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Research Article

Tethered Cord Syndrome: The Tip of the Iceberg — A Quasi-Experimental Observational Study

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Abstract

Background: Tethered Cord Syndrome (TCS) is an underdiagnosed neurological condition with heterogeneous clinical presentations. Although classically described in pediatric populations, it increasingly affects adults as well, with evolving recognition of occult forms and filum terminale pathology.

Objective: To evaluate clinical outcomes following surgical detethering and explore hidden morbidity associated with delayed diagnosis, conceptualizing TCS as "the tip of the iceberg."

Methods: A quasi-experimental observational study was conducted at a tertiary neurosurgical center. Patients diagnosed with TCS were divided into early surgical intervention and delayed/conservative cohorts. Clinical and functional outcomes were assessed over 12 months.

Results: Early intervention significantly improved neurological and urological outcomes compared to delayed management. Diagnostic delay was associated with irreversible deficits and reduced quality of life, consistent with previously reported literature on chronic tethering injury.

Conclusion: TCS represents a broader clinical spectrum than traditionally appreciated, including occult and adult forms. Early recognition and intervention improve outcomes and reduce long-term morbidity.

Key words. Tethered cord. Congenital anomalies of spine, diastematomyelia, filum terminale,
split cord.

Introduction

Tethered Cord Syndrome (TCS) is a neurological disorder caused by abnormal fixation of the spinal cord, resulting in pathological tension on the conus medullaris during growth and normal spinal movement. Persistent mechanical traction impairs spinal cord metabolism and blood flow, leading to progressive neurological, orthopedic, and urological dysfunction if left untreated1,2. Although TCS is commonly associated with spinal dysraphism in children, it can also occur in adolescents and adults, where clinical presentation is often subtle and diagnosis may be delayed.3

The clinical manifestations of TCS are heterogeneous. Patients may present with lower-extremity weakness, gait disturbance, sensory deficits, chronic back or leg pain, scoliosis, foot deformities, and neurogenic

bladder dysfunction. However, these symptoms frequently develop gradually and may initially appear unrelated, leading to repeated consultations before the underlying spinal pathology is recognized3,4. Delayed diagnosis allows chronic traction to produce progressive ischemia, impaired oxidative metabolism, and irreversible axonal injury, reducing the likelihood of complete neurological recovery after surgery.1

The concept of TCS as the "tip of the iceberg" reflects the discrepancy between visible neurological deficits and the larger burden of occult disease. Overt motor weakness often represents only the advanced stage of spinal cord dysfunction, whereas chronic urinary symptoms, bowel dysfunction, subtle gait abnormalities, musculoskeletal changes, and persistent pain may precede neurological deterioration by several years2,5. Failure to recognize these early manifestations contributes to delayed referral and missed opportunities for timely surgical intervention.

Early surgical detethering has consistently been associated with stabilization or improvement of neurological and urological function, particularly when performed before permanent neuronal injury develops6,7. Nevertheless, uncertainty remains regarding the impact of delayed diagnosis on long-term functional outcomes, especially in patients with occult or atypical presentations.

The present study uses the iceberg model as a conceptual framework to examine the hidden burden of TCS. By comparing patients who underwent early and delayed intervention, we aimed to evaluate how diagnostic timing influences neurological recovery, bladder function, and quality of life. We hypothesized that delayed recognition of subtle clinical manifestations is associated with greater long-term morbidity despite subsequent surgical treatment.

Materials and Methods

Study Design and Setting

This prospective, quasi-experimental observational study was conducted over a 5-year period at a tertiary-care neurosurgical center of PIMS Islamabad, to evaluate the clinical course and outcomes of patients with Tethered Cord Syndrome (TCS). A randomized controlled trial was not considered appropriate because withholding surgery from symptomatic patients would have been ethically unacceptable. Instead, patients were managed according to standard clinical practice, allowing comparison between those who underwent early surgical intervention and those whose treatment was delayed because of late presentation or diagnostic uncertainty.

Duration of study. March 2018 to June 2022

Patient Selection

Sixty-eight patients with a mean age of 14.2 ± 9.6 years were enrolled.

Inclusion criteria

Eligible participants had radiological evidence of spinal cord tethering together with neurological, urological, or orthopedic manifestations consistent with TCS.

