Post-Thrombotic Syndrome in Children: A Comprehensive Narrative Review

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Abstract
Background and Objective
Post-thrombotic syndrome (PTS) is a chronic, often debilitating consequence of deep vein thrombosis (DVT), characterized by pain, swelling, and venous insufficiency. With paediatric venous thromboembolism (VTE) increasingly being recognized due to improved diagnostics and rising hospital interventions, understanding PTS in this population is critical. This narrative review aims to consolidate current knowledge on the incidence, risk factors, diagnosis, and management of PTS in children, while identifying clinical and research gaps unique to this age group.

Methods
A narrative literature review was conducted from January 15– April 30, 2025, incorporating data from systematic reviews, cohort studies, and guideline papers. Key sources included peer-reviewed studies focused on paediatric thrombosis and PTS, particularly drawing from databases such as PubMed and EMBASE. Articles in English were prioritized, and both retrospective and prospective data were considered.

Key Content and Findings
This review highlights that the incidence of paediatric VTE is increasing, particularly in hospitalized and high-risk groups, with PTS occurring in up to 40% of children and 20% of neonates.

Major risk factors include involvement of multiple vessels, incomplete thrombus resolution, and recurrent DVT. Protective factors identified were regular physical activity, catheter-related DVT, and provoked thrombosis. Diagnostic challenges persist due to limited validation of assessment tools, with the Manco-Johnson instrument being the only validated paediatric-specific tool. Current management emphasizes anticoagulation, physical therapy, and selective use of thrombolysis or stenting in adolescents, though evidence remains limited.

Conclusions
PTS represents a significant, underrecognized burden in paediatric patients with prior DVT. Improved risk stratification, diagnostic criteria, and individualized management protocols are urgently needed. This review calls for multicentre prospective studies to better guide clinical decisions and inform policy for PTS in children.

Introduction
Venous thromboembolism (VTE), which includes deep vein thrombosis (DVT) and pulmonary embolism (PE), is a rising concern in hospitalized children.

Historically viewed as rare in children, the reported incidence of paediatric VTE has steadily increased, particularly in tertiary care and intensive care settings. This trend is largely attributed to heightened clinical awareness and improved diagnostic capabilities.

Among the most concerning long-term complications of DVT is post-thrombotic syndrome (PTS), a condition characterized by venous hypertension that leads to symptoms such as limb pain, chronic swelling, and skin changes. While adult literature on PTS is robust, paediatric data remain sparse. The paediatric population has unique physiological characteristics and risk profiles, necessitating a tailored approach to understanding and managing PTS.

Methods
The literature search strategy is summarized in Table 1.

Epidemiology and Incidence of Paediatric DVT and PTS
Recent studies estimate the annual incidence of VTE in children at 0.07 to 0.49 per 10,000 children, rising to as high as 106 per 10,000 among hospitalized paediatric patients (1). In the Netherlands, 94% of neonatal DVT cases were found to be related to central venous catheters (CVCs), whereas older children exhibited more heterogeneous risk factors (2).

Van Ommen (1) notes that paediatric VTE has been increasing by nearly 10% annually, driven by heightened awareness, more frequent use of central venous lines, and complex comorbid conditions such as cancer and inflammatory bowel disease. Despite being rare compared to adults, the absolute number of paediatric thrombosis cases is growing, making this a critical area for intervention. PTS incidence in children is reported to range widely from 9.5% to 70%, with a mean incidence of 26% based on a systematic review (3). A recent cohort study revealed a 20% incidence in neonates and 40% in older children, underscoring the need for age-specific assessment (2).

Pathophysiology of Post-Thrombotic Syndrome
PTS results from sustained venous hypertension following a thrombotic event. Damage to venous valves caused by thrombosis, either through obstruction or inflammation-induced fibrosis, disrupts normal venous return. This chronic dysfunction results in venous reflux and tissue oedema. In paediatric patients, physiological differences in vascular and coagulation systems

TABLE 1: . Literature search strategy.

