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Autism Spectrum Disorder - An Indian Perspective

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Published Date: March 15, 2018

ABSTRACT

Autism Spectrum Disorder (ASD) affects around 3 million people in the Indian subcontinent, and is being increasingly recognized as an important issue. The socio-ethnic diversity and varying cultural practices play a major role in the identification, perception and treatment of the disorder. This chapter reviews the clinical scenario, identification of the disorder, diagnostic tools and treatment considerations from the Indian perspective.

(For ease, the term Autism and Autism Spectrum Disorder (ASD) have been used synonymously in the chapter)

INTRODUCTION

Autism Spectrum Disorder (ASD) is a condition that affects individuals across social, ethnic and geographic groups. However, the way it is perceived, understood, accepted and treated may vary across regions, depending on cultural beliefs and practices. As suggested by prominent Indian psychologists, Indians largely emphasize conformity to social norms and value social relatedness, and hence, a disorder that is defined by deviant social functioning has special significance in the country.

HISTORICAL PERSPECTIVE

History of autism in India dates back to as early as1943 when A Ronald, a Viennese pediatrician in Darjeeling, gave an overview of the symptoms, etiology, types and treatment of 'difficult children'. He described a 'difficult child' as one who was not very backward than an average child; who was capable of being trained but showed abnormalities or deviation in the sphere of sensitiveness, inclination and volition [1]. Though the article written by Ronald did not mention the term 'autism', some of the symptoms described by him matched Kanner's description of autistic children. Published case reports and studies on Autism from India can be found from early 1960s onwards, though their numbers were substantially less as compared to western literature during the same time [2].

Till 1980, only few centres and some individual professionals were diagnosing children with autism, and knowledge amongst the larger medical fraternity was lacking. It was also seen that many patients with autism had received the diagnosis from abroad. By the early 1980s more professionals started being aware of the existence of this condition, but a majority of them believed that it was a rare disorder, difficult to diagnose and treat, and associated with poor outcomes [2].

Subsequently, as professionals and parents of children with autism started creating awareness in the community about the condition, by the late 90s, few autism specific organizations and schools came into being in different parts of the country [3].

Since the last two decades, awareness regarding autism in India has experienced tremendous growth in numerous domains: diagnosis, treatment options, parental involvement, pre-vocational and vocational options, human resource development, legislation, and research.

Prevalence of Autism in India

Similar to the western world, there has been an increase in the prevalence of autism in India over the years. Once considered rare, the current understanding is that autism is in fact one of the more common developmental disabilities. The increase in prevalence can be attributed mainly to increased awareness amongst professionals. Changes in case definition, earlier detection, and diagnostic substitution of cases may also be contributory. However, a true increase in prevalence cannot be ruled out, especially because advanced parental age at conception, and perinatal risk factors like prematurity and high-risk infant survival have increased over the years. Recent estimated prevalence of ASD in India ranges from 0.15% to 1.01% in various studies, depending on the screening method used, and the areas surveyed [4,5]. In the INCLEN study, the prevalence of ASD (then termed as PDD) was 1 in 125 in children 3-6 years and 1 in 85 in children 6-9 years of age. The prevalence in rural areas was 0.90%, 0.6% in hilly regions, 1.01% in urban areas, 0.1% in tribal areas and 0.61% in the coastal regions.

Even though there has been a vast increase in the number of cases being detected, majority of people with autism in India, especially adults, still remain undiagnosed, and do not receive the services they need.

Etiology of Autism

There is no known single cause for Autism Spectrum Disorder but studies suggest possible role of both genetic and environmental factors. Pre- and perinatal events like disorders of pregnancy, labor complications, fetal distress, low birth weight and premature birth have been studied and implicated in ASD. These risk factors are common in India, and have significant impact on the developmental outcome of children. A population based cohort study using a questionnaire to determine prenatal, perinatal and neonatal risk factors of Autism Spectrum Disorder, found advanced maternal age, fetal distress and gestational respiratory infections to be associated with ASD. Perinatal and neonatal risk factors associated with ASD were labor complications, pre-term birth, neonatal jaundice, delayed birth cry and birth asphyxia [6].

