

Simons Simplex Collection at the Interactive Autism Network: An Online Follow-Up Study

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Background

The Simons Simplex Collection at the Interactive Autism Network (SSC@IAN) is an online research network of families that participated in the SSC study who have agreed to be contacted about additional research opportunities. Participants in the SSC@IAN are members of simplex families, each of which has one child affected with an autism spectrum disorder, and unaffected parents and siblings. The online research environment affords a centralized platform to follow up with SSC families.

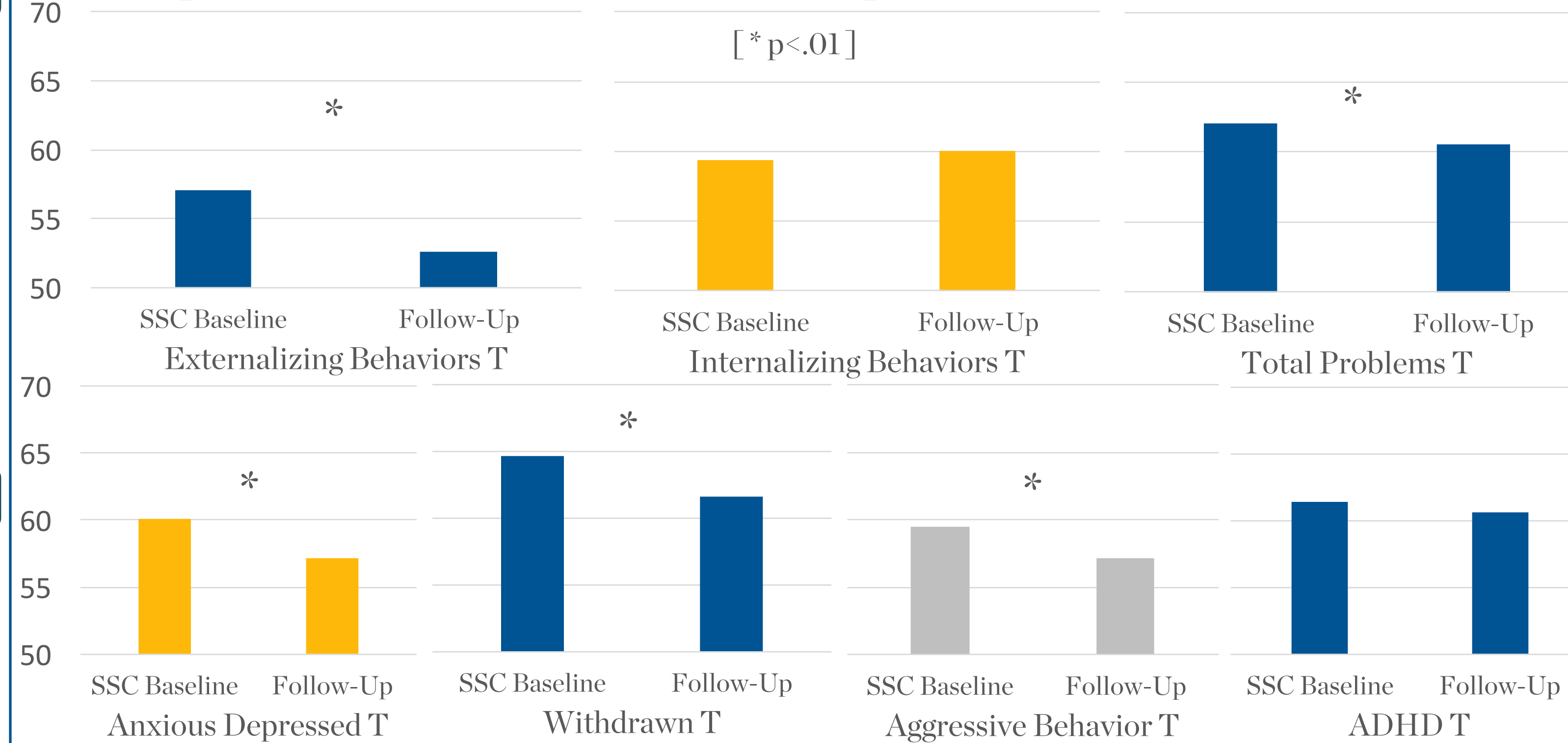
Objectives

The SSC@IAN follow-up was an online study to collect medical, educational, diagnostic, and psychosocial updates on SSC probands and their families 5 to 8 years following their baseline SSC evaluation. The baseline SSC cohort is a clinically and genetically well-characterized cohort that has proven valuable for research. The follow-up study aimed to provide researchers with the most up-to-date data on as many families as possible.

