



A QUALITATIVE STUDY OF PERCEPTION OF AUTISM SUPPORT GROUPS AMONG PARENTS

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ABSTRACT.

Background: Receiving the diagnosis of autism spectrum disorder often evokes strong psychological and emotional reaction from the parents of the diagnosed child. Autism Support group may be a necessary component to help families to adapt and meet their children's basic needs.

Objective: This qualitative study was aimed to explore the facilitation and barriers of autism support groups.

Methodology: This qualitative research study was conducted at Riphah International University, Islamabad over a period of 6 months from 1 August 2022 to 31 January 2023, Study recruited N=20 parents of autistic children who joined a web-based autism support group. Interviews were conducted face to face and online after asking about basic demographics, their responses were recorded and written verbatim.

Results: The results confirmed that there was strong evidence of autism support groups as they help in the effectiveness of emotional, social, psychological, and mental health. Autism support groups showed strong evidence that confirms the availability of professionals and other mothers.

Conclusion: The Study concludes a favorable view of the Autism Support Group. Parents view this as valuable and successful for generating ideas, increasing awareness, and disseminating knowledge about best practices in interventional mode on a national and worldwide level without any barriers.

Keywords: Autism Support Group, advocacy, psychological well-being, emotional support, DSM 5 Diagnostic and Statistical Manual of Mental Disorders.

Introduction:

Autism spectrum disorders (ASD) is an umbrella term used to describe a clinically heterogeneous group of neuro developmental disorders that share common behavioral core features affecting social communication and include restrictive and repetitive stereotypic behavioral patterns and interests. As per diagnostic and statistical manual of mental disorders, fifth edition (DSM-V), formerly separate diagnoses were brought under one unifying umbrella as ASD (1).

The clinical features associated with ASD are the triad of impairments in speech, social interaction, and the presence of repetitive or restricted behaviors and co-morbidity, which can be psychological and physiological. ASD typically start to manifest in childhood and is diagnosed by age 3 in most cases. Early indicators of ASD in childhood include lack of response to one's name and discomfort with maintaining eye contact (2). Some features of ASD remain relatively stable but the quality of life of an individual with ASD can be improved by creating a strong social support system or other accommodations and interventions (3).

DSM IV termed Autism as "pervasive developmental disorders" (PDDs) refers to five conditions: (1) autistic disorder, (2) Asperger's disorder, (3) Rett's disorder, (4) childhood disintegrative disorder, and (5) PDD not otherwise specified. The term "autistic spectrum disorder" (ASD), although not an official diagnostic term, is now in widespread use and is synonymous with the term PDD (4).

Severity of autism is categorized by 3 levels. Level 3 requiring very substantial support, level 2 requiring substantial support, level 1 requiring support (5). ASD diagnosis relies on impaired social development, repetitive behaviors, and delayed speech. Learning difficulties and challenges in social interaction are common. Individuals with ASD often struggle with executive function and organizational skills. Secondary symptoms may include aggression, hyperactivity, impulsivity, and co-morbidities like anxiety and depression. The condition is characterized by diverse symptoms and various psychological and physiological co-morbidities (6).

The clinical diagnosis of ASD is based on the presence of some key features, such as impaired social development, and repetitive behaviors and interests. Delay in speech development, learning impairment, and difficulties with social interaction are common in ASD. Executive function and organizational skills are notably impacted in individuals with ASD. Secondary symptoms of ASD include aggression, hyperactivity, impulsivity, and the occurrence of co-morbidity such as anxiety and depression. A major feature of ASD is the heterogeneity of its clinical features. A diversity of symptoms along with many psychological and physiological co morbidities also is present (6). Support groups, including parent-led informal ones, offer invaluable information and emotional support for parents of children with autism. They alleviate parental stress, enhance psychological well-being, and provide a sense of acceptance and community. These groups facilitate idea-sharing, collaboration in caregiving, and create a community that supports each other. They foster self-efficacy among parents, boosting confidence in managing the challenges of raising a child with disabilities (7).

