



# Validating the Brief Caregiver Satisfaction and Strain Index: A Pilot Study Examining Families with Autistic Children



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## Abstract

Many services for children and families worldwide have moved to online, digital and hybrid formats in recent years. The purpose of the current study is to pilot a scale that will assess caregiver satisfaction and strain related to various treatment services. Descriptive statistics, factor analyses, and correlational models were used to analyze the data. Results indicate that the factors are well explained by each variable and several correlations were found including household income associated with supportive providers, satisfaction with treatment, child making gains, and parent - provider communication. Participants in behavioral therapy indicated significant perceptions of treatment satisfaction, however they also produce perceptions of financial strain. The current study shows that the scales as designed may be useful in future research, and in assessing characteristics and service type against satisfaction and strain. Recommendations for future research are discussed, including a more extensive validation study of the presented scale.

**Keywords:** Autism; Parenting; Satisfaction; Caregiver strain; Socioeconomic status

## Introduction

In the wake of a global pandemic, many vulnerable populations have become adversely impacted by COVID-19. Children with neurodevelopmental disorders, like many other conditions that may require intensive educational support or therapies, have experienced significant consequences. Autism spectrum disorder (ASD) is one of the most rapidly growing groups of neurodevelopmental disorders found in early childhood. In addition to special education support, supplemental therapies either provided through educational funding, federal or state programs, or privately, are common and often essential for families managing and improving outcomes for autistic children. In the current post-COVID era, many children with neurodevelopmental disorders are still receiving related services via telehealth, or not at all. These imposed barriers to intervention are resulting in significant delays to intervention onset or even missed opportunities for intervention altogether [1]. Difficulties in obtaining help for children with special needs is an area of great concern for parents and professionals alike. A pertinent question that has been raised with the increase in the usage of telehealth to

deliver services for children with neurodevelopmental disorders is what the impact on parental satisfaction is. Previous research has found that even when services have been below what is best practice, parents may still report generally high levels of satisfaction. For instance, McIntyre and Zemantic [2] found that on average, children with ASD receive 13 hours of education and therapy per week and that parents generally rated high satisfaction despite having services below best practice guidelines. This is relevant as research has found that parent satisfaction in an early and intensive behavior intervention program was associated with the child's gains in functioning [3]. Similarly, Adib et al., [4] found parent satisfaction in a sample of parents of children with ASD to be correlated with higher levels of education, better access to medical support, and being better informed about parent support.

While we know that parent satisfaction is linked to better outcomes for children with neurodevelopmental disorders, we also are aware that parent/caregiver strain can have negative effects on outcomes for children with neurodevelopmental disorders. Lower education levels, children's sleep problems,

medical problems, and poor access to medical support have all been linked to caregiver strain [5]. The provision of professional services, however, has been found to moderate maladaptive coping in parents of children with neurodevelopmental disorders thereby reducing caregiver strain [6,7]. As such, there appears to be a unique relationship between caregiver’s satisfaction with services for their children with neurodevelopmental disorders and caregivers’ strain. The aim of the current study is to examine the factors associated with telehealth services in the wake of the COVID-19 pandemic and their impact on caregiver satisfaction and strain. Variables such as the type of service, telehealth or in-person services, and sociodemographic variables will be evaluated to better understand family-related, systematic factors that impact satisfaction and strain, which have overall impact on the family system at large. The following research aims drive the current study:

- i) To pilot a brief rating scale questions to measure caregiver satisfaction and strain that can be used in further research.
- ii) To determine what demographic variables may be associated with stress or strain in the time of the COVID-19 pandemic.
- iii) To determine if in-person versus remote services are correlated with satisfaction or strain.

**Methods**

**Recruitment and participants**

Recruitment took place via a social media platform in a group for parents of children with special needs in the New York City area and through email distribution. Because not all participants

may be regularly active in the group, it is difficult to estimate a participation rate. Participants completed written consent forms digitally before engaging in data collection. To be eligible for the study, the parent participant needed to be:

- a. At least 18 years of age.
- b. The parent of a child with ASD between the ages of 3 and 18.
- c. Their child needs to have been receiving therapy or services at the time of data collection.

