

HEALTH & WELLBEING OF WOMEN AND CHILDREN



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Health and Behavioural Problems of Children With Autism Spectrum Disorders: Coping Mechanisms of Parents

R. Madhumathi

Abstract

This study took a descriptive approach, collected information from 40 children with Autism Spectrum Disorders (ASD) in the age group of 6 to 18 years, in Nellore and Chittoor districts of Andhra Pradesh. Structured interviews were conducted to elicit information from parents (majority mothers) and assess the children with ASD by using ISSA and intake form. The results describe health and behavioural problems of children with ASD and also discuss the coping mechanism of parents of children with ASD and recommended strategies to parents of children with ASD to cope with the situation. This is an empirical paper extracted from ICSSR (Indian Council of Social Science Research), New Delhi Funded major research project entitled "Efficacy of Social Work Interventions for children with ASD and their families".

Introduction

Autism is a fast-growing neuro developmental disorder. The reports of the centre for Disease Control (CDC), USA, (2018) stated that 1 in 59 children have autism in the USA, (26th April 2018) and in India the prevalence rate ranges from 0.15 to 1.02% in various studies, depending on the screening method used and the areas surveyed (Rudra A.etal, 2017, Raina Sk et.al,2017) The children who suffer from autism have core deficits in communication, social interaction, restricted, repetitive and

stereotyped patterns of behaviours or interests. Autism in a child affects every member of the family in different ways. If the special child is in a joint family or in extended family normal siblings as well as grandparents are also affected.

Along with the core deficits as mentioned above, children with autism have health problems which lead to a lot of stress and burden among caregivers. They have comorbidities that include epilepsy, gastrointestinal distress, sleep disturbances, eating and feeding challenges, attention deficit and hyperactive disorder (ADHD), anxiety, depression, schizophrenia and bipolar disorders.

Review of Literature

Literature traces out that, many individuals who have autism spectrum disorders (ASD) experience elevated levels of health problems. (Filipek, 2005; Volkmar & Wiesner, 2004). Anecdotal and clinical literature has reported the association between physical health and behaviour problems in ASD (e.g., Goldson & Bauman, 2007; Volkmar & Wiesner, 2004) while some observe that the unique features of autism (i.e. impairments in communication and social interaction) can make it difficult for individuals to cope with their physical health problems and associated pain, often leading to behaviour outbursts. (Carr & Owen-DeSchryver, 2007; Groden, Cautela, Prince, & Berryman, 1994).

Research also documents that the prevalence of sleep disturbances ranges from 53% to 78% for children who have ASD compared with 26% to 32% for typically developing children. (Beth A. Malow, 2012). The key components of insomnia (sleeplessness) in children with autism are repeated incidences/episodes of difficulty initiating and /or maintaining sleep, including premature awakenings, leading to insufficient or poor-quality sleep. These episodes result in functional impairment for the child or other family members. In ASD insomnia is multifactorial. It includes not only behavioural issues but also medical, neurologic and psychiatric co-morbidities; it is also an adverse effect of the medication used to treat symptoms of autism and these co-morbidities. The children who have sleep problems may also have problematic daytime behaviours. Many parents are not able to understand the evidence of sleep disorders in children often go undetected and untreated. (Meltzer L.J, 2010; Owens JA, 2001). Many parents also have poor knowledge about sleep development and sleep problems, (Schreck KA, 2011).

Parents consult doctors with concerns regarding aggression, impulsivity, inattention/hyperactivity, or other behavioural issues that may be secondary to a sleep disorder. Medical practitioners often do not ask about sleep concerns or parents do not seek assistance. Raising a child with ASD puts tremendous strain on the parents and caregivers due to increased responsibility and social stigma. The stress of caring for a child with autism can affect the psychological and emotional wellbeing of parents and generate interpersonal conflict (Divan G et.al, 2012).

Factors that contribute to elevated stress in parents of children with autism also include the child's behavioural problems, lack of access to appropriate services, financial constraints and societal attitudes towards disability. (Desai MU et.al, 2012; Divan G et.al, 2012). Disability is sometimes thought of as a manifestation of past karmas of the child and or the family, and there are a lot of stigmas attached. When the financial situation is very poor, the upbringing of even normal children is a problem for many, in such a situation, caring for a child with special needs is all the more problematic.

