

# Assessing the Cultural Validity of the Parenting Stress Index-Short Form for Caregivers of Autistic Children in South Africa

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## Background

Globally, there is increased emphasis on strengthening caregiver capacity to support their young autistic children. The ACACIA Study is a type 1 hybrid effectiveness-implementation trial testing a Naturalistic Developmental Behavioral Intervention in South Africa. It is informed by 'Help is in Your Hands' online materials, featuring key components of the Early Start Denver Model (ESDM). The Parenting Stress Index-Short Form (PSI-SF) is used to assess the efficacy of these interventions in mitigating caregiver stress. Researchers across the globe have utilized confirmatory and exploratory factor analysis, a quantitative measure, to validate the PSI-SF. **There has been no validation of the PSI-SF to effectively measure stress for caregivers in South Africa, and to our knowledge, the tool has not yet been validated using qualitative or mixed methods approaches.**

## Objectives & Hypothesis

**Objective:** To assess the effectiveness of the PSI-SF in measuring stress for South African caregivers through descriptive statistics and cognitive interviewing.

**Hypothesis:** PSI-SF questions may need contextual and cultural adaptation for South African caregivers.

## Methods

**Design and Setting:** This is a mixed methods study. Caregiver coaching takes place in the Western Cape Education Department schools by early childhood development practitioners.

**Recruitment and Participants:** PSI-SF was distributed to caregivers from 04/2023-10/2023 (n=25). Cognitive interviews were done with a different group caregivers in 03/2024 in Cape Town (n=10).

**Measures:** PSI-SF: Administered at baseline (T0) and follow-up (T1) to 25 caregivers receiving 12 one-hour coaching sessions (intervention) and a control group. Rated on a 5-point Likert scale, it includes 36 items across three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC).

**Cognitive interviews:** Questions from the PSI-SF were identified for further exploration in cognitive interviews (Table 1) utilizing interview probes (Table 2). The following domains were created by study team to guide analysis:

*Understanding of the text:* How did the caregiver understand the words or phrases used in the statement? *Attitudes toward the question:* Did caregiver express any emotions when responding to the statement? *Diplomacy of response:* Did the caregiver's response on to the survey item reflect the thoughts they shared?

**Data Analysis:** Quantitative data from the PSI-SF was analyzed using descriptive statistics. Rapid qualitative analysis was utilized for interview interpretation, with predefined domains. Summary analyses were then condensed into a summary matrix to highlight the domains that were identified for each interview statement. Summaries were reviewed and verified by two independent study team members.

## Results

These figures help us to assess the impact of coaching in intervention group in comparison to the control group who did not receive caregiver coaching and assess the strength of the PSI-SF in evaluating stress, **with the assumption that caregiver stress should be mitigated through coaching. Blue lines indicate decreased stress from To-T1; Orange lines indicate increased stress.**