Genetic Considerations

Several studies support the strong role of genetics in the etiology of ASD. A study done at our centre found the prevalence of ASD in siblings to be 4.97% [7].

Worldwide, more than 100 different genetic and genomic changes have been reported in individuals with ASD, with several being shown to have a strong association. Some commonly noted ASD loci on chromosomal microarray (CMA) studies that have been studied in India include Engrailed-2 gene, RELN, ITGB-3, SLC6A-4etc. Family-based studies have indicated association of Engrailed-2 (EN-2) gene located on chromosome 7q36.3 with autism in an Indian population [8]. Another population based study found Monoamine Oxidase A (MAOA) on X chromosome to be significantly associated with ASD. The study concluded that the differential genetic effect in males and females might contribute to the sex ratio differences and molecular pathology of the disorder [9].In another Indian study, genetic association and gene-gene interaction analyses suggested likely involvement of ITGB3 and TPH2 in the pathophysiology of ASD [10]. No association has been found as yet for other ASD 'hotspot' loci, including HTR2A gene, which has been known to be associated with ASD in Korean and American populations [11]. However, most of the data is from one centre, and there is no conclusive evidence regarding the genes involved in ASD in Indian population, so more definitive studies are warranted.

Early Identification and Diagnosis

Parents as well as primary care physicians/ pediatricians play an important role in early identification of autism spectrum disorder. Till recently, there were no clear guidelines for screening for autism in India. The awareness regarding red flag signs for ASD was also less amongst primary care physicians and pediatricians. Therefore, early detection of autism depended on parents' perception and ability to identify problem behaviors and seek help for the same.

The timing at which families of children with autism become concerned about their child and seek medical advice is, on an average, 6 to 10 months later than parents in the US note symptoms in their children [12,13]. The delay in noticing symptoms can be partly attributed to the fact that

there are no obvious physical markers in most cases of autism. In first 2 years of life Indian parents are primarily concerned about motor development, and most children with ASD achieve these milestones on time; the lack of warm joyful expressions or atypical play may not elicit concern. Advanced rote skills of some patients, specially reciting of mantras, parroting A to Z and numbers may mask poor functional speech. Cultural influences on child development norms may also have an impact on the symptoms being recognized as problematic or not. Even though social relationships are highly emphasized in Indian culture, a quiet child who keeps to himself may be taken as a 'well-behaved' child, and parents may be often proud of such 'trouble-free' children. On the other hand, an overfriendly child and one who uses gestures for greeting like Namaste or touches feet of even strangers may be considered to be very respectful. Some mothers, who recognize the importance of social-emotional attachment may notice the peculiarities of a self-absorbed child, but their innate need to protect the child may lead them to dismiss signs of abnormal behavior. People living in rural areas, and those belonging to lower socioeconomic strata tend to accept and tolerate some degree of hyperactivity/ atypical play as normal. Finally, cultural acceptance of delayed language development in boys, and family history of delayed language development are important factors contributing to the delay in parental concern.In recent years, the mushrooming of playgroups and preschools has had an impact on early identification of symptoms, as teachers and caregivers note differences in development and behaviors more readily in the presence of other similar aged children.

Common symptoms that cause the initial concern are speech and language problems- including language delay as well as deviance in speech, followed by behavioral problems like hyperactivity, aggression, tantrums etc. Social impairments are often not the primary reason for concern, though parents often report social problems when asked. Problems with eating, sleeping and toileting, or medical or developmental difficulties such as seizures, a delay or regression in milestones, odd posture or gait and poor general understanding may prompt some parents to seek help [14]. With increased coverage of autism in media, as well as easy access to information, parents have started noticing obvious features like poor eye contact, atypical or repetitive play (lining of objects/ spinning of wheels), or autism specific motor stereotypies like rocking, hand flapping etc.