In light of the above, a part of an ICSSR funded major research project has been extracted to study the health and behavioural problems in a selected sample which helps to visualize the intensity of the problems in children with ASD and suggest the parents how to cope with the situation.

Methodology:

Aim: To study the health and behavioural problems of children with ASD and suggest strategies to parents to cope with the situation.

Objectives:

1. To study the socio-demographic details and clinical picture of children with ASD under study.
2. To Study the details of health and behavioural problems of children with ASD
3. To identify the scope for strategies to parents of Children with ASD to cope with the situation

Study Area: Community settings of Nellore and Chittoor districts.

Research design: A descriptive research design was utilised to obtain data to meet the aims and objectives of the study.

Sample:

By using simple random sampling technique, 40 children with Autism Spectrum Disorders were selected from community settings of Nellore and Chittoor districts of Andhra Pradesh to constitute the sample.

Tools for Data Collection:

To realise the objectives of the study, following tools were used for the study

1. Intake form
2. Indian Scale for Assessment of Children with Autism (ISSA)

Description of Tools:

1. Intake form: This form was used to seek information relating to demographic and clinical details like age, gender, functional level of child with ASD, education level of the child, age at diagnosis, associated problems of the child, birth order, history of illness in the family, prenatal, natal and early childhood history of the child with ASD, current problems of child with ASD, behavioural problems in child, stressors of the family, likes and dislikes of the child, history of previous interventions, medical problems of child with ASD, school history, Diagnosis, Selecting goals and objectives for Individualized Education Programme (IEP). The intake form was prepared based on the standard case history taking proformas used in standard National institutions in India for children with disabilities.

2. Indian Scale for Assessment of Children with Autism (ISSA) was used to assess the level of autism in children with autism spectrum disorders. This scale was developed by the National Institute for Mentally Handicapped, 2009.

ISSA is a 40 item scale divided into six domains-Social Relationship and Reciprocity (9 questions); Emotional Responsiveness (5 questions), Speech-Language and Communication (9 questions), Behaviour Patterns (7 questions), Sensory aspects (6 questions) and Cognitive Component (4 questions). The scores for the each item of ISSA range from 1-5, depending on the intensity, frequency and duration of a particular behaviour with the following anchors: Score 1 = Rarely (Up to

20%), Score 2 = sometimes (21-40%), Score 3 = Frequently (41-60%), Score 4= Mostly (61-80%), and score 5 = Always (81-100%). Scoring is based on information from parents and observation of the child following guidelines from the Manual of the ISSA. In the Speech-Language and communication domain the child should be rated 5 if he/she never developed speech or communication. Total ISSA scores range from 40-200. The lowest score represents no symptoms or symptoms which were present only rarely, and the maximum score indicates the most severe presentation of Autism. The following categories are recommended: Mild Autism: 70-107. Moderate Autism: 108-153, Severe Autism = 153 and above. (NIMH, 2009, SJ&E).

Results & Discussion:

The present data was taken from the ICSSR major research project with the aim to study the health and behavioural problems of children with ASD in the study. The sample constitutes 40 children with ASD who were randomly selected from the community settings of Nellore and Chittoor districts. Indian Scale for Assessment of Children with Autism (ISSA) was used to find out the degree of autism in children. Structured interviews were conducted with parents (majority mothers) to elicit information about health and associated problems. Children with ASD were observed directly and their behavioural problems were noted down

Age wise distribution of the children with Autism



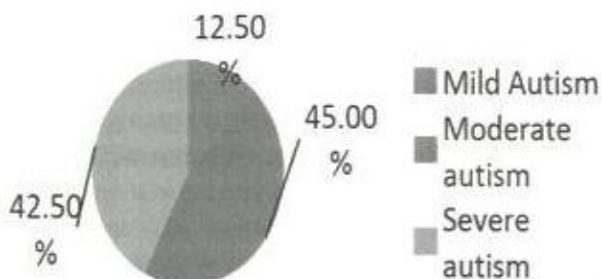
Children with ASD are distributed more (55%) in the age group of 6-11 years than the age group of 12-18 years(45%). It supports the prevalence rate in Autism as the estimated prevalence of ASD increased from 2011 to 2018 following changes in developmental disabilities (CDC,2018).

