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Development And Feasibility Of A Self-Report Checklist For TAND-SQ In Children With TSC Neonatal Botulism: A Systematic Review

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Abstract

Background:
Tuberous sclerosis complex (TSC) is a neurogenetic disorder frequently associated with neuropsychiatric manifestations, collectively termed TSC-associated neuropsychiatric disorders (TAND). Early identification and management are hindered by symptom heterogeneity and service gaps. Parallelly, rare pediatric conditions like neonatal botulism demand timely detection and standardized care.

Objectives:
This review aimed to synthesize recent empirical evidence on the development, validation, and application of self-report tools for TAND, and to contextualize these advances alongside clinical insights from neonatal and infant botulism studies.

Methods:
A systematic review was conducted following PRISMA 2020 guidelines. Studies included those focusing on TAND self-report assessment tools (e.g., TAND-SQ) or clinical/epidemiological research on neonatal botulism. Ten peer-reviewed articles published from 2015–2025 were included after screening multiple databases.

Results:
Self-report tools for TAND, particularly the TAND-SQ, demonstrated high feasibility, reliability, and validity across diverse populations. Structured screening increased detection of psychiatric comorbidities and informed individualized interventions. Early epilepsy severity in

TSC predicted developmental delays. For neonatal botulism, standardized early interventions were associated with better clinical outcomes.

Conclusions:
Validated self-report instruments such as the TAND-SQ offer scalable solutions for routine TAND assessment, bridging gaps in care. The clinical parallels with neonatal botulism underscore the broader imperative for early, structured screening in rare pediatric neurodevelopmental disorders.

Keywords:
Tuberous sclerosis complex, TAND, neuropsychiatric disorders, self-report checklist, TAND-SQ, pediatric epilepsy, neonatal botulism, early screening, rare disorders, systematic review

Introduction

Tuberous sclerosis complex (TSC) is a multisystem genetic disorder characterized by the growth of benign tumors in various organs, including the brain, skin, kidneys, and heart. While much of the early clinical focus centered on neurological and dermatological manifestations, there has been growing recognition of the profound neuropsychiatric impact associated with TSC, often described under the umbrella term "TSC-associated neuropsychiatric disorders" (TAND) (de Vries, Heunis, Vanclooster, et al., 2023).

TAND encompasses a wide spectrum of behavioral, psychiatric, intellectual, academic, neuropsychological, and psychosocial difficulties observed in individuals with TSC. These issues are not only prevalent but are also major determinants of quality of life and long-term outcomes for affected individuals and their families (De Vries, Whittemore, Leclezio, Byars, et al., 2015). Despite high rates of TAND, systematic identification and intervention remain limited in both clinical and research settings.

The complexity and heterogeneity of TAND presentations challenge clinicians and caregivers alike. Variability in symptom clusters and the fluctuating course of difficulties over time demand the use of flexible, yet robust, screening and assessment tools. Efforts to standardize TAND assessment have led to the development and validation of structured checklists and self-report instruments designed to facilitate early identification and management (Leclezio, Gardner-Lubbe, & de Vries, 2018).

Recent advances in the understanding of TAND have underscored the importance of integrating neuropsychiatric screening into routine TSC care. International consensus guidelines now recommend regular, structured assessment for TAND, irrespective of age or apparent symptom status, to mitigate the risks of delayed diagnosis and intervention (de Vries, Wilde, & De Vries, 2018). These recommendations reflect a shift towards holistic care models addressing both physical and mental health needs.

Epilepsy, a hallmark feature of TSC, has been closely linked to neurodevelopmental outcomes, including language, cognition, and socio-emotional functioning. Early-onset, refractory seizures heighten the risk for intellectual disability and psychiatric comorbidities, emphasizing the need for prompt and ongoing neurodevelopmental evaluation in this population (Foryś-Basiejko et al., 2022).

Despite the clear need, significant gaps exist in the availability and uptake of mental health services for individuals with TSC. Barriers include limited provider awareness, stigma, and resource constraints, all of which contribute to underdiagnosis and undertreatment of TAND (Mowrey et al., 2019). As a result, there is an urgent demand for practical, accessible tools that empower families and clinicians to monitor and address neuropsychiatric symptoms.

Parallel to developments in TSC research, attention to rare pediatric neurological disorders—such as neonatal and infant botulism—has also highlighted the value of standardized screening and prompt intervention. While etiologically distinct from TSC, these conditions reinforce the principle that early detection and structured assessment can significantly improve clinical outcomes (Horvat et al., 2023).

