Effect of Autism on the Individual and Their Family, A Study Conducted Among Autism Spectrum Disorder (ASD) Population in Kerala

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Abstract: This study explores and analyses the experience of family members of ASD individuals in Kerala .This paper examines the socio-psychological and cultural impact of ASD to the parents and siblings of ASD kids. This study was undertaken using an exploratory design and conducted 4 case studies along with in person semi – structured interviews to address the research question, apart from the collective case study research method, cross case analysis were done. This study was conducted in Trivandrum district of Kerala state India .The results emerged include 4 major things; one, all aspects of the family were affected with ASD. Second the parents of the ASD individuals are facing stress, depression and social isolation. Third there are some serious character aberrations found among the siblings. Fourth lack of support from the spouse especially husbands in the proper upbringing of the ASD child; Discussion of these research findings and the recommendations contributed to the current research and existing literature on the impact of ASD to the family.

Key words- Autism Spectrum Disorder, Family, Socialization, Triad of Impairments

1. Introduction

DEVELOPMENTAL disorders is a group of psychiatric conditions originating in childhood that involve serious impairment in different areas.Under the broad term developmental disorders the most significant is Autism spectrum disorder (ASD). ASD is an umbrella term used to cover a range of difficulties in three main areas of development. The label means difficulty in Communication skills, social interaction and imagination and flexible thinking skills.Autism spectrum disorder is a developmental disorder affecting a child at the age of three years in the three areas of communication , social skills , and imagination (triad of impairments) .The specific cause of autism is still not very clear , although research in this area points towards four main causes : biological, pregnancy/ birth related , neuro - chemical and neurological. There is an increase in the number of people being diagnosed with a ASD. The prevalence rate of autism spectrum disorder (ASD) is estimated to be 1 in 500 and incidence rate is approximately 1 in 91 000 people in India. The sex ratio of autism is one female for every four male children.

Autism not only changes the life of the child diagnosed, but also that of family members. Parents of an autistic child have to bear a lot of stress owing to complicated therapy schedules, home treatments, and juggling job responsibilities and family commitments. There is also financial stress coming from the expensive therapies and treatments. Parents of autistic children need to meet the needs of their children, as well as address the needs of their family.Such stress may affect family life in various adverse ways.

2. Research Problem

Even though the affected population is children with autism its damage is not only restricted to children but also to the parents and siblings. Kerala is a state having an increased awareness towards the early detection and intervention of developmental disorders including autism .After the early diagnosis of autism, most of the parents are not willing to accept that fact .The parents of autistic children live in a false assumption that their children will get cured after a short period of time in a natural course. Autistic children of these group of parents are vulnerable to all the damages due to ASD since they lack the appropriate treatments. This is a psychological issue of parents, siblings and that needs to be addressed. Hence this study throws light into the social and psychological issues of the individual and family of ASD population.

3. .Objectives

1. To explore the initial recognition and diagnosis of autism by the family
2. To analyse the nature of intervention services received by families of children with autism.
3. To analyse the impact on the family of having a child diagnosed with Autism.

4. Theoretical Background

A.Autism.

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, “all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome."

B.Family

amily as a domestic group of people, or a number of domestic groups linked through descent from: (1) a common ancestor, (2) marriage, (3) adoption, or (4) some other committed (romantic or otherwise) relationship. While many families have some form of kinship, many others possess no such tie.