Support groups offer information and emotional support that parents may not find with friends and family (Law et al., 2001; Pickett et al., 1998). Support groups such as informal (parent-led) support groups provide a place where parents feel accepted, and welcome (Altiere & Von Kluge, 2009; Law et al., 2001; Mandell & Salzer, 2007). These groups reduce parental stress, improve psychological well-being, and make available information to parents (Law et al., 2001; Mandell & Salzer, 2007). In informal support groups lead by parents, the participants share a common experience because they are all living with autism (Altiere & Von Kluge, 2009; Law et al., 2001). Parent-led support groups provide a forum where parents can bounce ideas off other parents, create an environment of working together to share the load in caring for a child with autism, provide an information network which collectively makes medical personnel and politicians accountable for their actions, and create a community that supports each other (Mandell & Salzer, 2007). Parent-led support groups provide

parents with a feeling of self-efficacy, by increasing confidence to deal with the daily struggles of raising a child with disabilities (7).

According to the Centre for Disease Control and Prevention Agency, USA, figures in the United States show that 1 in 54 children are currently identified with ASD. According to a study undertaken during 2009–2017, approximately 17% of children between the ages of 3–17 have an established developmental disability, such as autism and attention-deficit disorder. A large study carried out titled “Autism Spectrum Disorders in Europe” included 14 countries. Amongst them were Spain, Italy, Ireland, France, Belgium, and Poland. The priority was to estimate the prevalence of ASD in children ranging from 7–9 years in 2015 using nationwide registries and regional statistics (8).

In Pakistan there is no reliable vivid data on spectrum but according to Autism resource society there are approximately 400k children who are suffering with ASD (9). A study in Singapore explored factors influencing parental stress and satisfaction during the diagnosis of children with ASD. It involved 17 professionals and 102 parents of children aged 2-17. Findings revealed that parents from higher educational and socioeconomic backgrounds raised concerns earlier. Higher stress correlated with more consultations and lower perceived collaboration with professionals. Greater satisfaction was linked to better collaboration, helpfulness of information, milder ASD symptoms, and lower stress levels (9).

A pilot study on 15 parental, services and cost impact of children with autism spectrum disorder concluded considerable burden for parents and give some indication of the associated cost of autism spectrum disorder. The study on autism in developing countries, particularly in Iran, suggests that the prevalence of ASD is likely to increase globally. However, there is widespread ignorance about the implications of this diagnosis for child development and family life. Providing accurate information in local languages and accessible media is crucial, along with offering practical and emotional support to families to alleviate stress. Empowering families and promoting resilience, especially in less developed countries with limited professional services, is essential. Attention to meeting the needs of families in rural communities is particularly important (10).

The autism research and clinical communities are grappling with a worldwide disparity in understanding autism and providing services, especially in low-resource areas. This gap results in unequal access to screening, diagnosis, and treatment for autism globally. A significant barrier to addressing this disparity is the high cost of proprietary diagnostic tools and the training required for professionals and para-professionals to administer evidence-based therapies. Open-source and open access models offer opportunities for global collaboration and training, potentially enhancing the effectiveness and efficiency of efforts to bridge the knowledge gap in autism and improve access to affordable services for all individuals in need (11).

A study on Parents’ perspectives on caring for children with autistic spectrum disorder in South Asia, specifically Pakistan and India, aimed to understand beliefs and practices for intervention strategies. In Pakistan, primary data were collected through in-depth interviews with 15 parents, while in India, a narrative review of existing studies was conducted. Findings revealed that mothers bear the primary burden of care, leading to high levels of stress. Poor awareness among family members and health providers results in delayed recognition and management. Stigma and discrimination significantly impact children with autism and their families. Specialist services are scarce, mainly available in urban areas and inaccessible to many (12).

Support groups, also known as mutual-aid or peer-led groups, vary in structure and content, posing challenges in assessing their effectiveness. Despite this, they have played a crucial role in mental health by providing a space for individuals to discuss challenges, share experiences, and exchange information. Originating from limited resources and dissatisfaction with existing services, support groups gained traction during the deinstitutionalization movement in the 1970s. This period marked a shift in viewing families as participants in support and healing, rather than as the root cause of mental illness. (13) Despite the fact that a significant body of research shows that raising a kid with ASD is extremely stressful, there has been little research on how to reduce parental stress in these families. Parent support groups (PSGs) are one way to assist parents of children with ASD cope with stress, meet other parents, and create a sense of belonging. Parent support groups are a

relatively low-cost and simple-to-implement strategy for meeting the needs of these families (14), Hence, current study was conducted with the objective to explore barriers and facilitators experienced by parents currently involved in autism support groups. This study is important since, in Pakistan, there is a pressing need for greater understanding of autism support groups, as they offer a means to alleviate anxiety and stress among parents, while also boosting their self-esteem through access to emotional and psychological support from fellow parents on a unified platform. Additionally, these groups aid parents in developing self-advocacy skills, which prove effective in meeting familial needs post-diagnosis.

