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3 Parent training for Autism Spectrum Disorder

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10 Abstract

- 11 **Objective:** The main purpose of the present study was to investigate the
- effectiveness of behavior therapy training to mothers of autistic children on verbal
- and non-verbal improvement of their children.
- Materials and Methods: A total of 33 mothers of autistic children were selected
- 15 for training based on non-probability purposive sampling procedure. Autism
- 16 Spectrum Disorder (ASD) Knowledge Scale was used to assess mothers'
- 17 knowledge about autism and Vineland Adaptive Behavior Scale was used for
- assessment of the communication skill in autistic children.
- 19 **Results**: This study revealed that behavior therapy training significantly improved
- 20 communication skills of children with autism by training mothers. The results of
- paired t-test revealed that trained mothers developed improved communication
- 22 skills.
- 23 Conclusion: These results showed improvement in communication skills of
- 24 autistic children whose mothers were trained in behavior therapy.
- 25 **Keywords**: Behavior therapy, autism, training mothers.

Autism spectrum disorder (ASD) is a neuro-developmental disorder, manifested by

Introduction

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the presence of impairment in social communication and restricted, repetitive 29 behaviors. It can be observed in the early developmental period¹. According to a 30 census in Pakistan, 55 per cent of the population is under the age of 19, and 31 roughly there are 1,700,000 children with ASD² Literature search reveals that 1 32 out of 110 children suffer from this disorder in the developed countries. In a cross-33 sectional two-phase study conducted in children from 1-10 years of age, a 34 prevalence rate of 0.9/1000 with the highest occurrence of autism in the rural area 35 of Northwest India was observed. Pooled prevalence of childhood autism was 11.8 36 per 10,000 individuals in mainland China which is lower than estimates from 37 developed countries. In an Indian study it was reported by 80% of participants 38 (psychiatrists, psychologists and paediatricians) about difficulties in the diagnosis 39 of autism. There is no reliable epidemiological data of prevalence of autism in 40 Pakistan. The awareness of autism is deficient in developing countries including 41 Pakistan³2. 42 Literature showed main areas of concerns of autism are difficulties in social 43 interaction, limited interest in things and events around and repetitive behaviors⁴. 44 Due to lack of academic skills, limited communication and language, poor daily 45 living skills, no social play, these children with autism remain far behind in all 46 areas when compared to their peers. To improve performance in these above 47 affected areas in autistic children, an intensive and systematic training of staff and 48 parents is needed⁵. 49 Batool and Khurshid⁶ found that severity of ASD child and parenting self-efficacy 50 as significant predictor for improvement in symptoms of autistic children. They 51 suggested that training parents will help to manage challenging behaviors in ASD 52 children. Khan, Siddique & Jibeen⁷ highlighted great Emotional Adjustment 53

Problems, Health Adjustment Problems and Social Adjustment Problems in 54 mothers of ASD children as compared to normal group. Ali and Rafique⁸ explored 55 in mothers dealing with children negative thinking having various 56 neurodevelopmental disorders. The results showed professional help was taken by 57 51% mothers, support group help was sought by 5% mothers, rest 41% kept 58 worrying about the future of children and remaining 3% developed clinical 59 depression. 60 An article reviewed health care system in Pakistan, stating that in low economic 61 budget country like Pakistan; only about 1 % of country's annual budget is spent 62 on health. In this budget, it is very difficult to cope for ASD patients and parents, 63 thus parent education was recommended for improvement of ASD children⁹. 64 Parent-Mediated Intervention for Autism Spectrum disorders in South Asia was 65 conducted in India and Pakistan in year 2016, which is the only study that trained 66 parents in Rawalpindi and Goa. The training of parents was done in high-income 67 community that showed good results among children and achieved excellent 68 participant adherence¹⁰. Another study worked on parent–child interactions using 69 the Dyadic Communication Measure for Autism¹¹. The results showed that when 70 parents were taught specific way to communicate with ASD children, the 71 language development improved in autistic children. 72 Range of psychosocial interventions¹² have been carried out focusing on parent-73 child joint engagement, child symbolic play, social communication and imitation 74 related to staff or parents dealing with ASD¹³. Intervention based on behavioral 75 theory or communication-focused therapies showed positive outcome, however, 76 major permanent improvement in ASD symptoms were from parent mediated 77 interventions. In many studies the parents drop-out rate is also high, apparently 78 due to slow results regarding challenging behaviors at moderate level. Keeping 79 this point in view, the training is more focused on teaching behavioral methods 80