The lower age limit was set due to the difficulty with diagnostic stability of autism before 3, and the upper to not confound results specific to adulthood and no longer receiving educational services. Demographic results are reported in Table 1. Response to the survey yielded 38 parents who completed the study. All respondents reported being female, and the child’s mothers, except for one male father who completed the survey. Of the children that the parents were reporting on, 27 were male (59%) and 11 were female (24%). Children ranged from 4 to 18 years of age. The upper limit of 18 was placed on the study since many services, funding, and other facets relevant to the study may have been impacted by parents responding regarding their adult children. There was no lower age limit placed on participation. Income was reported as a range, with over \$120,000 plus per year as the more common income category in the sample. Nearly 74% of the participants were white/Caucasian, with the remaining 24% representing ethnic minorities. Most of the sample reported being a two-parent household, with nearly 40% of the sample endorsing both parents being employed in the home. All except one child was reported to have health insurance. The type of services received are reported in Table 2.

**Table 1:** Family Demographics.

Family Demographics		
Variable	N	%
<b>Parent role</b>		
Mother	37	97
Father	1	3
<b>Child’s gender</b>		
Male	27	71
Female	11	28
<b>Household composition &amp; Support</b>		
Two parents (heterosexual)	30	79
Single parent, one caregiver	4	11
Parent divorced, shared custody	1	2.5
Single parent with support	1	2.5
Two parents plus support	2	5
<b>Employment Status</b>		
Single parent, employed	4	11

Single parent, unemployed	1	3
Both parents in home employed	17	46
One parent in home employed	15	41
<b>Ethnicity</b>		
white/Caucasian	28	74
Black	4	11
Hispanic/Latinx	2	5
Asian	2	5
Mixed	2	5
<b>Total household income</b>		
10,000-30,000	2	5
30,001-60,000	8	21
60,001-90,000	9	23
90,001-120,000	7	18
121k +	12	32
<b>Child insured</b>		
Yes	37	98
No	1	2

**Table 2:** Service type.

<b>Service type</b>		
Variable	N	%
Public special education	28	23
Private special education	7	5
Speech therapy	28	23
Occupational therapy	23	18
Physical therapy	7	6
ABA/Behavioral Services	20	16
Music therapy	3	2
Other	7	7

**Measures and data analysis**

To address the presented research questions, a demographic and background information survey was created for this study. Parents were asked to complete each item in the survey online via Qualtrics. In addition to family demographic information, the parent was also asked to provide information about their child and the current service they receive. Examples of questions asked include the parents and child gender, the child age, household income, household structure. Parents were then asked to respond to nine satisfaction/strain questions related to their child’s services. Based on critical and extensive review of the related literature and the author’s expertise, a brief scale was developed to assess both satisfaction and strain in caregivers of children with ASD. Questions are listed within the results tables. Parents were asked to rate each question on a Likert-type scale (1 = strongly disagree; 2 = disagree; 3 = neutral; 4 = agree; 5 = strongly agree). Descriptive statistics were used to better understand the demographic information including service type gathered.

Descriptive statistics were also used to review the questionnaire responses. To identify the relationship between variables and determine if the sets of questions for strain and satisfaction statistically fit together, exploratory and confirmatory factor analyses were conducted. Correlational models were used to examine relationships between demographics and questionnaire results. Due to the limitations in sample variation, and/or responses, e.g. - all or most of the respondents were: mothers, had health insurance, had similar employment statuses, and a similar home demographic, there were limitations to the analyses that could be conducted.

To avoid the assumptions of normally distributed data, we opted for non-parametric tests to include the Mann-Whitney U Test rather than independent samples T-test. Spearman’s Rank Correlations, a non-parametric test, was used to test relationships between other survey questions to avoid assumptions of normally distributed data. All missing values were coded as “99,” and excluded from analyses where possible. Groups with limited

variation such as “primary child race” into “white vs. non-white children” were transformed to increase the statistical power of the testing of that group. We also created a measure variable, called “total therapies,” to examine relationships between the quantity of therapies the participant reported participating in among other indicators of strain, treatment/provider satisfaction, and perceptions of changes in plans/routines. We also reverse coded the default Likert scales of strong disagreement – strong agreement, as well as service delivery method so that correlations would show more interpretable results.

