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Parent's perception on Autism Spectrum Disorder (ASD): A focus group discussion study

Divya Sivagnanapandian[1]
MERF-Institute of Speech and Hearing
Hemavathy Raju[2]
MERF-Institute of Speech and Hearing

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Abstract

The aim of the study was to explore the parental perception on Autism Spectrum Disorder using Focus Group Discussion (FGD). 41 participants were included in the study, who were parents of children with Autism Spectrum Disorder. The participant's children aged from 3 to12 years and were receiving Speech and language intervention. The study comprises of three phases. Phase I include the development of guides/ questions from literature review, content validation was done. In phase II Focused Group Discussion were carried out for parents of children with Autism Spectrum Disorder and in phase III Thematic analysis was done. Parental knowledge on Autism spectrum disorder; their views and perspectives, communication modalities used by their children were explored. Parents reported that their children showed inappropriate emotions and behaviors but during Focus Group Discussion few parents helped other and advised them regarding the coping strategies used to manage their ASD child. The author also gave some recommendations to the parents/caregivers for the same. Knowledge about child's social relationship and pragmatic skills in his/her communicative environment and various treatment options available for children with Autism Spectrum Disorder (ASD) were also explored using Focus Group Discussion. Throughout FGD parent's gained knowledge, on usage of different strategies, available treatment options, environmental modifications and approaches used by parent's and found to have a better outcome. Thereby it helped parents to reduce child's inappropriate behavior in social situations and to facilitate communication and improved their positive attitude towards their children.

Keywords Autism Spectrum Disorder, focus group discussion, thematic analysis, parental perception

1. Introduction

Autism Spectrum Disorder (ASD) is the common developmental disorder found worldwide. The incidence and prevalence varies between each country. Prevalence of ASD in United States were 14.6 per 1000 (1 in 68) children in the age of 8 years (Elsabbagh, Divan, Koh, Kim, Kauchali, & Marcin, 2012). India is a populated country which contains nearly 1.3 billion and the prevalence of ASD found in Indian population was nearly about 1 in 1000 children in the age of < 10 years (Arora et.al, 2018). Rate of prevalence in

[1] Bio: Divya Sivagnanapandian is an assistant professor in the Department of Speech Language Pathology, MERF-Institute of Speech and Hearing (P) Ltd. 1/1, Tamilnadu, India. Her research interests cover Developmental and Acquired neurogenic Speech, Language and Swallowing Disorders. Corresp. author: Phone: 9962615650 Email divyaaslp228@gmail.com
[2] Bio: Hemavathy Raju (MASLP) works in the Department of Speech Language Pathology, MERF-Institute of Speech and Hearing (P) Ltd. 1/1, Tamilnadu, India.

India was found to be roughly about 1 in 500 or more than 2,160,000 people. Rate of incidence in India was roughly about 1 in 90,666 or 11,914 people.

Characteristics of ASD and its impact on Quality of Life (QOL) were assessed through International Classification of Functioning, Disability and Health (ICF Framework) (ICF, and Children and Youth version, ICF-CY). ICF framework consists of 3 domains, Body function include global psychosocial functions dispositions and intra-personal functions attention functions; Activities and participation include complex interpersonal interactions, basic interpersonal interactions and handling stress and other psychological demands and environmental factors were: immediate family, individual attitudes of immediate family members and health professionals (Mahdi et al., 2018).

Parent's participation plays a major role in the intervention of children with ASD. They encounter several challenges in their life, which could impact them psychologically. Parenting children with ASD causes chronic stress and difficulties (Harper et.al, 2013; McStay, Dissanayake, Scheeren, Koot, & Begeer et al., 2013). This could lead to reduced social interaction with the child. Some literatures have indicated that lesser outcomes from parents might be due to the exhibition of inappropriate behaviors (Lecavelier, Leone, &Wiltz, 2006) and impairment in social interaction (Baker-Ericzen, Stahmer, Brookman-Frazee, et al., 2005) in children with ASD. Caring and raising children with ASD is a task for parents and caregivers. And the parents need to adapt their professional lives and relationships to find the specific and appropriate solution for their children (Segui, Ortiz-Tallo, & de Diego, 2008). In spite of difficulties faced by the parents of caring for a child with ASD, many families take that in a positive way and achieve a good fit between the child's needs with ASD and the needs of the other family members (Bayat, 2007; Gerstein, Crnic, Blacher, & Baker, 2009).

The way parent perceives the problem, situational adaptation and their attitude towards the problems are important predictors of how they adapt to it. When it comes to perception of ASD it differs from parent to parent based on their cultural group they belong to, age etc. A negative perception of the situation as a catastrophe and feelings and guilt faced by the parents in daily living were main predictors of stress for parents of children with intellectual disabilities (Saloviita, Itaelinna & Leinonen, 2003) and parent of children with ASD (Bristol, 1987), whereas parent's positive perception helped in the reduction of stress and improved their welfare (Belchic, 2006; Olsson, & Hwang, 2002; Pozo, Sarria, & Brioso, 2014; Pozo & Sarria, 2014; Oelofsen & Richardson, 2006; Weiss, 2002).

The parents' viewpoint on ASD and the way they implement intervention strategies could influence the child's outcome. To find the parents perception of ASD, their experiences, challenges faced by the parents in daily routine, and the strategies used to control their child's IB, Focus Group Discussion (FGD) can be used an assessment method in which it allows the participants to share their experiences; it helps in obtaining depth of information about the children, also help the clinician to gather parent's perception about ASD. It aids in parental counseling which would improve the participants' belief/acceptance of their children. Focus group discussion is a qualitative

research method (group discussion) in which the moderator asks questions to the participants regarding specific topic. In this not only moderator asks questions there will be interaction happen among group members this helps in exchanging their ideas, thoughts, their points of view and their experiences. Focus groups are gaining popularity in health and medical research (Kitzinger, 1994). It is one of the ways to obtain information about personal and group feelings, perceptions and opinions about autism spectrum disorder from parents of children with ASD. It also assists parents of children with autism spectrum disorder.