The time between symptom recognition by parents and final diagnosis/referral by the primary care physician/pediatrician determines how early intervention is initiated. The average age of diagnosis in India, according to published studies, ranges from 42 months to 55 months. This suggests that there is a lag of about 14-24 months from the time parents raise concerns to receiving the initial diagnosis. Parents often report to have seen multiple doctors, before receiving a final diagnosis of autism. Physician factors contributing to a delay in diagnosis include reassurance by primary care physician/ pediatrician, misdiagnosis/ incomplete diagnosis, non-referral by physician despite identifying the problem and time lost in inappropriate referral [12,13]. It has also been seen that children who present with a medical problem are diagnosed later as compared to those who present with behavioral or developmental issues. This may partly be explained by

the fact that the treating doctor, due to busy schedules, addresses the medical problem for which the child is brought, and is generally unable to focus on developmental concerns in the same visit [14].

Another important cultural factor that may delay a timely diagnosis is the reliance of the family on 'prominent' or 'senior' doctors, rather than those capable of giving a correct diagnosis. It has been seen that many older doctors may have an outdated view of autism, and tend to brush aside parents' concerns, especially if the symptoms are mild [14]. Once the parents are convinced that the problem is insignificant, persuading them to accept the correct diagnosis becomes extremely difficult.

Often, doctors may not intentionally provide the diagnosis because they believe that parents may not understand the diagnosis, or because they find it difficult to communicate about the disorder to the parents. Quite often, parents do get offended on being told that their child has autism, and seek multiple opinions till they get reassured by someone, or convinced of the diagnosis. Also, many health professionals are unaware of availability of services and importance of early intervention in autism.

Older children, hitherto undiagnosed, are commonly brought with poor academics, or behavioral issues like hyperactivity or aggression. These children may be bullied in school and are prone to anxiety and depressive symptoms. These children are often diagnosed as ADHD, SLD or conduct disorder, and the primary diagnosis is missed.

A diagnosis of ADHD, or GDD, is considered to be socially more acceptable by the parents, and they cling to the diagnosis as they find it easier to deal with.

Despite all these factors, the average age at diagnosis has been decreasing because of growing awareness among health professionals, and increased availability of intervention services across the country. However, India is a country of stark contrasts, and families residing in remote areas often have to travel hundreds of kilometers in order to receive the correct diagnosis.

CLINICAL PRESENTATION

Clinical spectrum of autism in Indian children has been seen to be consistent with that of other cultures with the core features being relatively universal.

A descriptive study done in a hospital setting that primarily included moderate to severely affected cases described the commonest presenting complaints as delayed development, speech delay and 'being lost in one's own world'. Other symptoms included poor eye contact, impaired joint attention, no interest in toys or inappropriate use of toys and difficulty in toilet training. There was lack of imaginative and pretend play. Apart from behavior problems like hyperactivity, aggression and self-injury; pica, excessive mouthing of objects, and seizures were also significant concerns. Commonly observed motor stereotypies included hand flapping and rocking. Over-

reaction to the sound of a pressure cooker whistle or a mixer-grinder was an often-reported sensory symptom [15]. Common co-morbidities include ADHD, Intellectual disability and seizures.

In children younger than 2 years of age, clinical characteristics included poor response to name, no meaningful speech, lack of social interest in other children, no index finger pointing, lack of joint attention, inability to follow verbal commands, lack of pretend play, unusual play, and poor eye contact. Children with ASD displayed a wide variety of repetitive stereotypic behaviors including rocking, hand flapping, hand gazing, spinning, and toe walking. Non-functional use of objects manifested as spinning utensils, mouthing or licking toys, banging things, or lining and stacking them [15,16]. More than one-fourth of the children displayed self-injurious behaviors such as repetitive head banging, hitting oneself or scratching severe enough to cause bleeding [15].

