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### Variables Contributing to The Psychosocial Strain on Caregivers of Patients with Autism Spectrum Disorder

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## Background

Autism spectrum disorder (ASD) presents unique challenges for the patient, including social interactions and behavioral problems. ASD holds historical roots in being an under-defined and poorly understood disorder. Well, over the past several decades, we have seen an increase in publicity and advocacy of ASD.<sup>1</sup> In 2020, 1 in 36 children were identified with ASD, a dramatic increase from 1 in 250 in 2000<sup>2</sup>, concurrently following an increased burden that falls on caregivers.

Caregivers of patients with intellectual and developmental disabilities may be prone to depression and anxiety<sup>3</sup>; caregiver strain has especially been shown to be more extensive in those caring for children with ASD than in those caring for children with other types of disabilities.<sup>4,5,6,7</sup>

The wellness of the caregivers is intricately tied to the care of the ASD patients they look after. The overall well-being of the family impacts the child and any interventions involved with the child with ASD.<sup>7,8</sup> However, due to the recency in ASD diagnoses and research, much of the increased research has focused on the disorder itself or its pathophysiology in patients. There is not yet an appropriately proportionate amount of literature looking at the health utility related to psychosocial strain added to the caregiver role when caring for a patient with ASD.<sup>7</sup>

This project focuses on the caregiver's age and gender and their relationship to the psychosocial strain of caregivers of ASD patients being seen at the Rowan-Virtua Integrated Special Needs (RISN) Center in Sewell, New Jersey. Knowing and understanding the factors that are at play in caregiver strain can help create better-informed care for both the patients who are diagnosed with ASD and their caregivers. This is an ongoing and expansive initiative of the RISN Center, and this study contributes insight that will further RISN's goals.

## Results

**Table 1. Essential Coefficients – Age**

Age	Variable	Estimate	Standard Error	t-Statistic	p-Value
Number of observations: 31 Error degrees of freedom: 25 Root Mean Squared Error: 6.68 R-squared: 0.227 Adjusted R-Squared: 0.0722 F-statistic vs. constant model: 1.47 p-value = 0.236	(Intercept)	23.435	2.8804	8.1361	1.73E-08
	Time Dependency	-0.3824	0.28354	-1.3487	0.18954
	Emotional Health	-0.34689	0.75714	-0.45816	0.65079
	Development Items	1.1515	0.45389	2.5369	0.0178
	Social Relationship	-0.49594	0.43873	-1.1304	0.26904
	Physical Health	-0.27058	0.41341	-0.65452	0.51876

**Table 2. Essential Coefficients - Gender**

Gender	Variable	Estimate	Standard Error	t-Statistic	p-Value
Number of observations: 31 Error degrees of freedom: 25 Root Mean Squared Error: .53 R-squared: 0.044 Adjusted R-Squared: -0.147 F-statistic vs. constant model: 0.23 p-value = 0.946	(Intercept)	0.5147	0.22872	2.2503	0.033474
	Time Dependency	-0.0054347	0.022516	-0.24138	0.81123
	Emotional Health	-0.040208	0.060123	-0.66876	0.50978
	Development Items	0.01672	0.036043	0.4639	0.64674
	Social Relationship	-0.0019626	0.034838	-0.056333	0.95552
	Physical Health	-0.018231	0.032828	-0.55535	0.58359

Age and gender were analyzed in correlation to Caregiver Burden Inventory (CBI) items under a multiple regression model.

- A significant correlation was found between patient age and CBI Development scores.
- No significant correlation was found between gender and CBI items.

## Methods

At their RISN visits, caregivers completed the CBI questionnaire<sup>9</sup>, which comprised of 24 statement-based questions asking caregivers to rank how they felt about each statement from 0 to 4 (0=Never and 4=Nearly Always). Each category of statements, or items, was scored. The item categories include Time Dependency, Emotional Health, Development, Social Relationships, and Physical Health. Total score, survey comments, and individual ratings were also a part of the questionnaire.

Data extracted from the CBIs and patient charts were methodically organized into an Excel spreadsheet tailored to accommodate several variables relevant to our study and future investigations at RISN. Essential supplementary data included patient identification numbers, medical record numbers (MRNs), patient gender, first and last names, dates of birth, race, ethnicity, severity of ASD (as determined by DSM-5TR), caregiver names (identified through emergency contacts), caregiver gender, and the survey dates.

Our spreadsheet incorporated variables, such as the ASD spectrum level, that were determined by students and confirmed by an RISN provider. This collaborative effort ensured the integrity of our data. This analysis was conducted with the first 99 patients; since this has increased, a total of 295 patients, demonstrating the exhaustive nature of our data collection efforts. However, the analysis code has been built; thus, statistical calculations can be made as data is extracted. Correlational coefficients that estimated the relationship between the CBI categories and Age/Gender using a linear regression model in MATLAB.

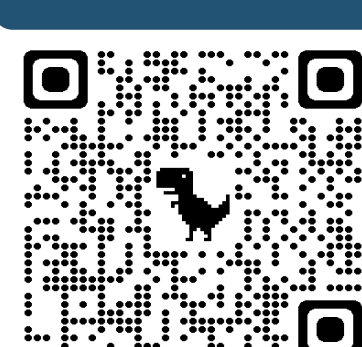
## Discussion & Conclusions

Based on the analysis performed, the positive coefficient for the Development items in the CBI indicates that an increase in the Development scores is associated with an increase in the patient's age. The t-statistic of age and CBI Development is 2.5369 with a p-value of 0.0178, which suggests a statistically significant relationship at a significance level of 0.05. However, when looking at the correlational data between patient gender and all CBI categories, no significant correlation was found. At this stage, a repeat analysis needs to be performed on a larger sample size since we only looked at 99 patients. We also will be able to include more patient data as we continue adding patients to the study cohort. With these initial results, further investigation can be conducted that explores specifically the time dependency category questions, and its effect on the categorical score.

### References



### Contact



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