

Predictive components in the structure of an intensive, parent mediated, early intervention for children with autism spectrum disorders in India

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Abstract

Introduction: The predictive factors of parent mediated, Early Intervention (EI) for children with Autism Spectrum Disorders (ASD) have not been studied in India; we document the structural therapeutic factors, which predict the EI outcome. **Methods:** Data of 77 children with an ICD 10 diagnosis of Pervasive Developmental Disorder (ASD in DSM 5), and completed a 12-week EI with proven effectiveness was collected from the database of a teaching hospital. We studied the structural therapeutic factors associated with EI outcome, as measured by Psycho-Educational Profile-Revised (PEP-R), while controlling the confounders with multiple linear regression analyses. **Results:** The Fine-motor skills improved in residential patients (t = 2.54, *P* = 0.02; 15 units). As the duration of intervention decreased at home per day, there was a significant decrease in Gross-motor skills (t = -2.67, *P* = 0.02; -15 units). With increase in duration of intervention in hospital per day, there was a significant increase (t = 2.86, *P* = 0.01; 30 units) in the Eye-hand integration. Cognitive-verbal skills acquisition decreased (t = -2.90, *P* = 0.01; 33 units) as the duration of intervention decreased at hospital. The use of medication did not predict any of the outcome factors. **Conclusion:** The above mentioned predictive factors should be monitored and titrated in the family context when children with ASD undergo parent mediated, EI programme. It is important to that the multidisciplinary family medicine teams reinforce these parents, who are the main column of support in primary-care settings for children with neuro-developmental disabilities in India.

Keywords: Autism, early intervention, India, parent-mediated, predictive factors

Introduction

The interventions using different approaches, for children with Autism Spectrum Disorders (ASD) in India, have been found to be effective.^[1] Among them, the effectiveness of a low intensity home-based and another clinic-based approaches have been documented^[2,3] Similarly, the effectiveness of an intensive, parent mediated, multi-component, early intervention for children with ASD has been described in a tertiary-care setting in India.^[4] Moderate to significant effect size has been

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Received: 05-06-2019 Revised: 06-06-2019 Accepted: 24-06-2019

Access this article online							
Quick Response Code:	Website: www.jfmpc.com						
	DOI: 10.4103/jfmpc.jfmpc_441_19						

demonstrated in the core features of ASD with this approach.^[4] However, as this form of intervention includes high level of multimodal inputs, including medications, it is essential to identify the therapeutic components that need to be further modified to have the best outcome in each of the targeted domain. In psychological interventions, the therapy components are broadly divided in to the structural factors (e.g. the frequency of therapy, duration of each session of therapy, the overall duration of intervention), content of therapy (e.g. the therapy is focused on cognitive domain, adaptive domain, coping skills, any specific problem identified by therapist or the patient) and process of therapy (e.g. the modality of approach, the patient-therapist dynamics). None of the 3 major group of factors mentioned above has been studied for parent mediated EI for ASD in the

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How to cite this article: Viswanathan SA, Russell PS. Predictive components in the structure of an intensive, parent mediated, early intervention for children with autism spectrum disorders in India. J Family Med Prim Care 2019;8:2218-22.

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Indian context. We hypothesise that there are specific structural therapeutic factors associated with such intervention outcomes. Therefore, the aim of this study is to identify the structural therapeutic factors associated with the intensive, parent mediated, multi-component, early intervention for children with ASD in India.

Methods

Setting and sample

This retrospective study based on chart review was conducted at the Autism Clinic of a teaching hospital in South India. The data of participants, enrolled over three years, were collected from their case records. All had an ICD-10 diagnosis of Pervasive Developmental Disorder (PDD), which includes Childhood Autism (F84.0), Atypical Autism (F84.1), Rett's Syndrome (F84.2), Other Childhood Disintegrative Disorder (F84.3), Asperger's syndrome (F84.5), Pervasive Developmental Disorder Unspecified (F84.9); the diagnosis of Overactive disorder associated with mental retardation and stereotyped movements (F84.4) was excluded because of its uncertain nosological status. These PDD categories are termed as ASD in this study for consonance with the current DSM 5 or future ICD 11 classificatory systems. All clinical diagnoses were made by consultant Child and Adolescent psychiatrists and endorsed by the multidisciplinary team consisting of Clinical Psychologists, Applied Psychologists, Rehabilitation Psychologist, Occupational Therapists, Speech and language Therapists, Special Educators and Specialist nurses with 4-22 years of experience.