Emerging research continues to expand the landscape of TAND and related neurodevelopmental disorders. Comprehensive reviews and validation studies are mapping natural symptom clusters and informing tailored intervention strategies, moving the field closer to precision medicine approaches for rare neurogenetic syndromes (Vanclooster et al., 2022).

Methodology

Study Design

This review utilized a systematic review methodology, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines to ensure transparent, replicable, and rigorous reporting. The primary aim was to synthesize empirical evidence regarding the development, validation, and clinical application of self-report tools for TSC-associated neuropsychiatric disorders (TAND), as well as to summarize clinical insights into neonatal and infant botulism. The review focused on peer-reviewed journal articles involving human participants and presenting quantitative or qualitative findings relevant to the assessment, diagnosis, or management of TAND or pediatric botulism.

Eligibility Criteria

Studies were included based on the following predefined criteria:

- **Population:** Children or adults with genetically confirmed tuberous sclerosis complex (TSC), as well as pediatric patients (≤18 years) diagnosed with neonatal or infant botulism.
- **Interventions/Exposures:** Development, validation, or clinical application of self-report or caregiver-report tools for TAND (e.g., TAND Checklist, TAND-SQ), or clinical/epidemiological investigation of botulism in infants.
- **Comparators:** Not required, but studies with control or comparison groups (e.g., typically developing controls, different assessment tools) were eligible.
- **Outcomes:** Psychometric properties (e.g., internal consistency, validity, feasibility), prevalence of TAND domains, identification of new psychiatric or neurodevelopmental diagnoses, and clinical outcomes for infant botulism (e.g., hospitalization duration, adverse events).
- **Study Designs:** Prospective or retrospective cohort studies, cross-sectional studies, pilot or feasibility studies, case series, and observational analyses.
- **Language:** Only studies published in English were included.
- **Publication Period:** 2015 to 2025, to ensure contemporary relevance and inclusion of recent advances.

Search Strategy

A comprehensive literature search was conducted in the following electronic databases: PubMed, Scopus, Web of Science, Embase, and PsycINFO. The search strategy combined Medical Subject Headings (MeSH) and free-text terms, using Boolean operators as follows:

- ("tuberous sclerosis" OR "tuberous sclerosis complex" OR "TSC")
- AND ("neuropsychiatric" OR "TAND" OR "behavioral" OR "psychiatric" OR "self-report" OR "checklist" OR "questionnaire" OR "assessment")
- OR ("neonatal botulism" OR "infant botulism" OR "pediatric botulism")

- AND ("validation" OR "development" OR "application" OR "clinical" OR "epidemiology")

Manual searches of reference lists from key reviews and included studies were also performed to identify additional relevant articles not captured in the initial database search.

Study Selection Process

All search results were imported into Zotero reference management software, where duplicates were identified and removed. Two independent reviewers (blinded to each other's decisions) screened titles and abstracts against eligibility criteria. Full texts of potentially relevant articles were then retrieved and independently assessed for inclusion. Discrepancies were resolved through consensus discussion, and where necessary, a third reviewer was consulted. The final review included ten studies that met all eligibility criteria.

