

Parent/caregiver experience with a web-based, self-administered TSC-Associated Neuropsychiatric Disorders (TAND) Checklist

Molly Valle, Kira Dies, Mustafa Sahin, Loren Leclezio
Boston University School of Medicine, Boston, Massachusetts

Background: Nearly all children with tuberous sclerosis complex (TSC) will be affected by TSC-Associated Neuropsychiatric Disorders (TAND) over their lifetime (~90%) and their quality of life is greatly impacted by these debilitating disorders. Each child with TSC has a unique TAND profile and many never receive assessment or treatment for their difficulties, as treatment is often focused on the physical manifestations of the disorder. With the evolution of holistic medicine, the approach to treatment has changed, with the narrative focusing on intersecting treatment of both the body and the mind to reach optimal health. The TAND Checklist was developed to minimize the treatment gap, and allow for standardized systematic assessment of children with TSC who may be suffering from behavioral, intellectual and emotional difficulties. Here, we explore parent/caregiver experience using a web-based, self-administered version of the TAND Checklist with the aim of assessing user preference and experience, as well as completeness of the TAND checklist and influence on clinical care. Method: Mixed methods, including grounded theory approach, were used to gather feedback from qualitative interviews from participants after completion of the web-based, self-administered TAND Checklist. Results: Twelve eligible participants completed the TAND Checklist. Qualitative interviews with n=7 participants revealed four central and interrelated themes related to (a) Preference (b) Experience (c) Completeness (d) Further assessment and care Conclusion: The web-based, self-administered checklist could be used as a resource to provide a gateway for intervention and treatment of neuropsychiatric difficulties in children with TSC and to diminish the treatment gap, allowing for earlier identification and management of these difficulties. Incorporating participant feedback, future directions for the TAND Checklist include continuing to allow patients to drive usage and use of the TAND Checklist as an education resource.