- and its generalization and maintenance. In majority of studies, the effective
- methods described rely on behavior therapy¹⁴.
- 83 A study conducted by Smith, Buch, and Gamby¹⁵ trained parents and
- paraprofessionals. They received 6, 1-day workshops in 5-months, in which they
- were taught application of applied behavior analysis principles with ASD children.
- Five of the six children rapidly acquired communication and self-care skills, but
- only two children showed marked improvement at follow-up, 2–3 years later.
- 88 Group Intensive Family Therapy (GIFT) highlighted parents as the therapist¹⁶.
- 89 Preschool ASD Children showed improvement on adaptive and cognitive
- 90 functioning.
- 91 However, in the context of described circumstances, the current study was
- 92 designed to examine how the training of mothers showed improvement in
- ommunication of ASD children. It is hypothesized that, there is a significant
- relationship between training of mothers and communication of ASD.
- The objective of the study was to investigate the effectiveness of behavior therapy
- training to mothers of autistic children on verbal and non-verbal improvement in
- 97 communication skills of their children.

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Method

- This is a quasi experimental design, with a pre post intervention to investigate the
- training of mothers and its effects on the communication skills of ASD children.
- The sample was collected through non-probability purposive sampling. The sample
- included 33 mothers calculated through G Power Analysis. The mothers who had
- ASD children in moderate to mild category were selected. The diagnostic selection
- was done through CARS (Childhood Autism Rating Scale). The age criterion of
- 106 children was less than 10 years. The minimum requirement of education of the
- mothers was graduation. The data was collected from Lahore Institute of Special

Care & Attention, Connections, Child and Family Psychiatry Mayo Hospital, 108 Lahore and Children Hospital, Lahore. Only those mothers who were willing to 109 participate in the study and fulfilled the inclusion criteria were included in the 110 study. Some refused due to time constraints, living out of city and some were not 111 allowed by husbands to do any such training. Few dropped out due to the change 112 of institute and residence. The time period of the study was from 8th May 2017 to 113 31 May 2018. 114 The inclusion criteria included mothers who had autistic children with mild to 115 moderate category of autism on CARS. They had not taken any workshop of 116 autism before and had no knowledge of autism. They were coming for assessment 117 and treatment of their children. Mother's education was atleast bachelors and 118 above. They were resident of Lahore only. 119 Exclusion criteria included children with moderate to severe ASD. Mothers 120 education was under graduate. Mothers were taking training elsewhere for autism. 121 Children aged above 10 were excluded 122 After approval letter for permission of data collection, concerned parents of ASD 123 were approached and briefed about the research. Research Information and 124 participant information sheet was given to them in which all the information about 125 research was written. 126 After taking permission from higher authorities, questionnaires were given to the 127 participants. Total 4 Autism institutes were approached. The permission letters for 128 conducting workshops was approved by concerned higher authorities. The consent 129 form was provided to willing participants and briefed about the nature of the study. 130 Total 50 questionnaires were delivered before conducting the workshops which 131 was pre-assessment of the knowledge related to autism, 45 questionnaires was 132 filled and returned. The incomplete questionnaires due to running short of time 133 134 were discarded. All the questions asked by participants were answered by the

- researcher during administration of questionnaires. Approximately 15 minutes
- were needed to answer all the instruments, however, some participants took longer
- time, whereas no participant was compelled for time. The response rate was 75%.
- This work followed the rules and procedures approved by the ethical standards of
- APA (American Psychological Association). The study protocol was approved by
- the Institutional Review Board of Ijaz Psychiatric Institute. All procedures
- 141 followed were in accordance with the ethical standards of the responsible
- 142 committee on human experimentation (institutional and national). The purpose of
- the study was explained to each participant, followed by a written consent.
- Participants were assured that the shared information will be used only for purpose
- of study and confidentiality will be maintained. The right to withdraw from study
- at that point was given to them.
- 147 The Instruments used in the study were:
- 1. A Survey of Knowledge of Autism Spectrum Disorder (ASK-ASD; Hansen,
- 2015). It queries participants about their background, experience and knowledge
- of characteristics of autism according to DSM V diagnostic criteria. The
- questionnaire also included a demographic section¹⁷.
- 2. Vineland Adaptive Behavior Scales: 2nd Edition (Sparrow, Cicchetti, & Balla,
- 2005), is a measure of adaptive behavior showing age-normed standard
- scores on communication and socialization domains. It is filled by parents¹⁸.
- 3. Childhood Autism Rating Scale (CARS). "The CARS is a widely used rating
- scale for the detection, diagnosis, and measurement of severity of
- impairment of autism.
- Parent training program was carried in groups of 33 parents in 11 sessions, 60 to
- 90 minutes duration, over 16 weeks and provided time flexibility. The course was
- designed in a way that parents could predict, manage and evaluate the challenging
- behavior that is associated with the ASD children¹⁹. Parents' expectations were

