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Evaluating the effectiveness of a Portage program on reducing parenting stress and enhancing child development in autism spectrum disorders

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Abstract

Background Autism spectrum disorder (ASD) manifests in early childhood and significantly impairs social and communicative functions. Parents of children with ASD typically experience higher levels of stress compared to parents of children with other disabilities or health issues. This study investigates how a home-based early intervention known as the Portage program influences parenting stress and improves family awareness by using the Parental Stress Scale (PSS), and Family Awareness Scale. We enrolled 41 children diagnosed with ASD and their parents in this study. The median age of the children was 4 years, with a predominance of males (80%). We measured changes in parenting stress and family awareness as primary outcomes, with the children's behavior as a secondary outcome.

Results Post-intervention assessments showed statistically significant improvements in parenting stress and family awareness ($P < 0.001$). Additionally, notable improvements were observed in the children's social, language, self-help, cognitive, and motor skills, as well as general developmental age and ratio.

Conclusions A 3-month engagement with the Portage program markedly reduced stress among parents and increased family awareness regarding ASD. Significant advancements were also noted in multiple developmental domains of the children involved.

Keywords Autism spectrum disorder, ASD, Parenting behavior, Parenting stress, Portage program

Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder presented with impairment of communication and social interaction as well as stereotyped behaviors [1]. In addition to its core symptoms that

interfere with relationships, academic progress, and everyday functioning, ASD is associated with a greater number of challenging behavior problems than any other developmental disability. These include both externalizing behaviors such as aggression and self-injurious behavior and internalizing problems such as anxiety. This, in turn, may negatively affect parents, and other family members, leading to adverse physical issues, chronic stress, depression, and anxiety [2–4].

Stressed parents frequently report issues with their families, such as marital conflict, decreased parental satisfaction and well-being, diminished parental competence and social support, as well as ineffective parenting. Their children are more likely to experience behavioral problems, subsequent psychopathology,

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depression, and a lower quality of life overall [5]. It is widely accepted that there are bidirectional influences between the well-being of children with ASD and that of their family members. The rise in parents' stress may lead to increased child behavior problems, thus likely creating further stress for parents [6, 7].

It is clearly established that parents of children with ASD experience significant levels of stress, at even higher rates than those with children who have other developmental disabilities or are typically developing [8–10].

Parents play a crucial role in obtaining tests and diagnoses, choosing and organizing treatment plans, controlling unusual behaviors, and working to further their child's educational and developmental abilities during the preschool years [11]. Parent involvement in behavioral treatment is considered a key element in the success of behavior therapy [7]. Unfortunately, parents with impaired psychological well-being and increased stress are less likely to participate in treatment for their children. Additionally, parent stress may reduce or mask the positive effects of ASD intervention [12].

There has been a noticeable surge in efforts to involve parents as integral contributors to ASD treatment, yet the exploration of how treatment engagement impacts parent stress remains largely unexplored in the existing literature [12, 13]. This gap underscores the necessity for more comprehensive, family-centered research approaches aimed at understanding the multifaceted effects of ASD, encompassing both the child and their familial support system. Notably, the Portage program stands out among the limited initiatives tailored for children with special needs, emphasizing the inclusion of families in decision-making processes regarding service types and associated interventions [14]. Despite these strides, studies investigating the influence of parenting behaviors on ASD are notably scarce [15], particularly within the Middle Eastern context, where interventional research addressing this crucial knowledge gap is notably absent. Therefore, this study within the Egyptian context serves as a pioneering effort to bridge this evident dearth of studies, offering valuable insights into the interplay between parenting dynamics and ASD outcomes within this unique cultural landscape [16].

Methods

Study design and setting

A quasi-experimental study was conducted in the autistic clinic et al. Kasr-Al Eini. The clinic serves children up to the age of 12 years.

Study participants

Forty-one children with ASD aged 2 to 12 years with their parents who were responsible for their home-based care participated in this study. Children were recruited according to their complaints, history, and diagnosis as shown in their medical records. In order to control for the confounding effects (e.g., neurological illnesses and medical treatments), the following exclusion criteria were established: children with neurological disease, children with severe mental retardation, and caregivers who had received any form of psychological education in the previous year specifically directed at alleviating the burden.

Sample size

Stata[®] 18 was used to calculate the sample size of a quasi-experimental single group pre-post study. Assuming 80% power, 0.05 level of significance, based on evidence from a previous similar study [17] and by considering the mean (\pm SD) parental stress score of 48.6 (\pm 9.9) and 42.7 (\pm 9.3) at baseline and follow-up, respectively, the sample size would be 27 participants. Adding 20% to anticipate dropout, a 33 participant is the minimally required sample for this study. The final analyzed total sample size was 41 participants.