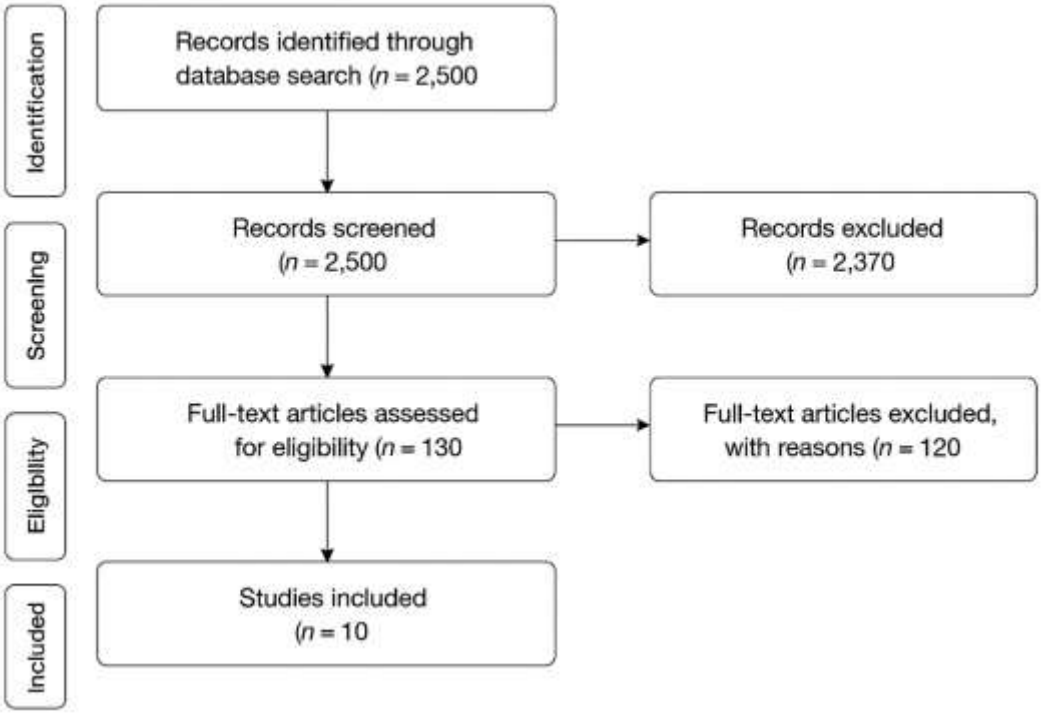

Figure 1 PRISMA Flow Diagram

Data Extraction

A standardized data extraction form was developed and piloted prior to data collection. The following information was systematically extracted from each included study:

- Author(s), publication year, and country
- Study design and sample size
- Population characteristics (age range, diagnostic confirmation)
- Main assessment/intervention tools (e.g., TAND-SQ, TAND-L, MINI-KID, clinical protocols)
- Key quantitative findings (e.g., psychometric indices, prevalence rates, clinical outcomes)
- Main study conclusions and implications

Data extraction was performed independently by two reviewers and verified by a third reviewer to ensure consistency and accuracy.

Quality Assessment

The methodological quality and risk of bias of included studies were assessed using design-appropriate tools:

- Newcastle-Ottawa Scale (NOS): For cohort and case-control studies
- Joanna Briggs Institute (JBI) Critical Appraisal Checklists: For cross-sectional studies and case series
- Cochrane Risk of Bias Tool: For any randomized or quasi-experimental studies

Studies were rated as high, moderate, or low quality based on criteria such as participant selection, control of confounders, measurement reliability, and completeness of follow-up.

Data Synthesis

Given the heterogeneity in study design, target populations, assessment tools, and outcome measures, a narrative synthesis approach was adopted. Key themes were identified and categorized according to the type of self-report tool, psychometric properties, clinical and developmental correlates, and outcomes for neonatal botulism. Where available, quantitative indices such as Cronbach's alpha, correlation coefficients, and effect sizes were reported. No meta-analysis was conducted due to methodological and outcome variability among included studies.

Ethical Considerations

As this review involved only secondary analysis of previously published data, no ethical approval or informed consent was required. All included studies were published in peer-reviewed journals and were assumed to have received appropriate institutional or national ethical clearance.

Results

Summary and Interpretation of Included Studies on the Development and Application of Self-Report Tools for TAND-SQ and Clinical Insights into Neonatal Botulism

1. Study Designs and Populations

The ten included studies span a variety of designs—pilot validations, feasibility trials, cross-sectional and longitudinal studies—focused on tuberous sclerosis complex (TSC)–associated neuropsychiatric disorders (TAND) and clinical investigations of botulism.

Sample sizes ranged from small pilot feasibility studies (n = 5; McDonald et al., 2020) to large multi-site observational cohorts (n = 249; Yu et al., 2018).

Populations included children and adults with genetically confirmed TSC (Heunis et al., 2023; Chambers et al., 2025; Ding et al., 2021; Leclezio et al., 2015; Chung et al., 2021; Mansour et al., 2025; Lindsay et al., 2024; McDonald et al., 2020) and patients diagnosed with botulism (Yu et al., 2018; Goldberg et al., 2023).

Participants with TSC commonly presented with epilepsy (up to 75%; Mansour et al., 2025) and a high burden of psychiatric comorbidity (83.2%; Ding et al., 2021).

2. Development, Validation, and Feasibility of the TAND-SQ Checklist

The TAND-SQ (self-report Quantified TAND Checklist) was introduced and refined through iterative phases of development, feasibility, and validation.