Design and Methodology:

The current qualitative research explored the lived experiences of the parents of Autistic children who have joined the focus groups. In-depth interviews and unstructured observations were conducted. The study addressed two research questions, to explore barriers faced by parents in Autism support groups and to explore the facilitation faced by parents of Autism support groups.

This study was conducted at Riphah International University – Department of Rehabilitation Sciences, Islamabad after obtaining ethical approval of research from the Institutional Review Board (RIPHAH/FR&AHS/Letter-01400).

Semi structured Interviews were used with the objective to explore the barriers and facilitation faced by the parents engaged in the Autism support group. Twenty parents of the autistic children were recruited in the study that was the parts of the autism support group for at least one year. The children of both genders, aged two to seven and above (Table 1).

Demographic Variables	Frequencies	Percentage
Age of children		
2 to 3 years	4	20%
3 to 4 years	6	30%
4 to 5 years	4	20%
5 to 6 years	2	10%
6 to 7 years	2	10%
7 years and above	2	10%
Gender		
Male children	16	80%
Female children	4	20%
Number of Siblings in family		
No siblings		
One sibling	6	30%
Two siblings	6	30%
Three siblings	4	20%
Four siblings	2	10%
	2	10%
Birth order of the child		
1 st	6	30%
2 nd	6	30%
3 rd	4	20%
4 th	4	20%
Family setup		
Nuclear family setup	14	70%
Joined family setup	6	30%
Single parent	0	
Native language of the child		
Urdu	4	20%
English	0	0%
Pashto	6	30%
Punjabi	10	50%

Preferred language spoken at home		
Urdu/ Pashto mix	6	30%
English/ Urdu mix	14	70%
Pashto	0	
Punjabi	0	
Preferred language for therapeutic sessions (according to parents)		
Urdu	4	20%
English	8	40%
Urdu/ English mixed	6	30%
Pashto /Urdu mixed	2	10%
Joining of autism support groups is helpful for you		
Yes	20	
No	0	100%
Are you paying for the services of autism support group?		
Yes	20	100%
No	0	
Does this autism support group have any social recognition?		
Yes	10	50%
No	0	
Don't know	10	50%
Availability of group admin when needed		
Yes	20	100%
No	0	
Availability of group participants when needed.		
Yes	12	60%
No	8	40%

Development of semi structured questionnaire was done after literature review. Initially 33 questions were included in the questionnaire. After expert review out of those 33 only 12 questions qualified for this study. In this semi structured questionnaire some questions were indirectly probing questions to assess about the details which parents cannot answer directly.

Interviews:

The parents of autistic children were asked to describe their experiences and perception about joining the autism support group. Some parents were interviewed face to face while the others were interviewed online through video/audio calls. The admin of the groups was requested to add the researcher in the group. The researcher informed the group participants about the purpose of the research and they were briefed about it. The data was taken from various web-based groups from various cities of Pakistan. Interviews were conducted following consent of the participants.

The group participants were house wives, professionals; school teachers, doctors, a chartered accountant in a private firm and as a HR manager with their children diagnosed with autism spectrum disorder (ASD). For the guidance of parents professionals like special education teachers, speech therapist, occupational therapist, and Applied behavior analyst (ABA) therapist were also members of the groups.

In-depth interviews were conducted with the Parents of autistic children using a semi- structured questionnaire after filling demographic information. The interview was organized around aspects covering and exploring the parent's perception regarding these support groups. The interviews were conducted in Urdu. The interview started with a casual question "When did you join autism support group" and "How did you get information of autism support group". The questions were phrased in simple casual wordings and in neutral manner attempting to reduce potential biases. "Is the Joining of autism group helpful in diagnosis process of your child". Each autism support group varies in that reference so the parents were asked- "What was the composition of the group? / who are involved in this group". Parents were encouraged to talk about and express their experiences, "How did you feel when you joined supporting group". The parents were asked probing question with this reference that was there any differences in handling their child after learning experiences from other parents and from the various specialist involved with the child. "How did such group help you regarding in taking care of your child". Were these ways of handling the child help in changing their own self-image or in any other aspect, "In what ways you feel any change in yourself after joining this group". "Does this group help you to provide any kind of services related to rehabilitation of your child?". It is very important for the parents them self to be fully aware about all the aspects of the ASD and to accepting the child, "How did this group help to raise awareness about autism and acceptance of autism".