Measures

The outcome measure for the intervention was Psycho-Educational Profile-Revised (PEP-R), which gives the global developmental age; imitation and perception, fine motor, gross motor, eye-hand coordination, cognitive performance and cognitive verbal are its subscales. The global developmental age of PEP-R has been validated for children with autism in India.^[5] The difference between the pre-intervention (measured in the 1st week of intervention) and post-intervention (measured in the 12th week of intervention) PEP-R global as well as subscale scores, rated in months were the dependent variables. The independent variables were the number of hours of intervention per day in the hospital (two to four hours), the time spent in following the intervention at home (1-5 hours), attending the intervention on an out-patient or residential basis. The confounding variables were the severity of ASD, severity of comorbid Global Developmental Delay (GDD) and the functional ability of the child measured with Autism Diagnostic Observation Schedule (ADOS),^[6] Gesell's Developmental Schedule (global developmental age scoring has been suggested elsewhere for the original versions)^[7,8] and Vineland Social Maturity Scale (VSMS),^[9] respectively. The study was reviewed and approved by the local Institutional Review Board and Ethical Committee (IRB number 2012/7822). Informed consent was not required because of the retrospective nature of this study; however, reversible anonymization of data was done to protect patient confidentiality and identity.

Intervention

The intervention was for 12 weeks, and the content of the intervention was based on Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH), PEP-R and The Carolina Curriculum for Infant and Toddlers with Special Needs.^[10] Throughout the 12-week program, the parents-using interactive group psycho education techniquewere taught about various aspects of autism and developmental disabilities.^[11] The process of the intervention was that each session of the therapist guided, parent mediated intervention process would start with a ten minute briefing about the goals for the day which are set on a weekly basis. The child was engaged in play routines and social stories (with parent as co-therapist); each parent-child dyad received applied behaviour analysis aimed at improving the behavioural control as well as interactive skills of parents using principles of rewarding and guided practice. The structure of the intervention was in the form of closed group conducted 5 times a week by 2 therapists (one Occupational therapist, one speech and language therapist) and each session lasted for 2-4 hours. The parents were encouraged to continue the intervention at home using adaptations to suit the home environment. Atypical antipsychotic medication was added to the intervention for target symptoms; details of the intervention are published elsewhere for further reading.^[4]

Statistical analysis

After ruling-out the violation of assumptions for the regression analyses, different multiple linear regression analyses were conducted with the continuous variables of the difference in global developmental score and various sub-scale scores as dependent variables. The influence of number of hours of intervention per day in the hospital, the time spent in following the intervention at home, attending the intervention on an out-patient or residential basis were studied as independent variables. The confounding effects of the severity of ASD, GDD and baseline functional ability of the children were controlled. All tests were two tailed, constant was included in all regression analyses, variance explained by the regression model was evaluated with R², and P of ≤ 0.05 was considered statistically significant; all analyses were done using SPSS (Version 16.0. SPSS Inc., Chicago, IL, USA).^[12]

Results

Participant characteristics

The mean (SD) chronological age of the 77 children in the study was 3.66 (1.64) years. Among the participants there were more boys (81.8%) than girls (18.2%) in the sample. The mean (SD) scores of the global developmental score, and the various PER-R subscale scores (dependent variables) are documented in Table 1.