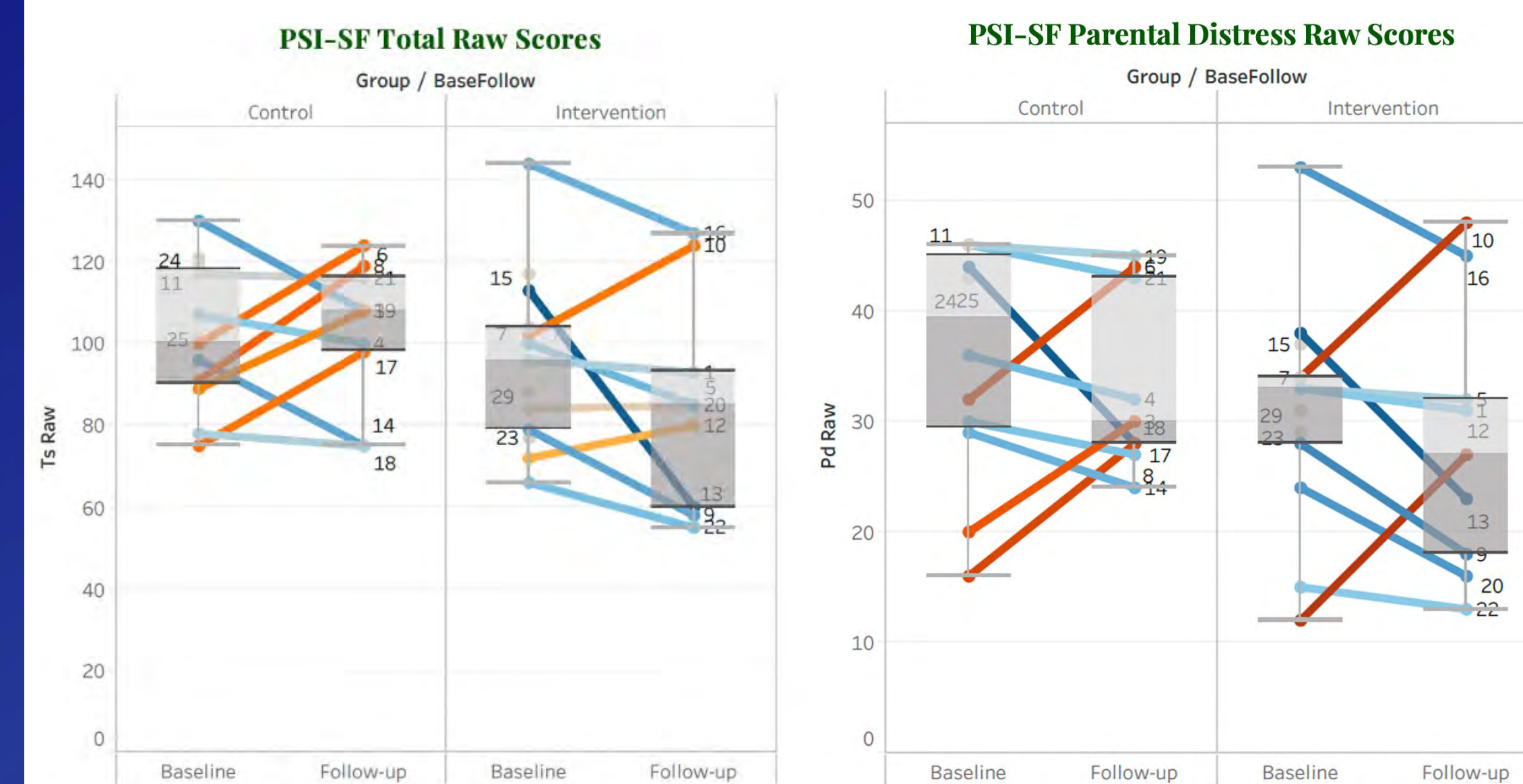


Figure 1. Total Score Raw Score for individual caregiver dyads from baseline to follow-up for intervention group and control group independently.