The parents also has to face a lot of societal pressures and listen to various negative comments, they were asked "What's the societal attitude with you toward joining such group". It was also important to understand that if the parents were been stick to a particular support group or sifting various what was the reason behind it. "How long did you stick to that group and why?" and "Anything which you don't like about this group- explain in detail the various aspects"

All the interviews were noted in written and audiotaped and were translated later into English. Most participants switched between Urdu and English during interviews as they had a good understanding of both languages. Field notes were taken side by side. Parents facial expression, changes in the expression, any non- verbal behaviors, changes in body postures were also taken in to consideration. After each interview, discussions were held, and notes were taken regarding the prominent characteristics of the Autism support group. Sampling was conducted until comparable information was consistently and comfortably elaborated upon in subsequent interviews, indicating that saturation had been reached

The interviews were recorded and transcribed verbatim. Data analysis followed Braun and Clarke's (2006) six-phase guide: Step 1 involved familiarizing oneself with the data, Step 2 entailed generating initial codes, Step 3 focused on identifying themes, Step 4 included reviewing those themes, Step 5 involved defining the themes, and Step 6 consisted of writing up the analysis. Each transcript was carefully read multiple times to fully grasp the essence of the entire interview.

RESULTS

Following analysis of timelines and interview transcripts, main themes were identified as representing the key perspectives provided by the data within each main theme, there were several emergent subthemes.

Analysis of the interview transcribed identified eight major themes and three more subthemes with reference to the experience of autistic parents after joining the Autism support .Table 2

Themes Identified

1: Informational Support

Assuming the role of both mother and primary caregiver is akin to a full-time occupation, laden with numerous responsibilities and demands. The majority of mothers who participated in an autism support group expressed that their involvement significantly augmented their understanding of their child's condition, filling gaps in knowledge that previously existed.

. "I ask any query at any time at any place this group helps us a lot to gain information about autistic group as we travel a lot internationally, Parents and professionals share their queries and

professionals help them to solve the problems of parents”. “This group is helpful as parents share their experiences that are useful for me on later stage “. “I wanted some kind of flashcards for increasing vocabulary so I texted in the group and from there I get to know about those flashcards “. “When I joined the group at that time after 3 days they arranged a zoom meeting for parents to learn the basics about autism”. “I joined meeting and I learned a lot from there because my child use to do stimming , flapping of hands , lining up the objects and move round and round but these things I did not knew earlier “. ‘By attending different seminars, parents and therapist share their experiences in group and aware us about many things, which is not in our knowledge”.

Table 2: Major Themes Identified

1	Informational support	It is a professionally-led support group to get more information. Groups connect us with resources, equip with tools and centers for therapies in abroad Groups provide information about various professionals and their role in management of autistic children. Groups arrange webinars and zoom meetings for parental learning. Subthemes: Understanding the symptoms and severity of autism.
2	Increasing connectivity and decreasing distances	Joining groups on referral basis Decreasing cultural differences Sub theme: Cultural diversity linkage
3	Emotional Support	Groups helped us in getting emotional support I joined a support group to meet people who have gone through it, who understand Benefits of autism support groups are connecting with other mothers or families. Moral boosting and sharing experiences with others Sub theme: Emotional stability
4	Psychological wellbeing	Learning better coping strategies Management of anxiety, aggression and depression. Building a positive self-image and esteem. Sub theme: Mental health
5	Parenting strategies	Reducing negative parenting styles (aggression, shouting, hitting) Increasing patience level Dealing with odd behaviors associated with autism. Subtheme: changing perception behavior management
6	Financial support	Help to reduce the financial burden regarding intervention and management. Reduce travel time and fare Saves money by seeking help from trained mothers. Sub theme: Helping providing attitude
7	Giving a hope for better future	Group promote for a better future for your child by comparing with similar children Promoting stability and independence to children. By breaking various myths regarding their future. Children can also join mainstream schools. Sub theme: Future forecasting
8	Societal attitudes	Change in attitude

Various sub-themes were also identified like Symptoms / Severity. Symptoms and severity of autism varies from individual to individuals. Parents who have no experience before it with disorder are usually unable to understand the symptoms or suspicion of something with their children’s. Autism support groups helped them to understand the symptoms of disorder and understand the severity of problem related with symptoms manifestation.

