

A Study to Assess the Knowledge on Autism Among Parents Attending at SRM General Hospital, Kattankulathur

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ABSTRACT

Objective: The aim of this study was to assess the knowledge on autism among parents and to associate the knowledge on autism among parents with their demographic variables and clinical variables. **Methods:** Quantitative approach and non-experimental descriptive research design was used. The data collection included two parts. Part A: Demographic variables, Part B: A Structured questionnaire to assess knowledge on autism among the parents. 50 parents who fulfilled the inclusion criteria were selected as samples using non probability convenient sampling technique. The study was conducted at SRM General Hospital, Kancheepuram dt. **Results:** The data were analyzed and interpreted based on the objectives using descriptive and inferential statistics. Among 50 parents, 26 (52%) parents have moderately adequate knowledge, 21 (42%) parents have inadequate knowledge, 3 (6%) parents have adequate knowledge and there is no significant association on knowledge on autism with their demographic variables. **Conclusion:** The future of any society depends on its children. Parents are laying the foundation for their child's lives. Parents must be supported, included as the primary caretaker and teacher of the child, and also give proper information about the care, disease condition and commercially available devices that can aid in achievement of independence of their children.

Keywords Children, Autism, Knowledge, Parents, Developmental disorder.

INTRODUCTION

Children are innocent, trusting and full of hope. Their childhood should be joyful and loving. Their lives should mature gradually, as they gain new experiences. Each child is a unique person, a person whose future will be affected for better or worse by the influences that mould his or her life during the early years. The future of any society depends on its children. Parents are laying the foundation for their child's lives. When a child born with developmental disorder, parents often need assistance in promoting normal developmental skills. There is no way to predict when a child should be able to master self help skills. Parents must be supported, included as the primary caretaker and teacher of the child, and also give proper information about the care, disease condition and commercially available devices that can aid in achievement of independence of their children¹.

Autism is a severe developmental disorder that begins at birth or within the first two-and-a-half years of life. Most autistic children are perfectly normal in appearance, but spend their time engaged in puzzling and disturbing behaviors which are markedly different from those of typical children. Autism is a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The degree may vary from mild to very severe and is hence it is known as Autism Spectrum Disorder. At the lower end

it is known as Classic Autism and at the upper end it is called Asperger Syndrome. On December 18, 2007, the United Nations General Assembly declared April 2 as World Autism Awareness Day. Autistic spectrum disorders (ASD) are a group of neuropsychiatric disorders with specific delays and deviance in social, communicative and cognitive development. ASD includes autism, asperger's syndrome, and pervasive developmental disorder- not otherwise specified (PDD-NOS). This review would discuss the following aspects of research done on ASD in India: clinical profile, rating scales, neurobiology, genetics, treatment and outcome. Databases such as PubMed, Google scholar, Indian databases such as INDMED, PsychINFO, and other sources were searched with relevant terms for preparing this review².

Autism spectrum disorders (ASD's) are a common set of neurodevelopmental disorders that are gaining attention. ASD's are so prevalent in the United States that the majority of the population either has a family member, or knows of someone diagnosed with an ASD (Inglese & Elder, 2009). Prevalence of ASD in the United States is estimated by the Centers for Disease Control and Prevention (CDC) to affect 1 in every 110 children, and has also shown to be 4 to 5 times more prevalent in boys than in girls (CDC, 2010). These rates demonstrate a calling for pediatric nurses to be familiar with the needs of this population and their families³.

Autism as it is known today was first described by Dr. Leo Kanner in 1943 (Inglese & Elder, 2009). His study consisted of 11 children, 8 boys and 3 girls. Dr. Kanner

Scoring interpretation		
Level of knowledge	Score	Percentage %
Inadequate knowledge	1 to 10	1 to 33
Moderately adequate knowledge	11 to 20	34 to 67
Adequate knowledge	21 to 30	68 to 100

Table 1: Frequency and percentage distribution of demographic variables related to parents.