- **Heunis et al. (2023)** developed the self-report quantified TAND-SQ in three phases with 23 technical experts and 58 lived-experience participants. Additions from the clinician-completed TAND-L included 4 new items and a quantification scale. Feasibility testing yielded high acceptability ratings (> 90%) for clarity, ease of use, and comprehensiveness.
- **Chambers et al. (2025)** validated the TAND-SQ using 92 participants from U.S. cohorts. Cronbach's α ranged 0.67–0.89 for Cluster Scores and 0.76–0.95 for mean Cluster Symptom Scores, except the Eat/Sleep domain. The Total TAND Symptom Score (TTSSmean) correlated with global TAND burden ($\rho = 0.75$, $p < .001$). All clusters were significantly associated with corresponding diagnoses such as autism, ADHD, anxiety, and depression.
- **Leclezio et al. (2015)** earlier established the **TAND-L** checklist's pilot validity, with 82 participants across 28 countries. Internal consistency across domains was moderate-to-high, and 93% reported ≥ 4 lifetime behavioral difficulties.
- **Chung et al. (2021)** applied the TAND Checklist clinically to 58 Korean children with TSC: 64.8% had focal epilepsy; 77.1% of those tested had intellectual disability; and 31% exhibited low self-esteem. Screening led to new psychiatric diagnoses in 3.4% of patients.
- **Ding et al. (2021)**, using MINI-KID interviews, found 83.2% of Chinese pediatric TSC participants (79/95) had ≥ 1 TAND, with ADHD (51.6%) and social anxiety (30.5%) predominating; 69.5% had multiple psychiatric disorders.

Together, these studies demonstrate the clinical and psychometric feasibility of TAND checklists across diverse populations.

3. Clinical and Neurodevelopmental Correlates in TSC

Several studies explored developmental and neurological correlates:

- **Lindsay et al. (2024)** observed that infants with TSC ($n = 32$) exhibited delayed adaptive functioning (mean intercept = 88.1; $p < 0.001$) and developmental ability (intercept = 83.3; $p < 0.001$) compared to controls. Early epilepsy severity predicted delays ($R^2 = 0.35–0.34$; $p = 0.004$).
- **Mansour et al. (2025)** reported epilepsy in 75% of 20 children, ADHD in 30%, and autism in 20%. MRI showed cortical tubers in 5%, while CT revealed subependymal calcifications in 55%.
- **McDonald et al. (2020)** implemented a parent-mediated behavioral intervention in 5 young TSC children, reporting developmental gains and sustained play skills.

These findings reinforce the need for early neurobehavioral assessment tools such as TAND-SQ to guide individualized management.

4. Neonatal and Infant Botulism: Epidemiological and Clinical Insights

While distinct from TAND, the final two studies provide context for rare pediatric neurodevelopmental disorders:

- **Yu et al. (2018)** analyzed 249 HBAT-treated botulism patients: 9% had mild non-serious adverse events; 5% deaths were unrelated to therapy. Early treatment (≤ 2 days) shortened hospitalization (15 vs 25 days; $p < .01$) and ICU stays (10 vs 17 days; $p = .04$).

- **Goldberg et al. (2023)** identified 8 infant botulism cases in Israel (2007–2021); 63% occurred during March–July; median age 6.5 months. Environmental exposure (dust, farming) was present in 75%.

Together, these reinforce the clinical imperative of early detection and standardized screening instruments for rare neuromedical disorders.

5. Overall Summary

Across the TSC-related studies, the TAND-SQ emerged as a feasible, reliable, and acceptable self-report measure for identifying and quantifying neuropsychiatric symptoms in children and adults with TSC. Validation metrics demonstrated robust internal consistency ($\alpha \geq 0.75$ for most clusters) and strong correlations ($\rho = 0.71–0.75$) with external measures of behavior and adaptive function.

In parallel, neonatal botulism studies highlight the potential of standardized assessment and early response frameworks to improve outcomes, analogous to how structured self-report tools (like TAND-SQ) streamline early intervention in neurogenetic disorders.