As for the need for this study, Pozo (2015) had found that there had been some factors (coping strategies and parents' positive and negative opinions on raising/ dealing with their child with ASD that may guide the method of intervention strategies which in turn promote parents' well-being. It was also noticed that parents with children with ASD undergo stress and anxiety. It has also been found that the emotional barriers the parents have faced have changed over a course of time.

As an adverse effect on changing negative perception to positive one, by providing professional interventions that help parents to adapt and apply the appropriate strategy to address the situation at a given time (Pozo, 2015).

With all of the above in mind, the aim of the study was to explore the parental perception on Autism Spectrum Disorder (ASD) using focus group discussion in the guidance of the following objectives.

1. To investigate parental knowledge and views on ASD,
2. To discover the communication modalities, speech and language abilities of children with ASD,
3. To predict parental concern about their child's inappropriate emotions in social situations,
4. To describe various behavior and sensory issues exhibited by children with ASD,
5. To explore the child's social relationship and pragmatic skills in his/her communicative environment,
6. To explore parent's knowledge on various treatment options available about ASD

2. Methodology

The study was carried out through Focus Group Discussion (FCD) method. Theme based inferences were done through thematic analysis.

2.1. Participants

The participants included in the study were 41, who were parents of children with ASD. The participant's children aged from 3 to12 years and were receiving Speech and language intervention. The participants in the group were divided based on child's age and based on duration of obtaining speech and language therapy.

2.2. Selection criteria

The participant children's age ranged from 3 to 12 years. All the participant children should have undergone speech and language

intervention. Native Tamil speaking participants were included. Participant children who had different severity of ASD can range from mild to severe degree. Parents who were in middle socio-economic status were included in the present study. Children with comorbid conditions were excluded.

2.3. Procedure

The study comprises of three phases. Phase I include the development of guides/ questions from literature review, content validation was done, pilot study was carried out and revisions of the questions were made. In phase II focused group discussion were carried out for parents of children with ASD and in phase III data analysis was carried out.

2.3.1. Phase I

Development of FGD guides and Content validity

Step 1: Familiarization

Over viewing all data and transcribing audio, reading through the text and taking initial notes,

Step:2 Coding the data

Coding in this study means highlighting sections of our text – usually phrases or sentences – and coming up with short and labels or "codes" to describe their content. All of the data were collated into groups identified at the stage of coding. These codes allow us to gain a condensed overview of the main points and common meanings that recur throughout the data.

Step 3: Generating themes

This includes the identification of –patterns among the codes that were created, and to start coming up with themes. Themes are generally broader than codes. Several codes were assigned into a single theme.

Step 4: Reviewing themes

The themes that are useful and accurate representations of the data were confirmed. If any problem encountered with the themes that are generated, they are split up, combined, discarded or new ones are created: into whatever makes them more useful and accurate.

Step 5: Defining and naming themes

Defining themes involves formulating exactly what we mean by each theme and figuring out how it helps us understand the data. Naming themes involves coming up with a succinct and easily understandable name for each theme.

Step 6: Writing up

Using the final themes responses were collected from the participants (e.g. through semi-structured interviews or open-ended survey questions). The results or findings section usually addresses each theme in turn. And inferences were determined from the theme responses. Finally, our conclusion explains the main takeaways and shows how the analysis has answered our research question.

The guides for conducting FGD for parents of children with ASD was collected and developed based on the literatures (such as ISAA National institute for the mentally handicapped-The National trust; Gona, Newton,

Rimba, and Mapenziet al., (2015); ASD parent interview(Oregon health and science university), open ended questions only were included in the study. The developed guides were given to 5 experienced Speech and Language Pathologist for the content validation. Then the guides were structurally revised and translated further into Tamil. Total of 21 questions were developed and was included under 5 domains. The domains were as follows:

1. Knowledge about ASD
2. Speech, language and communication abilities in children with ASD
3. Emotions
4. Social relationship and pragmatic skills
5. Behavioral aspects and sensory issues

Pilot study: Pilot study was conducted using developed guides which contain 4 participants in it. Participants were made to sit in a semi- circle form, video recorder and audio recorder was kept in a center position for recording the participant's speech. After that the moderator had given information to participants about the topic and the rules in it. And then the moderator started asking questions from the developed guides. The session was carried for about 45 minutes.
The responses which were recorded from the audio recorder were analyzed and the results were used to modify the questions, those modified questions were given to the experienced Speech and Language Pathologist. At the end, questions were simplified and finalized.

2.3.2. Phase II: Administration

FGD was conducted using developed guides. Total of 7 groups, each group contains 5 or 6 participants in it. Participants were made to sit in a semi-circle form, video recorder (Nikon D3300) and audio recorder (Sony recorder ICD- UX 533F) was kept in a center position for recording the participant's speech. Study was carried out in a quiet ambience.
Group discussion was started by welcoming the participants and the moderator introduces herself and the note taker. To build a rapport between each participant they were asked to introduce themselves. Initially the moderator had given information to participants about the topic, purpose of the focus group discussion and the rules in FGD. After that the moderator was started asking questions from the developed guides, the moderator started asking the general questions to build up the rapport between participants and then moved on to the specific questions, then the answers were collected from each participant as well as discussion was carried out between participants. All those answers were recorded in a video and audio recorder; the answers were also taken by the note taker in a written format. None of the participants were left out, all were made to discuss. The session was carried for about 45 minutes.

2.3.3. Phase III: Analysis

The collected data were transcribed in an International Phonetic Alphabet (IPA) revised to 2005; each participant answers were transcribed and were given for the

analysis. Written notes from the note taker were also used to analyze the data for clarification. As the data collected was qualitative in nature, thematic analysis (Braun, &Clarke, 2006) was done for analyzing each data. In Thematic analysis deductive approach was done in which the clinician will predict the data with some preconceived themes and expect to find reflected there, based on theory or existing knowledge.

3. Findings and discussion

Findings and inferences obtained from the focus group on parent's perception on Autism Spectrum Disorder are reported in descriptive summary method. Forty-one participants were included in the study, seven FGDs were conducted and the responses were analyzed and transcribed. The responses were compiled and discussed under the following domains.

1) Knowledge about ASD
2) Speech, language and communication abilities in children with ASD,
3) Emotions,
4) Social relationship and pragmatic skills
5) Behavioral aspects and sensory issues.

