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Maternal Stress and Maladaptive Behavior in Children with ASD Participating in a Multi-Disciplinary Program providing Medical Care, Dietetic Support, Educational Consultation and Family Resources: A Pilot Study

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Abstract

Background: Parents of children diagnosed with Autism Spectrum Disorder (ASD) frequently report significant stress related to their child's needs and behaviors. Families with access to a variety of intervention and support services and/or resources typically report experiencing lower stress.

Methods: In this pilot study, we examined the relationship between maternal stress and maladaptive behavior in 32 children with ASD enrolled in a 6-month center-based program providing medical care, dietetic support, and educational consultation. Mothers completed the Parental Stress Index-Long Form (PSI-LF) and Pervasive Developmental Disorder Behavior Inventory (PDDBI) at intake and at approximately 3 months post-enrolment.

Results: At intake, high maternal stress was reported but this was not related to a number of demographic variables. However, maternal stress was significantly correlated with the PDDBI *Autism Composite*, a measure of ASD severity. At approximately 5 months post enrolment, stress associated with the PSI *Child Domain* had significantly decreased and there was a significant reduction in PDDBI *Ritual* and *Arouse* domains over time.

Conclusions: In summary, implementation of a comprehensive intervention program for children with ASD, including providing family supports, was associated with improvements in some ASD behavioral domains over time, which may have contributed to reduced maternal stress. Developing and implementing a wide-ranging support program for parents raising a child with ASD may be critical for family stability, as well as for ensuring improved child outcomes.

Keywords: Autism; Behavior; Stress; Family supports; Intervention

Introduction

Parents of children with autism spectrum disorder (ASD) are faced with numerous potential challenges and daily stressors associated with parenting a child with special needs. They typically report higher levels of parenting stress when compared to parents of typically developing children [1] and parents of children with other disabilities [2-6]. The primary contributing factor to parental stress has been attributed to increased levels of maladaptive behaviors, specifically social-communication impairments and restricted and repetitive behaviors [7-9]. Increased parental stress may be influenced by a number of other factors, such as the lack of social support [10], the absence of effective coping strategies [11], and lower psychological well-being or depression in one or both parents [12,13]. Physical and emotional aggression, destruction, and self-injurious behaviors are also known parental stressors in ASD [14,15]. Impaired adaptive functioning may also contribute to increased parental stress by increasing child-rearing responsibilities [16], while tantrums, meltdowns [17], resistance [18], verbal or physical perseveration, and repetitive movements can result in judgment and criticism from others [19].

Financial resources, including both the costs of the diagnostic evaluation of their child and the ensuing specialized interventions, are substantial and may result in increased stress for the parents [20,21], particularly if the additional care of their child results in decreased employment [22]. Parents are likely to need significant emotional, mental, social, and physical support from neighbors, family, and friends [23]. However, many aspects of parents' lives change, including relationships with family and friends, daily routines, and hopes and dreams for the future (reviewed by [24]). Family members not understanding the difficulties of raising a child with ASD, may well be critical of the parents' approach to managing maladaptive behaviors [25] and parents may also feel judged by friends of typically developing children, who may criticize their child's behaviors and exclude them from social gatherings.

The complex challenges of caring for a child with ASD can also take a toll on parent health [26]. The lack of available respite care [27], the need for constant supervision [28], and issues with disruptive sleep [29] can result in chronic fatigue for the parent [30]. Managing other related health issues in a child with special needs, such as seizures, food allergies, and gastrointestinal issues [31] further exacerbate parental stress. Parents provide mixed reports related to the assistance from health care providers and their knowledge base related to assisting their child and family [32].

Implementing a well-supported family care approach that encourages participation by families in the intervention(s) provided will likely reduce parental stress resulting in positive outcomes for families [4,33-36]. While intensive, highly structured applied behavior analysis (ABA) programs are generally accepted as the gold standard for increasing adaptive and decreasing maladaptive behaviors in children with ASD [37], the nature and scope of adjunctive parental supports and resources have not been well studied. We therefore developed a program of care that would provide a variety of interventions, support services, and family resources, to examine whether participation in this program reduced maternal stress. The objectives of this pilot study were two-fold: firstly to examine changes in maladaptive behavior in children with ASD enrolled in a 6-month comprehensive family-based intervention program providing considerable family supports, and secondly to determine whether following completion of the study, mother's reported experiencing lower levels of stress.

Methods

Program criteria and provided services

The Bright Eyes (BE) program was designed to provide appropriate, intensive care for 50 children with ASD who might otherwise not have access to such interventions due to financial considerations. Specifically, the BE program assisted families in initiating appropriate medical care, dietetic support, and educational consultation, with follow-up appointments for up to 6 months (Figure 1). Admission to the BE program was assessed on a rolling basis. To qualify for admission, the child needed a diagnosis of ASD and had to be between the ages of 18 months and 12 years old at the time of admission.

Due to the increased financial costs of diagnostic and intervention services for ASD and the potential for increased parental stress [20,21], the BE program was designed for lower income families that met specific income requirements. Income requirements were based on the family's Adjusted Gross Income (AGI) as reported on their IRS 1040. Families qualified for admission into the BE program if their AGI was less than $60,000 for a family of 1 or 2 dependents, less than $70,000 for a family of 3 dependents, less than $80,000 for a family of 4 dependents, and less than $90,000 for a family of 5 or more dependents. Families were responsible for a small co-pay for each appointment ranging from $15-$75. These heavily subsidized co-pays ensured that each family's costs were minimized.