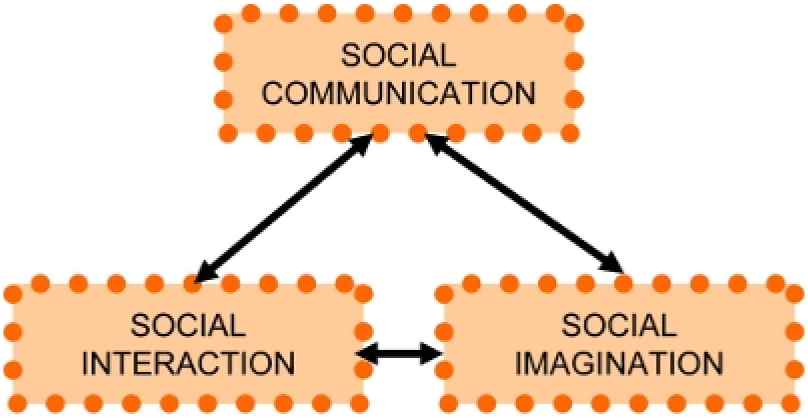
C.Socialization

Autism has become a very prominent problem over the past couple of years. One of the major problems that children with Autism face is their socialization. Socialization Process by which individuals acquire the knowledge, language, social skills, and value to conform to the norms and roles required for integration into a group or community. (www.businessdictionary.com). Socialization is the process by which children and adults learn from others. We begin learning from others during the early days of life; and most people continue their social learning all through life (unless some mental or physical disability slows or stops the learning process).

The human mind is capable of differentiating between true and false statements and the ability to tell what is real and what is not. However, many children with Autism are not able to distinguish between either of these scenarios (Gallagher, 2004). This is known as the theory of mind, or theory theory according to Gallagher. Having a problem with this kind of ability can alter the child's ability to socialize with their peers. Teachers and therapists have difficulties getting through to children with Autism because they have problems socializing with others and allowing others to socialize with them.

D. Triad of Impairments

The three main areas of difficulty which all people with autism share are sometimes known as the 'Triad of Impairments', as first described by Lorna Wing. They are:



Difficulty with Social Communication: Individuals with severe autism may never develop any speech whilst those with Asperger Syndrome may speak fluently, using full sentences. For all people on the spectrum it is the ability to use their communication skills that is impaired.

Difficulty with Social Interaction: A person with classic autism may appear withdrawn, aloof or uninterested in the people they meet and have difficulties around social relationships. Their ability to develop friendships is generally very limited.

Difficulty with Social Imagination: Social imagination allows us to understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine.

About 25% of people diagnosed with an autism spectrum disorder could be considered to have nonverbal autism yet the term **"nonverbal autism"** is not a part of the diagnostic criteria. In part, that's because there is no clear line between verbal and non-verbal individuals with autism. When referring to **verbal** children with autism, we are considering a broad spectrum of verbal behaviors, from minimally verbal to quite verbose, but lack the ability to use language in a meaningful way.Others can't use spoken language, but are able to communicate with written or typed language, American sign language, picture cards, or digital communication devices.

verbal child diagnosed with autism repeats bits and pieces from videos or other sources. This type of communication is called "echolalia." It's a unique form of speech - and though it's thought of as a "symptom," it can also be a great place to start working with the autistic child.

Echolalia is literally the repetition of words and sounds a person has heard either recently or quite a while ago.

Verbal children with autism are often echolalic, which means they do use words (and sometimes even use those words appropriately) - but their word choice is based on a memorized pattern.

Sometimes echolalia is immediate. For example, mom says "Johnny, do you want a drink?" and Johnny responds "You want a drink." Just as often echolalia is delayed.

The term "stimming" is short for self-stimulatory behavior, sometimes also called "stereotypic" behavior. In a person with autism, stimming usually refers to specific behaviors such as flapping, rocking, spinning, or repetition of words and phrases.

Stimming is almost always a symptom of autism, but it's important to note that stimming is also a part of most people's behavior patterns.

The biggest differences between autistic and typical stimming are the choice and quantity of stim. While it's at least moderately acceptable to bite one's nails, for example, it's considered unacceptable to wander around flapping one's hands.