Data collection tools

Demographic data of studied children with ASD were collected by the researcher and included age, sex, residence, birth order, number of siblings, history of consanguinity, parents' education, and parents' jobs.

Parental Stress Scale (PSS) is a scale intended to be used for the assessment of parental stress associated with parenting among both parents (mothers and fathers) of children younger than 12 years. It contains various measures of stress, emotion, and role satisfaction, including perceived stress, work/family stress, loneliness, anxiety, guilt, marital satisfaction and commitment, job satisfaction, and social support. It consists of a total of 101 item measures concerning life stress as follows:

- Child standards comprise 47 items (11 items for adaptability, 7 items for acceptability, 9 items for demandingness, 5 items for mood, 9 items for distractibility and hyperactivity, and 6 items for reinforcing parenting).
- Parent standards include 54 items (9 items for depression, 7 items for attachment, 7 items for restriction of role, 13 items for sense of competence, 6 items for social isolation, 7 items for relationship with spouse, and 5 items for parental health).

PSS includes 13 subscales distributed in two areas: child domain which includes 6 subscales and parent domain

which includes 7 subscales. This scale was applied by the researcher to both parents. In the case of households with more than one child, parents should provide responses about their typical relationship with their child. There are no right or wrong answers and questions need to be asked as they are written in the questionnaire. A previously tested and validated Arabic version of the PSS was used by Abidin [18]. It was completed and calculated by the researcher.

Family Awareness of Life Skills of Autistic Child Questionnaire (ISBN: 978-977-05-977-2928-7, e-mail: angloeb@anglo-egyptian.com), this scale consists of 72 phrases divided into two main categories collected and calculated by the same researcher:

- Family awareness of the social skills required for autistic children and for sub-indicators is devoted to this dimension, including social activities, social communication, social attention, awareness of place, and discrimination of persons.
- Family awareness of the independence skills required for the autistic child, with three sub-indicators devoted to this dimension: eating skills, dressing skills, and personal hygiene skills.

Portage is a home-based program for preschool children with special educational needs [19]; it was conducted by three authorities in southeast England. The Portage program has been extensively used with children who suffer from developmental delays and has been developed for children with ASD. The administration of the Portage program was supervised by a qualified portage trainer, abiding by a manual that was written by the portage service providing the program.

Follow-up was continued for 3 months by sessions every 2 weeks where each session lasted for 2 h. Assessment of parents and child education and application to the Portage program were done during follow-up visits, and the final reassessment was undertaken with all tools. The evaluation of the outcome and the intervention was also done by the same researcher under supervision by a qualified Portage trainer.

Statistical analysis

Data were fed to the computer and analyzed using IBM SPSS® software package version 20.0. (Armonk, NY: IBM Corp). Qualitative data were described using numbers and percentages. The Kolmogorov–Smirnov test was used to verify the normality of distribution. Quantitative data were described using mean, standard deviation, median, and interquartile range. The significance of the obtained results was judged at the 5% level. Wilcoxon signed ranks test for abnormally distributed quantitative

variables was employed to compare between two periods. Correlation was used to measure the degree to which two parameters move in relation to each other. Correlations are computed as the Spearman correlation coefficient (r), which has a value that must fall between -1.0 and $+1.0$.

Results

Forty-one children with ASD were included in this study and their responses were analyzed. Table 1 shows the basic demographic characteristics and the median age of the included children with ASD (4 years). 80% of the samples were males, and almost two-thirds of them (59%) lived in urban areas. More than one-third of them were the first (44%) among their siblings. The median number of siblings was 2 siblings. Consanguinity was present in 32% of them. The majority of fathers were employed (71%), with 46% having obtained their high school certificate (46%). The majority of mothers were housewives (76%) who were college graduates (34%) and secondary school graduates (32%).

Table 2 shows highly statistically significant improvement after the intervention when compared to pre-intervention results in all domains of PSS (parents, child, and total), family awareness (social, independence, and total), general developmental age, and Portage program parameters (socialization, language, self-help, cognitive and motor). Table 3 reveals the percentage of change in domains of PSS where the parents' domain reported higher change than the child domain (6.67% vs 6.52%, respectively). Table 3 demonstrates the percentage of change in family awareness where independence improved by 9.09%. Table 4 shows the correlations between the percentage of change in PSS and that of family awareness where parents' PSS score was significantly positively correlated with total PSS score ($r=0.709$, $P<0.001$). Moreover, the percentage change in total family awareness score was significantly positively correlated with both social and independence dimensions scores ($r=0.836$ and 0.795 , respectively, $P<0.001$).