Verbatim transcription was done for better understanding of the results.Few responses which were unique have been mentioned under each domain. The domains are as follows.

3.1. Knowledge about ASD

3.1.1. Parental knowledge about ASD

Overall, 37 out of 41 parents reported that children with Autism Spectrum Disorder exhibit inappropriate behaviors such as hand flapping, unexpected crying, frequent clapping, and inappropriate laughing. Because those children with ASD experience communicative difficulties they exhibit their emotions and needs through behaviors such as unexpected crying, inappropriate laughing etc. similar results were also found by Pearson et.al, (2006) that there was higher risk of, atypical behaviors, social skills problems, social withdrawal, depression were found in children with autism. Repetitive, stereotyped behaviors and self-injurious behaviors were the most commonly occurring symptoms in children with ASD as reported by Matson, Wilkins, and Macken (2008).

Fifteen parents stated that children with ASD were reported to have hyposensitivity to tactile and auditory stimulus. It could be because of the disturbances in the central nervous system this result in the failure of modulating and inhibiting the stimuli which in turn cause hyposensitive to tactile and auditory stimuli (Fisher, & Dunn, 1983).

Related results were also found by Wiggins, Robins, Bakeman, and Adamson (2009) they found that children with ASD showed more abnormal reactions to sensory input particularly for tactile stimulation, taste/ smell, and for auditory stimulation. Such sensory abnormalities were found to be one of the symptoms in ASD which has to be considered in diagnostic algorithms

for young children. Klintwall et.al, (2011) found that children who had self-injurious behaviors were presented with more sensory abnormalities.
American Speech-Language-Hearing Association (1981) suggested that children with ASD had severe communication impairment with completely absent speech or restricted that it cannot meet the individual's communication needs similar findings were also reported by 12 parents who stated that children with ASD had restricted communication and these children communicate predominantly through actions.

3.1.2. Knowledge about the cause for ASD

Cause for ASD was discussed and inferred that blood pressure during pregnancy were the cause for ASD as reported by 16 parents, seizures also one of the cause for ASD as reported by 10 parents, similar results were also given by Kinney, Munir, Crowley, and Miller(2008) they found that prenatal stress played a significant role in the etiology of Autistic Disorder, prenatal stress caused post-natal abnormalities such as seizures, cognitive deficits, and also triggered children to develop inappropriate behaviors.
Six parents mentioned as heredity which caused ASD. Muhle, Trentacoste, and Rapin (2004) reported that ASD was not a disease but a syndrome with multiple causes related to genetic and non-genetic factors and they also found that monozygotic twins were more prone to have autism compared to dizygotic twins and monozygotic twins also had predominant communication and inappropriate social behaviors.
One parent reported that Zinc deficiency could be one the reason causing autism. Yasuda, Yoshida, Yasuda, and Tsutsui (2011) suggested that infantile zinc deficiency might cause neural development disorders and autism spectrum disorders, and they also stated that autistic disorder could be treated or prevented using zinc supplementation.
Twelve parents stated post term birth as the cause for developing ASD. This could be because birth complications might result in brain injury which results in the increased risk of ASD. Xie (2017) found that preterm birth had a higher risk of developing ASD alone, both pre and post term birth had a higher risk of developing ASD with intellectual disability (ID) and also they found that with post term birth female children were more prone to develop ASD with ID than male children.

3.1.3. Symptoms exhibited by children with Autism Spectrum Disorder

When the parents were asked to describe about the symptoms which were exhibited by children with ASD laughing, crying, screaming, hands flapping these are all the symptoms of ASD children as reported by 30 parents. Pearson et al., (2006) suggested that ASD children should be carefully monitored for the occurrence of comorbid behavioral and emotional concerns, they also suggested that not all ASD children exhibit similar behaviors.
Many parents (30) reported that child with ASD display Preservatory/ Stereotypic behaviors. The reason of child exhibiting such behavior is explained in various theories, which state the following reason such as, as a resultant of behavior issue, Self-calm strategy, as manifestation of real interests, or by anxiety or a chemical or neurological issue child demonstrate

stereotypic behaviors. In such cases management options such as behavioral techniques to "extinguish" the behavior; If repetitive behaviors are a self-calming technique, sensory integration techniques help in regain a sense of control; if perseveration is a manifestation of real interests help the child to turn perseverative actions into meaningful activities; if it is caused by anxiety or a chemical or neurological issue, behaviors can be controlled through the use of pharmacotherapy.

Only one parent reported that a child with ASD doesn't accept the modifications on their daily routine, or variation in their constant use of objects. Insistence on sameness and an inflexible adherence to routines. Any deviation from these routines, can result in enormous anxiety and tantrums from an ASD patient

Similar results were given by Khan (2015) found that ASD children had low adaptation or adjustment capacity and they recommended parents to help the children with ASD to overcome the problem. Hence Applied Behavior Analysis (ABA) (Lovaas, 1987) proven to be an effective treatment both to break down resistance to changes and to build routines that reinforce positive behaviors, it helps children with ASD deal with transitions. Applied behavior analysts are adept at using the repetitive nature of autistic patients to create patterns and methods that are beneficial for long-term well-being and social skills.

3.1.4. Parental Knowledge about existing treatment options and consultation

Parents were asked about the treatment options available for children with ASD. Forty-one parents reported speech therapy, occupational therapy, Physiotherapy, Special education and behavioral modification as the treatment options. Werner (2010) suggested the importance of interprofessional collaboration between physiotherapist, speech therapist, Occupational therapist, social workers etc.

Three parents reported swimming class and music therapy as the treatment option for ASD children, similarly Lofthouse, Hendren, Hurt, Arnold, and Butter(2012) found that swimming lessons reduced hyperactive and repetitive behavior through the release of certain neurotransmitters, such as acetylcholine, or beta-endorphins and music therapy improved imitation of signs and words, increased longer eye contact and turn-taking, joint attention, it also initiated engagement and compliant behavior.

Forty parents reported pediatrician, Neurologist, psychologist, speech therapist, occupational therapists, ENT doctors and physiotherapist as the consultants. Strunk, Leisen, and Schubert (2017) suggested that inter professional relationship using multidisciplinary approach was found to be one of the best practices for the intervention, which results in effective treatment for children with ASD, to find the number of interprofessional relationship using multidisciplinary approach they took 47 literatures and found that there was the lesser number of interprofessional collaboration found using multidisciplinary approach.

