

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

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## Background

Autistic children with a wide spectrum of abilities, thoughts, and behaviors create fulfilling experiences for themselves, their caregivers, and their families. However, caregivers may experience emotional distress in response to a child's difficulty in engaging socially with the world.

Globally, there is increased emphasis on strengthening caregiver capacity to support their young autistic child. The Autism Caregiver Coaching in Africa (ACACIA) study is a type 1-hybrid effectiveness-implementation trial that aims to test the effectiveness of a cascaded task-sharing naturalistic developmental behavioral intervention (NDBI) in South Africa. The caregiver coaching intervention approach used in the ACACIA study is informed by 'Help is in Your Hands' online materials, which include core components of the Early Start Denver Model (ESDM). **Measures to assess the impacts of caregiver coaching interventions, such as the Parenting Stress Index- Short Form (PSI-SF), have not been validated on a global scale.**

## Objectives & Hypothesis

We seek to evaluate PSI-SF responses from caregivers of autistic children in South Africa to analyze the validity of this tool in measuring stress in our population through cognitive interviewing.

**We hypothesize that caregiver stress will be mitigated through direct, personalized, and accessible caregiver coaching. We further hypothesize that some questions used to measure caregiver stress may require contextual and cultural adaptation.**

## Methods

### Design and Setting

Caregivers are part of our NIMH/Fogarty-funded R01 in South Africa, a multicultural, multilingual country impacted by stark health disparities. Coaching occurs in the Western Cape Education Department schools by early childhood development practitioners.

### Recruitment and Participants

Participants are randomized to intervention and control following a baseline assessment.

### Measures

The PSI-SF is administered at baseline (To) and follow-up (T1) to caregivers (n=25) that receive 12 1-hour coaching sessions (intervention) and to the control group. Each item is rated on a 5-point Likert. It includes three subscales with 12 items each: Parental Distress (PD) subscale, Parent-Child Dysfunctional Interaction (P-CDI) subscale, and the Difficult Child (DC) subscale. We also administer a demographics survey at baseline.

### Data Analysis

Quantitative data from the PSI-SF is analyzed using descriptive statistics. We visualized within group differences to create box plots with connected dot-plot overlay for individual dyads to compare baseline to follow-up assessment raw scores for the control group and the intervention groups independently (Figures 1-4). The non-parametric Wilcoxon signed rank test for paired samples is used to compare group medians of the following scores between the baseline and post intervention time points.

### Cognitive Interviewing

Through data visualization and team discussions, questions from the PSI-SF have been identified for further exploration in cognitive interviews.

## 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 through a cultural context. **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.