Fig-2 Genderwise distribution of children with ASD



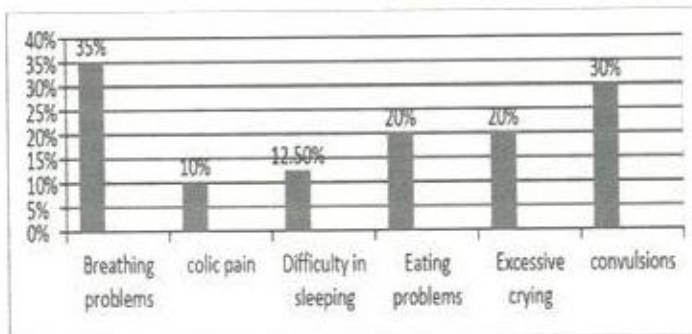
More occurrence of autism is observed in males (80%), than females (20%). Similar findings have been reported in other studies (David et al,2002, Broomely et al,2004, Benjak et al,2009; Tiraya et., al.,2015).

Level of Autism in children with ASD



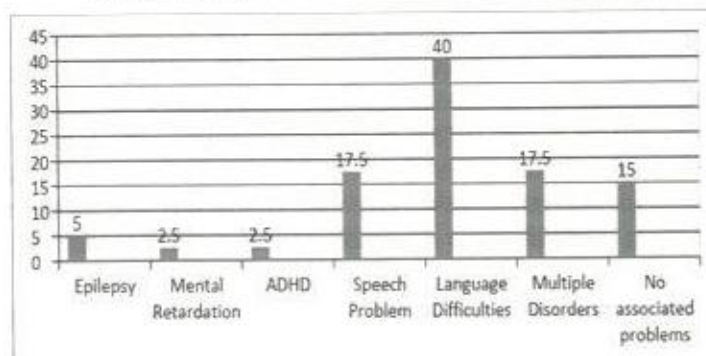
Majority of children with ASD were classified into moderate autism (45%) followed by 42.5 % who belong to the severe level of autism. This finding coincides with other studies Nikmat et al,2008, that out of 52 subjects, 29(55.8%) subjects perceived that their child's symptoms were within the severe level of ASD and in the study of Tiraya et al(2015), that majority of children with ASD were classified into the moderate and high functioning group

Health Problems among children with ASD in early childhood



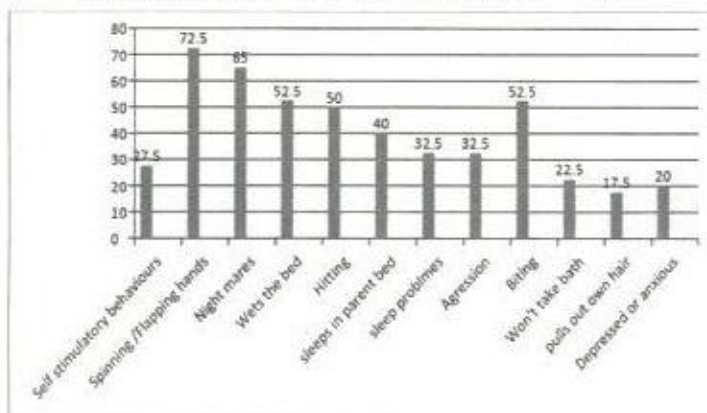
Majority of children with ASD have breathing problems (35%), and convulsions (30%) during early childhood period. Similar results were observed in the studies of Koegel et al, 1992, Matson et.al, 2007.

Associated problems in Children with ASD



In regards to the associated problems, 40% of children have language difficulties i.e., the speech ranges from a single word to 40 words (In this study) and 17.5% is non-verbal, no speech at all and 17.5% of children have multiple disorders. Similar results were observed in the studies of Koegel et al, 1992 (Linguistic Impairments).

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Behavioural Problems of children with ASD



As evident from figures 1-6, it can be observed that a large number (55%) of children are in the age group of 6-11 years. The majority of children with ASD are males (80%), and most of them have moderate (45%) and severe autism (42.5%) levels. The health issues prevalent during the early childhood of children with ASD are mainly breathing problems (35%) followed by convulsions (30%). Children also have associated problems viz; language difficulties (40%) i.e., the speech ranges from single word to 40 words (In this study), 17.5% are non-verbal, no speech at all, and 5% of children have epilepsy (under medication), 2.5% children have Attention Deficit Hyperactive Disorder, and the same percentage of children have mental retardation (2.5%), 17.5% of children have multiple disorders.

