

 <p>ISSN NO. 2320-5407</p>	<p>Journal Homepage: -www.journalijar.com</p> <h2>INTERNATIONAL JOURNAL OF ADVANCED RESEARCH (IJAR)</h2> <p>Article DOI:10.21474/IJAR01/12508 DOI URL: http://dx.doi.org/10.21474/IJAR01/12508</p>	 <p>INTERNATIONAL JOURNAL OF ADVANCED RESEARCH (IJAR) ISSN 2320-5407 Journal Homepage: http://www.journalijar.com Journal DOI:10.21474/IJAR01</p>
-------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

RESEARCH ARTICLE

“COPING WITH AUTISM: DIFFERENTIAL & UNIQUE PARENTING; MOTHERS JOURNEY TOWARDS ADAPTATION”-A QUALITATIVE STUDY IN INDIAN CONTEXT BASED ON GROUNDED THEORY APPROACH

Nisha Laila¹, Dr. Linu Sara George² and Shalini G. Nayak³

1. Senior Nursing Officer & PhD scholar, Department of Cardiology, All India Institute of Medical Sciences, New Delhi, India.
2. Professor, Department of Fundamentals of Nursing, Manipal College of Nursing, MAHE, Manipal, India.
3. Assistant Professor, Department of Medical Surgical Nursing, Manipal College of Nursing, Manipal, India.

Manuscript Info

Manuscript History

Received: 19 December 2020
Final Accepted: 22 January 2021
Published: February 2021

Key words:-

Autism Spectrum Disorder, Parenting, Children, Grounded Theory, Qualitative, Experiences, Mothers

Abstract

Objective: The main objective of this study was to explore the experiences of mothers parenting children with Autism Spectrum Disorder (ASD) with a view to formulate a conceptual model of parenting experiences based on the constructs identified.

Design & Methods: The study used grounded theory methodology in order to derive a conceptual model for parenting a child with ASD. The participants were mothers between the age group of 24-50 years undergoing parent child training from Autism training Centre, Northern India. The study is based on in depth interviews with twelve mothers who were meeting the eligibility criteria. The interviews were digitally recorded with a voice recorder. The anonymity and confidentiality of the participants were assured. The translated data were coded and categorised using open code software

Results: The qualitative data analysis revealed thirteen major categories and forty six sub categories and a core category was derived out of the concepts and formulated a conceptual model of coping with autism, Unique and differential parenting; Mothers Journey towards adaptation.

Conclusion: This qualitative study provides evidence for parenting experiences of Indian mothers of children with ASD. The findings would provide identification of problems, need based care and guidance for professionals.

Practice Implications: The conceptual model formulated could be used as a basis to test the hypothesis in various aspects of the concepts discussed in relation to mothers experiences of a child with ASD and thus a substantive theory of parenting a child with ASD could be developed in future after comparing and concept analysis of the existing parenting theories .

Copy Right, IJAR, 2021., All rights reserved.

Introduction:-

Autism Spectrum Disorder (ASD) is a lifelong disability and it is pervasive and impacts several aspects of child's functioning such as behavioural, emotional, and psychological and is often resistant to treatment with poor outcomes

Corresponding Author:- Nisha Laila

Address:- Senior Nursing Officer & Research Scholar, Department of Cardiology, AIIMS, New Delhi.

in child's development (Baghdadli et al, 2012). ASD is one of the complex neuro developmental disability that commonly manifest symptoms during early child hood period and affects various aspects of development in child such as social, communication and behaviour. The main cause of this disorder is the results of highly complex interaction between the genes, brain and behaviour through the developmental period (Sharma A, Nandini G, Sane H, et al, 2015). Hoogsteen and Woodgate (2013) reported that the caregiving task of mother for kids with ASD is difficult because these children have very unique needs and require more care, guidance, supervision, and support. Moreover, the particular circumstances in child's life create more stress and strain situations for mothers.