**Results**

An exploratory factors analysis yielded uniqueness scores for each of the variables within factors, all of which are below 0.06, indicating that the factors are well explained by each variable. Results from the exploratory factors analyses are reported in Table 3. Results from the confirmatory factor analyses are reported in Table 3 and factor estimates are reported in Table 4 ( $p < 0.05$ ). Results from the non-parametric tests for significance suggest

that child gender, race, and income produced no statistically significant results on type of therapy/service, strain (financial, physical, emotional), perceptions of satisfaction in provider services, provider communication & support, treatment/delivery method, and routine/plan changes. The child’s age was correlated to certain service/treatment delivery methods, and treatment or service types: Occupational and ABA/Behavioral Services was correlated with a respondent’s child age being a younger age ( $p = 0.03$ ). Service/treatment delivery method for special education services and related services was correlated with a respondent’s child being an older age ( $p = 0.05$ ). Child age was not correlated to other services not otherwise listed, perceptions of satisfaction with treatment gains towards goals, services satisfaction, provider support, spousal communication with provider, and all described indicators of strain. Household income was correlated to perceptions of supportive providers ( $p = 0.04$ ), satisfaction with the child’s overall treatment ( $p = 0.02$ ), the child making gains toward treatment goals ( $p = 0.03$ ), and spousal – provider communication ( $p = 0.032$ ).

**Table 3:** Exploratory Factor Analysis.

Factor Loadings			
	Factor		Uniqueness
	1	2	
Q18	0.885		0.236
Q19	0.893		0.188
Q20	0.811		0.333
Q21	0.665		0.55
Q22		0.806	0.394
Q23		0.609	0.578
Q24		0.563	0.55
Q25		0.887	0.248
Q26		0.637	0.522

**Note:** Minimum residual' extraction method was used in combination with an 'oblimin' rotation.

Respondents participating in behavioral/ABA therapy produced statistically significant perceptions of treatment satisfaction,  $z = -2/04$ ,  $p = 0.04$ . The respondent’s child participating in occupational therapies produced no statistically significant responses to questions of satisfaction with providers/provider communication or child progress. Mann-Whitney tests revealed that respondents participating in behavioral/ABA therapy produced statistically significant perceptions of financial strain ( $p < 0.05$ ). Perceptions of respondent strain were most frequently correlated with perceptions of: Having to change personal plans and routines and being involved in a higher number of treatment therapies. The respondent’s child participating in occupational therapies produced statistically different responses regarding financial strain, physical strain, and feeling the need to adjust ang change routines. The respondent’s child participating in ABA/Behavioral therapies produced statistically different responses regarding treatment satisfaction and financial strain.

A correlation matrix is presented in Table 5. Perceptions of treatment satisfaction, child making gains towards treatment, supportive providers, spousal - provider communication, treatment delivery types, were all positively correlated with one another ( $p < 0.05$ ). These same variables had an inverse relationship with respondents feeling that they had to change personal plans and routines. Feelings of financial strain ( $p = 0.001$ ), emotional ( $p = 0.06$ ), and physical ( $p = 0.00$ ) were all positively correlated with the feeling that they had to frequently change personal plans and routines. Higher levels of therapy involvement were positively correlated with feeling financial strain ( $p = 0.007$ ), physical strain ( $p = 0.031$ ), and having to change routines ( $p = 0.38$ ). Therapy delivery method for services and behavioral/ABA services was positively correlated with treatment satisfaction - e.g. – hybrid and remote delivery had the higher levels of satisfaction. However, hybrid and remote delivery for special education services was inversely related with perceptions.