Demographic Variables	Parents		
	Frequency	Percent %	
Age	18-23	5	10
	24-29	22	44
	30-35	23	46
Sex	Male	11	22
	Female	39	78
Religion	Hindu	34	68
	Muslim	6	12
	Christian	8	16
Education	Others	2	4
	Graduate	20	40
	High school certificate	18	36
	Middle school certificate	10	20
	Primary school certificate	2	4
Occupation	Profession	15	30
	Clerical, Shopkeeper, Farmer	17	34
	Skilled Worker	12	24
	Unskilled Worker	6	12
	1590 to 4726	2	4
Income	4727 to 7877	11	22
	7878 to 11876	24	48
	11877 to 15753	13	26
	Type of Family	16	32
Area of Resident	Joint	34	68
	Nuclear	32	64
Area of Resident	Urban	32	64
	Rural	18	36

found that many children with this new “syndrome” had been misdiagnosed as feeble-minded or schizophrenic because of their “autistic aloneness” (Kanner, 1943). Kanner describes these children as unable to “relate themselves in the ordinary way to people and situations”

and with an “extreme autistic aloneness” that “shuts out anything that comes to the child from the outside” (Kanner, 1943). Kanner’s observations are still relevant in the clinical manifestations of children with an ASD today. Three developmental deficits that reflect Kanner’s observations and are present in children with an autism spectrum disorder are: 1) altered social interaction, 2) an inability to communicate verbally and nonverbally, and 3) repetitive behaviors, including obsessive interests (National Institute of Mental Health, 2009; Inglese & Elder, 2009). Some common characteristics of children with ASD are sensory problems, sleep disturbances, poor communication and interaction, social isolation, and trouble adapting to new situations (Provost et al., 2009, Soulders, et al., 2009, Inglese & Elder, 2009, NIMH, 2009 Schnur, 2005)⁴.

A child diagnosed with autism may represent a constant source of stress on the family unit, as not only the caregivers affected, but also siblings and relationships among family members. The stress results mainly from the extremely antisocial, disruptive behaviours associated with autism, such as self-injurious, tantrum and obsessive compulsive behaviours, which may preclude a normal family life⁵.

Having to cope with the physical and emotional demands of caring for a child with autism poses a threat to the psychosocial wellbeing of parents and caregivers. Their self-confidence and self-esteem can be eroded in the face of totally unfamiliar child behaviour and unique demands.⁸ Caregivers of children with autism often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment. In addition, it has been shown in the studies that a high level of stress experienced by mothers of children with autism has an inverse relationship with the educational progress of the child⁶.

With knowledge of autism we can avoid aggravating the situation for children with autism. “The knowledge of the caregivers regarding the care of children with autism is highly important in rearing a child with autism. Knowledge of the caregivers is important in assessing the signs and symptoms, current condition, recurrence risk, carrying out the instructions and interventions prescribed by the physician, identifying the side effects of medications and handling the common behaviour problems at home. But the knowledge of the caregivers regarding the care of children with autism is inadequate. Through education and knowledge people with autism can considerably improve their level of functioning and quality of life. The need for information for the caregivers on a variety of unexpected skills, and support, is immediate and urgent⁷.

Research has demonstrated that parents can be effective implementers of behavioural, social, and communication programmes with their children with autism. Researchers have studied the effects of including parents as direct service providers in their children’s intervention process as a means of increasing the quantity and availability of intervention” It is important to identify children with autism and begin appropriate interventions as soon as

possible since such early intervention may help speed the child's overall development, reduce inappropriate

Table 2: Frequency and percentage distribution of level of knowledge on autism among parents.

Level of knowledge	Frequency	Percentage[%]
Inadequate Knowledge	21	42
Moderately adequate Knowledge	26	52
Adequate Knowledge	3	6

behaviours, and lead to better long-term functional outcomes. Parent education programmes have become an effective mode of treatment delivery for teaching families effective behavioural strategies to manage challenging behaviours in young children with autism⁸.

Autism is growing at a rate of 10-17 percent per year. At these rates, it is estimated that the prevalence of Autism could reach 4 million Americans in the next decade. The overall incidence of Autism is consistent around the globe, but is four times more prevalent in boys than girls. Autism knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of Autism's occurrence⁹.

In India the Autism cases have risen sharply over the last couple of decades. They were 17.40 lakhs in 2005, 40 lakhs in 2006, and today, the Autism-affected population in India would be close to a core. The role of the child's parents and family is crucial for early identification of their problems and successful implementation of services. Unlike professionals and service providers, parents can give round-the-clock intervention that the children absolutely need. Parents can effectively implement the behavioural, social, communication programmes with their Autistic children. Parent and professional collaboration is very much important and it includes strategies for initiating and supporting essential family involvement¹⁰.