After enrolment in the BE program, all parents completed a 1-2 hour intake appointment by phone to obtain information on the child's medical and developmental history, including info on the mother's pregnancy, labor and delivery, and any medical and/or developmental diagnoses for any siblings or first degree relatives. A statement of parental concerns and a review of current medical issues were also compiled. All BE program participants received the following plan of care: two comprehensive medical exams and follow-up appointments with a physician that included a physical exam and laboratory testing (comprehensive blood count, liver function tests, and vitamin D level), a review of past and current medications and responses, a review of previous therapies and outcomes, and detailed recommendations for on-going care; two dietetic consults with follow-up appointments with a registered dietician that included a review of feeding concerns, food allergies, and nutritional interventions and responses, the collection of anthropometric measures (height, weight, BMI and muscle measurements), and an oral health screen.

A diagnostic assessment was also conducted for each participant, which included the Autism Diagnostic Observation Scale (ADOS; [38,39]) and Autism Diagnostic Interview – Revised (ADI-R; [40]). Subsequent clinical diagnosis of each child was based on all the available data and determined by a licensed clinical psychologist with established research reliability on the ADOS and ADI-R, using DSM-IV criteria. An educational assessment and follow-up appointment with a behavioral/education consultant was also implemented. This included a comprehensive review of the past and current behavioral intervention services and recommendations for future behavioral intervention services. Handouts and recommended websites for learning about the Individuals with Disabilities Education Act, and preparing for an Individualized Education Program (IEP) meeting were also provided to assist parents in planning for and implementing the recommended educational interventions. When recommended by the behavioral/education consultant, the continuation of existing behavioral therapies or the implementation of a behavioral therapy program was encouraged but was not offered as part of the BE program. Therefore, the effect(s) of behavioral therapy and/or other adjunct therapies on child

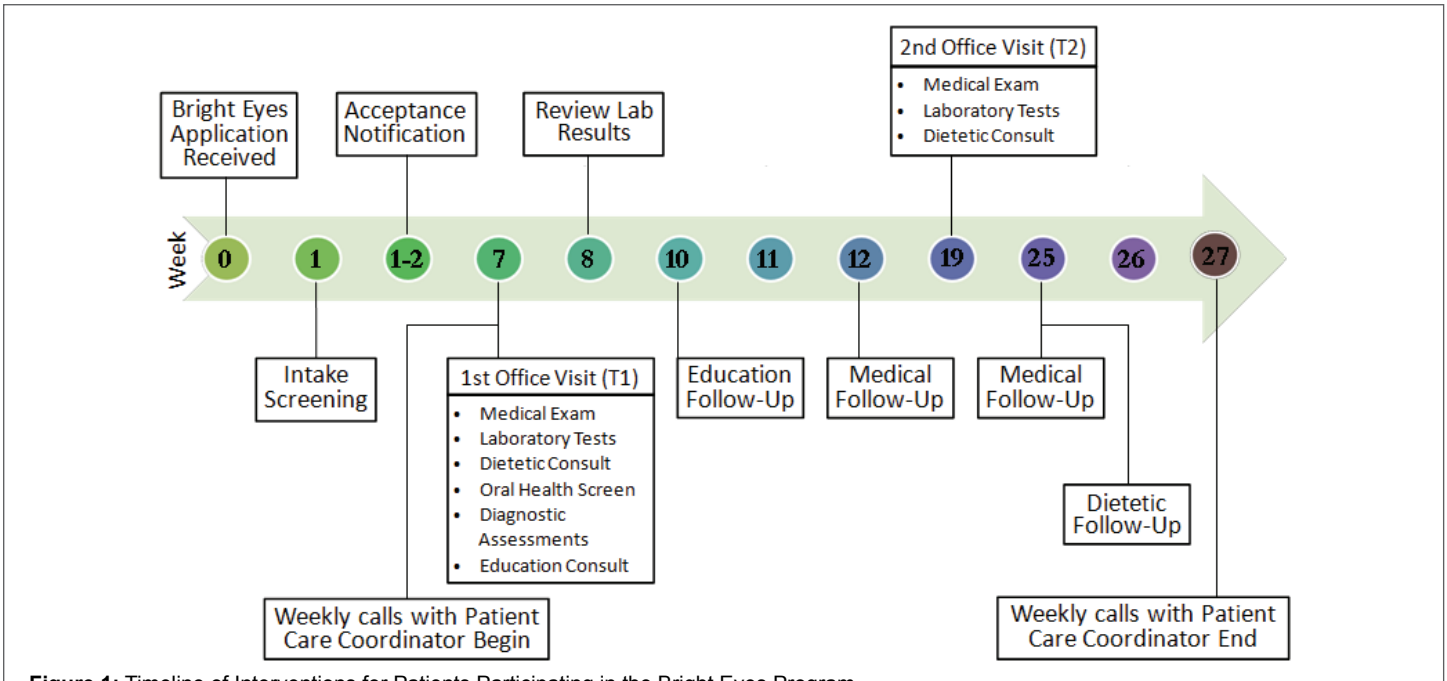

Figure 1: Timeline of Interventions for Patients Participating in the Bright Eyes Program

behavior during the BE program, could not be controlled for in this study design. Parents were also provided with state-specific information for obtaining financial assistance, such as through Medicaid waiver programs, to fund behavioral therapies. Finally, parents received a list of websites that provided information on obtaining an advocate or an attorney dedicated to special education law.