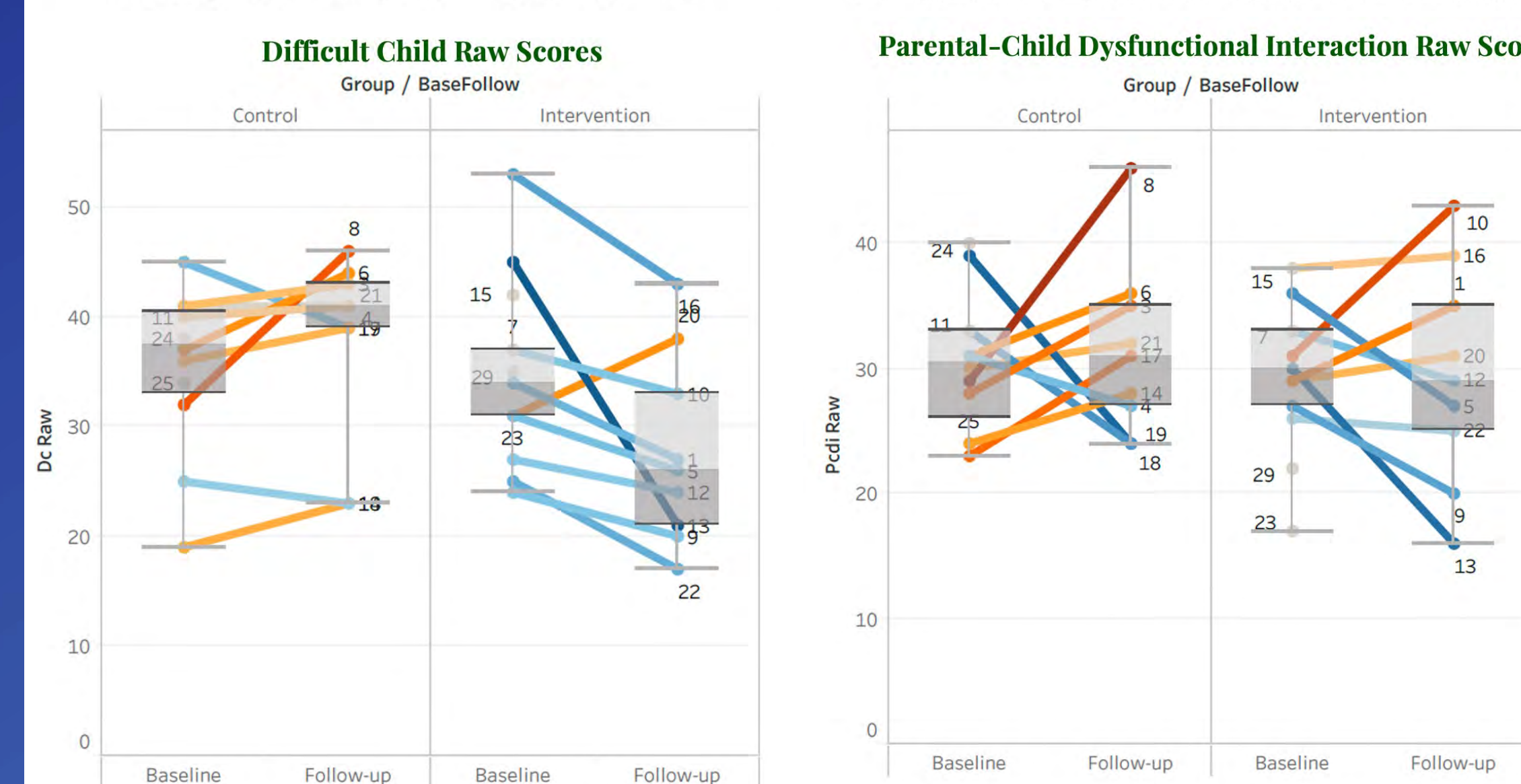


Figure 2. Parental Distress subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control group independently.