As India is having low awareness levels and high levels of stigmatization, there is an increased need for public education programmes on the care of children with autism.. No studies have been conducted on the level of knowledge and opinion of caregivers on the care of children with autism. Also very limited studies were conducted on the effectiveness on parental educational interventions. Families of children with autism need adequate knowledge about care of children with autism. In a country like India, where the awareness about autism is still emerging, and the availability of services is in rather short supply, the role of the service provider would best be described as multifaceted- an information provider, a leader, a supporter and a guide. So effective educational interventional programme need to be planned and implemented¹¹.

METHODS

Quantitative approach and non-experimental descriptive research design was used. A total of 50 parents who

fulfilled the inclusion criteria were chosen as samples by using non-probability purposive sampling technique. The study was conducted at ENT, Pediatric, Psychiatric, Speech Therapy, Occupational Therapy outpatient departments at SRM General hospital, Kancheepuram dt. The data collection included two parts. Part A: Demographic variables, Part B: A structured questionnaire to assess the knowledge on autism among parents..The Study variable was Knowledge on autism among Parents and the Demographic variable were Age, Sex, Religion, Educational Status, Occupation, Family Income, Types of Family, Place of Residence.

Criteria for sample selection

The investigator adopted following selection criteria to select the Samples.

The Inclusion Criteria were

Parents who are available at the time of data collection

Parents who are willing to participate in the study

Parents who are able to read, write, speak and understand Tamil or English

Parents with children less than 3 years

Parents who are attending Paedritic, ENT, Psychiatric, Speech Therapy, Occupational Therapy OPD's

Exclusion criteria

Parents who are medical professionals

Parents those who are having children with any mental disorders like mentally challenged

Parents those who are having child with autism

Ethical consideration

Formal approval was obtained from the Institutional Review Board and Institutional Ethical Committee of SRM University, Kattankulathur, Chennai, Tamil Nadu, India. In addition, the participants were informed of their right to withdraw anytime during the study.

Instruments

The Demographic and the Structured Questionnaire was developed by the investigator based on the review of literature, discussion with experts and investigators personal experience.The tool consists of 2 sections.Section-A deals with demographic details of parents such as age, sex, religion, educational status, occupation, family income, types of family, place of residence and Section-B consisted of 30 questions to assess the knowledge on autism among parents.

Scoring key

Each question was given 4 options. Each correct answer was awarded score 1. Each incorrect answer was awarded score "0"

Procedure for the data collection

Formal approval from the Medical Superintendent of SRM General Hospital at kattankulathur. The investigator explained the objectives and methods of data collection to the parents. Data collection was done within six days with effect from month of March of 02.01.2017 to 07.03.2017 in the outpatient departments and in 50 parents who satisfied the inclusion criteria were selected using non probability convenient sampling technique. The investigator communicated with Tamil language, introduced self to the parents, initially the parents were made comfortable at the outpatient departments and

structured questionnaire tool was given to them. The investigator collected information regarding section-A

table .2 shows assessment on level of knowledge on autism among 50 parents, 26 (52%) parents have moderately

