Evaluating computerized assessment of cognition in Down syndrome with caregiver administration

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Introduction

- Down syndrome (DS) is the most common chromosomal cause of intellectual disability, affecting approximately 1 in 707 live births per year (Mai et al., 2019).
- Pharmaceutical and behavioral interventions targeting cognitive skills in DS are increasing, however, a lack of rigorous outcome measures is a critical problem for interpreting findings (Esbensen et al., 2017).
- A critical step in improving cognitive outcome assessments for children with DS is to select measures that are informed by the DS neurobehavioral phenotype. Strategies include selecting measures that are appropriate for the developmental level of individuals with DS, as well as employing nonverbal assessments of cognition.
- There is a growing need for updated methods to remotely monitor performance. One solution is to allow caregivers to administer remote testing from home for children with neurodevelopmental disabilities (Kelleher et al., 2020).

STUDY AIMS

- Describe caregiver-supervised administration of a computerized cognitive assessment through behavioral coding of parent behaviors and child behaviors.
- Compare parent and child behaviors to child performance on a computerized cognitive assessment.

Methods

- **Participants:** Participants were 24 children with DS, ages 10 to 17 (M chronological age = 12.67, SD = 2.48; 54.2% male, 45.8 female).
- **Procedures:** Participants and their caregivers completed one study visit. Caregivers watched a training video before leading the iPad task.
- **Measures:** The study included a measure of inhibitory control, the NIH Toolbox Flanker Task. Computed scores and Age-corrected standard scores were used in analyses.
- The Flanker Task was administered by the participants' caregivers and administration was videorecorded. Parent and child behaviors were coded throughout Flanker Task completion (Table 1).

To feed the MIDDLE fish, choose the fish is	button that matches the way the MIDDLE s pointing.



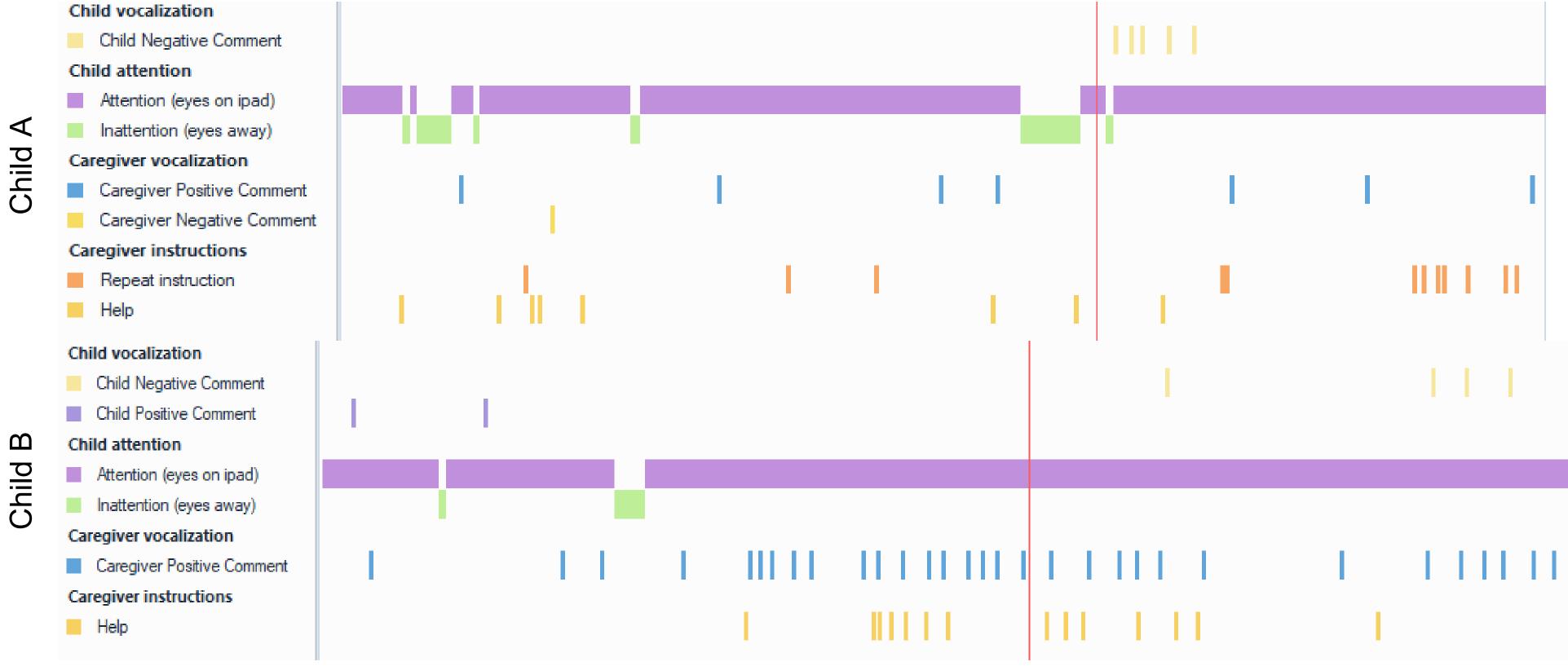
Table 1. Behavior	Coding Scheme
	Child vocalizations
Negative Comment	Verbal refusals, complaints, expressing wanting to leave/do something else, questions as to when they can leave, yelling about task in negative way
Positive Comment	Verbal affirmations, expressing liking task/something related to the activity, requesting more
	Child attention (mutually exclusive)
Attention	Eyes on the iPad
Inattention	Eyes away from the iPad
	Caregiver vocalization
Negative Comment	That's not how you do it, verbalizing child complete task wrong, you're not trying, you need to focus, comment on child's behavior i negative way
Positive Comment	Good job, you can do this, motivational statements, offering snack/juice, remind of reward
	Caregiver instruction
Caregiver Help	Giving too much information (outside of what is in directions), or doing the task for the child, can include gestures and hand-over- hand, saying what the instructions said again (after the initial giving of instructions)

Results

• Table 2 reports the mean, standard deviation, minimum, and maximum values for study measures.

