

Financial and Social Problems Faced by Parents of Child with Autism Spectrum Disorder in Pune City

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Abstract

Autism Spectrum Disorder is developmental disability caused by neurological disfunctioning in the brain. Some people with Autism spectrum disorder have differences such as a genetic conditions. Autism children plays with plays toys at every time. Autism spectrum disorder impact on the nervous system and it affects the overall cognitive, emotional, social, physical health of affected individual. There are some characteristics of autism disorder patients. They are unavailable to maintain eye contact and avoid the people. In these conditions parents of autistic child suffering more. Parents struggling more during treatment of autism disorder. Parents have other household responsibility. Parents additionally are handling expense of treatment. Parents not have idea for government scheme for autism patients. Parents are unaware about various nongovernmental organizations who working for autism disorder. In autism disorder speech therapy and medication are very effective in disorder. Patients needs special attendant with them. Majority parents take help senior citizen. In this study try to put on the solutions and various help resources for parents. If parents get various financial aid resources patient will get help for treatment. From this research study have to find out the social and economic problems faced by child with autism parents. Study on how stress affect to parents because of the social stigma. Financial stress during managing the treatment for autism child. This is study to find out the solutions to minimize economic and social problems faced by autistic parents.

Keywords Autism, Financial aid, Cognitive development, Economic problems and Government schemes.

Introduction

Autism spectrum disorder is developmental disability caused by neurological disfunctioning in the brain. Some people with have differences, such as a genetic conditions. Autism child Plays with toys with the same way and every time. Autism spectrum disorder impacts the nervous system and affects the overall cognitive, emotional, social and physical health of the affected individual. There are some common characteristics of autism disorders are avoid to people, does not keep eye contact. Parents struggling more during treatment of autism disorder. Parents have other household responsibility. They are handling expense of treatment. Parents not have idea for government scheme for autism patients. Parents are unaware about various Non Governmental Organizations who working for autism disorder. In autism disorder speech therapy and medication are very effective in disorder. Patients needs special attendant with them. Majority parents take help senior citizen. In this study try to put on the solutions and various help resources for parents. If parents get various financial aid resources then patient will get help for treatment. From this research study have to find out the social and economic problems faced by child with autism parents. In this case stress affect to parents because of the social stigma. Parents getting financial stress during managing the treatment for autism child. The range and severity of symptoms can vary widely. Common symptoms include difficulty with communication, difficulty with social interactions, obsessive interests and repetitive behaviors.

Early recognition as well as behavioral, educational and family therapies may reduce symptoms of autism. Parallel support for development stage and learning can improve the patient condition.

There are some common characteristics of autism disorders are avoids people and does not keep eye contact, does not respond to name ,does not show facial expressions like happy, sad, angry.

Patients not have point to show you something interesting. Restricted behaviors and repetitive behaviors and interests. People with Autism spectrum disorder have behaviors. These behaviors are interests set autism spectrum disorder apart from conditions defined problems with social communication and interaction only. Patients always repeats words or phrases is echolalia. Plays with toys the same way every time. Child does not focused on parts of objects for example wheels .This type of patient gets upset by minor changes, has obsessive interests. They must follow certain routines, flaps hands. Patient has unusual reactions to the way things sound, smell, taste, look, or feel, delayed language skills, delayed movement skills, delayed cognitive or learning skills, hyperactive, impulsive, and inattentive behavior, epilepsy seizure disorder, unusual eating and sleeping habits, gastrointestinal issues for example constipation, unusual mood or emotional reactions, anxiety, stress, or excessive worry ,lack of fear or more fear than expected. There are 5 types of Autism disorder. First is Asperger's syndrome.

Rett syndrome Rett syndrome to be part of a disease spectrum caused by mutations in gene in which there is duplication of the gene on the X chromosome. Rett syndrome causes serious deficits in almost every element of a child's life. Loss of mobility or gait abnormalities ,reduced muscle tone, microcephaly speech impairment.

Childhood disintegrative disorder Due to its late onset, there will be a loss of previously gained skills in social, verbal, and motor functioning in the child. Parents or professionals may not notice developmental changes such as language, communication, social interactions, and emotional development. Children may report hallucinations. A child who could communicate in two to three sentences may stop talking gradually. A child liked to cuddle may completely oppose physical contact.

Fourth type is kanner's syndrome. It have symptoms of ability to form emotional attachments with people, Uncontrollable speech, Obsession with handling objects, communication and interpersonal difficulties. Fifth type is pervasive developmental disorder. Have a symptoms of Improper development of skills such as motor, sensory, visual-spatial organizational, cognitive, social, academic, and behavioral, communication problems, underdeveloped speech and language skills, repetitive actions such as opening and closing doors repeatedly, abnormal sensitivity to taste, sight, sound, smell, and/or touch. This study will get help to create awareness among parents. Study will be helpful to minimize the vulnerability among parents. Information will collect through Google form and by interviewing with parents. Find out the solutions for financial and social problems faced by parents of child with autism.

Review of Literature

Lancet published in their article Aug 2018 (392)10146 in National Laboratory Medicine Journal. Many children and adults with autism spectrum disorder More adults with autism spectrum disorder can talk, read, drive, graduate from school and live in the community. They are even accounting for the differences in which people would meet the diagnostic criteria now and in the past and their respective levels of intelligence .They told that caregivers can be reassured that the situation has improved and will continue to improve, for most people with autism spectrum disorder .He explained that working with families, schools and community providers ,clinicians can make differences in the lives of individual children and adults by providing accurate and realistic information, support, and hope.

