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Importance of functional skills for children with autism: Its influence on the home adjustment of their mothers and fathers

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Abstract

Autism is a neurodevelopmental disorder that manifests in the first 3 years of age. It is characterised by abnormalities in communication skills and social interaction, restrictive, repetitive and stereotypical patterns of behaviour, interests and activities. A child on the autism spectrum may hardly use words to communicate, even though they are able to recite passages from videotapes or says the alphabet. Moreover, social deficits and repetitive behaviours may not be seen clearly in the early years but gradually it becomes more apparent as the child grows up. Children with autism lack functional skills; they cannot perform these skills without the help of parents. Teaching them functional skills are very challenging and enormous tasks for the parents hence it affects the parent's home adjustment. Thus an attempt was made to assess the impact of functional skills on the home adjustment of parents of children with autism before and after the influence of intervention program.

For the present study, a self- structured scale on home adjustment of parents of children with autism was used to obtain the required information. The total numbers of 190 parents (i.e. 134 mothers and 56 fathers) of autistic children (aged 5 to 10 years) were selected through purposive random sampling techniques from various special schools in Bangalore city. Among these, 55 parents (32 mothers and 23 fathers) were selected for the experimental group based on their willingness to participate in the intervention program and the remaining was considered as the control group. The parents of experimental group received the intervention program for 4 months on every Monday and Friday. The result showed that there was not much significant difference between the mean score of experimental and control groups for home adjustment of fathers of children with autism. And on the other hand, there was a highly significant difference between the mean score of experimental and control groups for home adjustment scales of mothers of autistic children. The study highlights the need for training the parents of children with autism on the importance and techniques of teaching functional skills to their autistic child, in order to help them able to perform their day to day tasks with less support.

Keywords: Autism, functional skills, home adjustment

Introduction

Autism is a neurodevelopmental disorders characterized by triad of impairments in communication skills, social skills and repetitive or unusual behaviours (American Psychiatric Association, 2000; Levy, Mandell, & Schultz, 2009; Sharan, 2006).^[12,17] According to Siriratrakha (2010)^[18], the word "Autism," was derived from Greek "Auto" referred to self which meant that to withdraw themselves in their own world comparing with glass wall or mirror separating themselves from surrounding society. It manifests in the first few years of life (Chakrabarti, & Fombonne, 2005).^[4] The prevalence of Autism in India at present is 1 in 66, among children between 2 and 9 years of age (Deshmukh, Mohapatra, Gulati, Nair, Bhutani, Silberberg *et al.*, 2013)^[7]. According to Centres for Disease Control and Prevention or CDC (2014), the prevalence of Autism in the United States is 1 in 68 children (1 in 42 boys and 1 in 189 girls) and it is likely to be occurred with males rather than females all over the world. Children with autism have limitation in their life; they have lack of functional skills (Jasmin, Couture, McKinley, Fombonne, & Gise, 2009). The lack of functional skills leads to dependency in performing their daily living activities. Functional skills are the skills that are required in the day to day life of an individual such as self-care skills, functional academics skills, vocational skills, social skills and community living skills (Collins, 2008)^[6].

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Autistic children need assistance from parents to perform these skills. Due to this parent's spent most of their time in taking care of their children and it becomes a very challenging and enormous task for them which in turn affect the parent's home adjustment. Many families cope with feelings of shame, helplessness and anger because of their child's disorder. This leads to reduced support and contact with close friends and family. In addition, parents of children with autism often have stress and mental health problems, associated with the challenges of caring their child. Thus, an attempt was made to assess the impact of functional skills on the home adjustment of parents of children with autism before and after the influence of intervention program.

Methodology

Objective

The first objective of the study was to assess importance of functional skills of children with autism. The second objective was to study the influence of functional skills on the home adjustment of their parents.