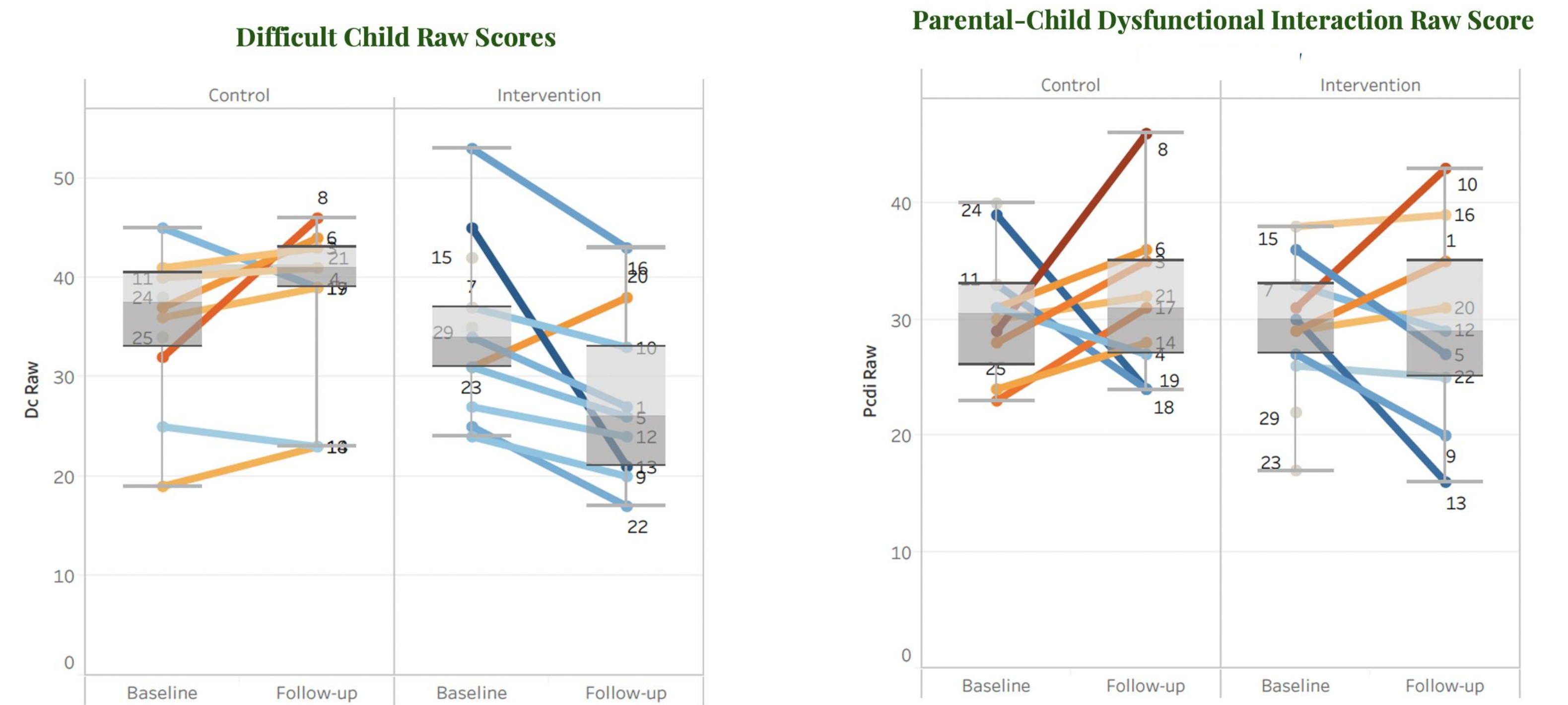


Figure 2. Parental Distress subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control independently.