A family-care coordinator/case worker provided emotional support to the parents and addressed any questions or concerns through weekly phone calls, as well as providing resources on recommended therapies. Families were encouraged to complete an anonymous questionnaire after completion of the BE program to provide qualitative feedback on the structure of the program in order to help us learn how to better serve the families in the ASD community.

Participants

This study has been independently reviewed and approved by the Austin Multi-Institutional Review Board and all work were carried out in accordance with the Declaration of Helsinki for research involving human subjects. The research was undertaken with the understanding and written consent of each participant's legal representative, and according to the above-mentioned principles.

In order to recruit participants, researchers met with each family admitted to the BE program to present the research, its objectives, and the parameters of the parents' and their child's participation. It was made clear that participation in the study was voluntary and that refusal to participate in research would not influence the services that their child and family would receive in the BE program. Children enrolled in the BE program, ages 18 months to 12 years of age and with an ASD diagnosis, were eligible to participate in research. Children were excluded from the study if they had been diagnosed with an additional genetic or neurological disorder, which may have impacted both the level of maternal stress and the types of behaviors presented by the child. Out of the 50 participants, one child was excluded from participating due to an additional diagnosis of Down's Syndrome. Of the remaining 49 BE participants, 7 families chose not to participate in the research study. Informed consent was obtained from the remaining 42 families prior to the collection of any research data. Four families withdrew from the BE program before all of the necessary research assessments could be completed; 1 subject was subsequently removed from the research study as subsequent diagnostic assessments could not confirm an ASD diagnosis, and 5 participants had missing/incomplete data that would have impacted the analysis. Study participants included 32 children: 25 males and 7 females with a mean age of 6 years and 10 months (range of 2 years and 1 month to 11 years and 7 months). There were 28 (87.5%) participants with a diagnosis of Autistic Disorder (AD); 2 (6.2%) PDD-NOS and 2 (6.2%) Asperger's Disorder. Age at time of diagnosis ranged from 1.8 to 6.61 years of age. The time lapse between receiving an ASD diagnosis and participating in this study ranged from <1 month to 8 years and 6 months. Subject demographic data is included in Supplemental table 1.

Family socio-demographic variables were obtained from the subject's medical charts and completed questionnaires and included mother's age, family income, mother's level of education, mother's job status, the number of dependents, and marital status (Table 1). Mean maternal age was 34 years. In regards to ethnicity, 75% families identified themselves as being Caucasian, 18.8% Hispanic, 3.1% African American and 3.1% unspecified. The median family income was $42,612, with 28% families earning less than $29,000 and 6% of families earning between $70,000-$89,000. More than 50% of mothers were college graduates, with 25% completing a graduate or professional degree. Conversely, almost 10% of mothers had a high school education or less. In regards to the mother's job status, 50% were homemakers, 28% worked full-time, 9% were students, 6% were unemployed, 3% worked part-time, and 3% were on maternity leave. The majority of families (72%) were married. Almost 90% of families had two or more children.

Research assessments

The Parental Stress Index – Long Form (PSI-LF) was completed by each mother at baseline and approximately 20 weeks post-enrolment. The PSI-LF is a 120-item self-report questionnaire that is commonly used for assessing parental stress in families with a child with ASD [24,31,41]. Parents rate their agreement or disagreement to each question using a 5-point Likert scale, ranging from strongly disagree to strongly agree, where a higher score means more stress. Parental stress scores are reported in two domains: i) the *Child Domain*, which represents stress resulting from parental perceptions of the child's contribution to the parent–child relationship, and ii) the *Parent Domain*, which represents stress attributed to the impact of the parental role on the parent with respect to psychological well-being, health, marital and other relationships, as well as situational and demographical factors that may cause stress within the family [42]. In addition, a *Total Stress* score is reported to evaluate the overall level of parental stress that one can experience, as well as a *Life Stress* index, which represents stressful dimensions in the life of the parent(s). A parent scoring above the 85th percentile identifies clinically significant levels of stress. A Defensive Responding scale that identifies individuals who may have scored very low, creating bias, is also generated. When the Defensive Responding raw score is low, respondents may be attempting to minimize their stress or their issues between themselves and their child, to create a more favorable impression. A low Defensive Responding score was reported for three mothers, but does not necessarily confirm that a true bias existed, only the potential for a bias [42]. These responders were therefore not excluded from analysis. Scores are reported for all PSI composites and domains but only the Total Stress and the Parent and Child stress domains are discussed in detail.

	N	Percentage
Mother's Age (years)		34.46 (6.01)*
Annual family Income (n=32):		
$5,000–29,999	9	28.10%
$30,000–49,999	11	34.40%
$50,000–69,999	10	31.20%
$70,000–89,999	2	6.30%
Mother's Education (n=31):		
1st-8th grade	1	3.20%
9th-12th grade	2	6.50%
Vocational/some college	10	32.30%
College graduate	10	32.30%
Graduate	8	25.80%
Mother's Job Status (n=32):		
Works full time	1	3.10%
Works part time	9	28.10%
Student	3	9.40%
Homemaker	16	50.00%
Unemployed	2	6.30%
Maternity leave	1	3.10%
Number of dependents (n=32):		
1	4	12.50%
2	17	53.10%
3	8	25.00%
4+	3	9.40%
Marital Status (n=32):		
Married	23	71.90%
Single/Divorced	9	28.10%

Table 1: Family demographic data
*Mean (SD)