5. Method

A. Profile area:

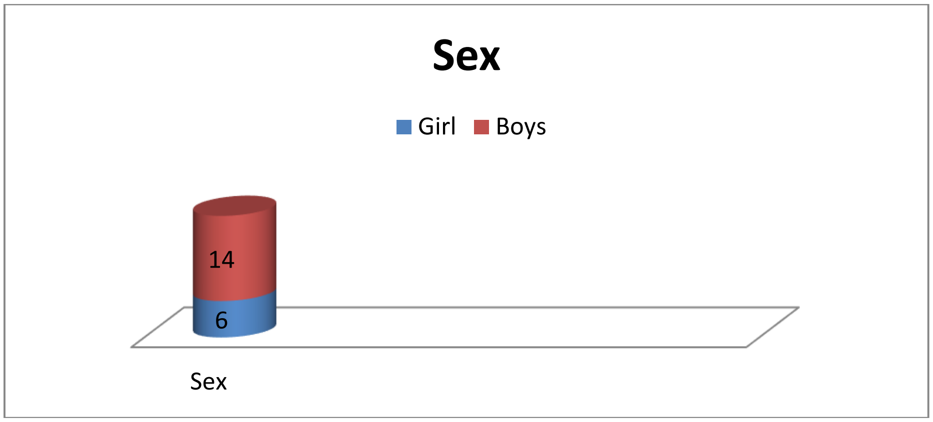
The present study is conducted in Kerala state, known as Gods own country. Kerala is a state located on the Malabar coast of South-West India. Kerala, India's most advanced society: With hundred percent literacy. World-class health care systems. India's lowest infant mortality and highest life expectancy rates. The highest physical quality of life in India. Peaceful and pristine, Kerala is India's cleanest state.The state enjoys unique and special geographical features the Western Ghats towering 500-2700 m in the east and with the Arabian Sea in the west, and networked by 44 rivers. The bordering states are Karnataka and Tamilnadu.

The profile area divided into two zones ie North zone and South zone.North zone included two districts Malappuram and Calicut.South zone included districts Trivandrum and Kollam.

Map1. Kerala state

B. *People:*

The participants of the study included the parents of autistic children and siblings who had undergone speech and language therapy under my supervision since 2010 – 2014 period and are residing in Calicut , Malappuram, Kollam and Trivandrum districts of kerala. Parents of autistic children who had undergone speech therapy before 2010 and after 2014 are excluded from the present study . Those parents of autistic children who had stopped coming for speech language therapy are also excluded from the study. Parents of about 20 autistic children were studied over the period of 4 years and their valuable comments and opinions contributed significantly to this study. Within this population of 20 about 6 male autistic children and 14 female autistic children ranging from an age group of 3 years to 15 years.



C. *Methodology*

The present study was a qualitative research study with exploratory and descriptive method conducted based on case study design model. In depth case study analysis of the child, parents and siblings of autistic children over 4 years was done. In addition to that for this particular paper semi structured interviews , informal discussions was conducted.

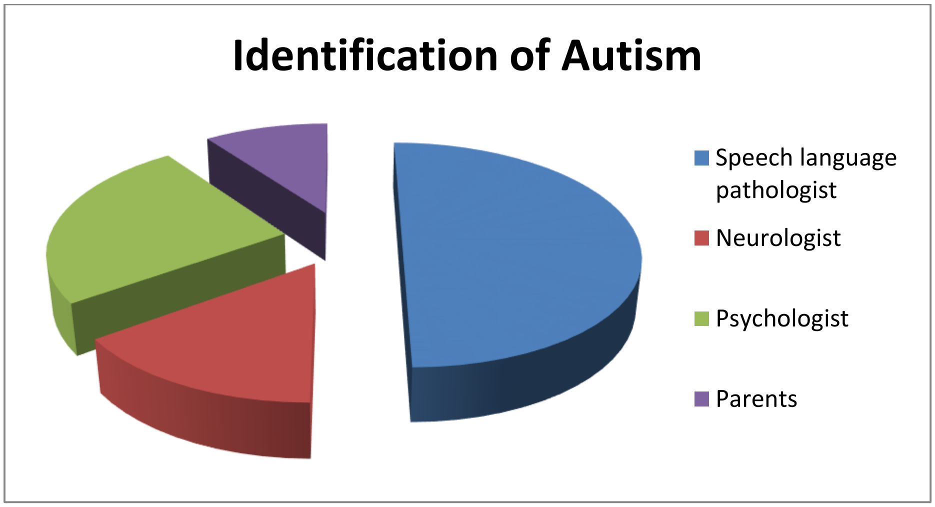
6. Results and Discussion

This study examined the impact of having a child with autism on the family. Below are the research findings for the three major areas of interest focusing on recognition and diagnosis, intervention services, and impact on the family.