Background:

Parenting a child with 'Autism Spectrum Disorder (ASD)' can be a great experience for parents and families. The widespread and the severe deficits associated with this disorder in children with ASD causes difficulties and challenges for parents mainly for mothers, including decreased self-efficacy for parenting, increase parenting stress, and more health-related problems compared with parents of both normal children and children with other developmental disorders. Moreover, financial challenges and time spend for parenting, increased divorce rate among parents and decreased overall family well-being signify the care burden associated with parenting child with ASD (Karst & Van Hecke, 2012). Stroke (2007) reported that 'parenting a child with Autism Spectrum Disorder' is challenging and impact the family life even though there is reported evidence of very good parenting among parents of children diagnosed with ASD. Several studies showed that parents suffer more stress and burden for care giving (Dunn, & Burbine, 2004; Scheive, Blumberg and Rice, 2007).

An integrative Review was done on "Risks and Protective factors for Stress self-management in parents of Children with ASD". The researchers used extensive search based on eligibility criteria using CINAHL, Medline and Psych Info. They included studies related to the context factors for parenting and were written in English. Based on review criteria included ninety-eight studies. The findings of the review revealed certain risk factors for parental stress management such as disease specific factors and physical, social and environmental, familial and individual factors. Also the parents were struggling to get a proper diagnosis and services for their children as a result they were frustrated with health care provider's knowledge of ASD and lack of communication (Bonis & Sawin, 2016). A study conducted by (Kristin and Daniel, 2014) to examine the association between self -compassion and wellbeing among 51 "parents of children with ASD" between the ages of 4-12 years using questionnaires. The findings of the study revealed that there is a positive association with 'self-compassion' and satisfaction in life and goal attainment and negatively associated with depression and parental stress. The parents reported child symptom severity is often the strongest predictor of negative adjustments. Findings indicated that self -compassion may play a significant role in wellbeing for parents of children with autism.

A study was conducted on "parental challenges of children diagnosed with Autism Spectrum Disorder". They used a qualitative interview study explored the parental experiences, challenges faced and the coping with autism among 20 parents. The findings emphasized that parents themselves believe they need extra support for care. These findings suggested for strategies and resources needed for parents of kids with ASD (Ludlow, A., Skelly, C., Rohleder, P. 2012). A study conducted by (Al-Oran & Yahya A, 2016) on the experience of parenting a child with ASD vary significantly according to different socio-cultural contexts. A review was done to investigate the stress levels of "parents of children with ASD" and examined the variables that predict parenting stress. They conducted systematic search of databases such as CINAHL, Springer, Ovid, ProQuest, PubMed and EBSCO between the years 2001-2015. This review included 35 articles and the findings showed that the socio demographic variables were influencing parental stress levels. Mothers of children younger than 6 years old reported the highest level of stress and a recent diagnosis, low educational level and a low monthly income were influencing the stress level of parents. The researcher also evaluated the impact of autism on parent's mental health and relationship with family.

A pilot study conducted by (Pushpalatha & Shivkumara, 2016) on "coping mechanisms and relationship of parents in families with a child having ASD in the National Capital Region of India. The findings revealed that parents were adopting various coping strategies like seeking information from professionals and adopting religious practices reading scriptures and getting support from family and society. The acceptance of the diagnosis and general optimism were found to be the most effective coping mechanism for families. The relationship between parents were mostly stressful. A study was conducted by (Minhas A, Vajaratkar V, Gauri D, et al, 2015) on "parent's perspectives of care of children with ASD in south Asia-views from Pakistan", with a view to identify the "beliefs and practices" regarding the care of children with ASD. The findings of the study were useful for developing strategies and

interventions such as building community and family support networks, training professionals and other health workers in community and motivated family members for providing evidence-based interventions.

