

IMPACT OF INTERVENTION PROGRAM ON FUNCTIONAL SKILLS FOR CHILDREN WITH AUTISM AND ITS INFLUENCE ON THE LIFE SATISFACTION OF THEIR PARENTS

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ABSTRACT

The objective of the research was to study the functional skills of children with autism and to assess its impact on their parent's life satisfaction through an intervention study. The samples consisted of 120 parents of children with autism between 5 and 10 years of age. The data was collected from various special schools within the Bangalore city through purposive sampling technique using self-structured scales. The quasi-experimental study with pre-test and post-test method was employed for the study. The pre-test data for both experimental and control groups indicated that children with autism lacked functional skills and their parents also had low life satisfaction. The results of post-test data for the experimental group found that there was a significant improvement in the functional skills and life satisfaction thus indicating that the intervention program was effective.

KEYWORDS: *Children with Autism, Functional Skills, Life Satisfaction*

INTRODUCTION

Autism is a neuro developmental disorder characterised by deficits in social interaction and communication along with the presence of restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders fifth edition [DSM-5], 2013; Lam, Aman, & Arnold, 2006; Wing, 1997). In India, around 3 million people are affected by autism (Juneja, & Sairam, 2018) and the disability has shown an increase over the last few years. While on the global front, Elsabbagh et al. (2012) reported that a median of 62 cases per 10,000 (i.e. 1 in 160) are found to be affected by autism.

Many children with autism may be hypersensitive or hyposensitive or both to certain smells, sounds, tastes, textures, lights, and touch. Some autistic children with hyposensitivity often failed to notice their body odor due to the lack of sense of smell. While, some of the hypersensitive children with autism dislike the smell of perfumes, shampoos, soaps etc. since the smell can be intense to them (The National Autistic Society, 2016). They have difficulty in back and forth conversation ((Minnesota Association for Children's Mental Health or [MACMH], 2014). Children with autism have very poor or no eye contact, they may have a delay in speech, some of them are non-verbal or have very limited speech and

others may have echolalia (the literal repetition of words or phrases spoken by other people). Some autistic children can speak fluently but their speech is awkward and inappropriate (National Institute of Neurological Disorder and Stroke or NINDS, 2018). In addition, they have difficulty to understand the distance that should be kept between people in a crowded environment (Otsimo, 2016). Due to the developmental and behavioral issues, children with autism have a lack of functional skills.

According to Webster (2017), functional skills are the skills that an individual requires in order to live independently. It includes self-care skills, functional academic skills, pre-vocational skills, social skills, and community living skills (Learning, 2003). They have difficulty in taking solid foods and have food restrictions due to sensory issues or communication difficulties, (Olivíé, 2012). Most of them are difficult to toilet train (Wu, 2010); and have irregular sleep patterns (Dominick, Davis, Lainhart, TagerFlusberg, & Folstein, 2007). They also have difficulty in understanding other's emotions (Research autism, 2017). Because of these issues in functional skills (FS), autistic children need assistance in carrying out the daily tasks or activities such as bathing, brushing, dressing, and taking a meal, purchasing, doing household chores, laundry, taking medicine, managing money, using transportation etc. (Cho, & Kahng, 2014). So, parents as the primary caregivers play an important role in taking care of their autistic children in every activity of daily life and maintain the household chores (Ravindranadan, & Raju, 2008). They have less time to take care of themselves as individuals (Ravindranadan et al., 2008) as well as typically developing children and spouse due to the extra amount of time that they require in dealing with the issues of their autistic child; including the extra time being spent in taking their child to various therapies e.g., speech and language therapy, occupational therapy (Sawyer et al., 2010) which in turns affect their life satisfaction. Life satisfaction is defined as an individual's judgment of how satisfied they are with their present state of affairs based on a comparison with criteria which each individual sets for him or herself (Diener, Emmons, Larsen, & Griffin, 1985).

A sense of low quality of life among parents of children with autism lead to various problems in their lives such as anxiety, introversion, social withdrawal, a sense of loneliness, loss of the meaning of life, the lack of efficiency in social relations, negative social behaviour, emotional unbalance, failure to form and maintain friendships, etc. (Asi, 2016). Thus an attempt has been made to study the impact of the intervention program on functional skills for children with autism and its influence on the life satisfaction of their parents.