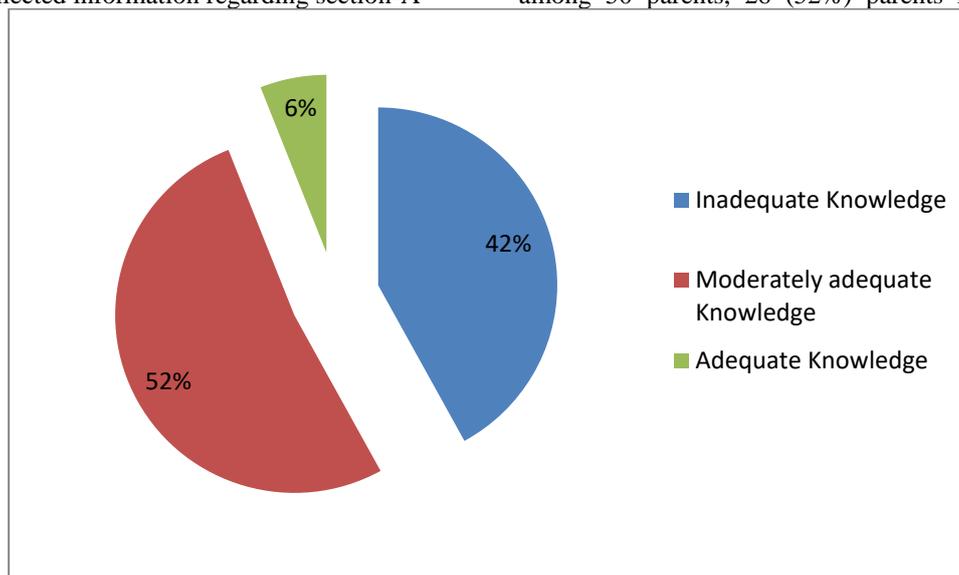


Figure 1: Shows percentage distribution of level of knowledge on autism among parents.

[demographic data] and section-B [knowledge assessment tools] and the responses marked simultaneously. It took around 15 minutes from each sample to obtain the necessary data. The investigator thanked the parents, nursing personnel for extending their fullest co-operation.

Statistical analysis

The information collected from the study participants was scored and tabulated. The data were entered into the master coding sheet and saved in Microsoft Excel. Statistical analysis was conducted using Statistical Package for Social Sciences-16. Mean, percentage, and standard deviation were used to explain the demographic variables, and Chi-square test was used to associate the demographic variables with Knowledge on Autism among parents.

RESULTS

In the current study, 50 samples were assessed for the demographic variables and it reveals that among 50 parents, 5 (10%) are in age group of (18-23), 22 (44%) are in age group of (24-29) and 23 (46%) are in age group of (30-35). 11 (22%) are males, 39 (78%) are females. Considering the religion, 34 (68%) are Hindus, 6 (12%) are Muslims and 8 (16%) are Christians and 2 (4%) are others. Regarding the educational status of parents, 20 (40%) are graduates, 18 (36%) are high school certificates, 10 (20%) are middle school certificates, 2 (4%) are primary school certificates. Considering the occupation, 15 (30%) are profession, 17 (34%) are Clerical, Shopkeeper, Farmer, 12 (24%) are Skilled Worker, 6 (12%) are Unskilled Worker. Regarding the income, 2 (4%) are earning (1590-4726) rupees, 11 (22%) are earning 4727-7877, 24 (48%) are earning 7878-11876, 13 (26%) are earning 11877-15753. Considering the type of family, 34 (68%) are nuclear families and 16 (32%) are joint families. Considering the place of residence, 32 (64%) are urban, 18 (36%) are rural.

Inference

adequate knowledge, 21 (42%) parents have inadequate knowledge, 3 (6%) parents have adequate knowledge.

Regarding association

There is no significant association on knowledge on autism among parents with their demographic variables

DISCUSSION

Children are not the future, they are the present. Childhood is a time of development. Like all children Autistic children also need help to satisfy their developmental needs. Identify their behavioural problems and correction is very important. Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed "different" from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of Autism can also appear in children who seem to have been developing normally. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.[12]

Autism is the fastest-growing serious developmental disability in the world. Autism affects as many as 1 in 150 children and 1 in 94 boys. More children will be diagnosed with Autism this year than with diabetes, cancer and AIDS combined. Boys are four times more likely than girls to have Autism. There is no medical detection or cure for Autism, but early diagnosis and intervention improve outcomes. Autism does not discriminate by geography, class, or ethnicity¹³.

Estimated number of individuals with Autism in selected nations on 2007 were, in China-1,100,000; India-2,000,000, United States-1,500,000, United Kingdom-650,000, Mexico-150,000, Philippines-500,000, Thailand-180,000 individuals are suffering from Autism. While the World Health Organization does not maintain global statistics on the prevalence of Autism spectrum disorders or appropriate treatments specifically, its 2007 Global

Burden of Disease report on mental and neurological disorders highlighted the critical situation the world faces with a growing population that includes those with Autism¹⁴.

Autism is increasing its proportion in our country. The alarming proportions by which it is rising can make India become the most populous country in the world having such neurological disorder. Approximately 4 million Autistic children and adults are there by the year 2020 it can well cross 8-10% of our population who will be falling under such category. As the medical community unable to find any suitable cause for its root, the only way available is early detection and intervention by which the symptoms of unacceptable language and behaviour can be minimized¹⁵.