Specification	Details
Date of search	January 15– April 30, 2025
Databases and other sources searched	PubMed, EMBASE, Cochrane Library, and reference lists of relevant articles
Search terms used	"post-thrombotic syndrome" OR "PTS" OR "postphlebitic syndrome" AND "children" OR "pediatrics" OR "adolescents" OR "neonates" OR "infants"; MeSH terms: "Postthrombotic Syndrome", "Venous Thrombosis", "Pediatrics"
Timeframe	From January 2000 to April 2025
Inclusion and exclusion criteria	Inclusion: Studies on PTS in children (≤18 years), English language, observational studies, cohort studies, systematic reviews, and relevant clinical guidelines. Exclusion: Case reports, editorials, conference abstracts without full data, adult-only studies
Selection process	Articles were screened by an independent reviewer (pediatric hematology fellow); disagreements were resolved by discussion and consensus with a senior hematologist
Any additional considerations	Preference was given to studies using validated pediatric outcome measures (e.g., Manco-Johnson instrument); data from both high-income and low-to-middle-income countries were included to ensure global relevance

complicate the understanding of PTS development, and age-specific studies are needed to clarify these mechanisms.

Risk Factors and Protective Factors

Several studies identify distinct risk factors for the development of PTS in paediatric patients:

1. Extent of Thrombosis: Involvement of three or more vessels and incomplete thrombus resolution were associated with a significantly increased risk of PTS in both neonates and older children (2).
2. Recurrent DVT: Children with a history of recurrent thrombosis had a higher likelihood of developing PTS.

But also some protective factors were identified such as (2):

1. Exercise (at least three times per week),
2. Catheter-associated DVT, and
3. Provoked thrombosis (e.g., from surgery or infection) .

Clinical Manifestations and Diagnostic Challenges

PTS manifests with limb discomfort, swelling, heaviness, and occasionally skin discoloration or ulceration. In paediatric populations, functional limitations can interfere with play, school attendance, and physical development.

Diagnosis in children remains challenging due to a lack of consensus on assessment tools. Adaptations of adult scales such as the Villalta score have been used as well as the CAPTSure score, but the Manco-Johnson instrument is the only one with validated paediatric data (Figure 1) (3, 4).

Regular clinical evaluations and patient-reported symptom diaries may assist in long-term monitoring.

Impact on Quality of Life

PTS can profoundly affect quality of life, especially in active children and adolescents. Chronic pain, reduced mobility, and cosmetic concerns (such as skin pigmentation or limb asymmetry) can contribute to emotional distress, reduced physical activity, and social withdrawal. Studies show that children with moderate to severe PTS often require long-term follow-up and rehabilitative services, further highlighting the burden on families and healthcare systems (2, 5, 6).

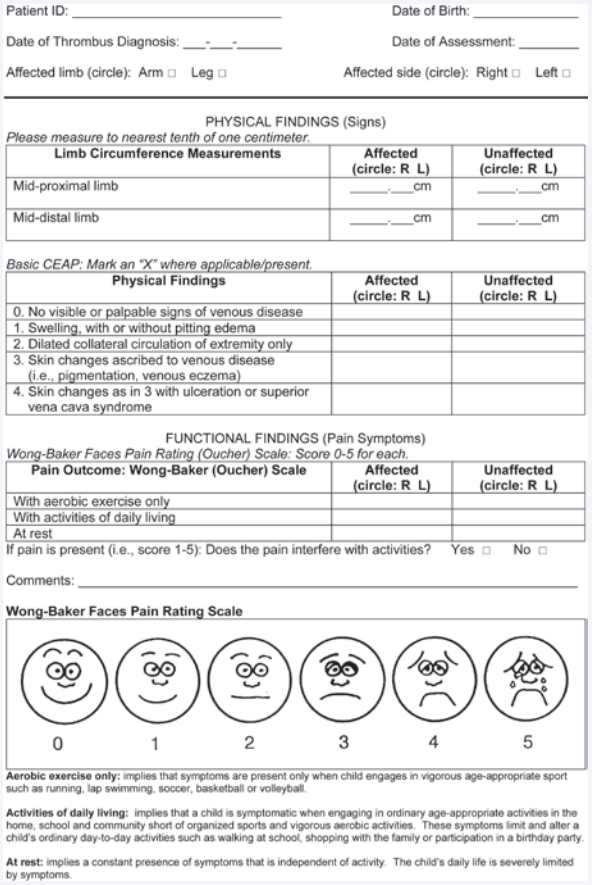
Management Strategies

Current treatment strategies focus on anticoagulation during the acute phase of DVT, aiming to prevent progression and recurrence. However, optimal strategies for preventing or managing PTS remain undefined in paediatrics.