I.Recognition And Diagnosis

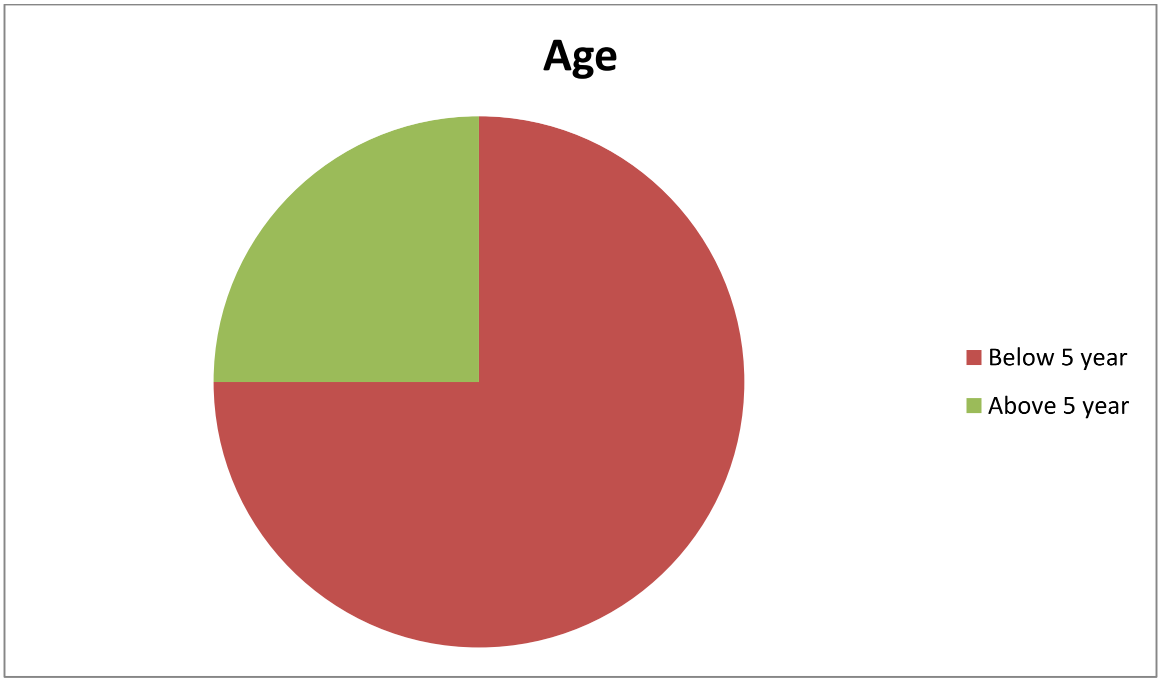
It is very important to find out the details regarding the recognition and diagnosis of autism .To get the result accurately siblings and parents were asked questions under four main headings.

A.The Person Who Identified The Autism



Pie Diagram 1 showing that who identified autism first

Most parents described how they were referred by their pediatrician to a specialist for an evaluation .Most parents (1 0 out of 20) said that a speech language pathologist diagnosed their child with autism, while the others received a diagnosis by a neurologist (n=3) or psychologist (n=5) and by the parents(n-2).



Pie Diagram 2 showing the age of identification

While their age of diagnosis ranged from 18 months to 12 years of age, most of the children with autism (1 5 out of 2 0) were diagnosed duringthe preschool years.The system seems to be set up in such a way that too much of referrals and long waiting times to get appointment with the professionals.