Joseph Alpert MD in 9 June 2020 in American journal of medicine .All adult patients with the autism spectrum can lead relatively normal lives. The patients with milder forms of the spectrum may not be

diagnosed until they reach adulthood. Sometimes individuals are on the spectrum are first diagnosed much later in life. This is due in part to a lack of awareness among medical practitioners.

Prognosis for individuals with autism generally depends on how early in life the spectrum was identified, the severity of disability, and the effect of the various therapies listed above. There is no total cure for autism, but the spectrum is not lethal. Many patients are unable to function normally in society. The management of this disorder can be challenging in adult patients with autism spectrum disorder.

Journal of mental disorder and treatment Agyekum H.A in 2018 mentioned about the challenges parents with autistic parent face are financial burden, stigma, challenges in performing childcare duties and inability to communicate with children. The study realized that the parents bear improving financial burden because of the expensive cost associated with the routine medical scans and check-ups that children had to get in relation to their intervention. These situation of financial burden on parents as they complained that they would not have to bear this cost had they had children without autism. In a similar situation parents faced stigma whenever they went to public gatherings with their autistic children. Parents having their autistic children trying to mainstream schools to their children. They complained of isolation and discrimination against their children.

Research Methodology The main Objective are to study the problem faced by autism parents. To study how parents adjusting with autism disorder and its treatment. To know social problems faced by autism patients parents. To know stress faced by autism parents. The scope is that to get help to many NGO who working on Autism patients. This study will get help to create awareness among parents. A Study will be helpful to minimize the vulnerability among parents. To rearing autism child parents take help of senior citizen. The hypothesis is that Parents facing financial stress because of costly treatment for autism disorders. For this study referred various books on Autism disorder, various literature and article review on autism. Read government schemes on autism and mental disorder. In given research study use secondary source of data collection.

Problem Formulation Autism spectrum disorder is a developmental disability caused by differences in the brain functioning. Some people with autism spectrum disorder have a known difference such as a genetic condition. Patient required long term treatment. Depending on your child's needs, speech therapy to improve communication skills, occupational therapy to teach activities of daily living and physical therapy to improve movement and balance may be beneficial. A psychologist can recommend ways to address problem behavior. There are no medications that treat the core symptoms of autism spectrum disorder. Some medications treat co-occurring symptoms. For example, medication might help manage high energy levels, inability to focus, or self-harming behavior, such as head banging or hand biting. Medication can also help manage co-occurring psychological conditions, such as anxiety or depression, in addition to medical conditions such as seizures, sleep problems, or stomach or other gastrointestinal problems. Psychological approaches can help people with autism cope with anxiety, depression, and other mental health issues.

Cognitive-Behavior Therapy is one psychological approach that focuses on learning the connections between thoughts, feelings and behaviors. During cognitive behavior therapy a therapist and the individual work together to identify goals and then change how the person thinks about a situation. To think how they react to the situation. Single parents cannot manage autism patient's. They need emotional and strong financial support. They will be more aware about government scheme. Improve the literacy rate among autism patients. To rearing autism child parents take help of senior citizen.

Findings Most autism disorders require lifelong treatment and care. This creates financial problems for the family. Families are forced to make significant employment decisions to adjust to their special needs. The absence of insurance that covers the treatment of autistic children contributes to the financial difficulties of parents. It need for a change in career, can change education, can change treatment.

Most of the parents or caregivers are difficult to acquire new skills. The financial strain on the family's income is one of the grueling challenges of an autistic child's parent. Parents face financial

problems of social activities. The family has to make drastic lifestyle adjustments to adapt the home to a new reality in terms of special parental treatment and long-term care for the child. Families may have to change their family dynamics and goals to accommodate the needs of the autistic child.

This change affects the relationship and communication levels between spouses and between parents and their other kids. Some couples feel like their needs are neglected, leading to emotional distance and a breakdown of relationships.

Parents focus more on the needs of their autistic kids. They may feel like they are paid less time and energy compared to autistic kids. This may lead to feelings of neglect, jealousy, hostility, and deterioration of sibling relationships. Social activities provide for parents.

Due to their high dependency on their parents they have to devote all their time and attention to their care. Some parents deliberately avoid family meetings because they worry about how their children might behave in public. Patients exhibit difficult behaviors such as tantrums, repetitive behavior and aggressive outbursts. Patients prefer to isolation from friends and families.

Parents of autistic kids may also avoid social gatherings due to negative stereotypes regarding autism due to social stigma. People may look at their kids differently, treat their kids differently from other kids, and exclude them from activities that may cause feelings of embarrassment.

Suggestions

1. Government Hospital can display the various scheme for autism spectrum disorder patients.
2. Private organization and government organization display the scheme available for autism spectrum disorder patients.
3. Private organization and government organization can conduct awareness Campaign for autism spectrum disorder patients.
4. Child psychiatrist can take initiatives for awareness for implementation of government schemes for autism spectrum disorder patients.
5. Autism spectrum disorder can treat by using medication and can maintain by counseling.
6. Parents counseling is most important part in autism spectrum disorder treatment.
7. Give parents psycho education about Strengthens processing abilities of patients, indulging in Authentic emotional relationship, learning to Communicate and Interact with purpose, learning to think on their own, Improve floor time to covers Social Problem Solving and Sensory Processing.
8. Give psycho education about oral placement therapy which gives speech clarity, Feeding Problems, Articulation, Chewing, Drooling, Taste Development, fluency in speaking and Many more.

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