Anticoagulation

Low-molecular-weight heparin (LMWH) remains the cornerstone of anticoagulant therapy and plays an important role in the prevention of PTS by promoting thrombus resolution and reducing DVT recurrence, which may in turn limit venous damage that contributes to PTS. Newer direct oral anticoagulants are being investigated for their safety and efficacy in children. Van Ommen notes that evidence supporting pharmacologic thromboprophylaxis in

FIGURE 1: The Manco-Johnson instrument for paediatric PTS outcome measurement.



Patient ID: _____ Date of Birth: _____

Date of Thrombus Diagnosis: ___-___-_____ Date of Assessment: _____

Affected limb (circle): Arm □ Leg □ Affected side (circle): Right □ Left □

PHYSICAL FINDINGS (Signs)

Please measure to nearest tenth of one centimeter.

Limb Circumference Measurements	Affected (circle: R L)	Unaffected (circle: R L)
Mid-proximal limb	____.___cm	____.___cm
Mid-distal limb	____.___cm	____.___cm

Basic CEAP: Mark an "X" where applicable/present.

Physical Findings	Affected (circle: R L)	Unaffected (circle: R L)
0. No visible or palpable signs of venous disease		
1. Swelling, with or without pitting edema		
2. Dilated collateral circulation of extremity only		
3. Skin changes ascribed to venous disease (i.e., pigmentation, venous eczema)		
4. Skin changes as in 3 with ulceration or superior vena cava syndrome		

FUNCTIONAL FINDINGS (Pain Symptoms)

Wong-Baker Faces Pain Rating (Oucher) Scale: Score 0-5 for each.

Pain Outcome: Wong-Baker (Oucher) Scale	Affected (circle: R L)	Unaffected (circle: R L)
With aerobic exercise only		
With activities of daily living		
At rest		

If pain is present (i.e., score 1-5): Does the pain interfere with activities? Yes □ No □

Comments: _____

Wong-Baker Faces Pain Rating Scale

0 1 2 3 4 5

Aerobic exercise only: implies that symptoms are present only when child engages in vigorous age-appropriate sport such as running, lap swimming, soccer, basketball or volleyball.

Activities of daily living: implies that a child is symptomatic when engaging in ordinary age-appropriate activities in the home, school and community short of organized sports and vigorous aerobic activities. These symptoms limit and alter a child's ordinary day-to-day activities such as walking at school, shopping with the family or participation in a birthday party.

At rest: implies a constant presence of symptoms that is independent of activity. The child's daily life is severely limited by symptoms.

paediatrics remains limited and emphasizes careful balancing of bleeding risk against potential benefit. Importantly, while effective treatment of DVT may reduce the risk of subsequent PTS, prophylaxis aimed solely at preventing DVT does not appear to alter the incidence of PTS once a DVT has occurred (1).

Thrombolysis and Intervention

In selected adolescents with iliofemoral DVT, pharmaco-mechanical thrombectomy and stenting may reduce PTS incidence, though evidence is limited (7).

Compression Therapy

Avila et al. demonstrated that compression gear (CG) was associated with a decrease in post-traumatic stress (PTS) scores in children at follow-up, provided it was worn for at least 8–12 hours per day for three or more days per week, and provided the pressure applied by the CG was relatively low (5).

Physical Therapy and Exercise

Regular physical activity has been shown to reduce PTS risk and improve limb function. Exercise regimens should be age-appropriate and individualized (6, 8).

Multidisciplinary Approaches and Long-Term Monitoring

Effective management of paediatric PTS requires coordinated care involving haematology, vascular medicine, rehabilitation/physiotherapy, nursing, and psychosocial support to address both venous pathology and functional impairment. This multidisciplinary care model should be paired with structured, long-term surveillance, as PTS may evolve slowly over years.