A research study conducted by Gorlin et al (2016) investigated the “experience of families living with a child with severe autism”. The researchers adopted phenomenological approach for data collection and analysis. The findings of the study indicated six essential themes. The themes derived were “family experienced autism as mysterious and complex”, “Severe autism behaviours that often caused self-injury, harm to others and damaged homes”, “Profound communication deficits resulted in isolation between the family and the child” and “stress from lack of sleep”, “Managing the child’s developmental delays”, “Coordinating and financing services” and “concern for the child’s future”, “Consequences of isolation from friends, school, public and health providers” and last theme was “Need for compassionate support and formed ‘hybrid families’ to gain support”. These study results highlighted the need for educating nurses about the unique needs of these children and families and need for health care policies and programs to support for these families caring a child with severe autism.

A qualitative study done by (GyunY, Cha-Soon Choi, and Se-JinJu, 2016) to explore the parenting experiences of mothers of children with Autism spectrum disorder. The findings revealed six categories and 12 subcategories were derived out of content analysis. The parenting experiences reported from mothers were, “difficulty in accepting limit imposed by the disease”, “discouragement”, “suffering and responsibility of a mother”, “changes in the family system”, “appreciation for small changes” and “hopes and promises for the future”. A cross sectional study conducted by (Sinha, D., Verma, N., Hershe, D. A, 2016) on parent’s stress, parenting style and resilience in three different group of parents with children having ASD, Specific Learning Disability (SLD) and children without a psychiatric disorder in Mumbai, India. The findings revealed that “parents of children diagnosed with ASD” exhibit greater stress as compared to parents having a child with Specific Learning Disorder and those having a child without mental disorders. The reported resilience score showed higher in authoritative parenting style than permissive with authoritarian parents. The study revealed that the parent’s perceived level of stress was affected by type of disability. Whereas parental resilience was influenced by parenting styles.

In India mothers of children with ASD are facing more stress and parenting challenges in their daily lives. This qualitative study explore more about their parenting experiences and day today struggles for caring a child with ASD.

Aim & Objective:-

Aim:

The aim of this study was to explore and describe experiences of mothers on parenting children with autism in order to obtain a holistic view of the experience as they have lived over a period of time.

Objective:

Explore and describe the experiences of mothers on parenting children with Autism-Spectrum Disorder with a view to formulate a conceptual framework based on their parenting experiences

Methods:-

Research Design:

In this study, the researcher used qualitative grounded theory design based on the work of Strauss and Corbin which aimed at exploring the experiences of mothers parenting a child with ASD. This study aimed to provide an in-depth qualitative view of the experiences of mothers parenting a child with autism spectrum disorder. The data generated were verified through systematic data collection and analysis of data pertaining to that phenomenon. This method helps the researcher to produce a substantive theory about mothers parenting experiences of children with ASD. An inductive approach was used in this study. Inductive process involved reviewing the raw data that emerged using the constant comparative method. (see Figure 1)

