

A Study on the Experiences and Coping Mechanisms of Parents with Autistic Children in Selected Panchayats of Kozhikode District, Kerala

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ABSTRACT

Autism is a global developmental disorder that involves early and severe impairment in the area of socialization, communication, and cognition. Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that begins early in childhood and lasts throughout a person's life. We know that it is a Neuro-Developmental condition, which is almost certainly biogenetic in origin, and that it affects the way in which information is processed in the brain autism is a spectrum condition, and as such takes many forms, from the non-verbal to a highly talkative for example, or from those who revel in sensory stimuli to those who find such encounters painful and distressing. The main objective of the study is to study the parenting experiences and coping mechanism of parents of children with autism. The researcher specifically examined difficulties parents may experience related to the diagnostic process, how parents respond and react to the diagnosis, what are the positive and negative parenting experiences and coping mechanisms used by parents, and identify specific challenges parents face related to raising a child with Autism.

Key Words : Autism, Autism Spectrum Disorder (ASD), Neuro-Developmental condition, Pervasive developmental disorder (PDD), Kanner's syndrome, Rett's syndrome, Childhood disintegrative disorder, Asperger syndrome.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that begins early in childhood and lasts throughout a person's life. It affects how a person acts and interacts with others, communicates, and learns.

In general ASD is loosely classified into five different types.

Pervasive developmental disorder (PDD) :

Children suffering from PDD show delay in development of social and language skills.

Kanner's syndrome :

This is most common type of autistic disorder. They live in their own world and have poor

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social interactions. They do not like any change in their routine. Individuals with this disorder get affected by loud sounds and cannot lead a normal life as they have low communication skills.

Rett's syndrome:

Usually seen in females and is quite rare. They are mentally retarded and show muscle atrophy. The individuals show repetitive hand movements.

Childhood disintegrative disorder :

The symptoms starts to appear in otherwise normal children between 2-4 years of age. They stop talking and interacting with people around them. Individuals start losing motor skills after the age of two.

Asperger syndrome :

Often misdiagnosed as obsessive – Compulsive disorder or Attention – Deficit disorder. They don't show normal social interactions and have problems communicating. Children with Asperger syndrome show repetitive actions and exhibit poor motor skills. Some are thought have talent on which if they focus on could reach great height.

We know that it is a Neuro-Developmental condition, which is almost certainly biogenetic in origin, and that it affects the way in which information is processed in the brain autism is a spectrum condition, and as such takes many forms, from the non- verbal to a highly talkative for example, or from those who revel in sensory stimuli to those who find such encounters painful and distressing.

The difficulty faced by families with a child included on the autism spectrum reveals a higher level of stress in the family system when compared to a control group of families with typically developing children. Families living with a child with autism have a peculiar life situation. Family dynamics suffers mobilizations, ranging from financial strains to aspects related to physical, psychological and social quality of life (QOL) of caregiver's.

An individual with autism may not express their basic wants or needs in the manner we would expect. Therefore, parents are left playing a guessing game. When parents cannot determine their child's needs, both parties are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious behaviors that threaten his/her safety and the safety of other family members (e.g., siblings). Stereotypic and compulsive behaviors concern parents since they appear peculiar and interfere with functioning and learning. If a child has deficits in social skills, such as the lack of appropriate play, stress may be increased for the family. All of these issues and behaviors are physically exhausting and emotionally draining for families. Taking an individual with autism out into the community can be a source of stress for parents. People may stare, make comments or fail to understand any mishaps or behaviors that may occur. Parents of children on the autism spectrum may experience a sense of isolation from their friends, relatives and community.

Review of Literature :

Bayat (2007) determined that families who demonstrated resilience had a greater ability to cope with their child's ASD. Resilience is the capacity to endure adversity while becoming stronger and more resourceful as a result. Bayat identified three key factors contributing to a family's resiliency: (a) an ability to understand the problem; (b) acknowledging their strengths and having an ability to look at the positives in the situation; (c) having a strong belief system. Although having a child with ASD has many negative aspects, parents do indicate there are a number of positive

changes in their lives as a result of having a child with ASD. Many parents report it has strengthened their faith and improved their spiritual self (Bayat, 2007)

Altierre and Von Kluge (2009) found parents who rated themselves as enmeshed believed they were able to function positively despite their child having ASD. Parents were able to seek social support during times of high stress, felt they had a strong social support network, and reported experiencing less depression and somatic problems.

Objectives of the Study :

General Objectives :

- To study the parenting experiences and coping mechanism of parents of children with autism.

Specific Objectives :

- To understand the socio-demographic profile of the parents of children with autism
- To study the parental experiences of parents of children with autism
- To find out the coping mechanism of parents of children with autism

Statement of the Problem :

Autism is a global developmental disorder that involves early and severe impairment in the area of socialization, communication, and cognition. A child's autism diagnosis affects every member of the family in different ways. Parents have their primary focus on helping their child with autism. Parents have to shift much of their resources of time and money towards providing treatment and intervention for their child. Thus the purpose of this study is to understand the experiences of parents with children with autism and the coping mechanism adopted by parents during the time of stress.

Research Design :

In this study Descriptive Research Design is used to study the parenting experiences and coping mechanisms of parents of children with autism.

University of the Study :

The Universe comprises of all the parents of autistic children who live in Koodaranhi and Kodenchery panchayat in Calicut District, Kerala.

Sampling :

Simple Random Sampling method was used to collect the samples for the study. Totally 40 parents from Koodaranhi and Kodenchery Panchayats were selected for the study.