**Table 4:** Confirmatory Factor Analysis.

Factor Loadings					
Factor	Indicator	Estimate	SE	Z	p
Satisfaction	Satisfied	1.254	0.1703	7.37	<.001
	Gains	1.128	0.1478	7.63	<.001
	Support	0.801	0.1578	5.08	<.001
	Communication	0.668	0.176	3.8	<.001
Strain	Financial	0.996	0.1921	5.18	<.001
	Emotional	0.436	0.0981	4.45	<.001
	Plans	0.615	0.156	3.95	<.001
	Physical	0.979	0.1642	5.96	<.001
	Adjust Routine	0.653	0.1521	4.29	<.001

**Table 5:** Factor Estimates. <sup>a</sup> Fixed parameter.

Factor Covariances					
		Estimate	SE	Z	p
Satisfaction	Satisfaction	1.000 <sup>a</sup>	0.154	-2.75	0.006
	Strain	-0.426			
Strain	Strain	1.000 <sup>a</sup>			

**Discussion**

The current study utilized a brief rating scale to measure caregiver satisfaction and strain to determine associations between demographic variables and stress or strain post pandemic in the early 2020’s when service types may still vary. The study also sought to examine the relationship between service type (in-person versus remote) and caregiver satisfaction or strain. Non-parametric tests for significance suggest that the only demographic of statistical significance is the child’s age, correlated with certain service/delivery methods and treatment or service types. Younger children appear to utilize both ABA/behavioral services and occupational therapies while older children used service/treatment delivery methods for special education services and related services. Interestingly, child age was not correlated to any indicators of strain. Household income was shown to be related to perceptions of supportive providers, satisfaction with child’s overall treatment, the child making gains toward treatment goals, and spousal-provider communication while reduce household income, wise associated with factors related to strain, and participation in ABA and behavioral therapy’s increased financial strain for some families. Results from the current pilot study indicate that a larger sample is likely needed to fully explore the factor model, however, based on exploratory factor analysis, the current scales appear to measure factors associated with satisfaction and strain across different dimensions. In doing so, the critical role that socioeconomic status, and in particular income, place was illuminated within the current study.

As this was a preliminary study, piloting a new scale, several

limitations exist. The study methodology involved only self-report scales. Self-report scales may be biased or inaccurate because they are based entirely on the honesty and accuracy of the individual reporter. This may create challenges in the construct being measured. Additionally, there were few participants, and although non-parametric tests for significance were utilized to accommodate for these numbers, a larger sample size is always desirable. The sample utilized was also recruited on a volunteer basis through social media. The sample was relatively homogenous. All participants but one reported being female, and 74% Caucasian/White. Still, despite these characteristics, the current study shows that the scale as designed may be helpful when use with small samples, or even in a clinical setting so that professionals can gauge the existing levels of strain and satisfaction within their respective populations. Future research should include a larger, more diverse sample. It would also be beneficial to utilize the piloted scale with parents with typical developing children versus parenting affected by neurodevelopmental disorders to further validate utility of the scale as well as utilizing the scales within the context of larger survey research. A full validation study should also be conducted with a larger sample.

**Conclusion**

Overall, the results of this study reveal many indicators regarding demographic characteristics and service type against satisfaction and strain. The study is reflective of the implications of these service-types and their impact on families. Several important findings were illuminated regarding sociodemographic factors, service type, and family variables and should provide to be a beneficial scale in follow up research.

## Author Note

Ethical approval was obtained from the Institutional Review Board (IRB) at Saint Joseph's University prior to recruitment.

## Authors Contribution

Dr. Harry Voulgarakis was the principal investigator and methodologist for the current study. He designed the initial draft of the scale items, ran statistical operations, drafted and edited the final manuscript.

Dr. Alyssa Soohoo assisted with interpretation of the results and drafting of the final manuscript.

Dr. Jessica Scher Lisa contributed to the initial development and planning of the scale as well as interpretation of results and drafting of the manuscript.

## Statements and Declarations

The authors confirm that they have no competing financial or non-financial interests and are not directly or indirectly related to the work submitted for publication.

## Data Transparency

The authors are willing to provide the current data set upon request. Please contact the corresponding author to request access to the data.

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