METHODOLOGY

Objectives

The objectives of the study were:

- To study the functional skills of children with autism
- To conduct an intervention program to train the parents of children with autism on teaching functional skills
- To assess its impact on the life satisfaction of parents

Sample

Total samples of one-twenty parents of children with autism between the ages of 5 and 10 years from special schools catering to the educational needs of children with autism in Bangalore city were identified through purposive sampling technique for the present study. Out of one-twenty, sixty parents belonged to the experimental group and another sixty of them were identified as the control group.

Tool used

A three-point Likert type rating scale was framed by the investigator to assess the functional skills of children with autism. The scale comprised of a total of 94 items in which the response options given to the respondents were “Never”, “Sometimes” and “Always”. Each item that was marked ‘never’ was given a score of 0, ‘sometimes’ was given 1 and ‘always’ was given 2 scores.

A life satisfaction scale also developed by the investigator was used to assess the life satisfaction of parents of autistic children. It is a five-point Likert type rating scale. The scale consisted of a total of 36 items in which 13 items were positive and the remaining 23 were negative. The items were rated as “strongly disagree”, “disagree”, “neutral”, “agree” and “strongly agree”. Positive items were given a score of 1, 2, 3, 4 and 5; whereas, negative items were reverse scored i.e. 5, 4, 3, 2 and 1.

Method

The method adopted for the present study was the pre-test post-test quasi-experimental method with an intervention program.

The investigator prepared a directory on the list of special school by collecting addresses and contact information of various special schools catering to the educational needs of children with autism in the city of Bangalore through online and from different websites. With the help of this directory, the investigator conducted a survey within the city of Bangalore to seek permission for conducting the study. The investigator interacted with the school authorities and explained the purpose of the study and then contacted parents of children with autism to collect data before and after intervention as well as to attend 16 weeks intervention program.

Pre-Test

The investigator established rapport with the respondents and briefed to them about the need and importance as well as the procedures of the study. Consent was sought from them to collect the data and assured them that the data obtained from them will be used only for the purpose of research. The pre-test data were collected from the respondents of both the experimental and control groups by administering the self-developed scales to assess the functional skills for children with autism and life satisfaction of parents of children with autism.

Intervention Program

The Assure model developed by Forest (2015), was adopted in developing the intervention module to teach functional skills to children with autism as well as to effectively carry out the intervention program (IP).

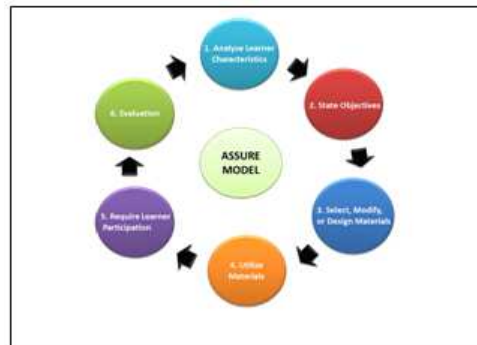


Figure 1: Assure Model by Forest (2015)

The description of ASSURE is given below:

“A” Stands for ‘Analyze the Learner Characteristics’

The first step in the process is to analyze the attributes of the learners. For the present study, the investigator analyzed the characteristics of children with autism through review of the literature and by reading a myriad of study articles, books, case studies and other online resources to identify the difficulties faced by the learners.

“S” Stands for ‘State Objectives’

After understanding the characteristics of children with autism, the investigator stated the standards and objectives for the intervention program, which aimed at training parents of children with autism on techniques of teaching functional skills to their autistic children.

The Second “S” Stands for ‘Select, Modify, or Design Materials’

After having a clear understanding about the children’s characteristics and learning objectives, the investigator identified the useful techniques and various teaching aids (audio-visual) such as power-point presentations, lectures, flashcards, worksheets, video clips, models, posters, etc. to be used during the intervention program.

“U” Stands for ‘Utilize Materials’

The step concerns about making a plan as to how to utilize the selected materials. The ASSURE model provides the "5 P's" as a guideline for proper utilization of materials and implementation:

Preview the Materials

After the preparation of the teaching aids, the investigator presented some of the teaching aids before the special educators and parents who were randomly identified to get their inputs and suggestions before the commencement of the IP.

Prepare the Materials

The investigator prepared the necessary power point presentation to give the content of each module along with illustrations, quotes, citations, videos and sample questions for the IP.