With respect to behavioural problems, a major number of children with ASD exhibited various types of problem behaviours. Among them, self stimulatory behaviours (spinning /flapping hands) occupies nearly three quarters of problems(72.5%), followed by Nightmares (65%), bed wetting (52.5%), biting (52.5%), hitting(50%), sleeping with parents (40%), sleep problems (32.5%), aggression (32.5%), rocking behaviour (27.5%), refusing bath(22.5%), Depressed or anxious(20%), pulls own hair(17.5%). etc. Behavioural problems in children with ASD leads, a lot of stress and burden among caregivers of children with ASD. Similar results were observed in the studies of Matson et.al (2007).

Coping Mechanism in parents of children with ASD:

To cope with these challenges, parents strap up a range of mechanisms including acceptance the child with ASD, resistance to accepting the fact, social withdrawal, reorganizing life and relationships, empowerment, seeking social support, changing expectations and turning to spiritual and religious beliefs (Divan G et.al, 2012). The socio-cultural diversity in India greatly influences the parental coping mechanisms. In the joint family setup, especially grandparents are the first line of support. The joint family system helps parents in caring for the child with special needs and managing other schedules. In nuclear families, or in families with lack of a support system, one parent (usually the mother) often compromises on professional goals to care for the child. Over time, some of these parents may reintegrate into parent support groups (Parent Associations) or resume working outside the home later as the child grows up. Some parents seem to seek comfort from the thought that autism in the child was due to past karma, and so the child was destined to be born with it. Many parents turn towards religious beliefs and lead life spiritually. Parents, who are unable to cope with the stress of dealing with a child with ASD, often have marital and family conflicts, and are prone to anxiety and depression. Parents who manage to cope up adequately devise strategies for creating a secure loving environment for their child and families despite the various adverse situations, financial constraints and limited services.

Recommended strategies to parents of Children with ASD to cope with the situation:

1. The need for therapeutic intervention (ADL training, speech therapy, occupational therapy, Sensory integration therapy etc.) should be determined; especially Individualized Educational Programme (IEP) to each child according to his age, needs, level of functioning, symptoms, and behavioural problems requires to be tailored accordingly .

2. Therapeutic interventions should begin with parent education in the use of behavioural approaches as a first-line approach. Psycho-educational Interventions also need to be taken up.

3. Appropriate medical intervention for the health problems of children with ASD should be provided

4. There should be follow-up after any intervention to evaluate the effectiveness and tolerance of the therapy. Follow-up may be conducted by telephone or in person. Timely follow-up allows for fine-tuning of treatment interventions, support of parents and provision of referrals if needed.

5. In addition to short-term follow-up (eg: 1-2 months), at long-term follow-up (1 year visit) the steps from the beginning of the IEP should be repeated.

6. Awareness needs to be created about various conditions of children with ASD, associated problems, behavioural problems, health problems importance of interventions, community support etc., which reduce stigma among parents and leads to welcoming societies.

7. There is need to formulate parent support groups, which help parents to overcome the situation with reciprocal exchange of feelings, emotions, and thoughts to train their children with ASD and also to raise their voice in developing training facilities, formulating policies and programmes with the support of NGO's, and government bodies and tap the available resources to train their children.

8. Strong policy initiatives may help persons with ASD attain their maximum potential and dignity as well as reduce the gap between them and the normal population. Right to Persons with Disabilities Act-2016 has included ASD under the category of disabilities. Parents must be aware of the latest acts and policies relating to their Special children and should know the procedure for certification. So that, the children with ASD can avail special benefits like inclusive education, scholarships, free travel in state transport buses, railway concessions, loans for self-employment and assistance for higher education. (RPwD Act, 2016).

Conclusions

Education programme should be established for family members who provide care for parents with ASD children, to support those who face burden by presenting knowledge about ASD and treatments, teaching, problem solving, communication

skills and providing coping skills. Press and media can play a major role in terms of providing caregivers with adequate information to deal with children with ASD to cope with the situation.

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