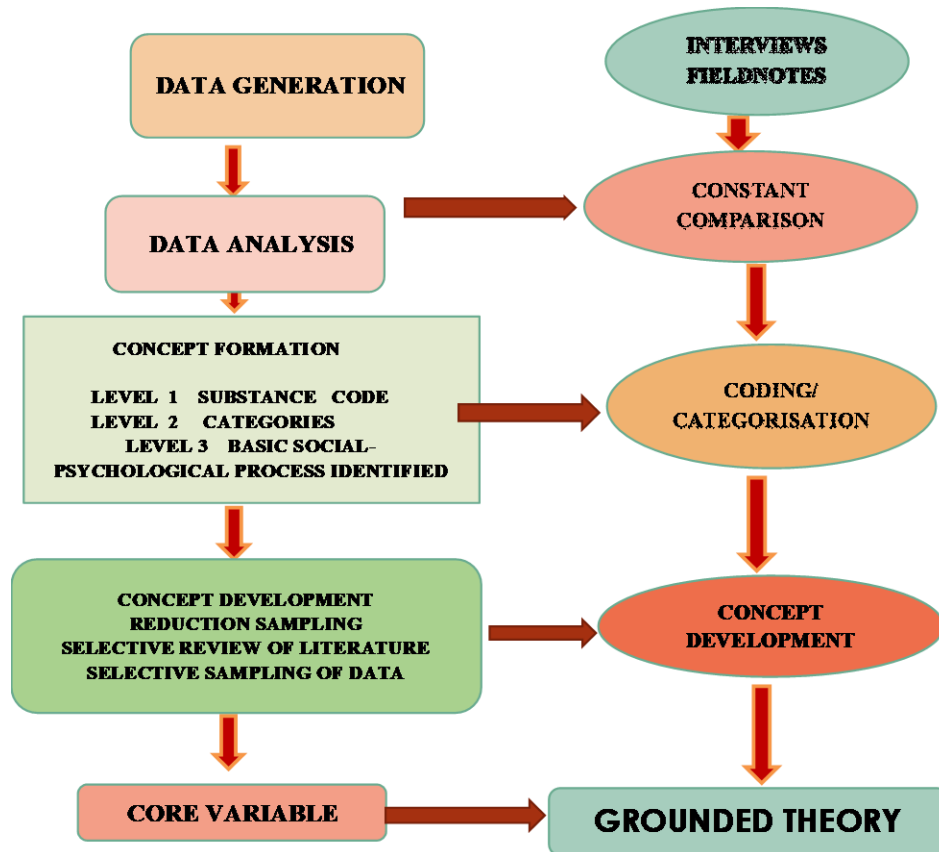


Figure 1:- Research Design for the study.

Sampling & Setting:

Participants were mothers of children with autism spectrum disorder between 24-54 years of age and they were undergoing parent education and training programme at the centre in North India. The participants were allotted based on sampling criteria. Theoretical sampling used for this study. The samples were selected based on theoretical data saturation since the study design used was a grounded theory approach. Data saturation attained after collecting and constantly analysing data from 12 participants. The study setting selected was National Autism Training centre located in National capital city of India (New Delhi), which is a non-governmental organisation. The centre provides special training and early intervention for children with Autism Spectrum Disorders along with training for parents of children with ASD. The centre provides facilities for children with ASD from different states of India.

Data Collection procedure:

Data for the study was conducted between February 10th 2018 and March 31st 2018. Before starting data collection, a recruitment flyer was given to the institution from where samples were selected. Mothers who expressed interest for the study were contacted and provided a detailed information about the study. The researcher got ethical clearance from Institutional Research Committee as well as Institutional Ethics committee before starting the study. Informed consent was taken from participants for audio recording and participation for the study and to ensure the confidentiality of the information, all participants were allocated specific alphabetic codes. The researcher established a rapport with the participants. Base line data of the mother and child were collected using questionnaires.

Data Collection Tools and Techniques:

In-depth semi-structured interview were used to better understand the life experiences of mothers of children with ASD as the meaning they placed on these experiences. A set of open-ended questions devised based on the reading of the literature on parenting a child with ASD, was used throughout the interview and served as guideline to offer structure and organisation to the interview process, probing questions that asked to elaborate on their stories also

asked. The leading question was “Describe your experiences of parenting a child with Autism Spectrum Disorder”? Twelve mothers were interviewed in different days and the language of the interview used were English and Hindi. Four mothers responded in Hindi and eight were expressed in English. The researcher remained open to the meanings attributed to mother’s experiences. The total length of the interview process was around 45 minutes-1 hour and were digitally recorded using an audio recorder. After interviewing the participants, the data was transcribed and translated to English. Field notes were noted during data collection.

Data Analysis:

Data were managed using Open code software (4.2 version) developed by ITS and Epidemiology, University of Umea (www.umu.se) and data analysis done using Strauss and Corbin’s synthetic approach to grounded theory. As the data were transcribed and analysed, the researcher conducted final meeting with the participants in order to verify the data through the use of member checking. This additional information also allowed the researcher to better categorize the data into appropriate themes and to develop certain constructs and helped to depict more accurate life story of mothers rearing children with Autism without misinterpreting the participants’ perspective.