Prepare the Environment

In this step, the investigator did preparations required to set up the learning environment like sufficient seating arrangement for the respondents, use of blackboard, screen for power point presentation, proper lighting in the room and teaching materials.

Prepare the Learners

The respondents were clearly informed about the objectives and duration of the intervention program to help the respondents in creating a roadmap of what they would be learning until the completion of the IP.

Provide the Learning Experience

In order to impart the functional skills for the parents during the intervention program, the investigator prepared the modules by incorporating the various teaching aids like flash cards, video clips, pictures, models, scorecards etc.

“R” Stands for ‘Require Learner Participation’

During this step, the respondents were instructed on how to use scorecard and how it helps in assessing the child’s progress while learning a specifically targeted behavior. They also showed the investigator how they used the scorecard at home in teaching functional skills to know their child’s progress. Further, the respondents have also shared their comments about what they learnt during each session. They were encouraged to ask questions or any other queries related to the challenges that they face in teaching FS to their CWA. The questions raised by them during the sessions were answered by the investigator.

“E” Stands for ‘Evaluation’

In this final step, the investigator evaluated the impact of teaching functional skills on the respondents including the evaluation of the teaching strategies and the materials used. Feedback both in oral as well as a written form was obtained from the respondents after each session. Some of them shared their experiences of teaching FS with their children at home. This enabled the investigator to understand the relevance of the sessions and the teaching materials used.

The intervention program was conducted by the investigator for only the respondents of experimental group to educate the parents on the need and importance of functional skills as well as to train them the techniques of teaching functional skills to their autistic child/children. It was conducted for a period of 16 weeks and lasted for 3 hours per session. The investigator addressed various topics using different techniques during the intervention program. Following topics were covered during the intervention program:

- Understanding autism: definition, causes, prevalence, symptoms and characteristics.
- Understanding functional skills: definition, types, need and importance of functional skills.

- The investigator also addressed various tips of teaching functional skills to children with autism. Functional skills include:
- Domestic or Self- Care skills such as brushing, toileting, bathing, dressing, eating, wash hands and night routine
- Functional academic skills such as to identify and read alphabets, number concept from a book, magazine or a paper, identify colors, recognize shapes, time concept, money concept, identify body parts and to identify the days, months and date from the calendar.
- Pre-vocational skills such as beading, drawing, stacking, paper folding, counting, preparation of files (using handmade papers), greeting cards envelopes, greeting cards, flowers, key chains, flower vase decoration, paper bags, Diya(Lamp) decoration and candle making etc.
- Social skills such as learning to make eye contact, telling the name, making friends, emotions, behaviors, helping others, greeting or praising others and apologizing to others.
- Community living skills such as following instructions, using public transportation, following rules in school, to know the role of community workers, to identify and recognize public places (post office, medical store, school, hospital, etc.).

The investigator employed various teaching techniques and strategies such as powerpoint presentations, flash cards, video clips, picture cards, puzzles, models, worksheets, lectures, posters, story-telling, lego blocks, group discussions, role play, hands on experience, etc. to explain the abovementioned topics to the participants.

Parents were taught how to use the scorecards to monitor the progress of their children's performance in learning a targeted skill. In addition, the respondents were taught how to use prompts if the child is not able to identify or follow steps taught by his/her parents. Respondents were also given home assignments, to ensure that they begin to teach their child the skills by using the techniques that they learned during the program. Coloring materials such as crayons, color pencils, paint boxes, color sheets, hand-made papers, foam sheets etc. were given to the respondents as incentives based on their attempts and efforts made in completing the home assignments. Further, oral and written feedback was also obtained from the respondents after each session.

Post-Test

After a gap of one month from the intervention program, post-test data was collected from the respondents of both the experimental and control groups using the self-structured tools. This was done to check the improvement in the functional skills of children with autism and the parents' life satisfaction.

On the completion of post-test, educational material in the form of a booklet was disseminated to the respondents of both the experimental and control groups for their reference in the future.

Further, the data was scored, tabulated and analyzed using a statistical test such as 't'-test to check the statistically significant changes in the response before and after the intervention program.