It is recommended that an initial standardised PTS assessment is carried out six months after DVT, followed by annual evaluations (± six months) using validated paediatric PTS tools. For non-neonates, monitoring should continue for at least 5 years, while neonates and children with CVC-associated DVT require extended follow-up for at least 10 years, reflecting the delayed and progressive nature of PTS in younger patients. This longitudinal approach enables early recognition of symptom progression, timely referral to supportive services (e.g., physiotherapy, pain management), and adjustment of interventions to preserve function and quality of life (5).

Research Gaps and Future Directions

There is an urgent need for multicentre trials, standardized outcome definitions, and paediatric-specific interventions.

Significant challenges persist in paediatric PTS research. The lack of standardized diagnostic criteria and outcome measures hampers data comparison across studies. Few randomized controlled trials exist, and many interventions are extrapolated from adult data. Ethical constraints and low incidence rates further complicate trial design. Investment in paediatric-specific studies and long-term cohort tracking is essential.

Further prospective studies and clinical trials are needed to validate diagnostic tools, determine the most effective prevention strategies, and evaluate the long-term outcomes of therapeutic interventions. International registries and multicentre studies will be vital to enhance understanding and optimize care for paediatric PTS. Collaborative networks and standardized treatment pathways may help streamline patient care and improve long-term outcomes.

Conclusion

Postthrombotic syndrome is a significant but often underdiagnosed complication of paediatric DVT. The rise in paediatric thrombosis cases mandates a systematic approach to diagnosis, management, and prevention of PTS. Greater awareness, standardized protocols, age-specific diagnostic tools, and interdisciplinary care models are essential to reduce long-term morbidity and improve quality of life. A multidisciplinary approach is key to effective care.

Statement

The author has no conflicts of interest to disclose relating to the topic discussed in this manuscript.

REFERENCES

1. van Ommen CH. Thromboprophylaxis in Children: Navigating Uncharted Waters. Hamostaseologie. 2025;45(4):302-11.
2. Klaassen I, Sari S, van Ommen H, Rettenbacher E, Fijnvandraat K, Suijker M, et al. Incidence and risk factors for postthrombotic syndrome in neonates and children in a single-center cohort study. Journal of Thrombosis and Haemostasis. 2025;23(1):181-9.
3. Goldenberg NA, Donadini MP, Kahn SR, Crowther M, Kenet G, Nowak-Gottl U, et al. Post-thrombotic syndrome in children: a systematic review of frequency of occurrence, validity of outcome measures, and prognostic factors. Haematologica. 2010;95(11):1952-9.
4. Avila ML, Brandao LR, Williams S, Montoya MI, Stinson J, Kiss A, et al. Development of CAPTSure(TM) - a new index for the assessment of pediatric postthrombotic syndrome. J Thromb Haemost. 2016;14(12):2376-85.
5. Avila L, Amiri N, De R, Vincelli J, Pullenayegum E, Brandao LR. Compression garments for the management of pediatric post-thrombotic syndrome: A prospective longitudinal study. J Thromb Haemost. 2021;19(12):3073-9.
6. Goldenberg NA, Brandao L, Journeycake J, Kahn S, Monagle P, Revel-vilk S, et al. Definition of post-thrombotic syndrome following lower extremity deep venous thrombosis and standardization of outcome measurement in pediatric clinical investigations. J Thromb Haemost. 2012;10(3):477-80.
7. Lombardi M, Glass J, Wasan S, Marston W. Acute iliofemoral deep venous thrombosis in adolescents and young adults is associated with hypercoagulable states and a significant incidence of post-thrombotic syndrome. Journal of Vascular Surgery: Venous and Lymphatic Disorders. 2025;13(4):102211.
8. Avila L, Betensky M, Cohen C, Ahuja S, Goldenberg N, Zia A. Clinical care of pediatric patients with or at risk of postthrombotic syndrome: guidance from the ISTH SSC Subcommittee on pediatric and neonatal thrombosis and hemostasis. J Thromb Haemost. 2024;22(2):365-78.