Regression in children with autism is often seen, thought the prevalence is not exactly known. It has been seen in studies that large majority of the parents report regression between 12 and 24 mo. Regression in the language domain, particularly in the expressive language sector, and usually occurs between 18 and 24 months of age. Regression is usually slow and subtle and also occurs in other domains like social skills and cognition, apart from language [16,17].

Thus, even though most of the characteristics seem similar, the diversity of culture and socioeconomic status in India may have an impact on the symptom expression and recognition. Commonly, children especially girls and young women are expected not to make direct eye contact with men, elders or strangers; as well as speak only when spoken to and not indulge in social chitchat. Tone of voice may vary across regions, with some dialects being spoken in a loud or 'warrior-like' tone even during normal conversation. In villages and rural areas, plenty of local colloquial is used which may be difficult to understand. In most Indian languages, the second and third- person pronoun (you, and he/she/they respectively) can differ depending on the addressee's age and familiarity with the speaker. Similarly relationships are named specifically depending on the relation to the particular person. For example, father's sister is 'bua', and mother's sister is 'mausi'. Gestures for greeting also differ across age and religion. Thus, in some societies, people are greeted with either folded hands (Namaste), or touching the feet of elders as a mark of respect; in others, 'salaam' is the main mode of greeting. In fact, contact gestures for greeting like hugging or shaking hands may not be acceptable. These subtleties of Indian culture are not only difficult to grasp, but also complicate the therapy [18].

While enquiring about and assessing play, it is seen that many children from lower socio-economic background don't have access to conventional toys, and are often seen to play with sand, mud, bricks and household utensils. These children, especially girls, are also burdened with household responsibilities, and don't have time or the opportunity to play with peers. Many families from lower socio economic strata as well as some with too much emphasis on academics are neither aware of their child's play nor interested in encouraging it. In children from higher

socio-economic groups, excessive use of smart phones and gadgets may manifest with rote use of westernized English, which may be taken as a positive attribute by the parents. Apart from this, increased solitary play and social isolation associated with gadget use masks the social difficulties and may contribute to them. The breakdown of traditional joint family system also is contributing to the changing symptomatology with lesser expectations to follow societal norms and lesser social interaction and peer group exposure. However, it has also resulted in breaking of traditional boundaries for women.

The cut-off at which all these normal variations in behavior converge into deviant, cannot be defined easily and this may impact the screening and diagnostic processes, and influence the prevalence rates of autism and broader autism phenotypes across regions.

SCREENING TOOLS FOR ASD IN INDIAN CHILDREN

Screening is a key step to identify children at risk for ASD and to facilitate early behavioral and educational interventions to improve outcomes. The Indian Academy of Pediatrics has recently issued guidelines for screening for ASD at 18 months and 24 months of age, using ASD specific screening tools [19].

Internationally standardized and validated tools for autism screening that are used in India include Modified Checklist for Autism in Toddlers (M-CHAT), Autism Spectrum Quotient (ASQ), Social Communication Questionnaire (SCQ), Social Responsiveness Scale (SRS), Autism Behavior Checklist (ABC) and Social Communication Disorder Checklist (SCDC). Of these, SCQ, SCDC and ASQ have been translated into Hindi and Bengali [20]. The translated instruments were found to show similar properties to the original instruments, and the results showed that these tools could be used for screening purposes in the sub-continent. However the tools were validated on a small population, and further studies need to be done on a larger subset of children before they can be used in epidemiological studies. Around 4% of children with Asperger Syndrome (DSM- IV criteria) did not meet the cut-off scores on these tools.

M-CHAT has been translated into many Indian languages, and Hindi, Bangla, Kannada and Tamil versions are available at the website. M-CHAT has been regularly used in clinical as well as epidemiological studies for screening of toddlers, and the prevalence rate of toddlers at-risk for ASD had been found to be consistent with large scale screening studies in other countries. However, in most of the epidemiological studies conducted, the second stage diagnostic assessment was not done [21]. A descriptive hospital based study found that all screen- positive CHAT children were found to fulfill DSM criteria for autism [15]. Conversely, in a retrospective study, all toddlers with autism were found to have failed M-CHAT [16].