While the ADOS and ADI-R are considered the gold-standard for diagnosing ASD [43], they were not designed to assess response to treatment [44], and the scales do not yield age-standardized scores derived from a normative sample [45]. The Pervasive Developmental Disorder Behavior Inventory (PDDBI) is a validated rating scale for assessing response to intervention in children with a pervasive developmental disorder, such as ASD [45,46]. The PDDBI includes 188 items divided into two behavioral dimensions: (a) Approach-Withdrawal Problems, assessing maladaptive behaviors and (b) Receptive/Expressive Social Communication Abilities, assessing social communicative competence. Each of these dimensions is comprised of a number of separate behavioral domains best reflecting that dimension. Each domain, in turn, is comprised of behavioral clusters best fitting that domain. Finally, each cluster consists of four or more items, rated on a four-point Likert scale (never, rarely, sometimes, often), designed to best describe the cluster [47]. Since both adaptive and maladaptive behaviors are assessed on the scale, the PDDBI is useful for treatment studies in which decreases in maladaptive behaviors and improvements in adaptive social and language skills relevant to ASD are expected [46,48]. The PDDBI was standardized for children with ASD, thus a T-Score of 50 with an SD of 10 is typical of children with ASD of a given age [46,49]. Scores above or below this level represent a progressive deviation from the standardization group. Maladaptive behaviors sample a wide variety of behaviors observed in both lower- and higher-functioning individuals and include stereotyped behaviors, fears, aggression, social interaction deficits, and aberrant language [46]. Higher domain T-scores indicate increasing levels of severity. The adaptive behaviors assessed include core features of the disorder such as joint attention skills pretend play, and referential gesture. Higher domain T-scores indicate increasing levels of competence. For the purpose of this study, the PDDBI was completed by the same parent at two-time points: at baseline (T1) prior to any services/interventions being provided to the family and at approximately 20 weeks post-enrolment in the BE program (T2), after considerable intervention and support had been provided. T scores are reported for all PDDBI domains but for brevity, only the Autism Composite, a measure of overall autism severity, is discussed.

Statistical analyses

Assessment of maternal stress and child behavior at intake: The percentage of mothers with clinically relevant *Total Stress* PSI scores and Parent and Child Domains Stress Scores (>85th percentile) at intake were calculated. Similarly, the percentage of children with an *Autism Composite* T-score above 60, between 40-60 and below 40, were also calculated.

Correlation between maternal stress and either demographic data or PDDBI domains: Pairwise correlation analyses were conducted between baseline maternal stress and selected demographic variables. In addition, pairwise correlation analyses were conducted between the maternal stress and the PDDBI composite scores.

Changes in maternal stress and child behavior from T1 to T2: Comparisons between measures assessed before and after participation in the BE program were conducted using the R lavaan package [50], which fits models using full information maximum likelihood (FIML). While all participants completed assessments before and after participation in the BE program, some responses were incomplete. Multiple incomplete responses in the same section of an assessment resulted in some domain scores or composites not being calculated. All validated domain scores/composites were included in each model, including cases in which participants were missing a domain score/composite. FIML estimation fits a maximum likelihood function for each individual case using all available data for each case then combines all cases to generate an overall maximum likelihood estimate of the data. FIML estimation is considered one of the optimal methods for the analysis of missing data [51]. Pre- and post-enrolment means for each of the measures individually were compared with a z-score, which is equivalent to a paired t-test with no missing data (i.e., the test compared whether the means were equivalent at pre- and post-enrolment; a significant effect indicates that there was change in the means between time points). Significant findings are reported when $p<0.05$.

Results

Maternal stress at intake

At enrolment (T1), 72% (23/32) of mothers had clinically relevant *Total Stress* PSI scores. This appeared to be driven by the *Child Domain* Scores rather than *Parent Domain* Scores for which 28/32 (87.5%) versus 6/32 (18.75%) mothers had scores >85th percentile, respectively (data not shown). Furthermore, out of mothers with clinically relevant stress scores at enrolment, 7/23 (30%) had *Total Stress* Scores of ≥ 99th percentile.

Child behavior at intake

At the time of enrolment (T1), 41.9% (13/31) of participants had an *Autism Composite* T-score above 60 indicating greater than average autism symptom severity for children of comparable ages; 54.8% (17/31) of participants had an *Autism Composite* T-score between 40 and 60 indicating average autism symptom severity for children of comparable ages; and 3.2% (1/31) of participants had an *Autism Composite* T-score below 40 indicating below average autism symptom severity for children of comparable ages (data not shown).

Correlation between maternal stress and demographic data

At the time of enrolment, maternal stress was not correlated with selected demographic variables including child age, maternal age, age at diagnosis, family income, and a number of dependents (Table 2). *Correlation between maternal stress and PDDBI composite scores:* Significant correlations between maternal stress and PDDBI composite scores were identified at both time points (Table 3). For brevity, only the *Autism Composite*, a measure of overall ASD severity, is reported here as this composite score takes into account all PDDBI data collected. The *Autism Composite* was correlated with Total Stress: T1: $r=0.67$, $p \leq 0.001$ and T2: $r=0.68$, $p<0.001$; with stress associated with the *Child Domain*: T1: $r=0.71$, $p<0.001$ and T2: $r=0.62$, $p=0.001$; and with stress associated with the *Parent Domain*: T1: $r=0.49$, $p=0.006$ and T2: $r=0.67$, $p<0.001$.