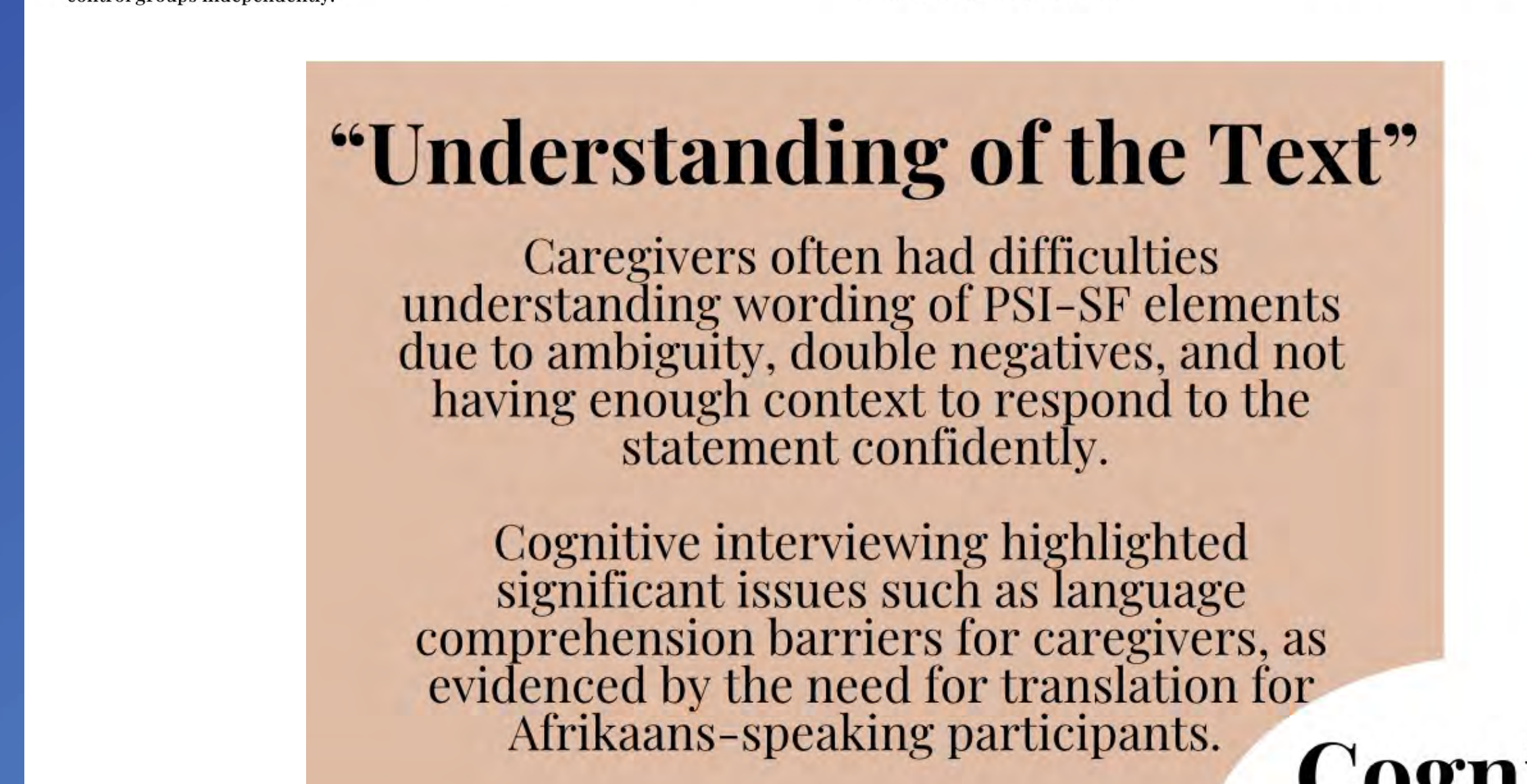


Figure 3. Difficult Child Raw Scores. Difficult Child subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control group independently.

