

An Assessment of the Cultural Validity of the Parenting Stress Index-Short Form for Caregivers of Autistic Children in South Africa: A Mixed Methods Study

Maame Amoako, BS^{1,2,4}, Marisa Viljoen, B.OT, MSc Me³, Musaddiqah Brown, MA³, Erin Campbell BSc, LLB, MBChB², Katlego Sebolai, MA³, Noleen Seris, MA³, Nokuthula Shabalala, MA, D.Phil³, Sandy Askew, MPH⁴, Elizabeth L Turner BS, MS, PhD⁴, Eric E Monson, PhD⁵, Petrus J de Vries, MBChB, FRCPsych, PhD³, Lauren Franz, MBChB, MPH^{1,2}

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Background: While caregiver coaching can teach caregivers early intervention strategies that they can use with their young autistic child during everyday activities, there is limited access to caregiver coaching in low-resource, culturally and linguistically diverse communities – a significant implementation gap. Because caregivers play a pivotal role in early intervention, it is important that the transactional process by which caregivers can both impact early intervention outcomes and be impacted by the intervention itself be understood. The Autism Caregiver Coaching in Africa (ACACIA) study is a type 1-hybrid effectiveness-implementation trial in South Africa. We hypothesize that caregiver stress will be mitigated through caregiver coaching, but the response may be affected by contextual factors such as poverty, limited resources, and limited social support, and that some questions used to measure caregiver stress may require contextual or linguistic adaptation.

Methods: We utilize a mixed methods approach, collecting quantitative data on caregiver stress by administering the Parenting Stress Index-Short Form (PSI-SF) pre-and-post 12, 1-hour caregiver coaching sessions in caregivers participating in a coaching intervention. Quantitative data was reviewed through team discussion, data visualization, and descriptive statistics to understand the trajectories for each dyad from T0 to T1, evaluate the change in perceived stress reported through each subscale of the PSI-SF, and identify questions that may require contextual adaptation. We utilize a think-aloud method of cognitive interviewing with probes to explore potentially problematic PSI-SF questions (n=10) with an additional 10 caregivers enrolled in the coaching intervention. Qualitative data is analyzed using directed content analysis with two independent reviewers.

Results: Pre and post-intervention trajectories for the Difficult Child (DC) subscale raw scores demonstrated decreased perceptions of stress in the intervention group compared to the control group ($p=.008$ with Wilcoxon Signed Rank Test). The Parenting Distress (PD) subscale, Parent-Child Dysfunctional Interaction (PCDI) subscale, and Defensive Responding subscale trajectories of perceived stress did not align with our hypothesis of decreased post-intervention levels of stress. We therefore sought to understand these inconsistencies through our cognitive interviews. We define 3 constructs including Response Affect (containing Diplomacy of Response), Understanding of the Text, and Cultural Applicability.

Conclusions: We discuss the emergence of each construct in the context of each interview item. Dependency of Response emerged spontaneously as a relevant contextual factor. Response Affect, Diplomacy of Response, and Understanding of the Text constructs emerge significantly throughout each interview item selected. Cultural Applicability is less prevalent, reflecting the difficulty in the subjective interpretation of responses influenced by culture independently. Our research reflects the importance of cultural, contextual, and linguistic considerations in quantitative research, highlighting that the PSI-SF requires contextual adaptation for caregivers in South Africa.