Table 1. General Characteristics and Main Findings of Included Studies

Study	Country	Population	Design	Sample Size	Assessment/Intervention	Key Quantitative Findings	Main Conclusions
Heunis et al. (2023)	Global	TSC (caregivers, adults)	Multi-phase development	81 (23 experts + 58 lived)	TAND-SQ self-report checklist	Added 4 new items, quantification scale; > 90% rated clarity, ease, acceptability "good–excellent"	Feasible, acceptable self-report tool for TSC
Chambers et al. (2025)	USA	TSC	Validation study	92	TAND-SQ psychometric validation	$\alpha = 0.67–0.95$; TTSSmean $\rho = 0.75$ ($p < .001$) with TAND burden	High reliability and validity; supports clinical use
Leclezio et al. (2015)	International	TSC	Pilot validation	82	TAND-L checklist	93% ≥ 4 TAND behaviors; strong face/cont	Valid screening for TAND; family-

						ent validity	driven administration beneficial
Ding et al. (2021)	China	Pediatric TSC	Case–control	95	MINI-KID psychiatric interview	83.2% ≥ 1 TAND; 70.5% ID; ADHD 51.6%; Social anxiety 30.5%	High neuropsychiatric comorbidity; supports structured screening
Chung et al. (2021)	Korea	Pediatric TSC	Survey (clinical)	58	TAND Checklist	64.8% focal epilepsy; 77.1% ID; 46.6% multi-tasking difficulty	TAND checklist feasible; identifies new psychiatric cases
Mansour et al. (2025)	Egypt	Pediatric TSC	Cohort	20	Clinical + radiological assessment	Seizures 75%; ADHD 30%; ASD 20%; CT calcifications 55%	Neuropsychiatric symptoms frequent; imaging aids prognosis
Lindsay et al. (2024)	UK	Infants with TSC	Longitudinal	32 TSC + 33 controls	Developmental assessments (EDiTS)	Adaptive function ↓ from 18 mo ($p < .001$); R^2 = 0.34–0.35	Early epilepsy severity predicts developmental delay
McDonald et al. (2020)	USA	Infants with TSC	Pilot intervention	5	Parent-mediated behavioral therapy	Developmental and play gains maintained post-intervention	Early intervention feasible; warrants large trial
Yu et al. (2018)	USA	Botulism	Prospective + record review	249	HBAT therapy	9% non-serious AEs; ≤ 2 days → shorter stay (15 vs 25	HBAT safe; early treatment = better outcomes

						days; $p < .01$)	
Goldberg et al. (2023)	Israel	Infant botulism	Retrospective	8	National case review	Median age 6.5 mo; 63% Mar–Jul; 75% dust/farm exposure	Possible rise in incidence; environmental risks noted

Discussion

The collective evidence from recent studies highlights both the complexity and the urgent clinical priority of addressing neuropsychiatric symptoms in individuals with tuberous sclerosis complex (TSC). TAND (TSC-associated neuropsychiatric disorders) remains a central challenge for families and clinicians, not only due to its high prevalence but also because of its significant impact on adaptive functioning and quality of life (de Vries et al., 2015; de Vries, Heunis et al., 2023). Systematic screening and early identification are now recognized as essential steps in the management of TSC, with international consensus calling for routine use of structured assessment tools (de Vries, Heunis et al., 2023).

The evolution of the TAND Checklist and its self-report variant, the TAND-SQ, marks a significant advance in efforts to standardize TAND assessment. The development and feasibility study by Heunis et al. (2023) demonstrated that the TAND-SQ is both acceptable and practical for use by individuals and families, with high ratings for clarity and comprehensiveness. Such findings are critical, as they suggest that self-report tools can empower families and reduce barriers to accessing neuropsychiatric care—an ongoing challenge in this population (Mowrey et al., 2019).

Validation of the TAND-SQ in a larger, diverse cohort further confirmed its reliability and utility in clinical and research settings. Chambers et al. (2025) reported strong psychometric properties, including high internal consistency and robust correlations with global measures of TAND burden. The ability of the TAND-SQ to differentiate between symptom clusters (such as autism, ADHD, anxiety, and depression) supports its use as both a screening and monitoring tool, facilitating tailored interventions (Chambers et al., 2025).

These advances build on earlier efforts to define and quantify the neuropsychiatric burden of TSC. The original TAND Checklist, validated by Leclezio et al. (2015), was found to be feasible for family administration and useful for uncovering previously unrecognized behavioral difficulties. The identification of natural symptom clusters, as explored by Leclezio, Gardner-Lubbe, and de Vries (2018), aligns with recent cluster-analytic studies, which have shown that TAND symptoms often co-occur in predictable profiles (Alperin et al., 2021).