B..Approximate Age Of Notice

All of the parents recognized that something was different in their child by age three. The average age of the child when the parent first recognized something was wrong was 18 months. In fact, three parents said that they felt something was wrong the day the child was born. Parents described observing behaviors that are typical signs of autism, including: lack of eye contact, rigidity when touched, self stimulatory behaviors such as hand flapping, toe-walking, sensitivity to certain noises, lack of social interaction, repetitive play, need for schedule, language delays, as well as loss of language. From the time they recognized that something was different to the time they actually received a diagnosis of autism ranged from six months later to ten and a half years later. However, most parents (1 4 out of 20) did receive the diagnosis within three years time. In the 6 cases where the diagnosis was made much later, it was due to the parent initially being told by their doctor that nothing was wrong, or the parent was given an incorrect diagnosis (i.e., PDD, OCD, ODD, and ADHD**)** and only later identified as having autism .

C.Acceptance of the Diagnosis

Most parents (17 out of 20) said they accepted the diagnosis. Only three parents doubted the initial diagnosis and sought a second opinion

D. Reaction to the Initial Diagnosis

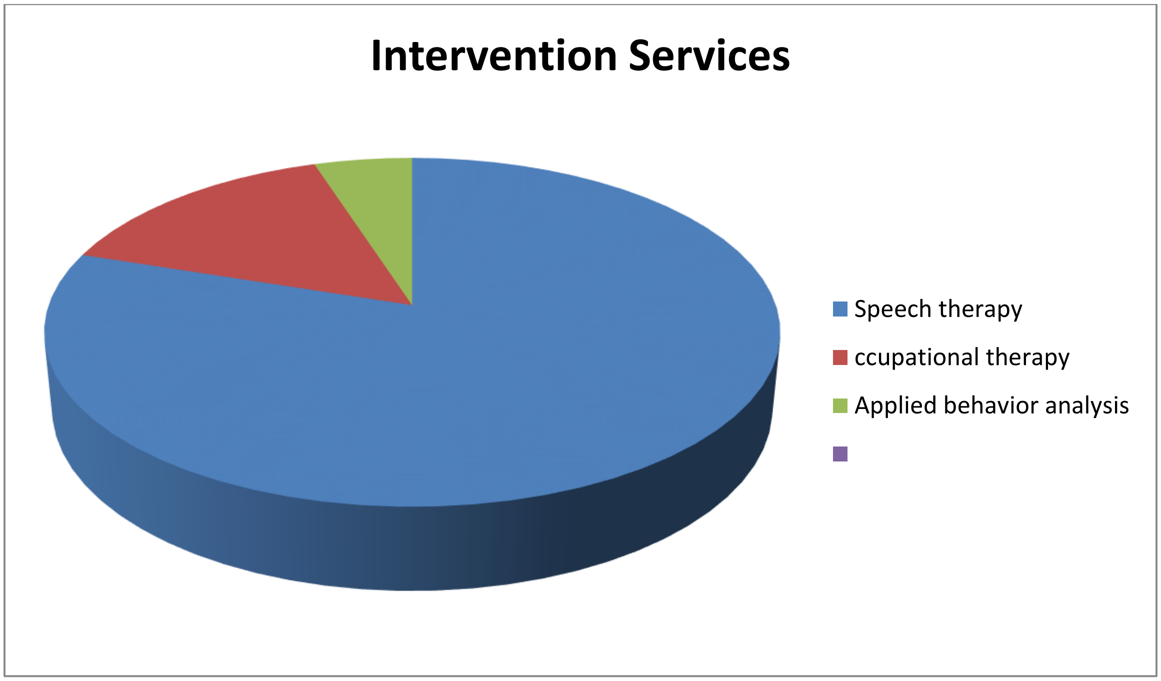
Parents often mentioned several emotions. The most common response was grief and loss (1 5 out of 20 parents), followed by self-blaming (mentioned by 3parents), shock /surprise (2 parents).Other than these many also felt feelings of despair, sadness, and even devastations. Some also felt the drive to move forward and explored the different ways of improving the child's present condition. Early diagnosis help the parents to understand what need to be done and halped them to plan for the future intervention program(Piper & Howlen 1992) Early diagnosis was very important since it helped most of the parents to set the first step towards their autistic child's improvement.