These findings were driven by the following PDDBI domains (data not shown): *Sensory* (T1: $r=0.62$, $p \leq 0.001$ and T2: $r=0.64$, $p \leq 0.001$); *Ritual* (ritualisms/resistance to change, T1: $r=0.38$, $p=0.033$ and T2: $r=0.42$, $p=0.003$); *Arouse* (arousal regulation problems, T1: $r=0.76$, $p \leq 0.001$ and T2: $r=0.67$, $p \leq 0.001$); *Fears* (fears and anxieties, T1: $r=0.50$, $p=0.006$ and T2: $r=0.68$, $p \leq 0.001$); and *Agg* (problems with aggressive behavior towards self and/or others, T1: $r=0.80$, $p \leq 0.001$ and T2: $r=0.81$, $p<0.001$).

Changes in maternal stress from T1 to T2

Mean *Total Stress* scores and stress associated with the *Parent Domain* did not change over time (Table 4, T1: 276.91 *vs.* T2: 272.86, $p=0.45$ and T1: 130.94 *vs.* T2: 133.37, $p=0.368$, respectively). Conversely, stress associated with the *Child Domain* significantly decreased over time (T1: 147.22 *vs.* T2: 139.25, $p=0.013$). Specifically, stress associated with the child's lack of adaptability (AD) and their demandingness (DE) was significantly reduced (AD, T1: 37.38 *vs.* T2: 35.13, $p=0.015$ and DE, T1: 28.47 *vs.* T2: 26.35, $p=0.014$, respectively). The parent's acceptability of their child's behaviors over time approached significance (T1: 21.5 *vs.* T2: 20.28, $p=0.058$).

Changes in child behavior from T1 to T2

Mean *Autism Composite* scores from the PDDBI were not significantly different over time (Table 5, T1: 58.97 *vs.* 56.91, $p=0.178$). However, there was a significant reduction in *Ritual* (T1: 53.0 *vs.* T2: 50.0, $p=0.008$) and *Arouse* (T1: 59.60 *vs.* T2: 56.12, $p=0.019$) domains.

Variable	Child Domain	Parent Domain	Child's Age	Mother's Age	Age at Dx	Time from Dx to Tx	Family Income	# of Dependents
Total Stress	r=.92	r=.90	r=.17	r=.14	r=-.06	r=.20	r=.23	r=-.18
	***p*≤0.001**	***p*≤0.001**	*p*=0.339	*p*=0.436	*p*=0.743	*p*=0.269	*p*=0.200	*p*=0.329
Child Domain		r=.68	r=.18	r=.14	r=.04	r=.16	r=.32	r=-.17
		***p*≤0.001**	*p*=0.311	*p*=0.441	*p*=0.821	*p*=0.368	*p*=0.072	*p*=0.351
Parent Domain			r=.13	r=.12	r=-.14	r=.19	r=.08	r=-.18
			p=0.467	*p*=0.497	*p*=0.453	*p* =0.287	*p*=0.678	*p*=0.335
Child's Age				r=.41	r=.54	r=.92	r=-.25	r=.19
				***p*=0.019**	***p*=0.002**	***p*≤0.001**	*p*=0.164	*p*=0.310
Mother's Age					r=-.12	r=.52	r=.24	r=.44
					p=0.499	***p*=0.002**	*p*=0.192	***p*=0.012**
Age at Dx						r=.19	r=-.37	r=.08
						p=0.311	***p*=0.036**	*p*=0.672
Time (yr) Dx to Tx							r=-.15	r=.18
							p=0.403	*p*=0.333
Family Income								r=.11
								p=0.557

Table 2: Correlations between maternal stress scores and selected demographic variables at the time of enrolment in the BE program
Abbreviations: Dx: Diagnosis; Tx: Treatment

Variable	REPRIT 1	AWP 1	EXSCA 1	REXSCA 1	AUTISM 1	REPRIT 2	AWP 2	EXSCA 2	REXSCA 2	AUTISM 2
	r = .58	r = .72,	r = -.36,	r = -.42,	r = .67,					
Total Stress 1	**p = <.001**	**p = <.001**	p = .048	**p = .028**	**p = <.001**					
	r = .58,	r = .73,	r = -.42,	r = -.48,	r = .71,					
Child Domain 1	**p = <.001**	**p = <.001**	**p = .018**	**p = .012**	**p = <.001**					
	r = .47,	r = .59,	r = -.18,	r = -.29,	r = .49,					
Parent Domain 1	**p = .007**	**p = .001**	p = .325	p = .144	**p = .006**					
						r = .53,	r = .74,	r = -.48,	r = -.48,	r = .68,
Total Stress 2						**p = .005**	**p = <.001**	**p = .014**	**p = .013**	**p = <.001**
						r = .43,	r = .65,	r = -.51,	r = -.51,	r = .62,
Child Domain 2						**p = .029**	**p = <.001**	**p = .008**	**p = .008**	**p = .001**
						r = .58,	r = .75,	r = -.39,	r = -.40,	r = .67,
Parent Domain 2						**p = .002**	**p = <.001**	**p = .05**	**p = .045**	**p = <.001**

Table 3: Correlations between maternal stress scores and PDDBI composite scores at Time 1 and 2
Abbreviations: REPRIT: Repetitive Ritualistic and Pragmatic Composite; AWP: Approach/Withdrawal Problems Composite; EXSCA: Expressive Social Communication Abilities Composite; REXSCA: Receptive/Expressive Social Communication Abilities Composite.