Sample

The total number of 190 parents (i.e. 134 mothers and 56 fathers) of autistic children (aged 5 to 10 years) was selected through purposive random sampling techniques from various special schools in Bangalore city. Among these, 55 parents (32 mothers and 23 fathers) were selected for the experimental group based on their willingness to participate in the intervention program and the remaining was considered as the control group.

Tool used

A self-structured five point Likert type rating scale was used to assess the home adjustment of the parents of children with autism before and after the intervention program. The scale comprised of 12 items (8 were positives and 4 items were negative) and the items were categorized under the following three dimensions:

Home Adjustment Related to Children with Autism

Home Adjustment Related to other family members

Home Adjustment Related to their time spent

Each of the dimensions has four items. The response options given to the respondents were "Never", "Rarely", "Sometimes", "Often" and "Always". Positive items were scored as 1, 2, 3, 4, 5 and negative items were reverse scored.

A checklist on functional skills of children with autism was also developed by the investigator. It was developed to check the autistic children's ability to perform their day to day living activities before and after the intervention program. This checklist consisted of five dimensions such as Self-care skills, functional academic skills, Pre-vocational skills, Social skills and Community skills. The response options given to them were "Never=0", "Sometimes=1" and "Always=2".

Method

Quasi experimental pre-post design with an intervention program was adopted.

Pretest

The investigator sought permission and consent from various special schools and organizations to conduct the study. Those parents who were willing to participate in the study were

considered as the sample of the study. Parents of children with autism of both the control and experimental groups were explained about the need of the study by the investigator. Further, the investigator built rapport with them and also assured them that the information obtained will be used only for the research purpose. The pre-test was conducted to assess the importance of functional skills for children with autism and its influence on the home adjustment of their parents. Intervention program was conducted after the pre-test was done.

Intervention Program

The intervention program was designed by the investigator to train parents on how to teach functional skills to their children with autism and helping the parents understand the need and importance of functional skills and how it influence on their home adjustment. The intervention program was conducted by the investigator over a period of 4 months from 10:00 am to 1:00 pm with short tea break. The investigator covered various topics related to children with autism, characteristics, causes, incidence rate, meaning and types of functional skills, its importance and the methods of teaching it to their children. Various teaching techniques such as power point presentations, flash cards, video clippings, lectures, posters, models, group discussions, role play, hands on experience etc. were employed by the investigator to explain the above mentioned topics. The investigator also gave assignments to the parents so that they could sit with their child at home and help him/her practice day to day activities. This was done with the objective of making the autistic child become independent in doing his/her task and also to ensure that parents begin to practice what they learnt at the time of intervention programme.

Post-test

After the completion of the intervention program, the home adjustment scale of the parents and the checklist of functional skills for children with autism were re-administered to the respondents of both the control and experimental groups. The investigator re-administered this in order to assess if there was any improvement in the functional skills of children with autism and how it affects their parents' home adjustment after the functional skills intervention program.

The data was scored, tabulated and analysed using statistical measures.

Result and Discussion

The socio-demographic information of the parents is discussed below. The majority (83%) of the parents were from the nuclear family. Most of the fathers (45%) were working for private job, 41% of them were business men, 11 % were government employees and 3% were labourers. 67 % of the mothers were homemakers and only 33% of the mothers were working. Research studies showed that fathers most likely did not quit job to become the primary care-giver for their autistic child, they often work to increase the income of the family. Mothers who worked outside the home often missed work, they were often required to accept part-time work or even give up on employment outside the home (Cidav, Marcus, & Mandell, 2012; [5] Gray, 2003) [8] to accommodate the needs of their child with autism (Montes & Halterman, 2008) [8].