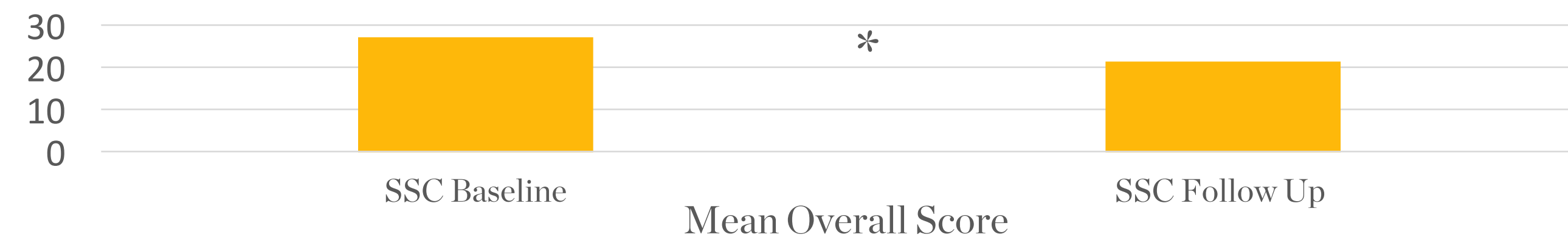
Methods

Families with probands under age 18 (n = 1313) were invited to participate in the Follow Up Study. SSC@IAN families completed 3 modules of surveys online. Each module included questionnaires (e.g., education, medical and diagnostic history) and repeat administration of standardized measures from the baseline SSC battery, including the Child Behavior Checklist 6-18 and the Repetitive Behavior Scale-Revised. Scores from the CBCL and RBS-R were compared with baseline results using paired sample T tests. Analysis of the CBCL combined data from 1.5-5 and 6-18 forms collected at baseline.