Domain/Composite	Mean (Time 1)	Mean (Time 2)	Difference	*SE*	*z*	*p* value
Total Stress	276.91	272.86	4.049	5.364	0.755	0.450
Child Domain	147.22	139.25	7.973	3.197	2.494	**0.013**
Distractibility/Hyperactivity (DI)	31.750	31.24	0.511	0.769	0.664	0.507
Adaptability (AD)	37.38	35.13	2.245	0.921	2.437	**0.015**
Reinforces Parent (RE)	13.38	12.32	1.054	0.843	1.250	0.211
Demandingness (DE)	28.47	26.35	2.118	0.862	2.457	**0.014**
Mood (MO)	14.75	14.28	0.475	0.597	0.795	0.426
Acceptability (AC)	21.50	20.28	1.225	0.647	1.893	0.058
Parent Domain	130.938	133.373	-2.436	2.706	-0.900	0.368
Competence (CO)	28.78	28.89	-0.104	0.897	-0.116	0.908
Isolation (IS)	15.78	15.56	0.217	0.541	0.402	0.688
Attachment (AT)	10.69	11.31	-0.621	0.527	-1.177	0.239
Health (HE)	14.59	14.70	-0.102	0.677	-0.150	0.881
Role Restriction (RO)	22.09	22.35	-0.252	0.702	-0.359	0.720
Depression (DP)	18.75	20.21	-1.460	0.928	-1.573	0.116
Spouse (SP)	20.25	20.55	-0.297	0.684	-0.434	0.664
Life	9.62	7.50	2.121	1.165	1.820	0.069

Table 4: Change in PSI Domain and Composite Scores from T1 and T2

Domain/Composite	Mean (Time 1)	Mean (Time 2)	Difference	*SE*	*z value*	*p value*
Approach/Withdrawal Problems						
Sensory/Perceptual Approach Behaviors(Sensory)	57.97	56.25	1.72	1.28	1.348	0.178
Ritualisms/Resistance to Change (Ritual)	53	50	3	1.12	2.673	**0.008**
Social Pragmatic Problems (SOCPP)	58.97	56.38	2.59	2.045	1.267	0.205
Semantic/Pragmatic Problems (SEMPP)	52.99	51.86	1.13	1.293	0.876	0.381
Arousal Regulation Problems (Arouse)	59.6	56.12	3.48	1.488	2.34	**0.019**
Specific Fears (Fears)	54.83	53.26	1.56	1.746	0.896	0.37
Aggressiveness (AGG)	58.49	56.3	2.19	1.674	1.305	0.192
Repetitive, Ritualistic, and Pragmatic Composite (REPRIT/C)	*58.87*	56.85	2.02	1.54	1.309	0.19
Approach/Withdrawal Problems (AWP/C)	*58.93*	57.48	1.45	1.685	0.862	0.389
Receptive/Expressive Social Communication Abilities						
Social Approach Behaviors (SOCAPP)	44.84	46.33	-1.49	1.122	-1.326	0.185
Expressive Language (Express)	48.91	49.14	-0.23	0.864	-0.264	0.792
Learning, Memory Receptive Language (LMRL)	46.93	47.38	-0.45	0.903	-0.502	0.616
Expressive Social Communication Abilities Composite (EXSCA/C)	47.1	47.92	-0.82	0.837	-0.979	0.328
Receptive/Expressive Social Communication Abilities Composite (REXSCA/C)	47.68	48.5	-0.82	0.927	-0.879	0.379
Autism Composite (AUTISM)	58.97	56.91	2.05	1.526	1.347	0.178

Table 5: Change in PDDBI Domain and Composite Scores from T1 and T2

Discussion and Conclusion

The challenges of raising a child diagnosed with an ASD are well documented [24]. Research has mostly focused on identifying factors that worsen the clinically significant stress surrounding an ASD diagnosis, including the child's behavior problems, sleep problems, emotion regulation deficits, and cognitive impairment [7,12,52]. It is also clear from the literature that supporting the family and ensuring their emotional and physical health is an extremely important aspect of overall management of ASD [53]. This pilot study investigated whether participation in a well-supported, comprehensive care program for children with autism resulted in a reduction in maladaptive behavior, and thus a reduction in maternal stress.

Consistent with previous studies the results of this study indicated that mothers of children with ASD reported high levels of stress [4,41,53], of particular concern, was the high prevalence (~70%) of clinically relevant levels of stress at enrolment. While the clinical cut-off has been reported as ≥ 90th percentile, baseline PSI scores among participants in this population were considerably higher than in other populations burdened by a high degree of stress, such as parents having a chronically ill child [54]. Specifically, high PSI scores in the *Child Domain* suggest that these children display qualities that make it very difficult for parents to fulfill their parenting roles, leading to dysfunctional mother-child interactions [55]. Negative outcomes have been predicted for parents of children with ASD that report high levels of parenting stress, including the development of anxiety, depression, anger, and reduced marital intimacy [56-59]. Furthermore, high levels of stress may counteract the effectiveness of early intervention for children with ASD [60].

Behavioral assessments were conducted using the PDDBI, a sensitive tool for scoring both adaptive and maladaptive ASD-specific behaviors [46]. The PDDBI consists of 5 composite scores, each derived from a subset of the 10 domain scores. An overall Autism Composite score, which takes into account data from all 10 domains, is also computed and is considered a measure of ASD severity. At enrolment, more than 40% of participants had an above average Autism Composite Score suggesting that the study population included a number of children with greater autism symptom severity than that typical of children with autism of a given age [45].