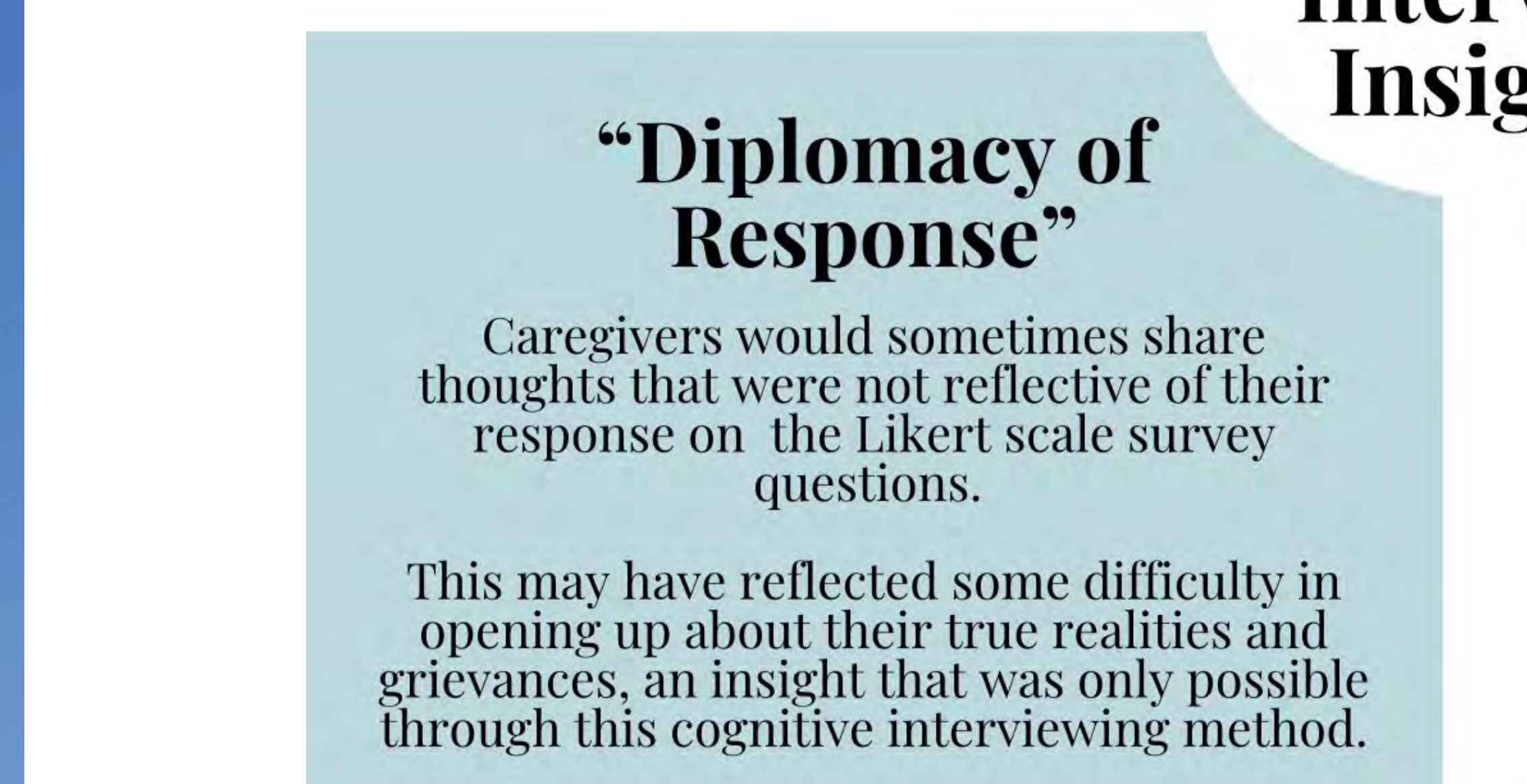


Figure 4. Parent-Child Dysfunctional Interaction subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control group independently.

Table 1. Potentially difficult PSI-SF questions for cognitive interviews

Subscale	Item
Parental Distress Subscale	1. I often have the feeling that I cannot handle things very well
	7. There are quite a few things that bother me about my life
	9. I feel alone and without friends
Parent-Child Dysfunctional Interaction Subscale	10. When I go to a party, I usually expect not to enjoy myself
	13. My child rarely does things for me that make me feel good
	14. When I do things for my child, I get the feeling that my efforts are not appreciated very much
	16. Sometimes I feel like my child doesn't like me and doesn't want to be close to me
Difficult Child Subscale	23. I expected to have closer and warmer feelings for my child than I do, and this bothers me
	25. My child seems to cry or fuss more often than most children
	33. Think carefully and count the number of things your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.,... ((1-3), (4-5), (6-7), (8-9), (10+))

Table 2. Probes for cognitive interviews

- Do you feel like you have a good understanding of the question?
- Can you repeat this question in your own words?
- What emotion does this question elicit for you?
- Can you tell us more about your answer?
- Did you think about any other answers when answering this question?

## Discussion

Caregiver responses revealed space for contextual adaptation of the PSI-SF across the domains Understanding of the Text, Attitudes Towards the Question, Diplomacy of Response. Dependency of Response emerged as a relevant domain, as caregivers often noted that their responses depended on circumstances and could vary depending on the situation.

This is the first study to utilize a mixed methods approach of assessing survey data and subsequently conducting cognitive interviews to gauge whether the PSI-SF is adequately assessing stress for caregivers in a specific cultural context. This study allowed for a **better understanding of the experiences and stressors of caregivers with autistic children in South Africa and the areas of difficulty in responding to the PSI-SF.** Cognitive interviewing offers an impactful way of highlighting statements or questionnaire items that may be perceived with difficulty, and adjust them to better fit the population, therefore being a better outcome measure.

## Conclusion

Adapting the PSI-SF for South African caregivers requires a nuanced approach to capture accurate perceptions of stress, **through the incorporation of qualitative analysis of caregiver narratives and involving caregivers in tool adaptation.** Future efforts aim to utilize insights from this study to enhance the PSI-SF for our study population.

## Acknowledgments

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### “Understanding of the Text”

Caregivers often had difficulties understanding wording of PSI-SF elements due to ambiguity, double negatives, and not having enough context to respond to the statement confidently.

Cognitive interviewing highlighted significant issues such as language comprehension barriers for caregivers, as evidenced by the need for translation for Afrikaans-speaking participants.

### “Attitudes Towards the Question”

Caregivers often expressed feelings of sadness, inadequacy in caregiving, and feelings of being overwhelmed.

Although we cannot conclude whether these physical and verbal expressions of emotion altered response choices but was a valuable component of performing cognitive interviews to really understand caregiver perspectives

### Cognitive Interview Insights

#### “Diplomacy of Response”

Caregivers would sometimes share thoughts that were not reflective of their response on the Likert scale survey questions.

This may have reflected some difficulty in opening up about their true realities and grievances, an insight that was only possible through this cognitive interviewing method.

#### “Dependency of Response”

A new domain emerged as caregivers would often share that their response depended on factors not clear in the survey item.

It also highlighted broader challenges related to the clarity and cultural relevance of survey statements.