There have been no published studies using Social Communication Questionnaire in the general population from the Indian Subcontinent. In a clinic-based sample of 30 children with ADHD, 28%children were found to be SCQ screen-positive [17]. In an unpublished study, 106

children with epilepsy were screened using SCQ, and 8 of 9 screen positive children fulfilled DSM-IV criteria. However, most parents perceived difficulties in understanding some of the items in the questionnaire, so SCQ may be too technical from parents' perspective.

A study conducted for estimating sibling risk used the Social Responsiveness Scale (SRS) for screening of siblings aged 4 and more, followed by diagnostic assessment using DSM-IV. All siblings who screened positive in SRS fulfilled diagnostic criteria for autism [7].

The autism behavior checklist (ABC) has potential utility for evaluation of children with ASD in resource-poor settings, as it is available free of cost. The sensitivity of ABC in the diagnosis of autism in Indian children was evaluated in a developmental clinic. By using the originally suggested cutoff score of 67, the checklist was found to have a sensitivity of 78%.When a lower cutoff of 45 was used, the sensitivity increased to 98% [23].

Though many screening tools are being widely used in India, majority of the population cannot decipher the original English versions. Many of these tools have been translated into local languages, but the psychometric properties of the translated versions have not been analyzed in detail. Screening tools like SCQ and SRS, meant for older children and adults are expensive, and may not be suited to resource poor settings. Additionally, cultural adaption and modification of the tool as per local socio-cultural and linguistic norms needs to be done before they can be used for population based screening.

Diagnostic Tools

Many clinicians are diagnosing ASD based on DSM-IV or DSM-V evaluation. Diagnostic tools include ADOS, ADI-R and CARS. The available diagnostic instruments for ASD are patented and expensive, and ADOS-G and ADI-R use requires mandatory international accreditation. The tools are not available in different Indian languages, with the exception of ADOS, which has been translated into Hindi and Bengali, but the translations are not freely available. However, some items like beach scene, birthday party scene etc in ADOS are unsuitable in the Indian scenario, as most children from lower socio-economic groups are unexposed to such events. Similarly, questions regarding one's boyfriend or girlfriend may be considered inappropriate. So, the reliability of the diagnosis of ASD in diverse socio- cultural settings using the available tools has been problematic.

The diagnostic accuracy, reliability and validity of Childhood Autism Rating Scale was studied in India, and a CARS score of > or =33 was suggested for diagnostic use in Indian populations, as against the universal cut-off of 30[24]. However, this study was conducted in a tertiary hospital, and hence would not be representative of the community. Also, many children had associated hyperactivity and intellectual disability; it is likely that higher scores in these domains contributed to overall higher scores. In our experience, many children with mild or high functioning autism have CARS score below the recommended cut-off of 30.

Indigenious Tools Developed In India

To overcome several of the limitations of internationally available tools, and to standardize diagnosis and thereby facilitate early intervention for children with autism, two tools have been developed in India- INCLEN Diagnostic Tool for Autism Spectrum Disorder and Indian Scale for Assessment of Autism (ISAA). These tools are available for free access.

DEVELOPMENT OF INDT-ASD

A team of experts developed the appropriateness criteria and tool over three rounds. During this process, the clinical criteria for ASD as presented in the ICD-10, DSM- IV TR Autism Diagnostic Observation Schedule (ADOS), Childhood Autism Rating Scale (CARS), Gilliam Autism Rating Scale (GARS), Modified Checklist for Autism in Toddlers (M-CHAT) and clinicians' views on the construct of ASD were reviewed. The construct and its sub-construct were adapted for its appropriateness in the Indian cultural context and converted into symptoms clusters for the clinicians and psychologists to rate during the diagnostic workup. Psychometric evaluation of the tool was done on 154 children. INDT-ASD was first developed in English, and has been translated into 8 Indian languages, namely Hindi, Malayalam, Odia, Konkani, Urdu, Khasi, Gujarati and Telugu.