3.2. Speech, language and communication abilities in children with ASD

3.2.1. Child's communication modality

When the parents were asked to describe about the mode of communication. 36 parents mentioned that children with ASD communicate their needs through crying, sign language, vocalization, by pointing, and by proto-declarative pointing.

Some ASD children have developed language in a slow manner, some have had difficulty in how to use the language to communicate with others, and overall children with ASD had delay in speech and language development. So they used sign languages, gestures, facial expression, proto-declarative, proto imperative pointing etc. to communicate their needs.

Diehl, Wegner, and Rubin (2010) found that children with ASD used multiples of communication modes such as speech, facial expressions, pointing, hand-flapping, vocalizations, picture symbols, negative emotions and assistive technology (e.g., speech-generating devices).

3.2.2. Child's receptive and expressive language skills

Parents were asked to give suggestion regarding the following question 'Are there any differences between comprehension and expression for the child?'18 parents reported that their children needed repeated commands and object pointing. Only one parent reported that the child confused between the commands given to them. As the ASD children have reduced attention span they have difficulty in comprehending the commands. So, the comments were needed to be repeated.

Papadopoulos (2018) reported that as children with ASD have difficulty in understanding other's speech; the author recommended that children should be treated according to the child's developmental level and child's age.

3.2.3. Presence of echolalia in child's speech and alternative method tried by parents to facilitate meaningful communication

Parents were asked to report whether their children repeat the speech of others. 07 parents mentioned that their children repeat others speech. 3 parents mentioned that if the child repeats others speech, clues were given for the child to answer the question. Children with ASD might not be able to effectively communicate with others because they struggle express their own thoughts and also, they might have delayed speech and language development so they imitate other's speech which in turn caused echolalia to the children with ASD.

Only one parent reported that there was the delay in repeating the speech or questions which was asked to them. Similarly, Neely, Gerow, Rispoli, Lang, and Pullen (2015) suggested that there was not a single treatment available to treat echolalia in ASD children and they stated that for immediate echolalia cues-pause-point intervention was effective, for delayed echolalia script training plus visual cues (Ganz, Kaylor, Bourgeois, & Hadden. 2008) and tact modeling plus positive reinforcement for appropriate responses were found as effective. They concluded that cues-pause-point and operant based treatments found as effective in treating echolalia in ASD children.

3.3. Emotions

3.3.1. Child's emotional status

The parents were asked to explain about how they identify their child's emotional status and inferred that most of the parents suggested that they identified their child's emotional status through facial expression and inappropriate behaviors. Yirmiya, Kasari, Sigman, and Mundy (1989) suggested that interpreting ASD child's emotional reactions especially through facial expressions were more difficult to identify and they also stated that children with ASD exhibit inappropriate emotions when compared with normal children.

3.3.2. Strategies used by the parents to reduce inappropriate behaviors in inappropriate situations

Parents were asked to explain about the strategies which were used to control their child's inappropriate behaviors. Based on severity and the behaviors exhibited, the strategy used to control their child's inappropriate behaviors would differ. 15 parents reported that their children didn't like the crowded places and they produced inappropriate sounds, screamed a lot and the strategy used was parents brought their child out from that place. Children with ASD may process some sounds from their senses differently. They may not be able to filter out those unwanted noises (eg: noise form the bell, mixie noises) from the signal which caused hypersensitive to those particular stimuli. Fritz (2017) suggested functional communication training, non-contingent reinforcement, differential reinforcement which helped in reducing inappropriate behaviors (such as hitting or biting in unpleasant events) in ASD children.

3.3.3. Parent's emotional reaction

Parent's perception on ASD will greatly impact on the child's outcome. To find the perceptions, parents were asked to explain about their emotional feelings towards their children. 21 parents accepted their child's condition and they felt happy when they were with the child, 27 parents worried about their child's condition, 10 parents were concerned about their child's future. Similar results were given by DePape, and Lindsay (2014) that some parents accepted their child's diagnosis and they moved on, but some of the parents were worried about their child's future and they were concerned about their child's difficulty in independent living. These differences could be because of the parent's perception towards ASD.

3.3.4. Parent's emotional reaction towards others concern

Twenty parents annoyed when others advised them regarding child's condition, similar results given by Brazier (2016) found that the parents were frustrated when others do not understand how ASD affects a child, and when others critic both the child and the parent unfairly.

3.4. Social relationship and pragmatic skills

3.4.1. Children's initiation and finishing of tasks

Fifteen parents reported that their children do not have problems in initiating or terminating the tasks. 11 parents stated that their children did

the activity with the parent's assistance. These problems in initiating and terminating the tasks could be due to the inability to withstand problem solving capabilities and inhibition in the executive function for ASD children. They often have difficulty in achieving the goals, and also an inability in sequencing and prioritizing which in turn cause difficulty in achieving the goals.

3.4.2. Children's social interaction with peer group

Children with ASD experience difficulties in adjusting to new environments, problem solving, peer group interaction; trouble understanding other's facial expression and body language. Themes related to children's socialization with peers were explored. 23 parents indicated that their children do not mingle with the peer group. Another three parents reported that in spite of mingling, they throw tantrums.

Three parents explained that their children mingle well with other children. Eight parents mentioned that their children mingle with other children but suddenly they beat or pinch or hug their peers. Four parents reported that their children just started mingling with their peer group. Two parents mentioned their children mingle with others but for a shorter period of time.

Finke (2016) reported that ASD children had difficulty in making and maintaining friends and also suggested that ASD children comprehends the concept of friendship, but they omit the concepts of self-disclosure, affection (Bauminger, & Kasari, 2000; Calder, Hill, & Pellicano, 2012). To overcome these issues, SLPs recommended few concepts to help the ASD children mingle with their peer group. The recommendations were the idea of equal status, the use of motivating and authentic activities, and the provision of repeated opportunities for interaction.