Outcome facto	rs		Predictive	e factors	Co	Model variance				
PEP R Subscale* (months)	Difference in Mean (SD)	Training hrs [†] perday <i>P</i> , β (95%CI)	Training home hrs ^{\dagger} per day <i>P</i> , β (95%CI)	Training setting <i>P</i> , β (95%CI)	Medications P, β (95%CI)	ID severity <i>P</i> , β (95%CI)	ASD severity <i>P</i> , β (95%CI)	Baseline function P, β (95%CI)	R^2	
Imitation	8.72 (7.13)	P=0.49 $\beta=13.95$ (-29.70, 57.61)	P=0.68 $\beta=2.79$ (-12.05, 17.64)	P=0.29 $\beta=-6.94$ (-20.94, 7.05)	P=0.50 $\beta=4.70$ (-10.14,19.54)	P=0.59 $\beta=0.67$ (-2.05,3.39)	P=0.73 $\beta=0.65$ (-3.36,4.66)	P=0.03 $\beta=8.53$ (1.11,15.95)	0.52	
Perception	13.56 (9.15)	P=0.99 $\beta=-0.42$ (-52.56,51.71)	P=0.40 $\beta=-6.99$ (-24.72,10.74)	P=0.72 $\beta=-2.75$ (-19.47,13.96)	P=0.61 $\beta=-4.23$ (-21.95,13.49)	P=0.42 $\beta=-1.23$ (-4.48,2.20)	P=0.69 $\beta=-0.89$ (-5.69, 3.90)	P=0.71 $\beta=-1.54$ (-10.41,7.32)	0.26	
Fine motor	10.35 (7.28)	P=0.17 $\beta=27.82$ (-14.18,69.82)	P=0.38 $\beta=-5.85$ (-20.13,8.44)	$P=0.03 \\ \beta=15.40 \\ (1.94,28.87)$	$P=0.20 \\ \beta=8.75 \\ (-5.52,23.03)$	$P=0.61 \\ \beta=0.62 \\ (-1.99, 3.24)$	$P=0.09 \\ \beta=3.28 \\ (-0.59,7.14)$	$P=0.31 \\ \beta=3.41 \\ (-3.74,10.55)$	0.48	
Gross motor	11.29 (8.41)	P=0.09 $\beta=31.28$ (-6.21,68.78)	P=0.02 $\beta=-15.33$ (-28.08, -2.58)	P=0.08 $\beta=10.40$ (-1.62,22.42)	P=0.16 $\beta=8.80$ (-3.94,21.55)	P=0.31 $\beta=-1.12$ (-3.46,1.21)	P=0.04 $\beta=3.76$ (0.313,7.21)	P=0.002 $\beta=11.62$ (5.24,17.99)	0.72	
Eye hand integration	11.24 (6.65)	P=0.02 $\beta=30.73$ (6.82,54.64)	P=0.33 $\beta=-3.71$ (-11.84,4.42)	P=0.11 $\beta=6.13$ (-1.53,13.80)	P=0.59 $\beta=2.06$ (-6.07,10.18)	P=0.13 $\beta=-1.11$ (-2.60,.379)	P=0.07 $\beta=2.04$ (-0.162,4.23)	P=0.27 $\beta=2.11$ (-1.95,6.18)	0.77	
Cognitive perceptual	9.79 (5.39)	<i>P</i> =0.49 β=9.00 (-19.10,37.11)	$\begin{array}{c} P=0.20\\ \beta=-5.86\\ (-15.42, 3.69)\end{array}$	P=0.88 $\beta=-0.62$ (-9.63,8.39)	P=0.96 $\beta=0.24$ (-9.32,9.79)	P=0.19 $\beta=-1.11$ (-2.86,.64)	<i>P</i> =0.98 β=-0.03 (-2.61,2.56)	<i>P</i> =0.07 β=4.40 (-0.38,9.18)	0.45	
Cognitive verbal	7.31 (6.06)	<i>P</i> =0.02 β=-33.89 (-59.89,-7.88)	<i>P</i> =0.59 β=2.21 (-6.64,11.05)	<i>P</i> =0.38 β=-3.43 (-11.77,4.90)	P=0.30 $\beta=-4.32$ (-13.16,4.52)	<i>P</i> =0.05 β=-1.62 (-3.24,0.00)	<i>P</i> =0.04 β=-2.48 (-4.87,-0.08)	P=0.17 $\beta=2.94$ (-1.48,7.36)	0.69	
Developmental score	8.00 (4.55)	<i>P</i> =0.40 β=6.07 (-9.21,21.36)	P=0.23 $\beta=-2.97$ (-8.17,2.23)	P=0.11 β=3.84 (-1.06,8.74)	P=0.16 β=3.59 (-1.61,8.78)	P=0.34 β=-0.42 (-1.38,0.53)	P=0.19 $\beta=0.89$ (-0.52,2.29)	P=0.001 $\beta=5.25$ (2.65, 7.85)	0.77	

Гabl	e 1:	T	he pred	lictor an	nd c	lepende	ent var	riabl	es in	the n	nultiŗ	le	linear	regression	n anal	lyses	with	confe	ounder	's con	trolle	d
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*=Psycho-Educational Profile-Revised. *=Hours

The mean (SD) of the number of hours of intervention per day in the hospital was 3.06 (1.71) hours, the time spent in following the intervention at home 1.12 (3.32) hours, and 24 (31%), and 53 (69%) attended the intervention on an out-patient or residential basis; there were 58 (75%) participants on atypical antipsychotic (mostly oral Risperidone of 0.25-1mg per day). All of them had 10.7-12 weeks of training. The mean (SD) ADOS score and functional ability (social age) in VSMS was 22.11 (3.19) and 2.18 (0.84) years respectively. There were 66 (86%) with comorbid GDD.

The predictive effect

The Fine-motor skills improved in residential patients than those attending as outpatients (t = 2.54, P = 0.02; 15.40 units). As the duration of training (in hours) decreased at home per day there was a significant decrease in Gross-motor skills acquisition (t = -2.67, P = 0.02); for every unit decrease in the time of training at home there was 15 unit decrease in the Gross-motor skills acquisition. With increase in duration (in hours) of intervention per day in the hospital, there was a significant increase in the Eye-hand integration (t = 2.86, P = 0.02); every unit increase in the duration (in hours) of intervention per day in the hospital, there was a significant increase in the duration (in hours) of intervention per day in the hospital there was 30 units of increase in the Eye-hand integration. As the duration of training (in hours) decreased at hospital per day, there was a significant decrease in Cognitive-verbal skill

acquisition (t = -2.90, P = 0.01). Thus, for every unit decrease in the time of training at hospital, there was 33 units decrease in the Cognitive-verbal skill acquisition [Table 1]. The Gross-motor skills also demonstrated a statistical trend towards receiving intervention as residential patient and duration (in hours) of intervention per day in the hospital. The medication factor did not statistically significantly predict any of the outcome variables. The outcome of Imitation, Perception, Cognitive-perception subscales and the global developmental age were not predicted by any structural factor. The effect of the baseline functional ability significantly predicted the global developmental score as well as some subscales [Table 1], and was statistically controlled for its confounding effect. Similarly, the severity of ASD and ID significantly predicted some of the subscales, and were statistically adjusted for their confounding effects [Table 1]. The R² values for the various multiple regression models ranged from 0.26 to 0.77.