Exclusion criteria

Patients with previous spinal surgery, traumatic spinal cord injury, or secondary tethering were excluded to maintain a relatively homogeneous study population.

Clinical Assessment

Baseline evaluation included a detailed neurological examination, assessment of motor and sensory function, musculoskeletal evaluation, and comprehensive urodynamic testing. Health-related quality of life was measured using validated patient-reported outcome instruments. Follow-up assessments were performed at 6 and 12 months after enrollment.

Outcome Measures

The primary outcomes were changes in neurological function, bladder function, and

quality of life. Secondary outcomes included pain relief, improvement in gait, sensory recovery, and postoperative functional independence.

Statistical Analysis

Data was analyzed by SPSS version 21

Continuous variables were presented as mean ± standard deviation, while categorical variables were expressed as frequencies and percentages. Independent-samples t-tests were used to compare continuous variables between study groups, and chi-square tests were applied to categorical outcomes. Multivariate analysis of variance (MANOVA) was performed to adjust for differences in age and baseline disease severity. Statistical significance was defined as $p < 0.05$.

Results

Patient Demographics

A total of 68 patients diagnosed with Tethered Cord Syndrome (TCS) were included in the study. The cohort comprised 38 males (55.9%) and 30 females (44.1%), with a mean age of 14.2 ± 9.6 years, reflecting the predominance of TCS in the pediatric and adolescent population while also including adult patients.

Table 1. Demographic Characteristics of the Study Population (N = 68)

Variable	Value
Total patients	68
Male, n (%)	38 (55.9%)
Female, n (%)	30 (44.1%)
Mean age (years)	14.2 ± 9.6

Clinical Presentation

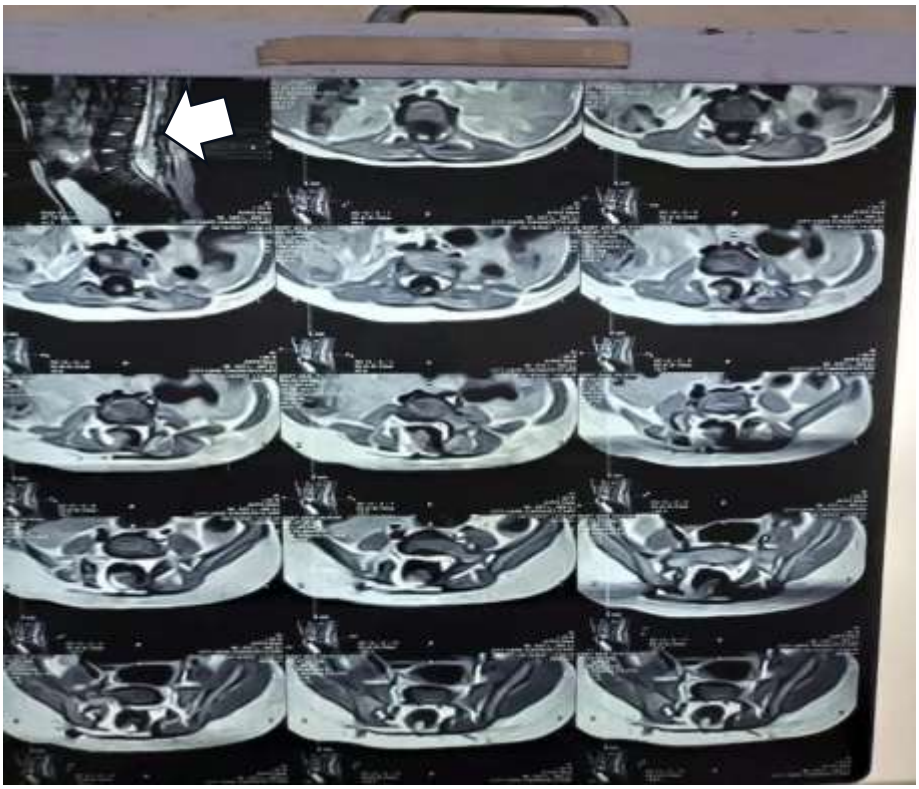
Back pain was the most frequently reported presenting symptom, affecting 76% of patients. Motor weakness was observed in 58%, while bladder dysfunction was present in 49%, underscoring the progressive neurological and urological involvement associated with TCS. Among pediatric patients, cutaneous stigmata suggestive of underlying spinal dysraphism were identified in 35%, orthopedic deformity of feet like club feet and high arch feet, and neuropathic ulceration along with autoamputation of feet was also observed in 1% of cases. Figure 4. And Table 2. Emphasizing the importance of careful physical examination during early clinical assessment.

