

Parents of Children with Autism: Stresses and Strategies

Dr. Nidhi Singhal

ABSTRACT

Considered to be one of the most complex developmental disorders, autism impacts various aspects of a parent's life. The present research addresses the gaps in previous research by examining the perceptions of stress levels, ways of coping, support systems and locus of control in mothers and fathers of children with autism and compares it with those of parents of typically developing children. Using the pretest-posttest design, the present study investigates how participation in an intervention program may bring about reduction in the levels of stress, increase the use of problem solving ways of coping including seeking social support, and bring in greater internal locus of control in mothers and fathers of children with autism.

The sample comprised of a group of children diagnosed with autism according to DSM-IV-TR criteria, 0-6 months prior to the study (n=20; mean age=4.2 years; SD=0.86); their respective mothers (n=20; mean age=30.5 years; SD=2.09) and fathers (n=20; mean age=33.3 years; SD=1.68). A closely matched control group comprised of typically developing children who had never received a diagnosis of any developmental, psychiatric, physical or learning disorder (n=20; mean age=3.8 years; SD=0.36) and their respective mothers (n=20; mean age=29.8 years; SD=1.68) and fathers (n=20; mean age=32.3 years; SD=1.75). Families where parents had any psychiatric, neurological or physical disability were excluded.

All the children were first assessed on the symptoms of autism and language and learning skills to develop an insight into each child's unique strengths and weaknesses. The information obtained from the detailed assessment of each child was used to explain the parents the nature of the disorder for their child and adopting intervention techniques for the family. Thus the in-depth knowledge of each child facilitated in personalizing the intervention program for each family. Then, the parents in the two groups were given a set of pretest measures, immediately after which the intervention program was started with the parents of children with autism. Spread over one year, the intervention program used the focus group method to provide knowledge to the parents on various aspects of autism including information on autism, its features and manifestations; sensory integration therapy; principles of various teaching techniques; legal systems and need for advocacy programs. Additionally, the program served as a

tool to collect data on the attitudes, beliefs and impacts of parenting a child with autism. The program was divided into four modules each of which focused on one aspect and was covered over three months. The parents were distributed in three groups with 12-14 parents in each group keeping the mother and father of each child together. Each group came together for a group session once a month and an hour of individual couple session 12-17 days after each group session. Thus over a period of one year each parent were part of a total of 84 hours (72 hours in focus group sessions and 12 hours in individual couple sessions) in the intervention program. After the program, the parents of children with autism were reassessed on the pretest measures.

The scores of the children in the two groups on the measures of symptoms of autism and language and learning skills were compared using t-test analysis for independent groups and individual item analysis. To assess the parental understanding of their child's autistic symptomatology the scores of the mothers, fathers and researcher were analysed using MANOVA. To examine the differences in the stress levels, coping styles, support systems and locus of control between the mother and father of a child and to compare them to those of parents with a typically developing child, the data on pretest measures was examined using a series of 2x2 ANOVA. Finally, to study the effects of the intervention program on the mothers and fathers of children with autism, data obtained on the pretest and posttest measures was analyzed via 2x2 ANOVA, with repeated measures on the second factor. All significant interactions were followed by simple effects analyses. To examine the relationships among various measures Pearson correlations was used. Data was analysed separately for mothers and fathers. The data obtained through the focus group discussions was analyzed qualitatively using grounded theory approach.

Results show that children with autism have significant deficits in social functioning, language/communication skills, self-help skills, and sensory areas and the manifestations varied with each child. Their adaptive and language and learning skills were significantly below those of the typically developing children. The results also show that although the parents of children with autism were in agreement with each other, as compared to the researcher they were able to identify significantly less features of autism in their child. Findings indicate that as compared to the parents of typically developing children both mothers and fathers of children with autism perceive lesser resources, report high stress levels; low social support; and greater external locus of

control. The results reveal that mothers and fathers experience the impact of their child's autism differently and consequently cope differently with emotional distress.

Following the intervention program, both parents experienced a significant decrease in stress levels and reported greater internal locus of control, however, mothers continued to remain significantly more depressed than fathers. Results revealed an increase in use of Social Support, Planful Problem Solving and Positive Reappraisal and a decrease in use of Confrontive, Distancing, Self-Controlling, and Escape-Avoidance ways of coping.

The qualitative findings chart the early experiences of the parents before and during the diagnosis, their search for meanings regarding the causes, course, cure for autism and the locus of control. The findings reveal the impacts perceived by the parents, on various aspects of their relationships, professional and social life. Finally, the results reveal the process of parental empowerment and a movement towards acceptance of their child and the presence of autism in their lives.

Results suggest that such parent training programs can prove to be very effective for parents of children with autism. The findings highlight the need to assess parental stress while at the same time recognizing that many families bring important strengths in coping and adjusting to the diagnosis of autism. With adequate intervention, the parental stress levels can be reduced and the parents can be taught to use effective coping strategies to deal with their situation.