Hypothesis :

There is a significant relation between the parenting experiences and coping mechanisms.

Tools of Data Collection :

In the study, Interview Schedule was used for data collection.

Findings :

- 60% of the respondents were mothers

- 52.5% of the respondents belong to the age group of 31-40 years
- As the majority of the respondents are mothers and significantly majority (32.5%) of them are homemakers
 - 62.5% of the parents of autistic children belong to nuclear family
 - 67.5% of the respondents live in rural area and their primary source of income is agriculture
 - 47.5% of parents have completed their S.S.L.C and only 7.5% are degree holders
 - 55% of children with autism come under the age group of 11-22 and 45% of them are below 10 years
 - 75% of the children with autism are studying in the class 1st standard to 10th standard
 - 67.5% of parents prefer private hospital for the treatment service and only 12% prefer government hospital for their children's treatment.
 - 85% of respondents said that their children are unable to make friendship with others
 - 82.5% of autistic children have the problem of inability to initiate and make conversation with others
 - 87.5% of the autistic children have absence or impaired imaginative and social play
 - 75% of the autistic children repeat the words and use of language
 - 77.5% of autistic children lack concentration
 - 90% of autistic children have the tendency of pre occupation with certain objects and subject
 - 67.5% have the capacity to adopt to certain situations in life
 - 87.5% of the autistic children have the capacity to convey through spoken language
 - 80% of the autistic children have the capacity to convey through written language
 - 75% of the autistic children have the capacity to convey through sign language
 - 52.5% of the autistic children use communication devise for communication
 - 50% of parents are having moderate level of parenting experiences with their children. They are able to treat their children with good parenting style. 50% of respondents suggest that working together on their child's behalf had positive rewards and they are having new and understanding friends. Correlation between the parenting experiences of autistic children and coping mechanisms of parents with autistic children. Both are positively correlated. As the parents are having good parenting experience their coping mechanisms are also better.
- 40% of the parents adopt high coping mechanisms to have an adjustment in their life, 35% parents have moderate level of coping mechanism and 25% of parents use low coping mechanism to adjust with the daily life conditions.

Suggestions :

- Design universal health care and workplace policies that recognize the full impact of autism.
- Proper monitoring of training institutions and provision of updated teaching/training materials and training to trainers/caregivers
 - Incorporate child's areas of expertise into his/her everyday activities and use them whenever possible as a way for he or she to learn and excel.
 - Provide the siblings with information about autism in a positive manner at their age level is necessary, and there are many children's books available now that can be very helpful to tackle set of challenges.
 - Findings from this study can be used by mental health and education providers who support and provide treatment to families who are affected by autism.

- Findings can also help in forming developmental theories by providing insight on how relationship development progresses between children with disabilities and their parents in contrast to typically developing children and their parents.
- These findings on diagnosis, family life adjustment, parental empowerment, and moving forward can inform the development of programs and services for families, provide insight for health care workers who advocate on behalf of parents, and provide valuable information to parents, particularly those of children newly diagnosed with Autism.
- Documenting the experiences of these respondents will contribute significantly to other people in similar circumstances. This will alleviate the current paucity of information relating to people associated with ASD and birthing, and their support services. It is anticipated that while recording difficult experiences, the documents will also highlight positive experiences that will be of considerable benefit to participants themselves, but also to others in similar circumstances.
- The need for careful diagnosis can be discussed as well as recent changes in thinking about autism that bears upon parental counseling. Suggestions are offered to facilitate the parents' understanding of their child's autistic condition, degree of cognitive and adaptive impairment, and long-range prognosis through institutions/doctors/social workers/support groups. Information should be provided to help in dealing with parents' questions about etiology and reactions to the diagnosis and in making recommendations for treatment and education.
- It is hoped that the findings can contribute to developing intervention and prevention programs aimed at improving the health and wellbeing of parents of children with a autism
- Social workers can play the role of an educator in spreading awareness about Autism, its symptoms, treatment and management among normal people to reduce misconception/stigma related to it. Provide counseling facilities to parents who breakdown both physically and emotionally after the diagnosis. Ensure early diagnosis of suspected children and ensure provision of continuous training for children with autism and their parents without fail.

Conclusion:

Having a child with Autism Spectrum Disorder is life altering. It can change how parents identify themselves, determine where and when they are able to go places, affect their friendships, change their social life, and affect career decisions. It alters relationships with partners or spouses and affects siblings.

Keeping this information in mind the researcher felt the need to study the parenting experiences and coping experiences of parents of children with autism in Calicut District. The researcher specifically examined difficulties parents may experience related to the diagnostic process, how parents respond and react to the diagnosis, what are the positive and negative parenting experiences and coping mechanisms used by parents, and identify specific challenges parents face related to raising a child with Autism. Another assumption was that the level of education and economic status of a family greatly influence parenting experience and coping mechanisms of parents of children with autism. But, this study shows that income and education of the parents does not impact greatly on the care and treatment of the child. Thus, a universal care plan and training for children and parents can be organized to ensure wellbeing of children with autism.

Another important finding is that all the parents understand the significance of early mode of intervention and various therapies and support groups have greatly assisted the children /parents/ siblings to handle important situations in life and get positive rewards in life towards working for the betterment of the child with Autism. Further researches can be done on the efficiency and

effectiveness of services provided by institution where children with autism and their families seek help. This will help to suggest better alternatives to the institutions how to provide standard and innovative ways of care and facilities to the children with autism and their family.

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