

**Chelsea Earley**  
**Mentor: Dr. Jennifer Bain**  
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## **Sleep as a Risk Factor for Increasing Parental Stress in Children with Autism**

### **Study Purpose:**

Autism Spectrum Disorder is pervasive, affecting roughly 1 in 59 children in the USA, according to CDC data. It can be a devastating diagnosis, especially to parents, the primary caregivers. While ASD is defined by deficits in communication and restrictive and repetitive behaviors, it also has many comorbid diagnoses including epilepsy, anxiety and sleep disturbances. We are interested in disturbances of sleep which can affect 40-80% of children with autism. One study showed that these sleep disturbances include sleep anxiety, bedtime resistance, sleep duration and parasomnias.

As would be expected, parents of children with autism report higher stress levels than parents in the general population. This negatively impacts family quality of life. Parental stress is measured by the PSI-SF (Parenting Stress Index- short form). This form, a shortened form of the PSI, look at 3 subscales including Parental Distress, Parental-Child Dysfunctional Interaction and Difficult Child.

We hypothesize that sleep disturbances in children with ASD will be associated with higher parental stress indices.

At Columbia, the Autism Task Force was created to better serve patients with Autism both in the hospital and in the Washington Heights community. The aim of the study is to help guide interventions in the Autism Task Force. If we are correct that parental stress is higher in patients with sleep disturbances, then the Task Force can work to create interventions directed toward improved sleep. Eventually we would hope to test those interventions to find if it improves parental stress.

### **Study Design:**

In this retrospective study we will use the Simons Databases: Autism Inpatient Collection and the Simons VIP Database. These databases include phenotypic information about patients with autism as well as demographic information and specifically, the PSI-SF scores of the parents. The Autism Inpatient Collection has data on 527 patients. The Simons VIP is a database of children with ASD found to have 16p11.2 deletion or duplication. The Simons VIP Phase 1 database includes information on 260 individuals.

We will analyze the databases separately.

For each database we will separate patients into 2 groups: those with sleep disturbances and those without.

**Statistical Analysis:**

Per an unpaired t-score power analysis for the AIC database, we can show a difference of 0.62 stress index score percentile to be statistically significant. This assumes each group to be roughly 50% of the total and a standard deviation of 2. This standard deviation is based on previous studies using PSI-SF.

Per an unpaired t-score power analysis for Simons VIP database, we can show a difference of 0.82 stress index score percentile to be statistically significant. This uses same assumptions as above.

We think a difference of 5% to be clinically significant, so with the number of patients in the databases, we have enough power to find a clinically significant result.

To analyze data we will use an unpaired t-test to compare the mean stress index score percentile.

We will also use a chi-square test on proportions to compare proportion of parents in each group whose stress index percentile is above 85%. 85% has been described as the cutoff of parental stress which indicates highest risk.

To control for severity of ASD, we will also compare PSI-SF scores for parents of children who are non verbal vs children who are verbal. In this way, we can make sure that sleep disturbances is not simply a marker of severe autism.

**Confidentiality of Study Data:**

Only investigators on IRB are granted access to the Simons Databases.

**Study Subjects:**

All subjects are patients with Autism whose parents have previously consented to be part of Simons databases.

**Potential Conflicts of Interest;**

There are no conflicts of interest to report

**Location of Study:**

Not applicable, as this is a retrospective database review

**Potential Risks:**

No anticipated risk beyond possibility of someone not involved in the study unintentionally seeing personal information.

**Potential Benefits:**

No direct benefits to patients in Simons databases. However results of study could lead to interventions which could benefit many children with autism and their families in the future.

**There will be no study drugs, medical devices or questionnaires involved in this study.**

**REFERENCES**

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