Table 2. Clinical Presentation of Patients with Tethered Cord Syndrome

Clinical Feature	Patients (%)
Back pain	76
Motor weakness	58
Bladder dysfunction	49
Cutaneous markers*	35
Orthopedic deformity of feet	35

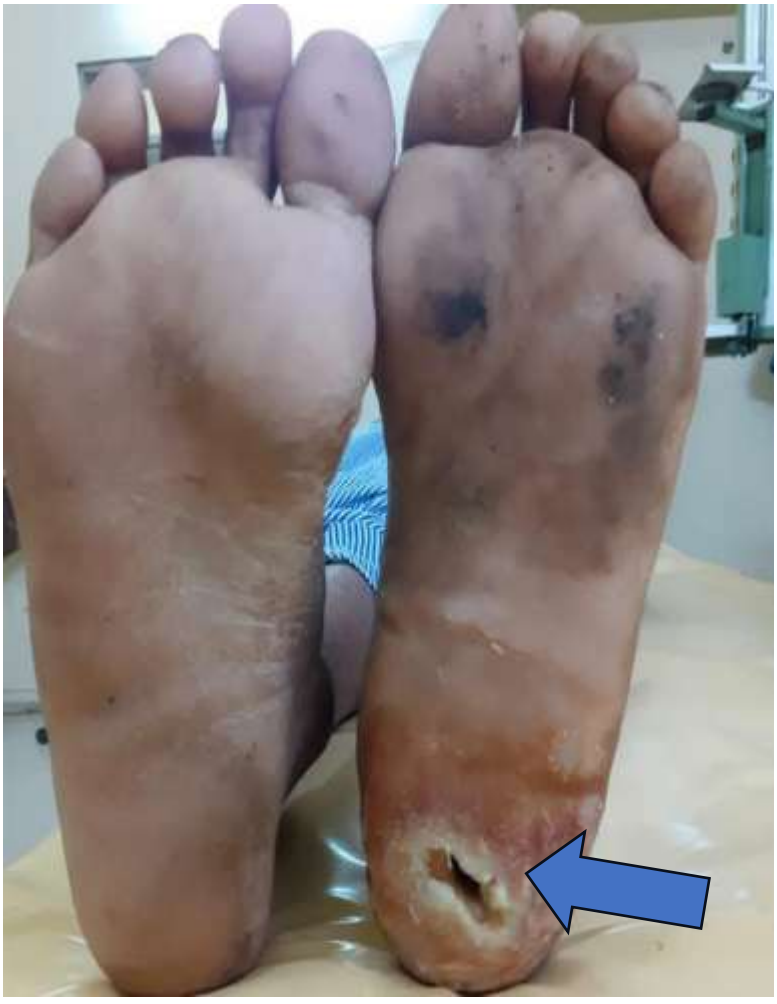
*Cutaneous markers were assessed only in the pediatric subgroup.

Figure 1, MRI Lumbosacral spine revealed (arrow) tethered cord, with bony defect and subcutaneous lipoma and terminal cyst.



Fgure 2, 4 years baby girl, with neuropathic ulcerating wound, and (arrow)autoamputation of 4,5th toes

Figure 3. A,16 years boy with high arch foot, neuropathic ulcerating wound.



NOTE, Figure 1,2,3 are published with consent from patientsDiagnostic Delay

The mean interval between symptom onset and definitive diagnosis was 18.4 months, indicating a substantial delay in recognizing the condition. Furthermore, 41% of patients had consulted two or more healthcare providers before receiving a definitive diagnosis, highlighting the nonspecific clinical presentation of TCS and the challenges associated with its early recognition.

Table 3. Diagnostic Delay

Variable	Value
Mean duration from symptom onset to diagnosis	18.4 months
Patients with ≥2 prior healthcare consultations before diagnosis, n (%)	28 (41.0%)

Baseline Characteristics

The study included 68 patients whose demographic and baseline clinical characteristics were comparable between the early intervention and delayed treatment groups. Forty-one percent of patients had consulted at least three healthcare providers before receiving a definitive diagnosis, reflecting the challenges associated with recognizing the condition during its early stages. Patients in the delayed group also had a longer duration of symptoms before treatment and presented with more advanced neurological and urological impairment.