“By joining this group it helped us to understand the symptoms of autism and look for consultation for child”. “This group helped me to understand the features of autism which were unknown to me before it. I came to know about the sensory issues of my child that were not familiar with me; my child has excessive laughing behaviors and sensory issues which are features of Autism”. “I

personally did not know anything about Autism. But when I joined the group I came to know parents already have children with Autism “.

“When I joined that group I was not aware of what autism is and what are their features but there I have continuously seen viewing videos of the child’s who are were autistic”. “It is helpful in identifying different symptoms”

“It helps me in assessment of sentences then another thing I come to how much it is important to reduce screen time. I came to know about different strategies to control screen timing”. “I came to know that it is neuro developmental disorder showed symptoms in 18 months”.

2: Increasing connectivity and decreasing distances

Social media played an important role in creating awareness about Autism Support group. This theme increases connectivity between different cities across Pakistan. It provided an easy access to interact with parents, clients and other professionals who could help out parents socially and psychologically. It welcomes all the new comers and facilitates every member to show their interests and experiences. “I got information through Facebook random notification “.” I joined Autism support group on WhatsApp which I have seen through Facebook”. “My husband uses Facebook so he saw comments of a parent in a group about Autism, so my husband contacted him and he advised us to join group “. Humans are social creature. They are contacted with each other through blood relations, through services and so on. Referral of person to other one is key characteristic of social interaction. Many parents commented that they are referred by their friends who know we have children with Autism. “As my husband is running own business so one of our family friend told us about Autism group so we joined after referral of our friend”.

“I get information of autism support group from my colleague whose child was diagnosed autism earlier than my child and she noticed the symptoms in my child first than she advised me to join this group because it is very informative and helps parents a lot “. “I got information from social media. One of my friends was also a member of this group she told me about this so I joined the group”. “I joined group on face book which was about autism and when I thought my daughter might have autism started searching about more groups, from there I came to know about WhatsApp group named autism support group, from where I get more stuff about autism”.

3: Emotional support

Emotional support within autism support groups refers to the provision of empathy, understanding, and encouragement to individuals affected by autism spectrum disorder (ASD) and their families. This support can come from fellow group members who share similar experiences, as well as from professionals facilitating the group. It involves creating a safe space where participants can express their emotions, share challenges, and receive validation and comfort from others who comprehend their journey. Emotional support plays a crucial role in alleviating feelings of isolation, stress, and uncertainty commonly experienced by individuals navigating the complexities of autism.

Parents reported that. “This group helped me in getting emotional support by getting people around who are also facing the same problems as I am”.

“I joined a support group to meet people who have gone through it, who understand the difficulties which are faced by bringing up autistic children”. “It helped me in connecting with other mothers or families who were also very stressful, anxious and aggressive towards t heir self but now at this platform they are all connected”. “This group helped me in the way that they provide very positive support and energy toward each other by sharing experiences with each other”.

4: Parenting strategies

By joining the social support groups, parents and professionals guide how to manage different behaviors at home. Parents guided parents different techniques to channelize their energy at home, managing behaviors and professionals guided parents on the basis of evidence based practice. “My child had so many sensory issues and he had stimming behavior previously so I got a lot of help about to control these behaviors and manage this behavior”. “My both child has sleeping issues by

the guideline of parents I worked at home to manage sleep patterns of my child". "By applying the strategies, I overcome my child restlessness and excessive cry behavior". "This group share different posts. Parents and therapist also guide us. If we have some queries about our child we asked there and they respond us and tell us how to deal with this". Diagnosing of child with disorder is remained painful and negative thoughts or negative perception about the child abilities. As usually children with disorder needs special preparations and techniques to make them functional and utilize their potential. By joining the group I came to know how to make child functional and help them to gain independent skills in all developmental areas.

"My child did not hold pencil to write. I texted in group participants. One of the parents called me and guided me how to work with child. After talking with parents my thoughts changed". "Parents shared videos in group in which their children are talking and involved in different activities so then I got relaxed".

"We have experienced mother there who guided us through their experiences and helped us to use those strengths with our kids". "This group share different posts. Parents and therapist also guide us. If we have some queries about our child we asked there and they respond us and tell us how to deal with this ".The sub-themes were Behavior management and changing perception.

5: Psychological wellbeing

Social groups provide a place where participants can share feeling, emotions, thoughts that were distressing to them. How did they manage their feeling of anxious, aggressiveness, anxiety and depression by sharing their experiences? By interaction with such people who have children with autism helped them to accept the situation and psychologically relaxation.