Discussion

It is documented that interventional research for ASD in low resource setting poses unique challenges. The impediments documented and therefore needs further research are the service delivery, graded care, health economic, awareness, misconceptions, delay in diagnosis and initiation of intervention in relationship to ASD.^[13] This study thus adds data to an important area of EI research in India.^[14]

In our previous research we established the effectiveness of an intensive, parent mediated, multi-modal early intervention for children with ASD.^[4] Hence, now it important to study factors that predict the intervention effectiveness. In such high input interventions, it is important to study the structure, content and process of the therapy; in this research we recorded the effect of the structural factors related to the intervention, which we have proven to be effective. It is interesting in this perspective to note that TEACCH as a stand-alone intervention has been documented as not so effective in children with autism.^[15] In our study, it is possible that TEACCH when combined with PEP-R and Carolina Curriculum for infants and toddlers' components of intervention, there is an add-on effect on the outcome effectiveness by other two intervention components. This speculation has to be further studied with factorial design methods in the future.

In our study of the structural factors studied, the improvements in Fine and Gross motor domains have been significant associated with the attending of intervention as residential patient. It is important to improve the motor performance in early intervention services for young children with ASD as it improves other areas of functioning, especially the visuo-spatial cognition and language functioning.^[16,17] Further factors in residential care like the milieu where they have more self-supportive interactions resulting in better outcomes is speculated and further studied. Secondly, the duration of intervention at home per day and duration of intervention in hospital per day has been found to be significant predictors of favourable EI outcome for Motor skills, Eye-hand integration and Cognitive-Verbal skills. This has been repeatedly documented in studies across the globe, which encourages a weekly intervention duration of approximately 40 hours, as critical, for the best outcomes.^[18] It is interesting to note that in our current study, the medication given to children did not statistically significantly influence the outcome that we measured. The implications of the positive findings are essentially that the intervention package should have a module for time management at home. This is important as the parent involved in the EI invariably has multiple roles in the family, and has to make plans to enhance the continuity of training at home; planning the time to help the child in improving the motor skills, ability to progress in integration of eye-hand functioning as well as the ability to conceptualise and communicate is pivotal. Other structural factors from the stance of Systems Theory has to be further characterised, especially the effect of the subsystems (eg. grandparents) in the home mileu and the role of supra-systems (like informal crèches, play-schools, toddler groups). These factors have to be incorporated in the future studies.

The strength of the study, firstly, is the identification of ASD by a multidisciplinary team based on the reference diagnosis of ICD 10. Secondly, the quantification of the intervention and the structural factors in the therapy has been quantified in an appropriate and standardised manner. In addition, the confounding effects of other variables that can influence the effectiveness of the parent mediated early intervention were statistically adjusted. The limitation of the study is the small sample size, and therefore precludes studying other factors associated with the content and process of the intervention.

The clinical utility of this study is that the higher duration of intervention at home per day and children with ASD receiving EI as residential patients predicts better intervention outcomes. These therapeutic factors that are within the control of family members need to be addressed in the family settings and other primary-care settings; the monitoring and dosing of these factors are crucial elements in maintain the required minimum training of children within their therapeutic window period of below 3 years of age. The involvement of family medicine physicians and other primary-care physicians, the first port of call for families with a child with neuro-developmental disability and in a unique position as gate-keepers for families' resources, will undoubtedly play critical role in the acquisition of the adaptive behaviours by coaching in context of these children.^[19] It has been documented that low-intensity Home-based EI have beneficial in the Indian context, with high neuro-developmental disability burden and low disability resources^[3] Thus, from a primary-care research perspective, it is imperative for the family physicians and primary-care physicians to identify the predictive components for enhancing the outcome of low-intensity Home-based EI in India.

We conclude that for the domains of Fine-motor, Gross-motor, Eye-hand integration and Cognitive-verbal skills in a child with ASD to improve, the duration of intervention given at home per day, overall duration of training per day, administering intervention as a residential patient are effective in predicting effective outcomes in intensive, parent mediated, early ASD intervention in India.

Financial support and sponsorship

Fluid Research Grant.

Conflicts of interest

There are no conflicts of interest.

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