RESULTS AND DISCUSSIONS

The socio-demographic information of the respondents and their children is discussed below. A majority (38%) of the children from the experimental group were between the ages 5 and 6 years. In the control group, the majority (36%) of the children were in the age bracket of 7-8 years. Majority of the autistic children both from experimental and control groups (87% and 78%) were boys. While thirteen per cent and twenty-two per cent from both the experimental and control groups respectively were girls. Studies have also reported that autism affects females less frequently than males (Werling, & Geschwind, 2013). With respect to the ordinal position of the child, the majority of 93% and 77% of the autistic children from experimental and control groups were first born.

Considering the age of respondents, the majority of the parents 74% and 68% from both the experimental and control groups were in the age bracket of 31-40 years. Most of them from the experimental and control groups (52% and 62%) were graduates. With regard to the occupation of the respondents, most of the mothers from both the experimental and control groups (53% and 55%) were homemakers. While 23% and 27% of them worked in the private sector. Eight and ten per cent of them from both the experimental and control groups were businessmen. The data also revealed that majority of the families from both the groups (52% and 45%) earned between Rs. 30,001/- and Rs. 50,000/- per month. Functional skills of children with autism based on the parent's response are given in table 1.

Table 1: Pre-Post Tests of Functional Skills of Children with Autism (Experimental and Control Group)

Dimensions of Functional Skills	Experimental Group			Control Group		
	Pre-Test (60)	Post-Test (60)	Significance of T Value	Pre-Test (60)	Post-Test (60)	Significance of T Value
Self-care skills	19.42 ± 6.85	27.53 ± 6.65	6.5838**	21.35 ± 7.10	24.58 ± 6.45	2.6096**
Functional academic skills	9.42 ± 5.76	13.28 ± 6.13	3.5566**	11.23 ± 7.65	12.52 ± 6.94	0.9679 ^{NS}
Pre vocational skills	6.07 ± 3.29	8.85 ± 3.20	4.6943**	6.77 ± 3.78	7.98 ± 3.10	1.9185 ^{NS}
Social skills	8.40 ± 3.26	11.37 ± 3.60	4.7398**	8.88 ± 3.83	9.68 ± 3.48	1.1981 ^{NS}
Community skills	5.55 ± 2.83	8.22 ± 3.13	4.9044**	6.18 ± 2.97	6.40 ± 2.48	0.4407 ^{NS}
Overall	48.85 ± 17.78	69.25 ± 17.87	6.2717**	54.42 ± 19.87	61.17 ± 17.81	1.9604*

** Significant at 1% level * Significant at 5% Level NS Not Significant

Table 1 revealed that at the time of pre-test, according to the parent's response, children with autism from both the experimental and control groups had low scores for the all the five dimensions of functional skills i.e. 'self-care skills, functional academic skills, pre-vocational skills, social skills, and community skills'. Research by Jasmin, Couture, McKinley, Fombonne, & Gise, (2009) also found that children with autism have poor functional skills.

After the intervention program was given, post-test results showed that based on the parent's response, children with autism from the experiment group had improved in their functional skills in all the dimensions. A highly significant difference between pre and post tests for all the dimensions of functional skills of their children with autism was observed. Such an increase in the functional skills of children with autism clearly indicates that the intervention program on training parents on techniques of teaching functional skills to children with autism was effective. In addition, children with autism become more independent and have a more positive life outcome if they learn to perform day to day living activities

independently (Carothers, & Taylor, 2004; Hume, Loftin, & Lantz, 2009).

For the control group, the post-test scores showed that there was a significant improvement in the self-care skills for children with autism at 1 % level. Post-test data revealed that not much improvement was observed among the parents of the control group except in the areas of self-care skills.

The following two studies show the evidence of the effectiveness of the intervention program on functional skills among children with autism.

Miyajima et al. (2017) designed an intervention programme on improving selective eating behavior for parents of children with autism and evaluate its effectiveness. The sample consisted of 23 parents of children (aged 3-6 years) with autism. Significant differences were observed before and after the intervention in the degree of difficulty perceived by parents, their degree of self-efficacy, the number of recommendations conducted by them, their subjective view of the degree of dietary imbalance, and the number of food items consumed by their children. The interventional programme was found to be useful.

