early and targeted SLP intervention significantly enhances feeding safety and supports early communication in children with West syndrome. These findings underscore the importance of integrating speech-language pathology into early multidisciplinary care for this population.

Keywords: West syndrome, speech-language pathology, feeding disorder, early intervention.

INTRODUCTION

West syndrome, a form of epilepsy that affects infants, was first identified by English physician William James West in 1841. (1,2) West syndrome is a rare epilepsy disorder defined by three key features: infantile spasms, abnormal brain wave patterns known as hypsarrhythmia, and a regression or stagnation in psychomotor development. (3) The causes of West syndrome could be either prenatal, perinatal or postnatal. West syndrome represents about 30% of all epilepsy cases occurring in infants. (4,5) This disorder occurs in approximately 2 to 5 out of every 10,000 infants, with a prevalence of about 1 to 2 per 10,000 children by the age of 10. In 90% of cases, the onset occurs within the first year of life. The condition typically peaks between 4 and 7 months of age and shows a male-to-female ratio of 6:4. Spasms generally last between 25 and 32 months, with about 85% of affected children experiencing resolution by the age of 5. However, episodes can occur up to 14 years of age. (6)

Children with West syndrome often experience a high burden of comorbidities—such as cerebral palsy, microcephaly, visual and hearing impairments, and feeding difficulties—which commonly arise as sequelae of perinatal insults.(7) Infants with West syndrome are at a heightened risk of dysphagia, with aspiration being a commonly observed complication in this population.(8) The presence of cerebral palsy, feeding difficulties, hearing impairments and intellectual impairment necessitates evaluation and treatment of speech, language, and feeding disorders by a specialized speech and swallowing therapist, making their involvement essential in the multidisciplinary care team. Several aspects regarding the feeding, speech and language characteristics of children with West syndrome remain unclear and underexplored, indicating the need for further research that considers the wide spectrum of severity

associated with the condition. This case series aims to highlight the role of speech-language pathologists (SLPs) in the assessment and intervention of feeding and language difficulties in children diagnosed with West syndrome.

CASE PRESENTATION

CASE 1:

Case History and Evaluation Findings

A male child, aged 15 months, was referred to the Department of Audiology and Speech Therapy at a paediatric early intervention and rehabilitation centre with primary concerns of age-inappropriate speech and language development, along with feeding difficulties. The child was a diagnosed case of West Syndrome, coexisting with quadriplegic dystonic cerebral palsy. There was no significant familial or prenatal history reported. He was delivered at full term via spontaneous vaginal delivery, with a delayed onset of birth cry, and had a birth weight of approximately 2.9 kg. Postnatally, the child required admission to the neonatal intensive care unit (NICU) for nearly one month, including oxygen support for 18 days. At 8 months of age, he experienced an episode of pneumonia.

Developmental milestones were markedly delayed, with no head or neck control achieved at the time of evaluation. Speech and language developmental milestones were also significantly below age expectations, with cooing first observed at 14 months of age.

Speech, Language, and Swallowing Assessment

Formal language assessment indicated severely delayed receptive and expressive language abilities, corresponding to a developmental language age between 2-3 months. Oral peripheral mechanism examination revealed structurally normal oral anatomy; however, oral musculature exhibited generalized hypotonicity. Notably, lip seal was absent.

Observations of feeding practices revealed that the caregiver routinely fed the child in a fully supine position. The child was maintained on a liquid diet consistent with Levels 0 to 3 of the International Dysphagia Diet Standardisation Initiative (IDDSI). Feeding utensils used included oversized spoons, which were ill-suited for the child's oral dimensions, and feeding was characterized by rapid presentation of successive boluses. These factors contributed to frequent spillage and episodes of coughing during feeding. Clinical signs such as a forward tongue thrust and tonic bite reflex were also observed. According to the caregiver, the child displayed selective eating behaviour, accepting only sweet-tasting foods and expelling other flavours.

Case 2:

Case History and Evaluation Findings

A male child, aged 18 months, presented to the Department of Audiology and Speech Therapy with concerns regarding delayed speech and language development, as well as feeding difficulties. The child had a confirmed diagnosis of West Syndrome. Case history indicated a preterm delivery via full-term lower segment caesarean section (FTLSCS), with an absent birth cry. The child had a low birth weight of 1.6 kg and a documented history of perinatal insult and neonatal hypotonia. He required incubation for 35 days and was placed on ventilator support for 5 days. Notably, on Day 3 of life (DOL3), the child experienced a neonatal seizure associated with hypoglycemia and hypocalcemia.