The tool has two sections: Section A has 29 symptoms/items and Section B contains 12 questions corresponding to B and C domains of DSM-IV-TR, time of onset, duration of symptoms, score and diagnostic algorithm. It is designed for diagnosis of ASD in children 2- 9 years of age and takes approximately 45-60 minutes to administer and score. A trichotomous endorsement choice ('yes', 'no', 'unsure/not applicable') is given to the assessor/interviewer. In addition, the clinician/psychologist has to make behavioral observations on the child and score the item as well. For any discrepancy in parental response and interviewer's assessment, it is indicated for each question whether parental response or assessor's observation should take precedence. Each symptom/item is given a score of '1' for 'Yes' and '0' for 'No' or 'unsure/not applicable'. Presence of ≥ 6 symptoms/item (or score of ≥ 6), with at least two symptom/item each from impaired communication and restricted repetitive pattern of behavior, is used to diagnose ASD.

INDT-ASD has high diagnostic accuracy and validity (sensitivity 98%, specificity 95%, positive predictive value 91%, negative predictive value 99%), taking expert diagnosis using DSM-IV-TR as gold standard. It has good internal consistency and high criterion validity. The convergent validity with CARS and divergent validity with Binet-Kamat Test of intelligence are significantly high [25].

INDIAN SCALE FOR ASSESSMENT OF AUTISM (ISAA)

ISAA is a valid and reliable Indian tool for diagnosing Autism and grading severity and disability among persons aged 3-22 year. Its envisioned purpose was to establish diagnosis, and to rate severity (that was converted to extent of disability), so that it enabled certification and

availing of benefits from 'Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act'. ISAA comprises of 40 items covering 6 domains; Social relationship and reciprocity, Emotional responsiveness, Speech-language and communication, Behavior patterns, Sensory aspects and Cognition. Individual items are scored on a Likert scale based on history and interviewer observation. Autism is diagnosed when the total score is ≥70. Severity is categorized as mild, moderate and severe Autism based on scores of 70- 108, 109-153 and >153, respectively [26].

TREATMENT CONSIDERATIONS

It is well established that Autism Spectrum Disorders cannot be cured, however early intervention can bring about fruitful results. Behavioral and educational interventions form the cornerstone of Autism therapy. However, most of these evidence-based interventions require specialized and highly trained professionals that are available in only a handful of government institutions. Private centre-based services provide sessions on a daily or alternate day basis, but the therapies are expensive and affordability becomes a significant issue for families from middle and lower socio-economic strata. Also, most of these centres focus on a particular aspect of autism like speech, sensory issues or academics, and holistic management is hardly considered. There is a lot of emphasis on occupational therapy, and surprisingly, many professionals also focus more on behavioral control, need-based communication, adaptive living and functional academics rather than social skills, pragmatic language development, or play.

Children living outside the major cities have virtually no access to any kind of intervention or therapy, and are at the mercy of local healers, or self-proclaimed 'curers' of the disorder. An internet search for 'Autism therapy in India' yields a variety of results, with many treatments guaranteeing 'cure' of the disorder. Treatment options advertised include but are not limited to homeopathy, Ayurveda, gut-cleansing treatments, music therapy, diet restrictions, dietary supplements, hyperbaric oxygen and stem-cell transplants. Most of these therapies have not been proven to be beneficial, but anecdotal case reports prompt parents to seek these highly expensive and often dubious therapies. The kind of treatment sought by parents for their child is also majorly influenced by their beliefs about the disorder and their expectations of the child's future. Parents, who lack insight about autism, and those who expect a complete 'cure' or instant response with treatment, are more likely to turn towards the therapies with 'tall claims but no clear benefits'. Often, by the time these parents realize the futility of their efforts, they have invested almost all their money and most of the golden period for intervention in these therapies, with no results.