Table 1: Parents perception of functional Skills of children with autism of control and experimental Group (Post-test)

| Dimensions of Functional skills | Fathers | | | | | Mothers | | | | |
|---------------------------------|-----------------------|-------|----------------------------|-------|-------------------------|------------------------|-------|----------------------------|-------|-------------------------|
| | Control group (n= 33) | | Experimental group (n= 23) | | Significance of t value | Control group (n= 102) | | Experimental group (n= 32) | | Significance of t value |
| | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | |
| Self-care | 27.09 | 10.04 | 29.39 | 7.07 | 0.9713 ^{NS} | 28.77 | 8.36 | 29.63 | 5.98 | 0.5399 ^{NS} |
| Pre academic | 14.09 | 9.29 | 15.57 | 7.83 | 0.6411 ^{NS} | 13.04 | 7.37 | 11.72 | 4.26 | 0.9630 ^{NS} |
| Pre vocational | 7.67 | 3.89 | 8.70 | 3.52 | 1.0362 ^{NS} | 8.80 | 3.71 | 8.88 | 2.83 | 0.1121 ^{NS} |
| Social | 11.06 | 4.14 | 11.74 | 4.53 | 0.5972 ^{NS} | 9.93 | 3.97 | 10.97 | 3.03 | 1.3623 ^{NS} |
| Community | 7.42 | 3.21 | 8.96 | 3.55 | 1.7361 ^{NS} | 7.68 | 3.15 | 7.66 | 2.38 | 0.0330 ^{NS} |
| Overall | 67.33 | 26.72 | 74.35 | 23.63 | 1.0402 ^{NS} | 68.23 | 20.57 | 68.84 | 11.73 | 0.1596 ^{NS} |

NS Not significant

Table 1A reveals that there is no significant difference between the scores of the parents (fathers and mothers) of control and experimental groups under all the dimensions of functional skills of their children with autism. They have lower scores for all the dimensions of functional skills since their autistic children have poor functional skills (Jasmin *et al.*, 2009) ^[10]. After the intervention program a slight improvement was observed among the experimental group of both the fathers and mothers with regard to the functional skills of their autistic children. In addition, notable improvements were observed in the overall scores of functional skills of the children. For children with autism learning functional skills is time consuming and the improvement is very gradual. It is necessary to help them learn step by step until they do it by themselves and they get habituated to their day to day activities in life. And, the training should be practiced simultaneously by providing the

learning process in routine activities for children to be able to perform by themselves with full potentiality with the minimum support.

Table 2A depicts the home adjustment of the parents of autistic children. Data clearly indicates that the time spent by mothers of experimental group is more when compared to the mothers of the control group. On contrary the adjustment made by both the fathers and mothers is more than the parents of the control group. This indicates that parents of the experimental group have improved in their home adjustment related to their children with autism after attending the intervention program. Parents also reported that being a primary caregiver of their children with autism, they had have support and take care of their children in performing their day to day activities (Koydemir & Tosun, 2009; ^[11] Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). ^[16]

Table 2A: Home adjustment of fathers and mothers of children with autism of control and experimental Group (Post - test)

| Dimensions of home adjustment related to | Fathers | | | | | Mothers | | | | |
|--|-----------------------|------|-----------------------------|------|-------------------------|------------------------|------|-----------------------------|------|-------------------------|
| | Control group (n= 33) | | Experimental group (n = 23) | | Significance of t value | Control group (n= 102) | | Experimental group (n = 32) | | Significance of t value |
| | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | |
| Children with Autism | 13.55 | 1.72 | 14.87 | 1.84 | 2.8193** | 8.61 | 1.70 | 11.53 | 1.14 | 9.0909** |
| Other family members | 12.48 | 2.41 | 12.35 | 1.99 | 0.2185 ^{NS} | 12.91 | 1.86 | 12.53 | 1.70 | 1.0292 ^{NS} |
| Time spent | 12.15 | 2.18 | 13.00 | 1.78 | 1.5855 ^{NS} | 12.43 | 2.03 | 15.28 | 1.51 | 7.3302** |
| Overall | 64.21 | 6.94 | 67.43 | 6.43 | 1.8065 ^{NS} | 55.47 | 4.75 | 63.41 | 4.11 | 8.5110** |