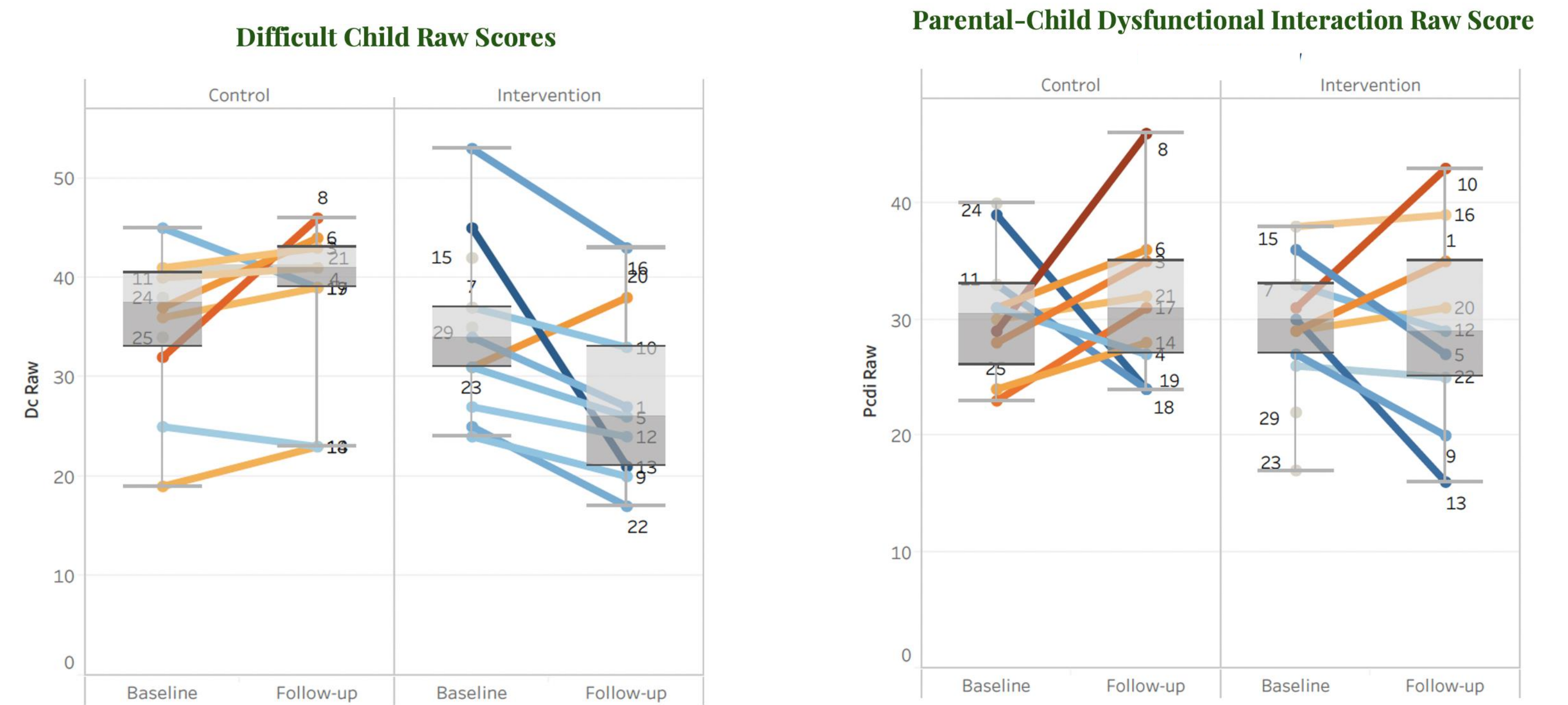


Figure 3. Difficult Child subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control groups independently.

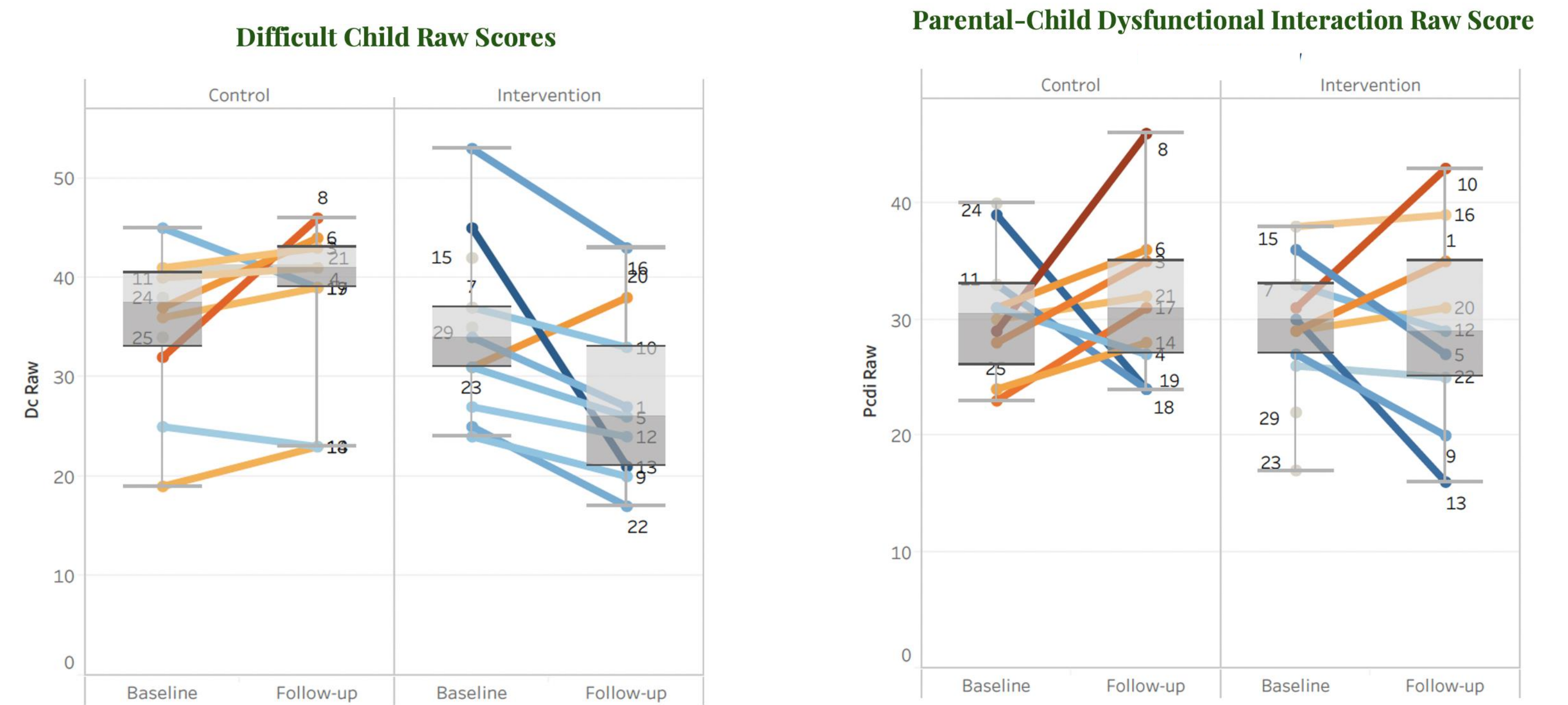


Figure 4. Parent-Child Dysfunctional Interaction subscale raw scores for individual caregiver dyads from baseline to follow-up for intervention group and control group independently.