Coffelt et al. (2014) determined if there is a functional relationship between video modeling intervention training (VIMT) via iPad and functional task performance in the home environment of a child with Autism Spectrum Disorder (ASD). They selected 3 tasks that can be learned in a short time frame and showed the video 1 or 2 times immediately prior to introducing the task to the child if unable to complete the task, they showed the video again and try to continue until finished. The results of the study found that children with ASD had decreased in negative behaviors; they decreased time to learn the skill, increased in the legibility of name and improved letter formation, increased in independence, improved attitude about activities, parent enjoyed working with a child more and parent feels empowered to help the child learn.

Table 2: Pre-Post Tests of Life Satisfaction of Parents of Children with Autism (Experimental and Control Group)

Dimensions of Life Satisfaction	Experimental Group			Control Group		
	Pre-Test (60)	Post-Test (60)	Significance of T value	Pre-Test (60)	Post-Test (60)	Significance of T value
Related to parent's own life	6.58 ± 2.06	9.05 ± 1.60	7.6119**	8.06 ± 2.01	8.38 ± 2.84	0.7160 ^{NS}
Related to their autistic child	7.16 ± 1.69	11.73 ± 2.41	12.0899**	8.80 ± 2.11	10.41 ± 2.95	3.4564**
Comparison with other parents of normal & disabled child	4.93 ± 1.31	6.56 ± 1.92	5.4606**	5.83 ± 1.43	5.78 ± 1.83	0.1676 ^{NS}
Family life & life satisfaction	9.05 ± 1.80	14.68 ± 3.42	11.3416**	9.71 ± 2.49	12.30 ± 2.80	5.3812**
Time spent with family members and friends	10.21 ± 1.84	15.90 ± 1.60	18.1673**	9.53 ± 2.65	13.40 ± 2.04	9.0104**
Related to support and development	8.95 ± 2.22	16.45 ± 2.23	18.5597**	10.10 ± 2.13	13.35 ± 2.51	7.6868**
Related to problem faced by them	11.91 ± 3.12	15.25 ± 3.15	5.8647**	10.66 ± 2.24	13.93 ± 3.02	6.7715**
Overall	58.81 ± 10.44	89.63 ± 11.90	15.1568**	62.71 ± 11.42	77.56 ± 14.45	6.2769**

** Significant at 1% Level; NS Not Significant

Table 2 depicts that during pre-test, parents of children with autism from the experimental as well as control groups had low life satisfaction in all the seven dimensions. Studies have reported that parents of autistic children have a low quality of life (Cappe, Wolff, Bobet, & Ardien, 2011; Johnson, Frenn, Feetham, & Simpson, 2011). After parents attended the intervention program, parents from the experimental group had shown significant improvement in their life satisfaction in all the dimensions. There was a highly significant difference between the pre-test and post-test scores for all the seven dimensions with the overall 't' value of 15.1568**. Many studies have shown the existence of a correlation in quality of life between parents and children. When the quality of life is improved among mothers, their ability to deal with their children with disabilities will also be increased, which emphasizes that the quality of life cannot be achieved for individuals with disabilities without achieving it among their parents (Alashwal, 2005).

For the control group, during the post-test parents had nominally improved in their life satisfaction related to the parent's own life. The 't' value 0.7160^{NS} showed that there was no significant difference between the pre-test and post-test scores.

Data also revealed that they had improved in their family life and life satisfaction, time spent with family members and friends, life satisfaction related to support and development and life satisfaction related to the problem faced by them. There were highly significant differences between the pre-test and post-test scores of the control group parents at 1% (i.e. 6.4393**, 8.0549**, 8.7211** and 9.2302**). This could be attributed to fact that the parents of the control group have gained knowledge about functional skills with their participation in the pre-test. Parents enriched their knowledge of how to teach FS to their children since it involved the daily living tasks and activities required for the normal day to day functioning. When they started teaching the functional skills to their child, their day to day pressure was lessened. This helped them to have a better life satisfaction.

CONCLUSIONS

Thus, it can be concluded that parents require training on the techniques of teaching functional skills to children with autism. There is a need for a comprehensive and structured intervention program on the techniques, which should be specifically tailored made for parents of children with autism. Such training for the parents on a regular basis, by keeping in mind the age appropriateness and developmental needs of their child will help in improving the life satisfaction too.

Further, when parents learn how to handle and teach these skills to their autistic child, there will be changes and improvement in their child's life; helping them to become more independent, reduce their problematic behaviors and make them become self-reliant at home, school, and community at large. This will help the child to mainstream into the society and help him/her with economic viability.

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