II.Intervention Services

Questions were asked under five main areas to obtain the information.

A.Services Provided And Difficulty Experienced In Obtaining Them

The most common services were speech therapy (n=16), occupational therapy (n=3), applied behavior analysis(n=1).



Other services mentioned by individual parents included counseling, music therapy, play therapy, neuro-feedback therapy, social skills training, and life-skills training, and group home placement for child.

B.Difficulties In Obtaining These Services

In terms of experiencing any difficulties in obtaining these services, 8 parents said they had no difficulty in obtaining services once their child was diagnosed with autism. However, 10 parents said other parents found it difficult to obtain services within their area. 2 parents said that they were placed on a waiting list.

C.Responses From Professionals

Parents were asked, How have you been treated with regard to your opinions and knowledge of your child's needs by professionals (doctors, therapists, etc.). Most of the parents (n=l 6) felt they had always been treated with respect, whereas the other parents interviewed (n=4) had experienced some disrespectful interactions with professionals.

D.Involvement From The Family In The Services

To obtain information regarding the families involvement in the Services many questions were asked .Most parents identified the mother (n=13) as the primary person who coordinated the services their child needed.6 people said both parents were involved , and only one said that the father took primary responsibility for services. This included transporting the child to and from meetings, as well as coordination of and attendance at meetings. Most parents also talked about the enormous amount of paperwork involved with obtaining and receiving the services.

E. General Feeling About The Services

7 of the parents felt that the services were good and they did not have any problems. However, the other 13 parents did describe some problems they were experiencing. Most typically, the parents talked about not being able to find a well-trained person to provide.The services (n=7), not having enough hours of the needed services (n=3), and the issue ofdistance in that in order to obtain the needed services, they were required to travel great distances .(n=3).

Many of the parents who approached speech therapist in the institutions like colleges experienced a difficulty due to changing speech therapist after a limited time period. This reduced the efficiency of speech therapy services provided since whenever the concerned speech therapist changed the autistic child took so many hours to get mingled with the new speech therapist.

Many of the parents who approached speech therapist were not happy with the therapy since they lacked quality professional experience and efficiency. Also many parents reported a lack of effective clinical hours. Many parents in the rural area were not able to get the services due to lack of professional nearby and also due to lack of Govt funded organizations in rural areas.

F .Most Effective Service

The most effective helpful services mentioned by parents included speech therapy (n=16), occupational therapy (n=3), applied behavior analysis (n=1),.Individual parents also listed respite, play therapy, social skills training, life skills training, having the one-on-one classroom aide, and being able to place their child in a group home. In terms of stresdcoping, most parents (n=15) said that the services they received greatly reduced their stress. However, 5 parents stated that their stress level actually increased as a result of the services (due to such things as paperwork, travel,meetings, dealing with providers).

After receiving the early diagnosis most of the family looked for intervention services that help their children and themselves too. From the responses of parents it is clear that many of them received services from speech therapist. The parents who obtained occupational therapy services were very less .One of the reasons could be that in Kerala the qualified occupational therapy professionals were very less and these services were only available in super specialty hospitals across Kerala. It is very clear from this point that those parents of autistic children who reside in rural areas of Kerala lack access to these qualified professionals.

III.Impact On The Family

Questions were asked under eight main areas to obtain the information.

A. Dealing With The Diagnosis

The over whelming majority of parents (n=17) used the word "stressful" to describe their experience. When asked, "How has the family dealt with this diagnosis? " many of the parents (n=l 0) talked about the need to adapt their schedules and the need to have structure within the home. Some parents described how they read and learned more (n=7) in order to deal with the diagnosis. Other parents made sure their child got the services they needed (n=2), and one parent discussed joining a support group to help them deal with the diagnosis.