	Mean	SD	Min	Мах
Flanker Computed Score	3.97	2.33	1.25	8.11
Flanker Standard Score	61.23	8.46	54	85
Total duration (minutes)	7.08	1.55	4.45	10.32
Attention (%)	96.41%	.05	83%	100%
Inattention (%)	3.59%	.05	0%	17%
Child Positive Comments	.83	1.93	0	8
Child Negative Comments	1.42	1.99	0	7
Caregiver Positive Comments	6.21	8.02	1	34
Caregiver Negative Comments	.96	1.48	0	5
Caregiver Help (repeat instruction and help)	13.38	11.97	0	43

• Figures 1 & 2 show data visualizations for two study participants.



• Figures 3 & 4 show the relation between coded behaviors and Flanker task performance.

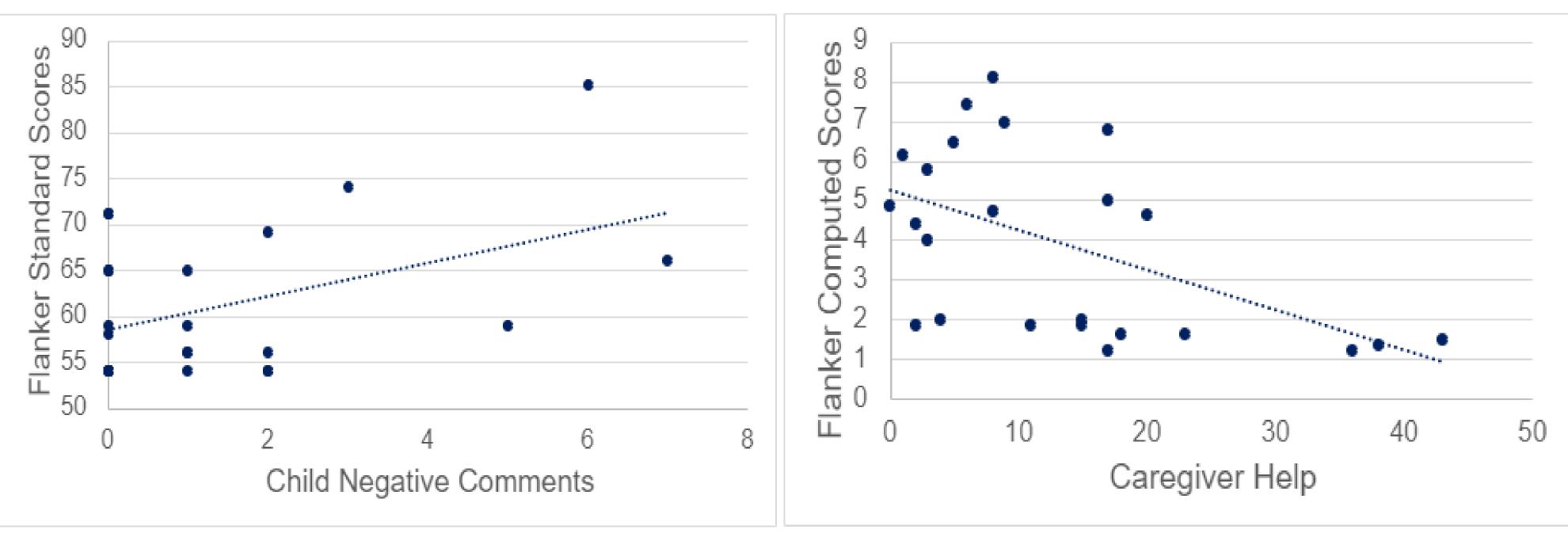


Figure 3. Child negative comments and Flanker SS, r = .44, p = .03





Figure 4. Total help and Flanker Computed Score, r = -.52, p = .009

Discussion & Implications

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Overall, child attention to the Flanker Task was high. Children displayed more negative comments (average between 1 and 2) than positive comments (average of about 1) during the task. Some children did not verbalize throughout the task.

Caregiver level of support varied (Caregiver Help). Some children received no assistance and some children received frequent assistance (43 instances of caregiver help). Overall, caregivers provided positive comments throughout the Flanker Task, with an average of about 6 positive comments.

• There was heterogeneity across caregiver and child behaviors during the Flanker Task (Figure 1 & 2). Child A demonstrated negative comments towards the end of the activity. Their caregiver engaged in helping behaviors frequently. Child B did not engage in negative commenting. Their caregiver positively reinforced them at a high rate throughout the task. They also provided help more frequently towards the end of the activity.

Children who exhibited less negative comments were more likely to have lower scores on the Flanker Task (Figure 3). In this study, children who had more negative comments demonstrated higher scores on the Flanker Task.

A greater amount of caregiver help was associated with lower scores on the Flanker Task (Figure 4). When caregivers were providing help, this did not seem to raise their child's scores. Caregivers who gave the least amount of help had children who displayed higher Flanker scores. This finding suggests that all caregivers were attuned to their child's abilities during the Flanker activity.

Conclusion

Understanding caregiver behavior is essential for remote monitoring of cognitive assessments to ensure validity and accuracy of task administration.

Throughout the computer task there was a variety of behaviors observed. Children varied on their level of attention and types of commenting (positive or negative). Caregivers also varied on their level of assistance (caregiver help), positive commenting, and negative commenting.

The variety in both child and caregiver behaviors suggests that training procedures may need to be adapted for different parent-child dyads participating in research.

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