Discussion

Parenting of a child with ASD is challenging, the inclusion of the parents and families of such children may yield beneficial outcomes for both of them. The Portage program has achieved positive results among children with simple intellectual disabilities, yet its effectiveness in ASD is inconclusive. Our study demonstrated that a 3-month intervention using the Portage program significantly alleviated parental stress and enhanced family awareness about ASD, confirming the program's efficacy in a Middle Eastern context. The improvements observed in parental stress align with findings from similar intervention studies, such as those conducted by Goedeke

Table 1 The distribution of age, gender, and order in the study population (no. = 41)

Variables	Median (IQR)
Child age in years	4.0 (3.0–7.0)
Number of siblings	2.0 (1.0–3.0)
Variables	No. (%)
Sex	
• Male	33 (80%)
• Female	8 (20%)
Birth order	
• First	18 (44%)
• Second	8 (20%)
• Third	10 (24%)
• Fourth	3 (7%)
• Fifth	2 (5%)
Residence	
• Rural	7 (17%)
• Urban	24 (59%)
• Suburban	10 (24%)
Father's job	
• Manual work	11 (27)
• Employer	29 (71)
• Professional	1 (2)
Mother's job	
• Housewife	31 (76%)
• Manual work	7 (17%)
• Employer	2 (5%)
• Professional	1 (2%)
Level of mother education	
• Illiterate	3 (7%)
• Primary school	11 (27%)
• Secondary school	13 (32%)
• College or higher	14 (34%)
Mother age (mean ± SD)	32.1 (6.3)
Level of father education	
• Illiterate	2 (5%)
• Primary school	7 (17%)
• Secondary school	19 (46%)
• College or higher	13 (32%)
Smoking	12 (29%)
Consanguinity	13 (32%)

IQR inter-quartile range

et al. in 2019 who revealed that healthcare providers' support was associated with a reduction in parents' care-related stress levels and concluded that parents are in need of education and support to help them in caring their children with ASD on an ongoing basis [20]. However, there is some evidence that parent involvement in interventions can increase parental stress as shown in Rivard and his colleagues' findings that their parent

training program, despite effectively reducing behavioral problems among children with ASD, led to a significant increase in parental stress after a year of treatment and explained that as participating parents perceived the coaching program as insufficient for fully treating their children's needs [21]. This difference could be rendered to cultural or methodological influences.

Additionally, implementing the Portage program among children with ASD in our study could produce positive changes in different child behavioral aspects such as social, language, self-help, cognitive, and motor skills. This is rendered to our implemented Portage program as it reduced the confusion of the parents about ASD, taught the parents and the families, and helped them to acquire the skills of optimal management of their children with ASD. This program promoted the positive constructive patterns of raising their children with ASD providing a lifelong approach to the studied parents, also, the program was directed to relieve their burden. The improvements resulted in child behavior in our study are in line with findings from similar intervention studies, such as Beaudoin and colleagues who demonstrated improvement in motor and social skills ($p=0.005$, 0.053 respectively) for children at risk of ASD, as well as in parent-child engagement ($P=0.01$) after 3 months of parental-mediated intervention [22]. Similarly, Al-Slaim and Al-Jdoua et al. (2020) found in their randomized controlled trial a significant enhancement in motor imitation skills among children with ASD after the application of a training program based on behaviorism [23]. As well as a recent systemic review concluded that interventions that included parents of children with ASD at school age had more moderately positive effects than those with children only [24]. Similarly, there is a general agreement from several studies that the early intervention with a Portage program had achieved positive outcomes on parents' perception and understanding of their children's conditions as well as improvements in different aspects of the behavior of children with special needs [14, 25, 26].

Our study revealed that percent change in both parenting stress and family awareness were not associated with their socio-demographic characteristics such as child's age, mother's age, and number of siblings. Likewise, Rovane et al. (2020) [12] found that child age had a non-significant correlation with parent stress. In contrast, McStay et al. (2014) [27] suggested that the association of child and parent characteristics with parenting stress is important to consider in interventions, like Portage programs, yet contrast with others, suggesting cultural or methodological influences.