Qualitative Data Rigor and Trustworthiness:

The derived themes and subthemes and the codes were validated by experts experienced in qualitative research before deriving the core theme. The Credibility refers to whether the findings of the study are believable and convincing which can be established by several methods. The three methods included in this study to ensure credibility were member checking, triangulation, and peer debriefing.

Results:-

Demographic Characteristics of Participants:

The majority, (n=7; 58.33%) of the participants were 30-40 years of age. All twelve (n=12; 100%) of were married and living with spouse and were belonged to Hindus religion. Majority of the mothers belonged to nuclear family n=7 (58.33%). With reference to educational qualification (n=8; 66.67%) of them were graduates and three (33.33%) of them had post -graduation. Eight mothers (66.67%) were unemployed or home makers. Majority (n=7; 58.33%) of the participant had a monthly income > 20,000, Most of the participants had not having a second child diagnosed with ASD i.e. n=11 (91.66%), only one (8.3%) had a second child with ASD.

Description of Child characteristics:

The child related data showed that most (n=7; 58.33%) of the children were between the age group of 6-9 years. Males dominated as far as the gender of the child was concerned (n=8; 66.67%). All children living with their mother (n=12; 100%). All children were diagnosed ASD between 1-3 years of age (n=12; 100%). All (n=12; 100%) were receiving special education services. Majority (n=8; 66.67%) of the children were having no associated comorbidities. Four (33.33%) children had associated comorbid conditions. Only 16.66% (n=2) of the children were taking medications. Majority (n=8; 66.67%) of the children were not able to communicate with their mother. Majority (n=8; 66.67%) of the children were not able to communicate with the family members. 66.67% (n=8) of children were not able to communicate with their teachers of the institution. Majority (n=10; 83.33%) of the children were showing maladaptive behaviours. Majority (n=12; 100%) of the children were having sensory issues. With regard to receiving support services from community, majority (n=8; 66.67%) of children were not getting any support services. All children (n=12; 100%) were not able to play with other children.

Emergenced Themes:

The findings of the qualitative analysis revealed thirteen major categories and the core category was emerged out of the thirteen major categories. These were discussed below. (See Table 1)

1. Positivity in parenting - ‘mother’, an angel of love, self -giving and self- sacrificing:

This theme describes the Mothers’ positive parent child interactions and descriptions of positivity related to child characteristics and behaviours as well as rewards and benefits associated with raising a child with ASD. The mothers are the symbol of self -giving and self -sacrificing for their child. This theme has six subthemes (table 1). One of the participant’s narrative support the essence of this theme. The following is the supportive verbatim for this theme.

“Now I am emotional to each child. Anu changed our attitude, Mentality changed when looking kids whether it is normal or not. It’s hardly matter. First, we are looking problems in children. But now seeing problems in parents

too. Parents is doing some mistake, that's why the child behaves like this. So mentality changed because of my daughter. Attitude changed. Before I was thinking this child is stupid and bad. When attitude changed, things changed” “Now she is attached with both of us.she attached with me more...because I understand her more...I understand everything. (Participant A)

2.Parenting struggles and challenges: Impact on mother:

Participants in this study reported that they were facing daily difficulties and struggles for dealing with the core problems in their child. This theme had two sub-themes which explain the theme in detail in terms of mother's struggles and challenges.Participant C verbalised as follows.

“He has lot of struggles... He cannot speak, and he is growing. He cannot tell what exactly. Though he is learning to communicate but it is very limited to his needs. Need based communication is there. Obviously, he didn't tell me what exactly he is feeling, what he wants from his side,if he wants to be his father ,sometimes he likes to go my sisters place, my niece ,he is very fond of her.Sometimes I feels that he is restless, because he wants to communicate with me something, but he cannot. That also bothers me a lot. Rightnow he is 7 and ½ year(Participant C)

Table 1:- Major Themes (Categories) and sub-Themes (Sub-Categories) derived after Qualitative data analysis.