- noted down at the beginning of the course. The feedback²⁰ was received at the end
- of the course, Question answer session was used to support findings from
- questionnaires which were completed in order to measure the impact of the
- training sessions on their attitude towards their children.
- 166 The course comprised six modules:
- 1) Introduction and analysis of ASD child behavior.
- 2) Learning intervention for children with ASD.
- 3) Identifying challenging behaviors and management.
- 4) Communication strategies for children with ASD
- 5) Abuse related behavior for children with ASD.
- All participants had to complete sponsor's evaluation form and post-course
- 173 questionnaire.
- In the first workshop, the initial assessment of the parents was done. Introduction
- to autism and analysis of child's behavior was taught. In the second and third
- workshop parents were taught how to analyze behavior and identify its form and
- function using ABC model^{21,22}. In the fourth workshop, parents were introduced to
- the different types of reinforcements and how to implement them on children with
- ASD. In fifth and sixth workshop parents were taught how to manage challenging
- 180 behaviors like temper tantrums, repetitive behaviors as moving in circular
- movements, spitting, flapping hands etc, sensory issues and sexual behavior,
- meltdown behaviors and mood swings. In seventh and eighth workshop they were
- taught how to deal with academics and communication skills of the children. In the
- ninth and tenth workshop practical demos and videos of the children were shared
- 185 for learning purposes. In the last workshop post assessment was done by giving
- survey form again to check the knowledge which could result in the improvement
- of the children and the Vineland was administered again on the children to see the

improvement in communication skills. The feedback related to the workshop was 188 also taken from mothers in the last workshop. 189

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Results

- 191 The results section comprised of two dimensions, the first dimension covers 192 demographics characteristics of data, second dimension includes inferential 193 statistics which will provide information about the tested hypotheses in current 194 study. 195 Demographics represented that majority of the parents were living with spouse 29 196 (75.1%). Small number lied in the category of separated and widowed (1.3%). The 197 family background of most of the participants was Urban (57.7%). Most of the 198 participants (58.7%) fell in the category of moderate socio-economic status. The 199 average mean age of the participants was 35 years; they had an average of 2 200 children. The mean age of autistic child was 5 years 5months. Moreover, most of 201 family systems were joint 18 (54.5%) which indirectly reflect their support from all 202 family members as compare to nuclear 15 (45.5%) style of family. Most of the 203 parents were post-graduated 19 (57.6%). 204 The major emphasis of study was to highlight the importance of training of 205 mothers for the ASD child communication. For this purpose, the following 206 measure were used: Autism knowledge survey and Vineland II. There was a 207 significant correlation between training of ASD mothers and communication of 208 ASD children. 209 It was hypothesized that after training mothers would perform better on autism 210
- knowledge survey test. Paired sample t test was carried to compare the mean score 211 of Autism Knowledge Survey before training and after training among mothers of 212 ASD. A paired t-test showed that the difference between conditions was 213 statistically significant (t=46.89, df=32, p<.000) the magnitude of the differences 214

in the means (mean difference =46.21, 95% CI: 44.20 to 48.21). Table shows that there is a significant difference in mean score of mothers before training and after training on Autism Knowledge Survey. Moreover, the results are significant which proved that the knowledge of mothers increased due to training which would result in improvement of communication skills of ASD children To assess the impact of mothers training on the ASD communication VABS was done for post assessment of children. Table shows a significant difference in mean score of communication of ASD pre and post on measure of Vineland II subscale

Discussion

communication (VABS).

The study investigated the efficacy of behavior therapy training to mothers of autistic children by focusing on improvement in communication skills. According to Nazish Imran (2014) there is need to train the caregivers of ASD in Pakistan. There are few dedicated child psychiatric units in the provinces of Punjab and Sindh which are actively engaged in treatment of ASD. These services are almost missing in the two provinces, Baluchistan and Khyber Pakhtunkhwa. Michael²³ have shown the importance of parents' involvement. The early intensive behavioral intervention often include parent as therapist. According to him this approach is important since getting parents involved in these treatments as early as possible is advisable. A lifelong treatment model of parent training would be sensible, for early intensive behavioral treatments. In this sense, this study provided empirical evidence to support our Hypotheses, and underlining the importance of training ASD mothers as a way to increase the communication skills of ASD.