3.4.3. Child's performance in group activities (interactions, turn taking). Strategy used by the parents to overcome the difficulties

Themes were discussed about children's performance in group activities and inferred that 19 parents reported that their children had poor turn taking skills, they didn't mingle with others in the group (the child used to cry, scream), Lack of group participation might be due to the deficits in the development of social skills and motor development which limits the child to engage in group activities. Memari, et al., (2015) found that only minimal group (12%) of ASD children were physically active in participation. And also found some of the factors which limit their physical activities those are lack of opportunities, financial concerns and socio demographic factors.

3.4.4. Support from their family members

Themes were discussed regarding their family members support.20 parents reported that there was good support from their family members. 13 parents reported that there was not enough support from their family members. Similar results given by Khan, Ooi, Ong, and Jacob (2016) they found that most of the parents felt that there was not enough support from the public as well as from their relatives but parents from the same boat provided support to them, as well as some of the parents reported that there was enough support from the family members. And the parents from the same

boat helped other parents, by acting as advocates for other parents who have ASD child; they also advised them regarding the coping strategies used to manage their ASD child.

3.5. Behavioral aspects and sensory issues

3.5.1. Child's expression of inappropriate behavior and strategies used by parents to reduce the behaviors

Most of the children with ASD exhibit their emotions or they communicate their needs through behaviors, this could be due to the impairment which is present in both comprehension and expression of language and also due to the difficulty which is present in expressing their emotional feelings. Themes regarding child's behavior were explored. 12 parents stated that the children flapped their hand and the parents asked the children to stop the behavior or they scolded them, or they beat their children or by giving positive reinforcement parents reduced the child's behavior. Jumping was one of the behaviors exhibited by the children and the parents used to scold or beat their children or they asked their children to stop the behavior as reported by 08 parents. Most of the times children with ASD exhibit their feelings through emotional outbursts this was because they have difficulty in identifying others' emotions as well as difficulty in communicating their own emotions this causes trouble in communicating with others in the social situation.

Boyd, McDonough, and Bodfish (2011), they used consequence based intervention (e.g., repetitive vocalizations, saying no, differential reinforcement etc.) and antecedent based intervention (e.g., social initiation skills) for lower order behaviors (i.e., stereotyped movements, repetitive manipulation of objects, and repetitive self-injurious behaviors) and for higher order behaviors (i.e., compulsions, rituals and routines & insistence on sameness) they used cognitive behavioral therapy and applied behavioral approach, and they found there was the reduction in the repetitive behaviors which was noted in ASD children using those interventions.

3.5.2. Child's behavior in specific situation acts as a communication barrier. If yes, what situations are most difficult and strategies used by parents to overcome the same?

Children with ASD exhibit symptoms of hypersensitive or hyposensitive to the auditory stimuli and most of the children express their negative emotions through behaviors. 24 parents reported that the children do not like to be in the crowded place (such as function, temple, bus) they scream, cry, beat others, pull the parent from that place, run here and there, beat and bite themselves, produced inappropriate sound. Among the parents, six beat their child to control their behaviors, six parents scold their children, three parents gave positive reinforcement (such as bubbles, eatables, balloons) to the child, two parents lifted their child and keep with them, nine parents came out from that place. The reason behind this hypersensitive to particular stimulus is because children with ASD may process some sounds from their senses differently. They may not be able to filter out those unwanted noises (eg: noise form the bell, mixie noises) form the signal which causes hypersensitive to those particular stimuli. Maskey, Lowry, Rodgers,

McConachie, and Parr (2014) took nine fluent children with ASD and they reported that those children had fear for crowded places or for stimulus (eg: pigeon, bus, car, vacuum cleaner), they used cognitive behavioral therapy (CBT) with exposure in a virtual reality environment (VRE) and they found that eight of nine children were able to tackle the fear towards particular situation and four children was able to completely overcome from the fear. Results evidences CBT with VRE was the effective treatment for specific phobia in ASD children.

3.5.3. Behaviors expressed by the child. If yes, how will you overcome that?

When child expressed inappropriate behaviors/ Temper tantrums, parents controlled the behaviors using various strategies. Few avoided the situations and some parent showed anger towards the child, only one parent stated that reinforcement as the strategy these are all the strategies used by the parents to control the child's behavior. Similarly Bennie (2017) reported that temper tantrums are the behaviors which were exhibited by ASD children due to the delay in the development of speech and language. To overcome that the author gave some recommendations to the parents/caregivers those are: recommended to determine if it's a tantrum or a meltdown, recommended to remove the audience, change the topic, recommended to encourages the child, also recommended to praise the child once the tantrum was over.

3.5.4. Child's sensory perception of taste

Children with ASD also experience difficulty in taste sensation. Themes regarding taste were explored. 31 parents reported that their children were able to identify various taste. In contradictorily, 2 parents reported that their children have poor taste sensation, they had difficulty in identifying the differences between each taste.

Bennetto, Kuschner, and Hyman (2007) they used electro-gustometry to identify the taste detection threshold in ASD children. They found that ASD children were significantly less accurate in identifying sour tastes compared to normal children and marginally less accurate for bitter tastes, but there was no difference in identifying salty and sweet stimuli. And they concluded that chemosensory problems in ASD children occur at the cortical level rather than brainstem level.

3.5.5. Child's ability of discrimination between hard and soft object

Seven parents reported that their children had difficulty in identifying the soft and hard. Fifteen parents stated that their children don't had problem in identifying the differences. Dysfunction in brainstem was found to be a key region which caused sensory modulation (Ornitz, 1983) and also there was the role of cerebellum which caused sensory abnormalities (Schmahmann, Weilburg, & Sherman,2007). Klintwall et.al., (2011) reported that sensory issues among ASD children differs between each ASD children according to autistic subgroups, that in the subgroup of nuclear autism sensory/perceptual abnormalities were founded to be more.

3.5.6. Child's behavior on environmental sound and the methods used by parents to overcome

Themes discussed on the topic of sensory issues15parents reported that their children exhibit odd behaviors for specific environmental sounds and the strategy used was they used to pamper their child, or they avoid those situations, parents also tried various strategies to desensitize the sounds the child exposed to. Klintwallet.al., (2011) found that over reactivity to sound was one of the sensory issues found in ASD children, 44% of the children had this issue. Maskeyet.al., (2014) they also found that in ASD children there was a reduction of fear towards sounds after the implementation of CBT and VRE, they concluded that this may be the effective treatment for specific phobia in ASD children.