Themes	Sub-Themes
Category 1:Positivity in parenting - ‘mother’- an angel of love, self -giving and self- sacrificing	Understanding Child's abilities and limitations Role of mother as primary therapist Mother's attitude and- relationship with child Developing bonding and companionship with child Feelings of pride Self -Compassion
Category 2 : Parenting struggles and challenges: Impact on mother	Daily struggles and difficulties facing for child care Disease specific challenging Child characteristics
Category 3: Developing competency and self -efficacy for parenting	Coaching and Training the child Scheduling and structuring daily routines in child Ensuring optimal growth and development for child Ensuring child's safety and protection Disciplining the child Sense of coherence for parenting
Category 4 : Challenges in diagnostic process	Diagnostic uncertainties Attitude of medical professionals for ASD diagnosis Mother's Initial reactions and early coping
Category 5: Improving adaptation within family life: Impact on family	Family cohesion and attitude Difficulties for siblings Attitude and relationship with spouse Accepting the disability
Category 6: Role of interpersonal support systems	
Category 7: Maternal strategies and practices linked to child's functioning	Strategies for Self -care activities for child Adopting strategies for difficult behaviors in child Strategies adopted for communication Managing sensory issues in child Developing socialization skills Developing independency in child Academic challenges and Training

Category 8: Managing crisis in life	Frustration & Crisis situations in life Career, leisure time and health consequences
Category 9: Stress and coping: psychological impact	Causes of stress and distress in mother Comparing the child with neurotypical child Coping with stress Questioning by mother Religiosity in mother Subjective appraisal and internal capabilities
Category 10: Maternal beliefs, Perceptions and Worries	
Category 11 : Societal awareness and stigma: Social impact	Isolation and self –isolation Public interferences with child Attitude of society and people
Category 12 : Future concerns and goal setting	Ambitions and future goals Taking decisions Hoping &Optimism for future
Category 13: Learning more about autism and empowering self	Seeking professional Advises Managing resources Acquiring knowledge and training through courses

3. Developing competency and self- efficacy for parenting:

This theme has six subthemes (table1).All participantsweredescribed that they were developing competency and self -efficacy for parenting by various strategies such as coaching and training their child, ensuring optimal growth and development for child, maintaining a routine and structure in life, disciplining the child positively, providing safety and protection for the child. All mothers verbalised that they are coaching and training their kids at home in-order to function effectively. The narratives which support this theme is explained below.

“Some of the skills like his ADLs. Most of the ADLs he should aware of that. He is just five,so he is learning.. Probably after some years he will able to do that and all..(laughing).I am hoping so...ADL(Activities of Daily Living) and communication part majorly I am focusing on that...because communication is one of thing which I think any kind of behaviour issues from communication only.. So I think the most priority for me is ADL and communication.(Participant E).

4. Challenges in diagnostic process:

Instability of identifying the core characteristics of ASD by the experts causes delay and uncertainties in ASD diagnosis and as result mothers faced struggles and difficulties at the initial years. The mothers were frustrated initially to get an accurate diagnosis for their child. Also they perceived for loss of precious years for starting therapies and interventions for the child. This theme has three subthemes

“I don’t know that he is having autism. Or some timesbeforelike one year of his age he don’t have an eye contact with others. So we went to a doctor and doctor told us he is having autism and autism was diagnosed.Starting time we consulted a lot of doctors and we searched a lot.Starting time the child has a lot of difficulties, and what is autism means...and what we should do.and should not do.Is there any treatment for this?So for this which all places we roam around.. Finally we came to know that he is having autism. Butits took a lot of time for us.(Participant F).

5.Improving adaptation within family life:

This theme has four subthemes.Specific adaptation of family towards parenting a child with ASD according to the characteristics of the child by overcoming the challenges.Many participants were stated that family members did not understand the disorder, even if they accepted the diagnosis, and feeling difficulty to accept the child in certain occasions thus could not provide the needed support. Participants verbalised the nature of spouse’s support in providing care and they were trying to keep a balance in family in order to function the child optimally.