Given the significant reductions in parental stress and enhancements in child development documented in our study regardless of the child's age, mother's age, or

Table 2 Comparing PSS, family awareness, and Portage program at baseline and post-intervention (no. = 41)

Scale	Baseline median (IQR)	Follow-up median (IQR)	P value*
Parental Stress Scale			
• Child domain score	179 (169:184)	169 (152:174)	<0.001
• Parents domain score	197 (193:208)	182 (178:196)	<0.001
• Total score	378 (367:393)	352 (338:365)	<0.001
Family awareness			
• Social skills domain	84 (78:90)	90 (82:94)	<0.001
• Independence skills domain	73 (65:81)	80 (70:89)	<0.001
• Total score	159 (144:169)	171 (152:182)	<0.001
General development age	42 (26:60)	53 (30:61)	<0.001
General development ratio	65 (57:71)	67 (59:73)	<0.001
Portage			
• Socialization	48 (29:61)	52 (39:63)	<0.001
• Language	48 (24:60)	49 (26:60)	<0.001
• Self-help	48 (26:60)	50 (28:60)	<0.001
• Cognitive	48 (26:60)	49 (28:64)	<0.001
• Motor	50 (30:60)	52 (32:61)	<0.001

* Wilcoxon-signed ranks test

Table 3 Percentage of change in PSS and family awareness (no. = 41)

Percent change in PSS	Mean ± SD	Median (IQR)
• Child domain score	5.95 ± 6.12	6.52 (4.44:8)
• Parents domain score	6.57 ± 2.56	6.67 (4.85:8.59)
• Total score	6.3 ± 3.29	6.23 (5.28:8.16)
Percent change in family awareness		
• Social	7.27 ± 4.86	7.29 (5.81:8.89)
• Independence	9.68 ± 4.34	9.09 (6.67:10.96)
• Total	8.2 ± 4.3	7.78 (5.92:9.94)

The outcomes of our research contribute to the theoretical understanding of Portage program impacts on ASD, particularly highlighting how structured parental involvement can modify the trajectory of child development and parental well-being.

Conclusions

A 3-month Portage program could achieve a significant improvement regarding the stress for parents and their children with ASD and family awareness concerning the autistic child as well as improvements in social, language, self-help, cognitive, and motor skills.

number of siblings, the implementation of the Portage program could be considered a viable addition to current therapeutic strategies for families dealing with ASD.

Strength and limitation

One of the notable strengths of this study is its focus on the Egyptian context, which provides unique insight

Table 4 Correlation of percentage change in PSS, family awareness, and demographic data (no. = 41)

Variables	% change in PSS				% change in family awareness					
	Parents		Total		Social		Independence		Total	
	R	P	r	P	r	P	R	P	R	P
Parents % change			.709**	<0.001	.047	0.772	-.161	0.316	.092	0.565
Total PSS % change	.709**	<0.001			0.066	0.683	-.291	0.065	-.078	0.629
Social % change	-.047	0.772	0.066	0.683			.564**	<0.001	.836**	<0.001
Independence skills % change	-.161	0.316	-.291	0.065	.564**	<0.001			.795**	<0.001
No. of siblings	-.036	0.824	-.095	0.554	-.151	0.347	0.028	0.862	.030-	0.854
Child age	0.032	0.841	.106	0.51	0.022	0.891	0.043	0.788	.091	0.571
Maternal age	0.242	0.127	0.184	0.248	0.038	0.812	.186-	0.244	.177	0.268

r Spearman correlation coefficient

into how early intervention programs like Portage can be adapted and effectively implemented in culturally distinct settings. While our findings are promising, they must be considered in light of the study's limitations such as the relatively small sample size and its limited generalizability beyond the immediate cultural setting, in addition to a wide range of included children as the level of stress and parenting of young children may differ from those of older children. There were some limitations that emerged while conducting this study as the absence of children from some follow-up visits when they were busy with their exams and only parents came for the study follow-up. In addition to merging all responses from mothers and fathers as one category due to the small number of fathers as they may experience parental stress differently from mothers, it is recommended to examine parenting stress in mothers and fathers distinctively.

Abbreviations

ASD Autism spectrum disorder
PSS Parental Stress Scale

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Authors' contributions

RB, MS, OA, Sh E, and SS contributed equally to the study. All authors have read and agreed to the submitted version of the manuscript.

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Availability of data and materials

Available on request.

Declarations

Ethics approval and consent to participate

Ethical approvals were obtained from the research committee at the Faculty of Medicine, Cairo University, Egypt, and the ethical and research committee of the Family Medicine Department. Objectives of the study were explained to all participants and informed written consent was obtained at the start of the study. We confirm that the participants' data was not used for any other purpose beyond this study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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