Table 1. Comparisons between PSI-SF total and subscale scores in intervention and control

Assessment	Intervention (n=9)	Control (n=9)	Between group comparison of change scores	p-value
Total Score Raw Score				
Wilcoxon Signed Rank	W = -10.5	W = 5.5	72.0	0.25
p-value	p = 0.25	p = 0.57		
Parental Distress Raw Score				
Wilcoxon Signed Rank	W = -7.0	W = -1.5	82.5	0.81
p-value	p = 0.46	p = 0.89		
Parent-Child Dysfunctional Interaction Raw Score				
Wilcoxon Signed Rank	W = -5.0	W = 5.0	75.5	0.4
p-value	p = 0.59	p = 0.59		
Difficult Child Raw Score				
Wilcoxon Signed Rank	W = -17.0	W = 9.5	56.5	0.008
p-value	p = 0.04	p = 0.21		

Table 2. Demographic data

Characteristic	ACACIA Intervention No. (%) or mean ± SD (n=33)	Wait-list Control No. (%) or mean ± SD (n=12)
Child physical sex at birth		
Male	12 (36%)	12 (100%)
Female	1 (3%)	0 (0%)
Child's ethnicity		
Coloured	7 (54%)	8 (67%)
African	5 (38%)	4 (33%)
Other	1 (8%)	0 (0%)
Child's home language		
English	11 (85%)	10 (83%)
isiXhosa	0 (0%)	2 (17%)
Afrikaans	1 (8%)	0 (0%)
isiZulu	1 (8%)	0 (0%)
Primary caregiver's ethnicity		
Coloured	6 (60%)	6 (50%)
African	5 (50%)	4 (33%)
White	1 (8%)	2 (17%)
Other	1 (8%)	0 (0%)
Primary caregiver's marital status		
Married	10 (77%)	6 (50%)
Single	1 (8%)	4 (33%)
Partner	2 (15%)	2 (17%)
What is your family's total household income per month?		
Less than R4500 per month	1 (8%)	2 (17%)
Between R4 501 and R52 000 per month	7 (54%)	8 (67%)
More than R52 001 per month	0 (0%)	1 (8%)
Unreported	4 (31%)	1 (8%)
When you think of the total income of your family, do you consider your family to be		
Struggling or just getting by	5 (15%)	7 (58%)
Doing okay or managing well	6 (18%)	5 (42%)

\* Coloured: refers to members of multiracial ethnic communities in South Africa who may have ancestry from African, European, and Asian people.  
 \*\* "Other ethnicity" refers to children and caregivers of mixed race

## Acknowledgments

I would like to thank the Duke University School of Medicine for providing funding for this project through the Bernard J. Carroll Scholarship in Psychiatry, and to the NIMH/Fogarty funded R01 in South Africa (R01MH127573 (LF)(PJF)).



## Next Steps Related to Cognitive Interviewing

The tables below highlight the next portion of our project: the cognitive interview. **We will utilize interview probes (Table 3) to help guide participants in thinking through and verbalizing responses to questions from the PSI-SF.** This process will help us understand the cultural or linguistic factors that guide responses to specific survey questions. **We have selected questions (Table 4) from the PSI-SF through thorough visual inspection of the trajectories from control and intervention group for each subscale within the PSI-SF, in combination with team discussion regarding PSI-SF questions that participants may find confusing or unclear.**

Table 3. Interview probes for cognitive interviews

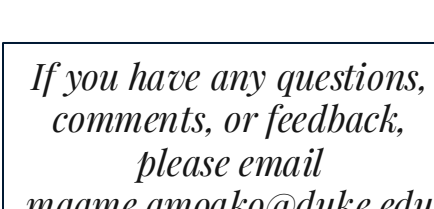
- Do you feel like you have a good understanding of the question?
- Can you repeat this question in your own words?
- What emotion does this question elicit for you?
- Can you tell us more about your answer?
- Did you think about any difference answers when answering this question?

Table 4. Potentially difficult questions to be used in cognitive interviews

- Parental Distress Subscale
- I often have the feeling that I cannot handle things very well
  - There are quite a few things that bother me about my life
  - I feel alone and without friends
  - When I go to a party, I usually expect not to enjoy myself
- Parent-Child Dysfunctional Interaction Subscale
- My child rarely does things for me that make me feel good
  - When I do things for my child, I get the feeling that my efforts are not appreciated very much
  - Sometimes I feel like my child doesn't like me and doesn't want to be close to me
  - I expected to have closer and warmer feelings for my child than I do, and this bothers me
- Difficult Child Subscale
- My child seems to cry or fuss more often than most children
  - 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+))

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