3.5.7. Hyper/ Hyposensitivity to tactile stimuli and the strategy used by parents to overcome

Most of the children with ASD have the symptom of hypersensitive or hyposensitive to the tactile stimuli. Themes regarding the sensitivity were explored. When exposed to tactile stimuli, children with ASD didn't express any specific behaviors as reported by twenty-three parents. Fourteen parents reported that their children are hypersensitivity to tactile stimuli. Similarly Klintwallet.al, (2011) found that 19% of the ASD children had sensory issue of over reacting to touch.

4. Conclusion

FGD were carried out for parents of children with ASD and data analysis was carried out. Inferences were derived under the following domains.

4.1. Knowledge about ASD

Across 7 FGDs which was carried out, it was inferred that parents reported that children with ASD exhibit inappropriate behaviors such as hand flapping, unexpected crying, frequent clapping, and inappropriate laughing. It could be because those children with ASD experience communicative difficulties.

The reason of child exhibiting such behavior was explained in various theories, which state the following reason such as, as a resultant of behavior issue, self-calm strategy, as manifestation of real interests, or by anxiety or a chemical or neurological issue child demonstrate stereotypic behaviors. In such cases management options such as behavioral techniques to "extinguish" the behavior; If repetitive behaviors are a self-calming technique, sensory integration techniques help in regain a sense of control; if perseveration was a manifestation of real interests help the child to turn perseverative actions into meaningful activities; if it was caused by anxiety or a chemical or neurological issue, behaviors can be controlled through the use of pharmacotherapy.

Regarding management options parents stated that speech therapy, occupational therapy, physiotherapy, special education and behavioral modification as the treatment options for children with ASD. Other parents mentioned pediatrician, Neurologist, psychologist, speech therapist,

occupational therapists, ENT doctors and physiotherapist as the consultants for ASD.

4.2. Speech, language and communication abilities in children with ASD

Parents mentioned that children with ASD communicate their needs through crying, sign language, vocalization, by pointing, and by proto declarative pointing. Because some children with ASD have delay in language development, some have had difficulty in how to use the language to communicate with others, and overall children with ASD had delay in speech and language development. So, they used sign languages, gestures, facial expression, proto declarative, proto imperative pointing etc. to communicate their needs. Children with ASD might not be able to effectively communicate with others because they struggle express their own thoughts and also, they might have delayed speech and language development so they imitate other's speech which in turn caused echolalia to the children with ASD. Few children needed repeated commands and object pointing. As the ASD children have reduced attention span they have difficulty in comprehending the commands. So, the comments were needed to be repeated.

4.3. Emotions

Most of the parents suggested that they identified their child's emotional status through facial expression, through child's inappropriate behaviors. Children with ASD display inappropriate expressions this was because those children with ASD face difficulties in sharing emotions due to anxiety, they don't know to show appropriate emotions and others also experience difficulties in reading those children's emotional reactions. Children with ASD may process some sounds from their senses differently. They may not be able to filter out those unwanted noises (eg: noise form the bell, mixie noises) form the signal which caused hypersensitive to those particular stimuli. Hence the children make inappropriate sounds. From the findings it was also inferred that 21 parents accepted their child's condition and expressed a sense of ease. Few annoyed when others advised them regarding child's condition and expressed difficulty. So, counseling to parents can be provided. So, through counseling parent can accept the child's behavior and through Behavioral modifications therapy, these inappropriate behaviors can be controlled and monitored by parents in social situations. Hence parents also will not develop any negative emotions towards their child with ASD.

4.4. Social relationship and pragmatic skills

Eleven parents stated that their children did the activity with parent's help. This problem in initiating and finishing tasks could be due to the inability to withstand problem solving capabilities; and there was the inhibition in the executive function which was noted in ASD children. They often have difficulty in achieving the goals, and also due to the inability in sequencing and prioritizing which in turn caused difficulty in achieving the goals.

Parents of children with ASD indicated that their child doesn't mingle with the peer group. The reason behind this difficulty mingling with peer group for children with ASD because they h had trouble with starting and keeping

conversations going they also had difficulty adjusting to new environments, difficulty in problem solving, difficulty taking part in other children's activities, trouble understanding other's facial expression and body language. Lack of group participation might be due to the deficits in the development of social skills and motor development which limits the child to engage in group activities Few parents reported that the child expressed poor turn taking skills. Hence Speech Language Pathologist can counsel the parent about the importance of reinforcement. So, when parents provide well socially - use behavior-specific praise (and concrete reinforcement if needed) to shape pro-social behavior can help the child with ASD. Parents can model and practice desired behaviors to child; providing structured social interactions; communication through possible social scenarios and use visual aids, turn taking and reciprocity during social interaction, these skills can make child acquire coping skills and techniques that boost their social skills.

4.5. Behavioral aspects and sensory issues

Behavioral issues such as children flapping their hand, temper tantrums and also children with ASD expressed inappropriate behaviors. From the above findings it was inferred that nearly 30 parents reported children exhibit odd behaviors for specific environmental sounds. The reason behind this hypersensitive to particular stimulus is because children with ASD may process some sounds from their senses differently. They express difficulty in identifying and differentiating unwanted noises (eg: noise form the bell, grinder noises) form the signal which causes hypersensitive to those particular stimuli. Hence the parents instructed the child to stop the behavior or they provide negative/ positive reinforcement. Most of the times children with ASD exhibit their feelings through emotional outbursts this was because they have difficulty in identifying others' emotions as well as difficulty in communicating their own emotions this causes trouble in communicating with others in the social situation.

Parents also used strategies like to calm the child or desensitize the sound. Few expressed that their children are hypersensitivity to tactile stimuli. This could be because of the sensory issues which present in children with ASD. Hence Occupational Therapy and sensory integration therapy should be incorporated. Therefore, selective intervention for few sensitivity issues can be provided for better outcome

5. Future directions

Through FGD, parental perception on children with ASD was explored. Hence parent's gained knowledge, on usage of different strategies, available treatment options, environmental modifications and approaches used by parent's and found to have a better outcome. Thereby it helped parents to reducing child's inappropriate behavior in social situations and to facilitate communication. This study also helps parents to monitor the child's progress and promoting better outcome which improves the child's overall Quality of Life.