** Significant at 1% level NS Not significant

On the other hand, no significance difference was found between the parents of both control and experimental towards the home adjustment related to other family members. This is because most of the parents face many challenges in taking care of their autistic child (Weiss, Wingsong, & Lunsky, 2014) ^[19]. Parents slowly understanding that they also need to devote time to the rest of the family members. According to Braithwaite (2016) ^[2], even the fathers are also involved in the areas of caring their autistic children and most

of them are mainly, or equally, responsible for their children's daily care routines, including morning and bedtime routines as well as managing sleeping problems. These are some of the prime reasons that parents spend moderate amount of time with their other family members. The intervention programme has enabled the parents to understand the needs of not only their autistic child but also how to care for the other members of the family.

Table 3A: Relation between functional skills of children with autism and their fathers' home adjustment (Experimental)

| Home Adjustment (HA) related to... | Functional Skills | | | | |
|------------------------------------|-------------------|--------------|----------------|-----------|-----------|
| | Self-care | Pre-academic | Pre-vocational | Social | Community |
| Helping the child with autism | 0.1367 | 0.1440 | - 0.0414 | - 0.1784 | - 0.1748 |
| Other family members | - 0.2038* | - 0.0947 | - 0.1916 | - 0.2361* | - 0.0428 |
| Time spent | - 0.1045 | 0.0260 | 0.0000 | - 0.0618 | 0.1580 |

* Significant at 5% level

Table 3B: Relation between functional skills of children with autism and their mothers' home adjustment

| Home Adjustment (HA) related to... | Functional Skills | | | | |
|------------------------------------|-------------------|--------------|----------------|-----------|-----------|
| | Self-care | Pre-academic | Pre-vocational | Social | Community |
| Helping the child with autism | - 0.1122 | - 0.3282** | - 0.1294 | 0.0611 | 0.0698 |
| Other family members | - 0.0368 | 0.2346* | - 0.0661 | - 0.2839* | - 0.0410 |
| Time spent | 0.2304* | - 0.2535* | 0.0388 | - 0.0827 | 0.2258* |

** Significant at 1% level * Significant at 5% level

Table 3A and 3B reveals the relation between functional skills of children with autism and their fathers' and mothers' home adjustment. It can be seen that parents need some more time to understand the fact that they need to concentrate on the other responsibilities and also on the other family members. They should also focus on the quality time spent with other immediate family members.

Further the data shows that even though there is an improvement in the functional skills not much improvement is seen in the home adjustment. This could also attributed to the fact that parents have made adjustments in the other areas like marital, health, financial, social and emotional adjustment. Parents of these children say that they have less privacy between their spouses as they spend much of their time and energy in caring their child as well as managing their child's problem behaviours (Pozo, Sarriá, & Brioso, 2011) [15]. As parents, they are responsible for providing their child with opportunities to learn and grow in order to become a productive citizen in their later life. However, the responsibilities associated with being a parent of an autistic child does not come easily as the behavioural challenges and social communication deficits that characterize autism often are correlated with increased financial and emotional burden on their parents (Järbrink, Fombonne, & Knapp, 2003) [9]. These emotional and financial burdens can affect their parents and families bonding and this in turn leads to fractured family relationships and poor home adjustment (Mills, 2014) [13]. Thus it can be concluded that providing training to children with autism on functional skills should be begin early with appropriate intervention.

Conclusion

Parents lack knowledge of teaching functional skills to their children with autism. So, they need to be taught on the importance of functional skills and the techniques of teaching it to their autistic child. Parents should train their child in functional skills based on the age appropriateness and developmental needs of the child. Teaching functional skills to their autistic child helps in creating more time for the other family members and also helps the autistic child to develop a sense of self awareness and; help him/her become more independent. Thus reducing their responsibilities of caring only for their child with autism and diverting the parents focus on the other household activities.

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