Neurological Outcomes

Patients who underwent early detethering experienced significantly better neurological recovery than those treated later. Complete or substantial improvement in neurological symptoms was observed in 78% of patients receiving early surgery compared with 22% of those in the delayed group ($p < 0.05$). At 12 months, 82% of patients in the early intervention cohort demonstrated objective improvement in motor strength and sensory function.

Urological Outcomes

Recovery of bladder function followed a similar pattern. Sixty-four percent of patients treated early regained normal or near-normal bladder function, whereas only 19% of patients in the delayed group achieved comparable improvement. Urodynamic studies also demonstrated a 45% increase in bladder compliance and a significant reduction in involuntary detrusor contractions following early surgical detethering.

Quality of Life

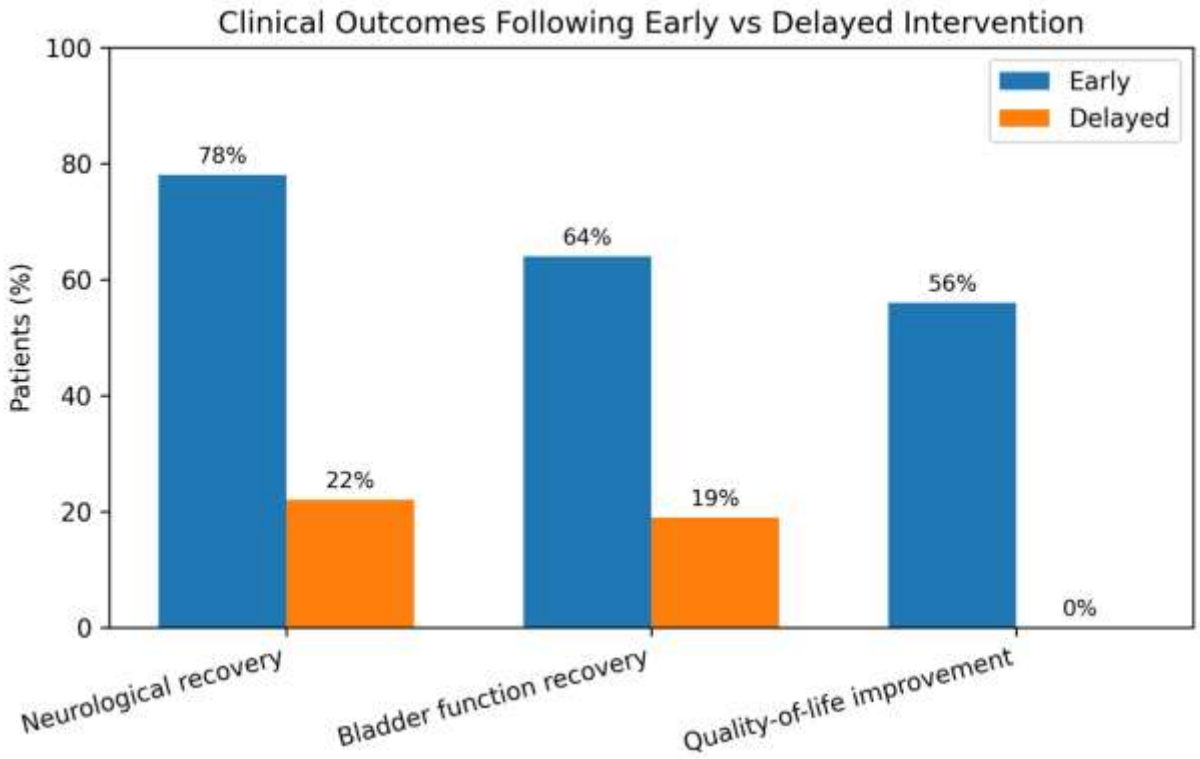
Patients undergoing early intervention reported a 56% improvement in standardized quality-of-life scores during follow-up. In contrast, individuals with delayed treatment continued to experience limitations in mobility, bladder control, and daily activities despite surgery.