Hence future research on FGD can focus on identifying the parental knowledge. Implementation of all strategies and profiling treatment

outcomes through the knowledge gained through FGD and also can focus on improving parental attitudes, self believe and provide support group across all aspects.

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Appendices

Appendix 1

FOCUS GROUP DISCUSSION THEMES (In English)

Research question 1: Knowledge about Autism Spectrum Disorder (ASD)

4.1.1 What do you think about autism?
4.1.2 What would be the causes for autism, based on your perception?
4.1.3 What type of symptoms does the children with autism exhibits, based on your perception?
4.1.4 What type of treatment will be given for the child with autism and to whom will you go for consultation?

Research question 2: Speech, Language and Communication abilities in children with ASD

1. How does your child communicate his/her needs with you or others (for eg: gestures, crying)?
2. Are there any differences between what he/she expresses and what he/she understands? Eg: Is your child has the ability to follow your commands. Give some examples
3. When you question or Communicate with your child, have you observed any repetitive use of language (Echolalia)? If yes, What would you do/ what modification you do to correct that?

Research question 3: Emotions

1. How will you find your child's emotional status (eg: he/ she is happy or sad about something)?
2. What strategies will you use to reduce your child's inappropriate emotions in social situations?
3. How do you feel when you are with your child? Explain about that
4. How do you feel when others concern about your child's attitudes?

Research question 4: Social relationship and Pragmatic skills

1. Does your child have difficulty initiating or finishing tasks such as homework?, If yes what type of strategies will you use to overcome that?
2. Does your child mingle with his/her peer group, if yes describe how?
3. How does your child perform in group activities (interactions, turn taking). If you find it to be difficult for them, how do you help them overcome that
4. How your family members do support you?

Research question 5: Behavioral aspects and sensory issues

1. Does your child show any odd physical mannerisms or odd way of moving his hands or his body that look the same each time, e.g., flapping hands when excited, walking on his toes, flicking his fingers, spinning his body?. If yes, what type of strategies will you use to stop that?

2. Does the child exhibit any kind of odd behaviors at any situations, which leads to interrupt child's communication? If yes, what situations are most difficult and explain how will you overcome that?

3. If the child doesn't like the situation, will the child become aggressive, show temper tantrums, self -injurious behavior. If yes, how will you overcome that?

4. Do you feel that your child has any difficulty in sensing taste (bitter, sour, sweet, and spicy). If yes, give some examples

5. Does the child have difficulty in discriminating/ differentiating between hard and soft touch. If yes, give some examples
6. Does the child exhibits any odd behaviors for any kind of environmental sounds? If yes, what kind of sounds exhibits odd behaviors, what behaviors does the child exhibits and how will you overcome that
7. Do you feel that your child doesn't like others to touch him/ her? If yes, what type of behavior does the child exhibit to avoid that?

Appendix 2

FOCUS GROUP DISCUSSION THEMES (In Tamil Language)- International Phonetic Alphabet

I. /ɔtIsʌmpʌtrIarIḍʌl/

1. / ɔtIsʌmpʌtrIjə ʊŋəlInkarʊṭʊ/
2. /ɔtIsʌṭIrka:nəka:rənʌmjEnəva:gəIrʊkʊmjEndrʊ niŋʌljEnʊgIrirgʌl/
3. /ɔtIsʌmuləkʊlənḍʌIgʌljEnḍəvIḍəarIgurIgalʌIvælIpʌdʊṭʊva:rgʌl/
4. /ɔtIsʌmuləkʊlənḍʌIgʌlʊkʊ jEvIḍəma:nəsIgIʧʌIvʌlaŋəpʌdʊm ʊŋalInkʌrʊṭʊ, niŋʌlja:rʌIʌnʊgʊvirgʌl/

II. /pæʧʊ mʌtrʊmmolIṭodʌrbʊ/

1. /ʊŋʌlkʊlənḍʌIavʌn/ avʌlInṭævʌIgalʌIjEva:rʊvælIpadʊṭʊva:rgʌl/ ʌrIvIpa:rgʌl (jE. Ka: sʌIgʌImuləma:gə, alʊgʌImuləma:gə) /
2. /avʌn/ avʌlpʊrInḍʊkolvʌḍIlʊm, vElIpʌdʊṭʊvʌḍIlʊmjEḍEnʊmværʊpa:dʊ ʊləḍa/

3. /niŋʌlkElvIkæta:loʌlaḍʊ ʊrʌIja:dIna:lo ʊŋʌlInkʊlənḍʌIkilkʌndənʌdaṭajʌIvElIpʌdʊṭʊgIra:rgʌlə, mindʊmmindʊmsorkəlʌIkurʊḍʌl, a:mEndra:lʌḍənʌIEva:rʊ niŋʌlsʌrIsEIvirgʌl/

III. /ʊnʌrvʊgʌl/

1. /ʊŋʌlkʊlənḍʌIn ʊnʌrʧInIlʌjʌIniŋʌlEva:rʊkʌndʌrInḍʊ kolvirgʌl (jE. Ka: avʌn/ avʌlmʌgIlʧIja:gəalaḍʊ sogəma:gəIrʊkIra:l/ IrʊkIra:njEnbəḍʌI)/
2. /sʌmugənIləjIl ʊŋʌlInkʊlənḍʌIværʊpʌtəsEjʌlgəlʌIvælIpʌdʊṭIna:lniŋʌljEvIḍəjʊkṭIjʌIpajʌnpadʊṭIaʧæjalʌIkʊrʌIpirgʌl/
3. / ʊŋʌlkʊlənḍʌIjʊdʌnniŋʌlIrʊkʊmpolʊḍʊ Eva:rʊ ʊnʌrgIrirgʌl, vIrIva:gəkuravʊm/
4. /mʌtravʌrgʌluŋʌlkʊlənḍʌInnʌdəṭʌjʌIpʌtrIʌkarʌIkolʊmpoḍʊ ʊŋʌlIn ʊnʌrvʊ Eva:rʊIrʊkʊm, vIrIva:gəkuravʊm/