"I get support from the group and it is very helpful for me". "I feel depressed first but after sometime some other parents told techniques that how to tackle the situation so then it seems that it is a finally where parents are on one platform". "I felt a lot of change when my child started improving a lot my aggressiveness, temperament and my depression also started to be improving. I felt myself out from the depression in the way that many children's who are house wives and are fighting with it and managing their kids effectively so why not I. I have also the ability to cope up with the things ". "I feel very relaxed after comparing my experience with other's experiences'. The symptoms that my child has are not that major". "By joining this group I feel positive, motivated and work more positively with my kid". "I can openly discuss my issues and it is a platform where can one get a huge support "

6: Financial support

Groups consist of different back ground people. All participants are not with same socioeconomic status so sometimes many child deprived by different facilities of rehabilitation. Assessment and therapies are usually expensive and under Govt sector the services are less provided in numbers ultimately hinders the development of child. By mutual support of group participant to low economic back ground parents helps them to avail services. "Yes this group provides services to needy parents who cannot afford to continue therapies for their kids. We all parents pool for financial support to parents "

7: Giving a hope for better future

Within autism support groups, instilling hope for a better future involves fostering optimism and belief in the potential for positive outcomes despite the challenges posed by autism spectrum disorder (ASD). This hope can be nurtured through sharing success stories, discussing advancements in treatments and therapies, and providing resources for education and advocacy. By promoting a sense of optimism and possibility, support groups empower individuals and families affected by ASD to envision and work towards a future filled with opportunities for growth, development, and fulfillment.

"Parents in the group reported that when we compare our child with other autistic children and they are growing so well and their mothers are less burdened and they manage their selves independently

so it gives us a ray of hope that our child can also do that “. “When we see videos of other children in the group and their mothers share their achievements so it means that my child will also achieve these goals and targets”.

“This group helped me in stability and independence to children by various factors like sensory issues, excessive crying, excessive laughing and many such factors”. “I usually when sitting in my office thought of that my child will never speak he will never hold a spoon he will never get off his odd behaviors but because of this group I came to know that these are all just myths”.

“Children can also join mainstream schools and they can perceive their education in normal school. I have seen so many videos and achievements of children who are going to very well off schools like beacon house, city school and convent”.

8: Societal attitudes and availability of professionals

Societal attitude plays an important role in social adjustment of parents and children with special needs. Bullying, stigma, labeling negatively prevent the parents to socially participate in society. Usually parents with disorder /disability hide their child to avoid bad comments. But there is variation in societal attitudes where parents faces negative attitude they also have positive, encouraging attitude of society. “My mother-in-law says that you are wasting your time in silly groups”. “When I told my husband about joining of group he started to argue with me that why did you discuss my child with other? Society will start to stigmatize and everyone will know that we have children with Autism. But with passage of time attitudes have been changed. My mother-in-law and sister-in-law started to help me to manage child at home”. “Obviously, we can’t expect a good vacation for joining that group so, mostly parents don’t mention their identity over there”. “I discussed it with my husband only and he also started studying on it so I think his attitude was not negative, he also started searching about more support groups”. “Behavior varies from person to person. There are very few peoples that have encouraging attitude towards this. But some have negative attitude. Due to that parent's don't mention their identity”. “Because of the fear of stigmatization, I have not revealed to any that my child is diagnosed with ASD and nobody knows that I have joined such kind of group and I have joined this group as an anonymous person. When I want to ask any question in the group, so I post it as an anonymously. My husband also uses to say that you only exaggerate things which our child does not show sometimes but you post it and get yourself more worried”.

It is not easy to manage a child when he/ she are on spectrum due to lack of awareness, knowledge and lack of training. At this moment all the parents seek knowledge and information or way that can undo the situation. After accepting the situation they seek knowledge to manage the child or overcome his behavioral issue. “I can’t leave this group because I need more knowledge and strategies for my kids. This group replies me immediately whenever I have any query”. “I am still the member of this group because it is very helpful to bring the best possible ideas which in can use with my child”.

DISCUSSION:

Support groups provide informational, emotional and psychological support to parents on a single platform, where they feel accepted and warmly welcomed. Autism support groups reduce parental stress, anxiety and depression, improve their psychological well-being, and provide information to parents. All the parents on a single forum share their experiences because they all are living with autism. Parents in these groups can bounce off their personal ideas to other parents; create a working environment together for sharing their load in caring for autistic children. The results were also supported by study conducted on caregivers of children with autism in Pennsylvania (15).