“My family is very supportive.That may be a reason why I am not feeling much stress. I never heard from my family members that my child is mentally ill or mad. My mother and father everybody is telling he is a special child and God sent him specially for us.so that we are able to care him more.Never thought that he is a burden for us.So I

never felt much stress and my family never place me in stress. If any problems they will come immediately to my home”(Participant B)

“There is no family support. One thing is they think the child is ‘pagal’ means mad. So not giving much importance for him. Actually what these kids need that will not getting like love and affection from others. That is not getting. Then I didn’t like to go to there and stay with my family.... Completely cutoff from them. Everything I am facing a lot of difficulties.(Participant D)

6. Role of interpersonal support systems:

This theme reflected that formal and informal support systems helps the mothers to manage stress associated with parenting child with ASD and strengthen their role and wellbeing in society. In this study the mothers experience with formal and informal support systems varied. Most of the participants were verbalised that they are getting support from society only from the institution in which they are getting training. The following narratives helps to understand this theme.

“Yes, after coming to the training centre, we have our own big groups and all. We speak to people and they were support also. But out of centre I don’t think there are much friends. Because they are not aware about that and they don’t know what to do and what not to do. There is a great support for me. Even from teachers or any other people and some of our class mates are mothers only. That positivity comes with me which helps me to work with as much as possible”(Participant E)

7. Maternal strategies and practices linked to child’s functioning:

This theme defines that participants are adopting various strategies and practices for functioning of their child with ASD. This theme has seven sub themes. All participants were adopting a problem -focused strategy for child’s functioning like (strategies for communication issues, strategies for controlling different behaviours, strategies for developing socialisation skills and developing self -help skills in childlike toileting, bathing, dressing, eating) in order to improve mother’s parenting efficacy and psychologic wellbeing. These strategies helps mothers to better coping with difficult situations. The following verbatim of Participant C supports this theme.

“For toilet training we are using Picture Exchange only (PECS only). So every time we are going to toilet I will show him the picture that we are going to toilet. He cannot asks me to go to toilet. Still he is not understanding that concept. So I have to carry him every 1 and ½ hour to the toilet. So that is bit difficult for me. Because he is grown now”. “Now he is on behavioural therapy and its ABA type. When I had come here it was difficult for me to control few of his behaviour like crying or screaming. Every time I used to tell him how much you are screaming, please keep quiet and am getting disturbed and he used to scream more and more. Now I know how to handle that behaviour. We are working on it. Behavioural therapy started 6-7 month back. A bit of improvement, but not very much”(Participant C).

8. Managing crisis in life:

A combination of stressors and family adjustment difficulties can cause frustration and distress and can cause crisis in life of ‘mothers of children with ASD’. Mothers in this study verbalised that they were faced difficult situations in their life. Still they are facing some difficult situations in their life because of their child’s disability. This theme has two subthemes. (Table 1)

“When we heard isolation is the main cause we resigned from USA and come here because we feel that if we live along with family the things will be better. But things was not better, even she started regressing more. We didn’t know what is autism? Absolutely blank that time. Keep on crying, blaming each other, fighting, shouting, not only Anu, we both (husband) very horrible and terrible. I paid three lacks for therapies” (Participant A)

9. Stress and coping strategies for child rearing:

Parenting a child with ASD depicted by participants as difficult and challenging that caused increased stress on mother in their daily life. All participants in this study verbalised stress feeling due to difficulty to communicating with the child, dealing with difficult behaviours, lack of support for child care and lack of support from family members as well as from societal attitude towards the child. Mothers coping with their stress in the form of comparing with neurotypical child, questioning and spiritual beliefs. Some participants coping with some activities

like playing and listening music and most of them were coping with using the support services getting from the institution. This theme has three subthemes (Table 1)

Yes. Sometimes people around you doesn't understand. Sometimes family people also have some other things to do... This is not the only thing in their routine. So that time when nobody support us, and a lot of work, that time I feel stressed and I and my husband used to fight, but most of the time my husband used to stay quiet..... See, if I starts thinking there are so many thing. But I avoid those things frankly because its make me stress. (Participant E).