IV. /sʌmugə ʊrʌvʊ mʌtrʊmnʌdʌImʊrʌIṭIrʌnŋʌl/

1. /ʊŋʌlkʊlənḍʌIjEḍEnʊmsEjʌlgalʌIṭodʌŋʊvaṭʌrkʊmmʊdIpaḍʌrkʊmsIrəmpʌdʊgIra:lə/ sIrəmpʌdʊgIra:nə (jE. Ka: vitʊpa:dʌm), a:mjEnra:lniŋʌlaʧæjalʌIma:trʊvʌḍʌrkʊ jEvIḍəjʊkṭIjʌIkʌIja:lʊvirgʌl/

2. /ʊŋʌlkʊlənd̪ʌIsʌgəvjad̪ʊ kʊlənd̪ʌIgʌlʊd̪ʌnpʌləguva:la/ pʌləguva:na, a:mjEndra:ljEvId̪ʌma:gəpʌləguva:rgʌlvIvʌrIkʌvʊm/

3. /ʊŋʌlkʊlənd̪ʌIkʊlʊ nʌdavʌdIkʌIgʌlIljEva:rʊsEjʌlpʌdʊgIra:r, avʌrgʌlsIrəmpʌdʊgIra:rjEndrʊ niŋʌljEnʊgIrirgʌljEnIlʌd̪anʌIEva:rʊ sʌma:lIpirgʌl/

4. /ʊŋʌlkʊdʊmbʌʈInarInoʈʊlʌIpʊ jEva:rʊ ʊlʌd̪ʊ vIlʌkʊgə/

V. /nʌdʌʈʌIʌmsʌŋʌlmʌtrʊm ʊnʌʧIsIkʌlgʌl/

1. /ʊŋʌlkʊlənd̪ʌI ʊŋʌlkʊlənd̪ʌIjEd̪EnʊmvErʊpʌtəsEjʌlgalʌIsEIvʌd̪oʌlʌd̪ʊ kʌIgʌlʌIʌlʌd̪ʊ ʊdʌlʌIʌsʌIʈʊkondʊ Irʊpʌd̪ʊ ʊnda:, (jE. Ka: sʌnd̪osʌma:gəIrʊkʊmpolud̪ʊ kʌIgʌlʌIa:tʊvʌd̪ʊ, ka:lvIrʌlgʌllInʌdʌpʌd̪ʊ, KʌI vIrʌlgalʌIʌsʌIʈʌI ʊ kondIrʊpʌd̪ʊ, ʊdəlʌIsʊlʌtrʊvʌd̪ʊ) a: m Endra:laʧæjalʌInIrʊʈəjEvId̪əjʊkʈIjʌIpʌyʌnpadʊʈʊvirgʌl/

2. /ʊŋʌlkʊlənd̪ʌIjEd̪EnʊmværʊpʌtənʌdaʈʌIgalʌIjEd̪EnʊmsulalIlvElIpʌdʊʈgInra nara:,ʌvId̪ənʌdʌʈʌIgala:l ʊŋʌlkʊlənd̪ʌIpIrʌrʊdʌnʈodʌrbʊkolvʌd̪IlʈʌdʌIjErpʌdʊgIrad̪a, a:mEndra:ljEvId̪əsulʌlʈodʌrbʊkolvad̪ʌIkʌdInəma:kʊgIrʌd̪ʊ ʌd̪anʌIEva:rʊ niŋʌlEd̪IrkolgIrirgʌl/sʌma:lIpirgʌlEnbʌd̪ʌIVIrIvʊpʌdʊʈʌvʊm/

3. /ʊŋʌlkʊlənd̪ʌIkʊ jEd̪EnʊmsulnIlʌIgʌlpIdIkʌvIlʌIEndra:lkilkʌdəEdʊʈʊka:tIlEd̪ænʊmnʌdʌʈʌIg alʌIvElIpʌdʊʈʊvʌd̪ʊ ʊnda: (nid̪a:nʌmIlʌnd̪əvErIpIdIʈʌl, ʌd̪Igama:nəkobʌmvʌrʊd̪ʌl, tʌnʌIʈa:neka:jʌpʌdʊʈIkolʊd̪ʌl) a:mEndra:lEva:rʊ ʌd̪ʌnʌIsʌrIsEivirgʌl/

4. /ʊŋʌlkʊlənd̪ʌIkʊ sʊvʌIʌrIvʌd̪IlEd̪ænʊmkʌdInʌmIrʊkIrəd̪ʊ Endrʊ niŋʌlEnʊgIrirgʌla: (InIpʊ, kʌsʌpʊ, ʈʊvʌrpʊ, ka:rʌm) a:mEndra:ljE. Ka: ʈʌrʊgə/

5. /kʌdInəma:nəmʌtrʊmmEnmʌja:nəʈodʊd̪ʌlʊkʊ IdʌjeIrʊkʊmvErʊpa:tʌIkʌndʌrIjə ʊŋʌlkʊlənd̪ʌIkʊ sIramʌm ʊlʌd̪a:, a:mEndra:ljE. Ka: ʈʌrʊgə/

6. /ʊŋʌlkʊlənd̪ʌIkʊ jEd̪EnʊmsʊtrʊʧʊlʌlolIgʌlʊkʊ jEd̪EnʊmvIʈjasʌma:nənʌdaʈʌIgalʌIvElIpʌdʊʈʊvʌd̪ʊ ʊnda:, a:mEndra:lEvId̪ʌma:nənʌdaʈʌIgalʌIEvId̪ʌma:nəsʌʈʌʈIrkʊ vElIpʌdʊʈʊva:rgʌlmʌtrʊmniŋʌlʌd̪ʌnʌIEva:rʊ Ed̪Irkolvirgʌl/

7. /ʊŋʌlkʊlənd̪ʌIkʊ mʌtravʌrgʌlʌvarʌIʈodʊvʌd̪ʊ pIdIka:d̪ʊEndrʊ niŋʌlEnʊgIrirgʌla:, a:mEndra:l ʊŋʌlkʊlənd̪ʌIEvId̪əsEjʌlgalʌIvælIpʌdʊʈIʌd̪anʌIʈʌdʊpa:r/