Many conferences are going on across India to increase awareness and inform about the alarming rise of Autistic cases. The conference 'Autism, the hidden disability', is on the increase in India' being held on 2008 October 14th at Chennai. The conference opened to parents, teachers, doctors and students. The conference provided the information on Autism in India and about the importance of enhance the awareness among the parents and caregivers¹⁶.

A study describes about the parents knowledge about recurrence risk in Autism spectrum disorder. The sample of their study was parents of children with Autistic spectrum disorder at Australia. They conducted structured telephone interview among the parents of 21 children who are suffering from Autism spectrum disorder. The result shows that only one of 21 parents knew about the recurrence risk. They concluded the study as the current provision of information about recurrence risk to families affected by Autism spectrum disorder is inadequate¹⁷.

CONCLUSION

The main goals when treating children with autism are to lessen associated deficits and family distress, and to increase quality of life and functional independence. In general, higher IQs are correlated with greater responsiveness to treatment and improved treatment outcomes. No single treatment is best and treatment is typically tailored to the child's needs. Families and the educational system are the main resources for treatment. In India, the professionals can train and give proper knowledge to parents in setting up their own individualized treatment programmes for their child

REFERENCES

1. Bassa DM. A case of early infantile autism. *Indian J Psychiatry* 1962;4:73-6.
2. Venkoba Rao A, Sreedhar KP. A case of early infantile autism. *Indian J Psychiatry* 1975; 7(2): 138-43.
3. Narayanan HS. A report of clinical observations and management in 7 cases of childhood autism. *Indian J Psychiatry* 1978; 20(1): 93-7.
4. Sreedhar KP, Venkoba Rao A. A questionnaire for the detection of early infantile autism. *Indian J Psychiatry*, 1976, 18(4): 266-72.
5. Srinath, S., Chowdhury, J., Bhide, A.V., Narayanan, H.S. & Shivaprakash. Descriptive study of infantile autism. *NIMHANS Journal* 1989; 7 (1), 77- 81.
6. Malhotra, S., Chakrabarti, S., Gupta, N., Kumar, P. & Gill, S. Pervasive developmental disorders and its subtypes: sociodemographic and clinical profile. *German J Psychiatry* 2003.
7. Bharat S, Srinath S, Sheshadri SP, Girimaji S. Child and Adolescent Psychiatry - in patient facility. *Indian J Psychiatry* 1997, 64 (6), 829-32.
8. Duggal HS, Dutta S, Sinha VK, Basu S, Pandey S, Nizamie HS, Nizami A. neurobiology of asperger's syndrome: a case study and overview. *Indian J Psychiatry*, 2001, 43(3): 267-72.
9. Arora M, Praharaj SK, Sarkhel S, Sinha VK. Asperger disorder in adults. *South Med J.* 2011; 104(4):264-8.
10. Malhotra S, Kumar D, Gupta N. Rett's syndrome. A neurodevelopmental disorder: report of two cases. *Neurol India* 2002; 50, 330-3.
11. Malhotra S, Gupta N. Childhood disintegrative disorder. *J Autism Dev Disord.* 1999; 29(6):491-8.
12. Jaydeokar S, Bal G, Shah N. Childhood disintegrative disorder. *Indian J Psychiatry* 1997; 39:85.
13. Malhotra S, Singh SP. Disintegrative psychosis of childhood : an appraisal and case study. *Acta Paedopsychiatrica* 1993; 56, 37-40.
14. Singhi P, Malhi P. Clinical and neurodevelopmental profile of young children with autism. *Indian Pediatr* 2001; 38(4): 384-90.
15. Datta AK, Mandal S, Bhattacharya S. Autism and mental retardation with convulsion in tuberous sclerosis: a case report. *Cases J.* 2009; 31; 2:7061.
16. Kar N, Khanna R, Kar GC. Autistic features in children with mental retardation. *Indian J Psychiatry* 1993; 39 (4): 304-8.
17. Purkayastha M, Girimaji S, Srinath S, Sheshadri SP. Clinical profile in mental retardation. In: Hegde R, Malhotra S, Shah LP, editor. *Research endeavours in child and adolescent psychiatry in India.* 1997: 48-53.