Delayed Diagnosis

Delayed diagnosis was associated with substantially worse long-term outcomes.

Patients in this group reported significantly higher levels of chronic pain, psychological distress, and functional dependence. Psychological distress scores were approximately 3.4 times higher than those observed in the early intervention group, highlighting the broader impact of prolonged spinal cord tethering beyond neurological impairment alone. Demographic Characteristics

Figure .4



Discussion

The present study demonstrates that patients who underwent early surgical detethering achieved significantly better neurological, urological, and quality-of-life outcomes than those treated after prolonged symptom duration. These findings are consistent with previous reports showing that chronic spinal cord traction produces progressive metabolic impairment, reduced regional blood flow, and axonal degeneration, changes that become increasingly irreversible with delayed intervention .7,8,9

The iceberg model provides a practical explanation for why diagnosis is frequently delayed. While motor weakness or sensory loss often prompts neurosurgical referral, many patients initially present with isolated urinary symptoms, chronic pain, gait abnormalities, or orthopedic deformities.

These subtle manifestations may not immediately suggest TCS, resulting in prolonged diagnostic pathways involving multiple specialties before the underlying pathology is recognized.10,11 In our cohort, more than two-fifths of patients experienced multiple healthcare encounters before receiving a definitive diagnosis, highlighting the need for greater clinical awareness.

Our findings also support previous evidence that early detethering offers the greatest opportunity to preserve neurological function.12,13 Patients treated soon after diagnosis demonstrated significantly greater recovery in motor function and bladder control than those managed later. Similar observations have been reported in literature, who found that neurological recovery is closely related to symptom duration and preoperative functional status13. Once prolonged traction has produced irreversible neuronal injury, surgery primarily prevents further deterioration rather than restoring normal neurological function.

Neurogenic bladder deserves particular attention because it is often one of the earliest manifestations of TCS but is frequently underestimated.[14] Chronic bladder dysfunction not only affects quality of life but also increases the risk of recurrent urinary tract infections and renal complications16,17. Our findings reinforce previous studies showing that early surgical release improves urodynamic outcomes more consistently than delayed intervention

The study also highlights the importance of multidisciplinary evaluation. Collaboration among pediatricians, neurologists, orthopedic surgeons, urologists, rehabilitation physicians, and neurosurgeons may facilitate earlier recognition of patients with subtle or atypical symptoms. Such an approach could shorten diagnostic delays and reduce the burden of irreversible neurological disability14.

Despite these encouraging findings, the present study has several limitations. The single-center design and relatively small sample size may limit generalizability, while the non-randomized methodology introduces potential selection bias. In addition, follow-up was limited to one year, preventing assessment of long-term neurological outcomes and recurrent tethering. Larger multicenter prospective studies are needed to validate these findings and identify reliable clinical or imaging markers that predict disease progression and surgical response. The study demonstrates that patients with Tethered Cord Syndrome frequently present after a prolonged period of symptoms. Back pain, motor weakness, and bladder dysfunction constituted the predominant clinical manifestations, while diagnostic delay was common, with nearly half of the patients undergoing multiple healthcare consultations before the diagnosis was established. These findings reinforce the concept of TCS as the "tip of the iceberg," where the readily identifiable clinical features represent only a small portion of a broader, often unrecognized disease burden

Clinical Implications

The results emphasize the importance of maintaining a high index of suspicion for TCS in patients presenting with persistent lower-limb weakness, unexplained gait abnormalities, chronic back pain, urinary symptoms, or cutaneous markers of spinal dysraphism. Earlier diagnosis and timely surgical referral have the potential to preserve neurological function and reduce long-term disability.

. **Conclusion**

Tethered Cord Syndrome is a progressive neurological disorder in which much of the disease burden develops before obvious

neurological deficits become apparent. Our findings demonstrate that early diagnosis and timely surgical detethering are associated with superior neurological recovery, improved bladder function, and better quality of life compared with delayed treatment.

The iceberg model provides a practical framework for understanding this hidden burden of disease and highlights the importance of recognizing subtle neurological, urological, and orthopedic symptoms before irreversible spinal cord injury occurs. Improving clinician awareness, strengthening multidisciplinary collaboration, and promoting timely referral pathways may reduce diagnostic delays and improve long-term outcomes for patients with Tethered Cord Syndrome.

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