Older children with good cognition are often diagnosed and managed as SLD or ADHD instead of ASD, and hence, hidden disabilities including inability to sustain friendships, poor conversational skills, inability to understand implied meaning or sarcasm and poor understanding of social rules remain largely untargeted.

Available standard forms of therapy are mostly ABA-based and include an eclectic mix of play-based interventions, sensory integration, social skills training, special education, speech and language therapy and group therapy. However, the therapies are usually not as intensive or clearly defined as recommended in Western literature.

PARENT-MEDIATED TRAINING

With the expected number of children with ASD in India likely to be around 30 lakhs, providing therapist-mediated services to the patients on a regular basis is not practically feasible, and parent mediated therapy becomes a necessity. Parents as co-therapists at least partially address the problem of limited access to services and may be an effective alternative intervention for children with ASD. It has been the primary mode of therapy in India for many years even before it was reported in Western literature. It was basically commenced by a group of parents of children with autism in order to fulfill the unmet needs of their children. Few of these parents obtained training from international experts and also took the initiative of spreading awareness in the community regarding autism. Many of them later started their own centres and provided therapy to the children, and also trained other parents. With increasing awareness amongst professionals and rising recognition of this condition, facilities for management were established in some medical colleges as well. However because of their huge patient loads, parent mediated intervention again became the primary modality of intervention.

Parent-mediated training ensures delivery of therapy in natural settings, and is also economically advantageous. It ensures that training occurs throughout the day, thus facilitating generalization of acquired skills. Parent-mediated interventions have been reviewed in many studies, and the general consensus is that parents who receive appropriate training, gain skills in the delivery of interventions, thus improving joint attention, social communication and behaviors of their children with ASD [27].

Parent-mediated intervention can be delivered in various forms. In few government centers, the parents or primary caregivers are trained to deliver therapy to their child on a daily basis. At our centre, an individualized education plan is formulated after detailed assessment, keeping in mind the needs of the child and the family, the core deficits and associated behavioral problems. The program is explained to the parents/ caregivers in detail, and the basic techniques of intervention are demonstrated. This training program is given to the parents in the form of a daily schedule, with the teaching activities being incorporated into the family's daily routine. Emphasis is given to social interaction, functional communication and play. Follow-up sessions are scheduled according to feasibility, and the program is reviewed on a regular basis.

Some centres across India conduct parent-group programmes over few weeks or days at the time of diagnosis, in which the parents are trained to manage challenging situations and work more effectively with the child.

In Eastern cultures like India where the family practices are 'child-centric' with the grandparents contributing to the upbringing and care of the children, parent-mediated interventions, especially those in which grandparents and siblings are also involved, work quite well. However, in some situations, this may not be as effective, especially when the mother is considered to be primarily responsible for all household chores, and taking care of children and elders in the family whence she may not get enough time for the affected child. Some mothers working outside the home may lack adequate time to provide therapy, especially if there is lack of social and family support. In addition, many parents may suffer from anxiety, depression, or even have autistic traits, which hinder their ability to fully engage in training activities with their child.

In a randomized trial of parent-mediated intervention for autism spectrum disorder in south Asia (PASS), task-shifting to non-specialist health workers was used as a strategy to deliver the intervention in two academic centre's in India and Pakistan. Though the study showed favorable effects with respect to parental synchrony and child communication initiation aspects of dyadic communication (as compared to PACT trial from which it was adapted), intervention effects on the parent-reported measures for language and social communication were absent. This could possibly be attributed to lower levels of perceived competence, parental stress, poor awareness of the disorder, lack of social support [28]. A study of the treatment mechanisms in the PACT trial suggested additional parental support as one of the objectives of treatment to increase efficacy of parent-mediated interventions [29].