Maternal stress at the time of enrolment in the BE program was not correlated with the child's age. The literature reports mixed findings with Mash and Johnston reporting that younger children with ASD were perceived as more stressful for parents than older children [61], whereas Bristol reports the opposite was true [62], suggesting that the influence of a child's age on maternal stress requires further study. There is very little data examining the role of maternal age on maternal stress in parenting children with ASD. One study reported that being an older mother of a child with ASD contributed to increased maternal stress [56], although this did not appear to be a significant factor in the current study.

Maternal stress was not associated with family income, although this is recognized as a significant stressor [32]. It has been well established that raising a child with ASD can drain a family's resources due to expenses such as evaluations, home behavioral programs, and various therapies [20,63], many of which are not covered by insurance. All of the families enrolled in the BE program were receiving comprehensive, heavily subsidized services, which may have contributed to a lower level of maternal stress in the present study. Although the majority of mothers in this study were well-educated (almost 60% were college graduates), 34% mothers were either unemployed or working part-time at the time of their child's enrolment in the BE program. Mothers are often the primary caregiver and decision maker for their child with ASD, and therefore have to devote considerable time and personal resources to obtaining health care services for their children [21]. This may reduce the mother's ability to sustain paid employment [22] placing additional restrictions on their parenting role, and affecting their feelings of self-worth.

Maternal stress in the *Total Stress score*, and the *Child* and *Parent Domains,* were significantly correlated with the PDDBI Autism Composite score at both enrolment and post-intervention. This finding was driven by several characteristics of the child's behaviors, including sensory and perceptual approach behaviors, ritualisms and resistance to change, arousal regulation problems, specific fears, and aggressiveness. Post intervention, maternal stress related to the *Child Domain* had significantly decreased. Specifically, stress associated with the child's lack of adaptability and their demandingness was reduced. Noh and colleagues suggest that parenting is particularly affected by both the child's lack of *Adaptability* (e.g. the child's inability to adjust to changes in the social environment) and the child's *Demandingness* (e.g. the frequency and severity of the child's behavioral problems such as crying, disobeying, and seeking attention and requesting assistance [64].

Post intervention, the PPDBI Autism Composite scores were not significantly decreased, however, there was a significant reduction in *Ritual* and *Arouse* domain scores. The *Ritual* domain describes the child's ritualistic and repetitive behaviors and their need for sameness; whereas the *Arouse* domain describes mostly non-communicative or unresponsive behaviors that reflect emotional constriction and problems with self-regulation [45]. As previously discussed, the core deficits associated with ASD such as impairments in social communication, or restrictive/repetitive behaviors are likely the most stressful for parents [9,24].

Overall, the study indicated that there was a positive relationship between maternal parenting stress and ASD severity in children at the time of enrolment in the BE program. Following implementation of a comprehensive treatment program and providing considerable family support over the duration of the program, a significant reduction in children's maladaptive behaviors, such as sensory seeking behaviors and hyperactivity/hypoactivity, and a reduction in maternal parenting stress associated with the child domain, were reported. It is difficult to determine what aspect of the BE program may have contributed to the reduction in maladaptive behaviors since the plan of care was extensive and recommended interventions were tailored for each child. Furthermore, children may have been receiving adjunct therapies outside of the scope of the BE program, which could not be controlled for.

While not a formal part of this study, feedback from study participants through an anonymous and confidential questionnaire provided at the completion of the BE program noted several things. The majority of participants completing the questionnaire reported behavioral services would have been beneficial to include, in addition to the educational recommendations. Furthermore, the weekly calls with the family care coordinator were considered invaluable to families in providing continued support. One parent noted: "Great to have calls every week, I've never heard of such a support system". Another parent noted that "Having someone to report to was vital to keeping us going on the recommendations. It was a great resource for answering questions". The benefits of the weekly phone calls with the family care coordinator were highlighted by the majority of families enrolled in this study and underscore the importance of appropriate parental support in any child intervention program.

There are a number of published studies examining the benefits of a family-centered approach for parents of children with autism. For example, Keen and colleagues examined two types of parent-focused intervention that either included a workshop and 10 home-visits or a self-directed video-based intervention [65]. The professionally supported intervention resulted in reduced child-related parenting stress and increased parenting self-efficacy relative to the self-directed intervention. In another study, mothers of children with ASD who enrolled in a stress reduction intervention for 8 months reported less personal stress and dysfunctional parent-child interactions, as well as less anxiety and depression, and improved sleep and life satisfaction [66]. Since parental stress affects both the parents and the child, as well as the quality of their relationships, parents of a child with ASD would likely benefit from direct and systematic intervention, distinct from those offered directly to the child [4]. Similarly, Tonge and colleagues reported that parent education, behavior management, and counseling interventions resulted in significant improvement in overall mental health and a reduction in anxiety, insomnia and family dysfunction in families with a child with ASD [67]. These, and similar studies indicate that in order to assist families that have a child with ASD, access to family-centered resources, supports, and services are essential. While our study did not provide formal skills training, behavior management, or counseling for parents, all families participating in the BE program were provided with information on disability-specific organizations, advocacy training, grant funding, and respite care providers, as well as resources for accessing appropriate mental health professionals and/or support groups for the parents and siblings.

There are a number of limitations to the current study. The BE program is not a validated intervention for ASD, nor was it designed as such, so there is limited information available regarding its effectiveness. Rather, the BE program provided comprehensive care for children with ASD and their families who might otherwise not have access to such interventions due to financial considerations. The PDDBI was the only standardized ASD assessment included and it is an informant-based assessment rather than a direct measure of the child's behaviors in a standardized setting [43]. Thus, the scores may in part reflect the rater's perceptions and biases. While there are other more commonly used measures for assessing maladaptive (e.g. Childhood Autism Rating Scale) and adaptive (e.g. Vineland Adaptive Behavior Scales) behaviors, the PDDBI examines changes in both adaptive and maladaptive behaviors, and was specifically designed to disentangle change due to treatment/intervention from change due to development [46].