B..Different Ways Of Impact

The parents were also asked, "In what ways has this impacted the family? (e.g.,stress, coping, daily life, vacations, free time away from child)." Most parents offered multiple answers to this question. The most common response was that there was little or no time for vacations (n=10), followed by the need to plan ahead (n=8), and the stress this placed on the marriage (n=2).

Other ways that having a child with autism impacted a family included having little or no free time for self (n=12), child not being able to have friends (n=4), the impact on mom's career (n=2), and safety concerns (n=2).

C.Reactions Of Siblings

Four of the children with autism had no siblings. For the other sixteen families, most of the parents (described how the sibling experienced resentment and for jealousy toward the brother or sister with autism).Parents also talked about siblings feeling sad (n=2), afraid (n=2), and awkward (n=l). Only two parents said the child's sibling was accepting.

Most parents tried to help the sibling deal with the situation by talking about educating the sibling about autism (n=4), spending extra time alone with the child (n=5), involving the sibling in the therapy (n=2), making sure to involve the whole familyin activities (n=l), and separating the children when there was fear of being hurt (n=l).

D.Attitude Of Grand Parents

Within the 20 families involved in this study approximately 60% (n=45) of the grandparents were described by the parent as being accepting of their grandchild's diagnosis, while about 40% (n=27) were not accepting.

E.Attitude Of Relatives

All of the parents focused on their own siblings. Most (n=16) of the parents interviewed said they had brothers and / or sisters who were accepting and supportive of their child with autism. However, due to distance, most of these aunts and uncles were not actively involved in the care of their niece or nephew due to distance. Few of the relatives of the parents (n=4) were not ready to accept the autistic children.

F. Financial Issues

Families having only one parent as the breadwinner (mostly father) and the mother who is the primary care giver dealt with more financial issues for the intervention of autistic child. Fathers were not ready to spend money for the sake of their autistic child. Mother tried to provide services within the limits significantly reduced the effectiveness of the intervention program which was given to their child.

G. Maintaining A Social Life

Keeping up outside friendships as a couple and as a family is healthy. But getting through picnics and parties can be difficult with an autistic child. Many children with autism have trouble with social interactions and changes in routine. Still, parents find a way to cope.

H. Marital Impact.

The parents of autistic children had a 9.7 percent chance of getting divorced than did their peers. Marital stressors can include the following ; parents often accept their child’s autism diagnosis at different times and in different ways, which causes conflict. Spending time together becomes difficult because of the numerous commitments and inconsistent schedules. It’s often challenging to find child care for autistic children. Financial stress may cause problems between spouses.

V.Limitations

There are several limitations to this study. The sample consisted of only 20 parents interviewed from kerala state. Those who responded may be much more comfortable with their situation in terms of proper and early diagnosis, level or services, and treatment by professionals. The sample obtained may have consisted largely of very comfortable parents receiving appropriate services and not of those families who have the stories of inadequate resources and poor services. The other parent in the family was not interviewed about their perspective which may have differed greatly. Two people can give very different answers to the same situation or experience.

Some of the interview questions asked the parent to reflect back on experiences and feelings from many years ago which can greatly affect recall of information. This could lead to inaccurate answers to some of the interview questions.

7. Conclusion

Families of children with autism shared common feelings mostly expressed a great sorrow, despair and some of them showed a hope for tomorrow with proper planning and by setting proper goals. From this study its evident that not only the children with autism needs assistance but the parents especially mothers also needed proper counseling and some assistance too. Care should be given to t he siblings to reduce the stress caused due to lack of time spent with them. Even when services are found, there can be a lack of qualified people to fill the positions which leads to even more frustration. Proper education of parents and siblings of autistic children are needed to have a pleasant family environment which again directly or indirectly helps the children with autism to come up by breaking the shell of autism.

8. Acknowledgement

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