Comparisons of SSC Baseline and Follow-Up CBCL Scores in SSC@IAN Cohort



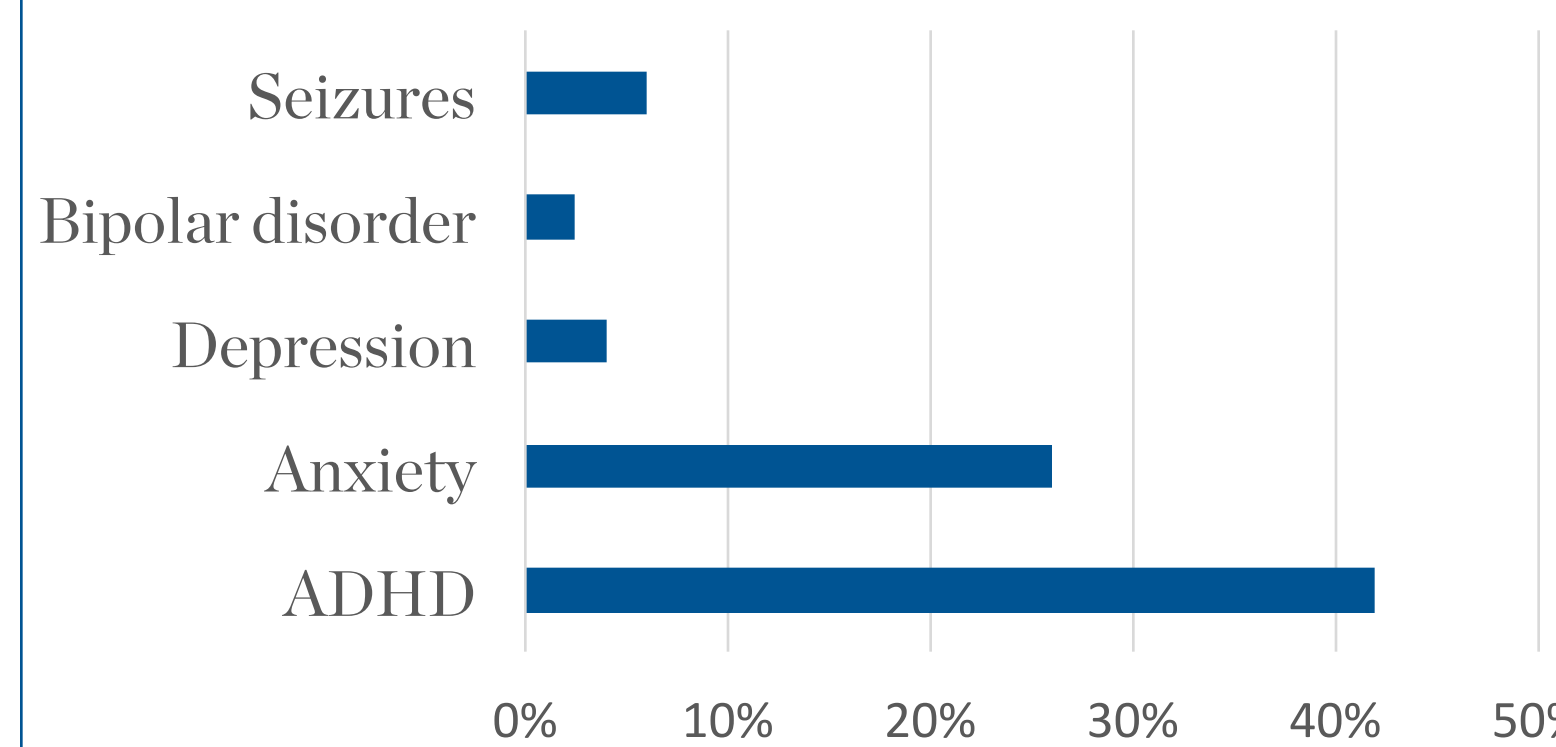
SSC Baseline and Follow-Up RBS-R Scores



Medication use at Baseline and Follow-Up in the SSC@IAN Cohort (n=350)

	Baseline	Follow-Up
Antidepressants	9%	20%
Antiepileptic	2%	9%
Mood Stabilizers/ Antipsychotics	9%	16%
Stimulants	16%	37%
Sedatives/Tranquilizers	2%	3%

Frequencies of Comorbid Diagnoses at Follow-Up



Results

425 (32%) of invited participants completed some portion and 288 (22%) completed all measures. Male to female ratios and previous IQ and CBCL scores were comparable between the whole baseline SSC cohort (n=2644) and the follow-up sample (n=418), suggesting a representative sample (FSIQ 81 vs. 83; VIQ 78 vs. 80; NVIQ 84 vs. 86; p>.05). Age at the time of baseline for this sample ranged from 4 to 11 (M 8.1 years) and is currently 8 to 17 years (M 12.9 years). Probands showed significantly lower scores in specific areas at follow-up compared to baseline, including RBS-R Overall Score (mean total score 27.0 vs 21.7; p<.01), and CBCL Externalizing Behaviors T-score (M 57.1 vs 52.7), Total Problems T (M 62.1 vs 60.6), Anxious Depressed T (M 60.1 vs 57.2), Withdrawn T (M 64.7 vs 61.6), and Aggressive Behavior (M 59.5 vs 57.2), each p<.01. Internalizing Behavior T-scores (M 59.3 vs 60.0) and ADHD T (M 61.4 vs 60.6) scores were similar between baseline and follow-up. At follow-up, parents reported high frequencies of comorbid diagnoses or treatment for ADHD (42%) and anxiety (26%), with relatively lower frequencies of depression (4%) and bipolar disorders (2.5%). Seizures were reported at 6%. Medication use doubled. Multiplex ASD was newly reported in 17 (4%) families with first degree relatives and in an additional 12 (2.8%) families with second or third degree relatives.

Conclusions

The SSC@IAN Follow-Up study provides additional longitudinal data for researchers to investigate outcomes in this well-characterized ASD cohort. Improvements in repetitive behaviors and behavior problems were seen over time in a representative sample. However, consistent with other studies, anxiety disorders and ADHD are common comorbid conditions now reported in these older children and teens with ASD. The stability in actual ADHD symptoms, but high rates of diagnosis and sharply increased stimulant medication use, likely reflect both changes in clinical practice and increasing demands on attention with age. Similarly, the great increase in overall medication use could indicate persisting behavioral difficulties that need to be addressed as the children age and encounter more complex daily demands.