Further understanding regarding how behavior therapy training of mothers influenced the verbal and non-verbal communication skills was achieved through examining a theorized path model. Two general findings were evident from the

results of this study. First, the findings of this study suggested that training of ASD 242 mothers have increased their knowledge about autism, before training their 243 knowledge have significant differences with after training. Jones with his 244 colleagues suggested that knowledge of ASD had a positive, small relation with 245 parenting satisfaction, suggesting that parents with knowledge about ASD might 246 also be more satisfied in their caregiving role²⁴. Furthermore, in our study there is a 247 significant difference in mean score of trained mother. The results showed that 248 knowledge of mothers related to autism increased after training of behavior 249 therapy. Secondly the training improved communication skills of mothers, which 250 resulted in enhanced communications of their ASD children. 251 Our results supported previous research that was conducted by Fathalipouri; they 252 provided training of play therapy to mothers of autistic children in a way which 253 could efficiently improve the autistic children's communications.²⁵ It was 254 concluded that play therapy can successfully increase the abilities of non-verbal 255 communication. One of these types of training of autistic mothers can effectively 256 increase communication skills of ASD children. The pre and post intervention 257 researches reported significant improvements in knowledge of parents, which 258 showed improvements in autistic children's behavior and communication. Thus 259 parent-mediated intervention is beneficial in management of children with ASD²⁶. 260 Our findings supported those reported in previous researches; the importance of 261 giving training of behavior therapy to parents for improvement in communication 262 skills and challenging behaviors of ASD children. Parents feel more proficient and 263 self-assured in dealing with the challenging behaviors²⁷. 264 The results provided encouraging results for autism supporting staff for arranging 265 training workshops for mothers. Previous empirical studies have demonstrated that 266 parents of children with autism help effectively in education of their children. In 267 another study, the effects of a family education program taught parents the use a 268

research-based discrete trial method. The trained mothers felt more competent in 269 dealing with autistic children by using modeling techniques²⁸. 270 In study by Chu the parent training was delivered in group to parents in 11 sessions 271 of 90 minutes duration over 16 weeks. Findings of this research suggested that 272 Parent Training Program proved to be effective in decreasing problem behaviors in 273 children²⁹. It was revealed that nearly all parents of children with special needs 274 275 face lot of challenges related to their children. The problem can be of accessibility, affordability or a combination of these issues, especially in developing countries. 276 Thus to deal with these issues worldwide, the concept of parents as co-therapist 277 seemed to resolve issues of accessibility and affordability to some extent. He 278 highlighted the role of "key worker", a person; parents could approach for advice 279 about any problem associated with the child's case or condition. The responsibility 280 of the key worker is to maintain regular contact with the family and work with 281 professionals from a range of services to support the child. Thus this study strongly 282 agreed with the importance of parents training; it also supported our hypothesis 283 that, there is a significant relationship between training of mothers and 284 communication of ASD. 285 In our present research, the course comprised of six modules of behavior therapy. 286 For children with ASD, a 24-week parent training program was greater to parent 287 education for reducing disruptive behavior on parent-reported outcomes, although 288 the clinical significance of the improvement was uncertain. The rating of positive 289 response judged by a blinded clinicians was greater for parent training vs parent 290 education.²² 291 This study helped to bring awareness for understanding the basic facts and 292 functions of challenging behaviors in ASD children and it helped parents to 293 examine the root cause of the manifested behavior, and thus manage the 294 manifested behavior of their ASD children in better way. It provided valuable 295

information for the development of training programs, considerable attention to 296 this sensitive issue would help improve communication skills of ASD children. 297

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Conclusion

These results showed improvement in children with autism whose mothers were 300 trained rather educated in behavior therapy. It showed parents how to better 301 manage the verbal and non verbal behavior of their children. The improvement in 302 the quality of their life, after attending the course was observed in their feedback 303 form. It helped in improving the mental health of mothers and provided guidelines 304 to psychologists and policy makers to develop psycho-education and intervention 305 strategies. 306 CCSO/GS

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Table 1: Pearson's Product-Moment Correlation Coefficient between Training of mothers and improvement among ASD communication (N=33)

Variables	Training of mothers	Communication of ASD child	M	SD
Training of		.17**	83.67	13.96
mothers Communication of ASD child	.17**		259.15	20.57

Note. M = mean; SD = standard deviation. **p < 01

Table 2: Mean, Standard Deviation, and t value on Autism Knowledge Survey among Mothers of ASD and on VABS (N=33)

Variable		Pre and P	95% Cl			
		Pre	Post	t	p	LL UL
AKS	M SD	80.10	34.14	46.89	.000	[44.20, 48.21]
	SD	4.18	4.19			
Communicat	tion M	33.15	73.4	15.4	.000	[45.60,
	SD					48.21]
On VABS		4.08	14.6			

Note. M = mean; SD = standard deviation; Cl = confidence interval; LL = lower limit; UL = upper limit. $ns \ p > .05$

Figure 1: Scree Plot of Autism knowledge survey (AKS)