Another limitation of this study is the small sample size and there was considerable variability in subject demographics. For example, the participants included children of varying ages (range 2.1 to 11.6 years of age), and maternal stress is typically associated with having younger children with ASD [61]. The study also enrolled children with diagnoses of Autistic Disorder, PDD-NOS, and Asperger's, and it has been suggested that parents of children with Asperger's have higher levels of stress than parents of children with Autistic Disorder [68]. This could not be examined in this study due to the low number of children participating that had a diagnosis of Asperger's. There was considerable variability in the age at which a child was diagnosed with ASD, and/or the time between the child's diagnosis and study participation. For example, the study included both newly diagnosed children for whom enrolment in the BE program was the parents' first experience with interventions for ASD, as well as older children that had been diagnosed several years earlier for whom the parents had many different experiences with prior interventions, with varying degrees of success.

Finally, the complexity of the interventions provided and the correlational design of the present study do not allow the determination of causal relationships between parental stress and children's behavioral characteristics, and the specific interventions that were implemented.

In conclusion, while the majority of mothers indicated high levels of overall stress at enrolment, stress associated with the parent-child relationship was significantly improved after completion of the BE program. Furthermore, significant improvements in the children's ritualistic and arousal behaviors occurred over time. These findings provide insight regarding the effectiveness of a short-term, a comprehensive intervention program for children with ASD and the importance of developing and providing wide-ranging supports for their parents to help them manage the increased stress levels associated with raising a child with ASD. Service providers should consider these findings when developing intervention programs for children with ASD, and their families. These supports may be critical for family stability, as well as ensuring improved child outcomes.

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Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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Subject	Gender	Age (yr, m)	Ethnicity	ADOS Dx	ADI-R Dx	DSMIV Dx	Age at Dx (yr, m)	Time since Dx (yr, m)
1	M	2y, 1m	Caucasian	ASD	None	PDD-NOS	2y, 1m	<1m
2	M	2y, 6m	Caucasian	Autism	Autism	AD	1y, 11m	7m
3	M	3y, 0m	Caucasian	Autism	Autism	AD	2y, 8m	4m
4	F	3y, 7m	Caucasian	Autism	Autism	AD	3y, 2m	5m
5	M	3y, 8m	Hispanic	Autism	Autism	AD	2y, 2m	1y, 6m
6	M	4y, 0m	Caucasian	Autism	Autism	AD	2y, 4m	1y, 8m
7	M	4y, 5m	Hispanic	Autism	Autism	AD	2y, 7m	1y, 11m
8	M	4y, 5m	Caucasian	Autism	Autism	AD	2y, 11m	1y, 6m
9	M	4y, 6m	Caucasian	Autism	Autism	AD	2y, 10m	1y, 8m
10	M	4y, 8m	Caucasian	ASD	Autism	AD	1y, 10m	2y, 11m
11	M	5y, 5m	Caucasian	Autism	Autism	AD	2y, 5m	3y, 0m
12	F	5y, 7m	Hispanic	Autism	Autism	AD	2y, 2m	3y, 5m
13	M	5y, 7m	Caucasian	Autism	Autism	AD	1y, 11m	3y, 8m
14	M	5,y 10m	Caucasian	Autism	Autism	AD	2y, 8m	3y, 1m
15	M	6y, 5m	Unknown	Autism	Autism	AD	4y, 2m	2y, 2m
16	M	6y, 5m	Caucasian	Autism	Autism	AD	3y, 1m	3y, 4m
17	M	6y, 5m	African Am	Autism	Autism	AD	3y, 7m	2y, 10m
18	M	6y, 10m	Caucasian	Autism	Autism	AD	3y, 2m	3y, 7m
19	F	7y, 2m	Caucasian	Autism	Autism	AD	3y, 10m	3y, 5m
20	M	7y, 5m	Caucasian	ASD	Autism	PDD-NOS	3y, 5m	4y, 0m
21	M	7y, 7m	Caucasian	Autism	Autism	Asperger's	4y, 4m	3y, 4m
22	M	8y, 5m	Hispanic	Autism	Autism	AD	2y, 7m	5y, 10m
23	F	8y, 6m	Hispanic	Autism	Autism	AD	3y, 1m	5y, 5m
24	M	8y, 11m	Caucasian	Autism	Autism	AD	6y, 7m	2y, 4m
25	F	9y, 2m	Caucasian	Autism	Autism	AD	2y, 11m	6y, 5m
26	M	9y, 8m	Caucasian	Autism	Autism	AD	2y, 1m	7y, 7m
27	F	9y, 8m	Caucasian	Autism	Autism	AD	5y, 0m	4y, 8m
28	M	9y 11m	Hispanic	Autism	Autism	AD	5y, 2m	4y, 8m
29	M	10y, 5m	Caucasian	None	Autism	Asperger's	3y, 10m	6y, 7m
30	M	11y, 2m	Caucasian	Autism	Autism	AD	3y, 10m	7y, 5m
31	F	11y, 5m	Caucasian	Autism	Autism	AD	3y, 7m	7y, 10m
32	M	11y, 7m	Caucasian	Autism	Autism	AD	3y, 1m	8y, 6m

Supplemental Table 1: Subject demographic data