CHALLENGES FOR THE FAMILIES AND COPING MECHANISMS

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 [30]. Factors that contribute to elevated stress in parents of children with autism include the child's behavioral problems, lack of access to appropriate services, financial constraints and societal attitudes towards disability [30,31]. Disability is sometimes thought of as a manifestation of past karmas of the child and/or the family, and there is a lot of stigma attached. When financial situation is very poor, 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.

To cope with these challenges, parents harness a range of mechanisms including accommodation or acceptance of a biological basis for ASD, resistance to biological basis, social withdrawal, reorganizing life and relationships, empowerment, seeking social support, changing expectations, and turning to spiritual and religious beliefs [30]. The socio-cultural diversity in India greatly influences the parental coping mechanisms. In the joint family setup, extended family members, especially grandparents are the first line of support. The joint family system provides scaffolding that 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 aspirations to care for the child. Over time, some of these

parents may reintegrate into parent support groups, or resume working outside the home later as the child grows up. Some parents seem to seek solace 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 perceive prayers as a powerful tool in enhancing their relationship with god. 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.

PROGNOSIS

There are hardly any long-term studies on prognosis of children with ASD in India. A study on effectiveness of early intervention, as evidenced by retention in mainstream schools, showed that 76.5 % of the children who completed the EI program were integrated in regular schools, 2 to 7 y after having completed the program [32].

In another parent-reported study with a median follow up period of 10 years (range 3- 15.6 years), it was seen that out of 80 children with mild-moderate autism, 22% were attending regular school, 42% had need-based speech, 30% were able to share experiences, 25% had meaningful friendships and 46 % had achieved ADLs at follow-up. Parent participation in therapy administration was significantly related to better outcomes in this study [33].

AUTISM IN ADULTS IN INDIA

There are not many published studies or data on Autism in Indian adults. Whether an adult gets a diagnosis of Autism, or any social-communication disorder depends a lot on socio-cultural perception. In India, men are generally considered to be quiet, and stern. There is little information on how adults with autism function with respect to daily activities, household chores, socialization, education, occupation and leisure. A study was carried out to obtain information on the daily routine of 54 adults with autism [34]. All the adults were living with their parents, and 1 was married. 59% of the adults, especially high-functioning ones, attended a structured setting (rehabilitation centres, job-coaching, high school or workplace) during the day, and few of them engaged in some meaningful activities both inside and outside their home. Some adults were not allowed to spend time outside the home because of challenging behaviors like hitting, screaming, removing clothes, masturbation etc. Another reason for the adults staying at home was the lack of enough suitable work and training facilities and centers, even for adults with no disruptive behaviors. This study was carried out in the national capital, and most respondents belonged to middle or higher income group. Adults located in smaller cities and towns may be unlikely to have a diagnosis of ASD, and would hardly have access to intervention or suitable structured settings. Adults with severe maladaptive behaviors may be physically restrained or kept hidden from the society. It is the need of the hour to provide appropriate structured environments and meaningful opportunities for growth, in order to respect the dignity of these adults.

LEGAL PROVISIONS FOR PEOPLE WITH ASD

Rights of Persons with Disabilities (RPWD) Act, 2016 has included ASD under the category of disabilities. The RPWD Act recognizes the equality of persons with disabilities and prohibits direct or indirect discrimination on the basis of disability. The Government of India has notified guidelines for the evaluation of the disabilities and procedure for certification. Subsequent to certification, 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 [35].

CONCLUSION

Socio-cultural factors play a major role in early identification, diagnosis and management of Autism Spectrum Disorder. There is a need to enhance awareness of ASD and its impact on families in order to facilitate early detection and intervention. Also, the need of the hour is to expand appropriate evidence based services in health, educational and social sector. Strong policy initiatives may help persons with ASD attain their maximum potential and dignity, as well as mitigate the gap between them and the 'normal' population.

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