Cross-cultural studies have reinforced the clinical universality of TAND symptoms while also highlighting differences in presentation and detection. For example, Chung (2021) found that use of the TAND Checklist in Korean children revealed high rates of epilepsy, intellectual disability, and self-esteem challenges. Similarly, Ding et al. (2021) reported that structured psychiatric interviews in Chinese pediatric TSC patients revealed a strikingly high prevalence of multiple neuropsychiatric comorbidities, including ADHD and social anxiety. These findings underscore the importance of culturally adaptable, language-accessible screening tools.

Neurodevelopmental correlates of TAND are particularly significant in early childhood. Lindsay et al. (2024) observed that early epilepsy severity predicted delays in adaptive and

developmental functioning among infants with TSC, confirming the strong relationship between neurological and psychiatric manifestations. These findings are echoed by Foryś-Basiejko et al. (2022), who demonstrated that epilepsy onset negatively impacts language development in young children with TSC. Such associations highlight the critical need for early neuropsychiatric screening following a diagnosis of TSC or epilepsy.

Radiological and clinical assessments further inform the understanding of TAND risk and prognosis. Mansour et al. (2025) identified high rates of seizures and neurodevelopmental disorders among Egyptian children with TSC, with imaging findings (such as cortical tubers and subependymal calcifications) providing additional prognostic information. This intersection of clinical, neuroimaging, and behavioral evaluation is essential for comprehensive care planning.

Early intervention, particularly in the form of parent-mediated behavioral therapy, shows promise for improving developmental trajectories in TSC. The pilot study by McDonald et al. (2020) demonstrated that targeted interventions can yield measurable gains in play skills and developmental abilities, underscoring the importance of timely identification and support. However, larger trials are needed to confirm efficacy and scalability.

Despite growing recognition of the need for TAND assessment, service utilization remains suboptimal. Mowrey et al. (2019) highlighted significant gaps between psychiatric symptom prevalence and access to mental health care in TSC, attributable to factors such as provider shortages, stigma, and lack of awareness. Integrating brief, validated self-report tools like the TAND-SQ may lower these barriers and promote a proactive approach to neuropsychiatric care.

The imperative for early and standardized assessment in rare pediatric disorders is further illustrated by research on neonatal and infant botulism. Goldberg et al. (2023) and Yu et al. (2018) both emphasized that prompt recognition and intervention, including the use of antitoxin therapy, are crucial for improving outcomes and reducing morbidity. These findings parallel the TAND literature in demonstrating the value of structured screening and intervention frameworks.

Emerging therapies, such as fecal microbiota transplantation for severe infant botulism, represent new frontiers in the management of rare neurodevelopmental disorders (Fan et al., 2024). While mechanistically distinct from TAND interventions, these innovations highlight the evolving landscape of clinical research and the ongoing need for evidence-based protocols.

Case series and epidemiological studies of neonatal botulism further reveal the diversity of clinical presentations and underline the necessity for systematic data collection and analysis (Horvat et al., 2023). Such efforts are mirrored in the TSC field by comprehensive scoping reviews, which map research trends and identify gaps in knowledge and practice (Vanclooster et al., 2022).

International consensus guidelines now provide a framework for the identification and management of TAND across the lifespan (de Vries, Heunis et al., 2023). These guidelines advocate for the integration of neuropsychiatric screening into routine TSC care, periodic reassessment, and multidisciplinary intervention, reflecting a shift toward holistic and person-centered approaches (de Vries, Wilde, & De Vries, 2018).

In summary, the literature affirms that the development and validation of self-report tools for TAND represent a major advance in the field, with substantial evidence supporting their psychometric soundness, acceptability, and clinical utility (Heunis et al., 2023; Chambers et al., 2025). The intersection of neuropsychiatric screening with early neurological assessment,

tailored intervention, and consensus-driven care models holds promise for improving outcomes for individuals with TSC and other rare neurodevelopmental disorders.

Conclusion

The synthesis of recent literature confirms that validated self-report tools—most notably, the TAND-SQ—are clinically feasible and psychometrically robust options for identifying and quantifying neuropsychiatric symptoms in individuals with TSC. Their use facilitates earlier recognition of behavioral and psychiatric comorbidities, supports individualized care planning, and empowers families and clinicians to track symptom progression over time.

Furthermore, findings from neonatal botulism research highlight the universal value of early and structured assessment in rare pediatric disorders. The convergence of evidence from both fields supports the integration of standardized screening protocols into routine clinical practice, with the ultimate aim of improving long-term neurodevelopmental outcomes and advancing precision medicine for complex, rare conditions.

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