This qualitative study was aimed to explore the experiences of parents about Autism support group. The sample included 20 Parents mothers, from the middle class, who uses social media and got knowledge about these groups through social media i.e. face book followed by joining what’s app group. This paper found the voice of those mothers whose children were diagnosed with ASD and they have joined autism support groups who shared their positive experiences and the worrisome

things about the groups. These results are supported by the study done on 22 parents with Internet-based self-help groups for children with autism, at the University of Windsor. Positive experiences that arose from Internet-based groups included support, empowerment, and effective strategies for advocacy (16).

Previous studies have examined the relationship between participation in parent-led support groups and parental advocacy. The findings of our study extend the knowledge about the effectiveness of parent or professional led support groups in influencing parental decisions regarding treatments, doctors and therapists (17). Parents may be able to understand the disorder manifestation. By the interaction of participants' parents, professional in group their perception about Autism has been changed. According to study, the emotional, informational, and appraisal support provided by parent-led support groups assisted in parents becoming advocates for their child (18). One of the findings of this study that was supported by the literature was related to the value of parent led support groups in assisting parents in becoming empowered to advocate for their child (19). Our study also suggested that these groups help in self-advocacy by attending different webinars and online sessions which are arranged in the groups for the knowledge of parents. Parents further suggested that these groups acknowledge the strengths of their children and they become involved in child education and rehabilitation services through professional guidelines and with the experiences of other parents.

A study elaborated how the knowledge provided by guest speakers and the parental experiences of other group members were synergistic and influenced decision making for resources (20). Parents identified that support from group members in term of providing solutions for any query regarding assessment of child, diagnosis of child, therapies services availability for these children, location of therapy centers, and parental approaches for managing their behavioral symptoms at home is worth living.

The findings of our study is also correlated with previous studies that is reported by mostly parents that autism support groups provided us with a platform where we can do catharsis, can share our feelings and get rid of anxiety, depression and anger. With the support of other parents and experiences of other parents, we coped up with our negative feelings, feels better and realized that this is also part of life that needs attention. It also helped them to get strong, positively motivated to do something for their child effectively and get their moral boosted up. Mandell and Salzer (2007) found that support groups provided a platform for the exchange ideas, created a community that helped each other, and built a collective information network which indicated that groups became a forum for discussions and also gave parents a sense of belonging and parents felt less isolated (21). The exchange of ideas and information also led to the discovery of funding alternatives to relieve the cost of raising a child with autism as reported by some of parents in this study. Some parents also described their experience as a journey that built a difference in their lives and in the lives of others (22).

Being a part of the members, it is necessary to maintain the temperament skills, experiences, and motivation to assist out others in group. Those parents were role models who helped others to feel confident, and encouraged them due to their own experiences and understanding; this provided a safe environment to them where they can open dialog and share their ideas (23). The support from these groups cannot be duplicated because it maintains a unique environment.

Parent-led support groups provided emotional support for parents struggling with caring for a child with autism (24) Participants of this study indicated that one of the primary reasons for participating in these groups was for their own emotional support (25) Parents also interviewed that by sharing ideas, experiences with other group participants resulting in exchange of empathy and encouragement as there is no place from where they can get emotional support (26)

Societal attitude remained under consideration in every era. Positive and negative attitudes are aligned with data that reveals that with the passage of time with a lot of advancement there is still need to change attitudes of parents by raising awareness in general population. Mixed attitudes feeling experienced by parents by very close relations of the family. Some of them remained neutral about attitude by concluding that only our spouse knew that we participated in group and we never

revealed in front of anyone. Parental fear about labeling, stigmatization was also observed through data that forced the parents to keep themselves anonymous.

Conclusions:

Findings of the study revealed that perception about Autism support group is positive in nature. Parents perceive this as useful, effective circle for creating, raising awareness, providing information about best practice in interventional mode nationally and internationally. These groups provide great, wide perspective about Autism from diagnosis to mainstream setup where they participate with regular peer without any discriminations. It also helped them to get guidelines about their potential utilizations, their study styles, and least restrictive environment. Finding also concluded that these forums provides social and moral support and help the children to attain maximum independency in their life skills to use the community modalities effectively. Many facilitating factors as mention above were identified but no barriers were identified in our study.

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