Neuroimaging findings (MRI) indicated evidence of ischemic injury, with patchy areas of gliosis observed in the bilateral parieto-occipital lobes. At the time of evaluation, the child had not achieved neck control but was noted to make occasional vocalizations. He demonstrated adequate auditory attention and orienting responses to sound

Speech, Language, and Swallowing Assessment

An oral peripheral mechanism (OPM) examination revealed that while the

structural integrity of the oral cavity appeared normal, functional deficits were evident. Generalized hypotonia was present, along with a persistent bite reflex. Feeding was notably impaired; the child was dependent on a liquid diet corresponding to Level 3 of the International Dysphagia Diet Standardisation Initiative (IDDSI) framework due to the absence of chewing skills. Feeding difficulties were further characterized by excessive drooling, poor lip seal, and signs of aspiration—including coughing episodes—particularly during feeds administered in the supine position by the caregiver.

Formal language assessment revealed significant delays across both receptive and expressive domains, with a language age equivalent to 0–6 months. The child demonstrated vocal responses when spoken to, indicating emerging communicative intent.

Intervention Strategies and Outcomes for Case 1 and 2.

The intervention plan comprised three primary goals: (a) enhancement of oromotor strength, (b) facilitation of safe swallowing and feeding skill development, and (c) provision of language stimulation. Oromotor strengthening, attenuation of the tonic bite reflex, and elicitation of mandibular chewing movements were facilitated through a combination of sensory stimulation, targeted oral motor exercises, and the use of therapeutic tools such as chewy tubes. The feeding therapy sessions ranged from 45 minutes to one hour long, weekly once for a period of 4 months.

Caregiver training was an integral component of the intervention. The child's mother was educated and provided with hands-on demonstrations regarding appropriate feeding postures, optimal bolus delivery techniques, and selection of feeding utensils tailored to the child's oral dimensions. These modifications led to the establishment of a safer swallowing pattern and feeding routine, with a notable reduction in aspiration risk, oral spillage, and forward tongue thrusting behaviours.

Furthermore, the case 1 was gradually exposed to a variety of taste profiles—including sweet, salty, mildly sour, and bland flavours—during feeding sessions to improve oral sensory acceptance and reduce food selectivity. As a result of these interventions, the child demonstrated measurable progress by advancing on the International Dysphagia Diet Standardisation Initiative (IDDSI) framework from Levels 0–3 to Level 6 (soft and bite-sized consistency), indicating improved oral intake capabilities and chewing efficiency.

Concurrent language stimulation activities elicited emerging communicative behaviours, including vocalizations, suggesting the initial development of prelinguistic expressive skills.

With respect to case 2, following consistent feeding intervention and caregiver training, the child demonstrated significant progress in oral feeding skills. He began to accept a wider range of food textures and consistencies without signs of aspiration or coughing during meals. Over time, the child advanced from a dependence on liquidized feeds (IDDSI Level 3) to successfully tolerating minced and moist food consistency (IDDSI Level 5), indicating improved oral-motor coordination and bolus control. Additionally, there was a marked improvement in lip seal, which contributed to a noticeable reduction in drooling during feeding sessions.

DISCUSSION

West syndrome is a rare epileptic encephalopathy of infancy, characterized by a clinical trial of infantile spasms, hypsarrhythmia on electroencephalogram (EEG), and developmental delay or regression. The condition typically presents between the first week of life and three years of age, with a peak onset around six months.(1) Common comorbidities associated with West syndrome include global developmental delay or intellectual disability, autism spectrum disorder, cerebral

palsy, as well as visual and auditory impairments. Children with infantile spasms are at increased risk of developing dysphagia, and aspiration is frequently observed in this population. (8) Moreover these children also exhibit delayed speech and language development which is supported by findings in the literature. (4,8) Early identification and management of these comorbidities are crucial for reducing the risk of respiratory infections and for promoting optimal growth and overall quality of life. (9) Consistent with existing literature, both cases in this study presented with feeding difficulties. One child also had a documented history of lower respiratory tract infection, specifically pneumonia, highlighting the need for a comprehensive feeding and swallowing assessment. Based on the evaluation findings, both cases were provisionally diagnosed with feeding disorder and delayed speech and language development secondary to West syndrome. Regular therapeutic intervention led to improved caregiver confidence in conducting safe feeding practices, thereby reducing the risk of aspiration and its associated medical complications. Furthermore, both children demonstrated progress in their oromotor functioning along with the ability to tolerate a wider range of food textures, and showed notable improvements in weight gain.

CONCLUSION

This case series emphasizes the critical role of speech and swallowing therapy in managing feeding and communication difficulties in children with West syndrome. Early, individualized intervention and caregiver training led to improved feeding safety, reduced aspiration risk, and emerging communication skills. These outcomes highlight the importance of integrating speech-language pathology into the multidisciplinary care of this population. Further research with larger cohorts is warranted to establish standardized intervention protocols and long-term outcomes for this unique population.

Declaration by Authors

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