10. Maternal beliefs, perceptions and worries:

This theme defines that participants have certain beliefs, perceptions and personal worries about the child's condition. These beliefs are one of their coping adopting for parenting a child with ASD. Most of the participants believed that getting a disability certificate for the child is difficult. Mothers perceived that they carrying some defective gene, so it will affect if they want a second child in future, attitude of people perceived as negative and that may resulted in difficulty to integrate into society and getting educational services for the child.

"If sibling also a special child then what will do? Then we taking care of whom? Then if the second baby will be a neurotypical child, or if that child doesn't accept Anu and because of second child if we starting avoiding Anu, then what will be her future? If there is a neurotypical child our full focus will be on her academics and focusing on her career and all. Then Anu become neglected. So better not to go for second one" (Participant A)

"If I die, suddenly what will happen? Actually that is the most important thing or that is the nightmares I get that doesn't mean that I will live forever (laughing). Many, many times I thought like that. Now till the time I am there whatever he can learn, because I have seen one thing that there will nobody else to take care of him, that is for sure" (Participant C)

11. Social awareness and stigma:

This theme has three subthemes. This theme describes the attitude of society towards children with ASD and its impact on participants. Participants during their interview verbalised that the societal awareness for children with Autism Spectrum Disorder is poor. The people doesn't know the term "Autism". They are labelling the child as 'mad' and mentally ill. They were perceived that it should be difficult to go out public places due to bad judgement and isolation from the public and criticise them as bad parenting. They were facing these problems from the society. The supporting narratives of this theme is given below.

"If people are aware of what is autism, they should respect the people and their families as well. Its not something very different or very special. People make you feel different. That is the biggest problem. They isolate us and we get isolated ourself. If people are ok with whatever conditions you are in and we are fine with this condition of our kid. If somebody is putting you down every time then it becomes difficult. It becomes painful". (Participant C)

12. Future concerns and goal setting:

This theme reflected that participants have concerns for their child's future. Mothers were setting goals for guiding their children to reach their goals with hopes of independence and integrating to society. Most of them verbalised that they were not concentrating more on academics of their child. But mainly for the child's independency and body functioning so that they are able to live in society. This theme has three subthemes (Table 1) and the following narratives helps to better understand this theme.

"Now my goal is to help him independent so that after our life he will be able to do his work and not depend on others... Am not thinking that after us who will take care of him, but I would like him to be independent as much as possible so that he can live alone also. He will never needs somebody's help like somebody should feed him and do for him. He has to do his work independently. That's my main thing that I should make him independent". (Participant B)

13. Learning more about autism and empowering self:

Participants in this study were interested to learn more about autism and trying to get more training and practice in this field for training their child. Five participants in this study were doing courses in Autism special education and one mother is already trained in autism and she is doing a job as special educator. This theme emphasises the need for advocacy and empowerment needed for mothers in the field of ASD in order to empower her child. The mothers

are utilising the resources as well as getting training for therapies and interventions by seeking advises from professionals. This theme has three subthemes and the following narratives describe this theme.

“Actually this course (Special education for autism) I am doing for my child. I don’t have any plan that I have to become a special educator. But I am planning that in which school he is now I will join in that school for him. That’s why I need to be trained. If special education facilities will not be available then I can work with him. This is the thing that I need to work with him. I didn’t thing more in this field. I am doing this for him only”. (Participant B)

Based on the findings of analysis a proposed model of “Coping with autism, Unique and differential parenting; Mothers Journey towards adaptation” was generated. The model indicated that mothers were adopting a unique parenting for their kid with Autism spectrum disorder. There parenting strategies and practices were individualised and based on the child’s functional needs. So their parenting is differential in context of Autism Spectrum Disorder.

Formulation of a conceptual model based on categories derived out of qualitative analysis:

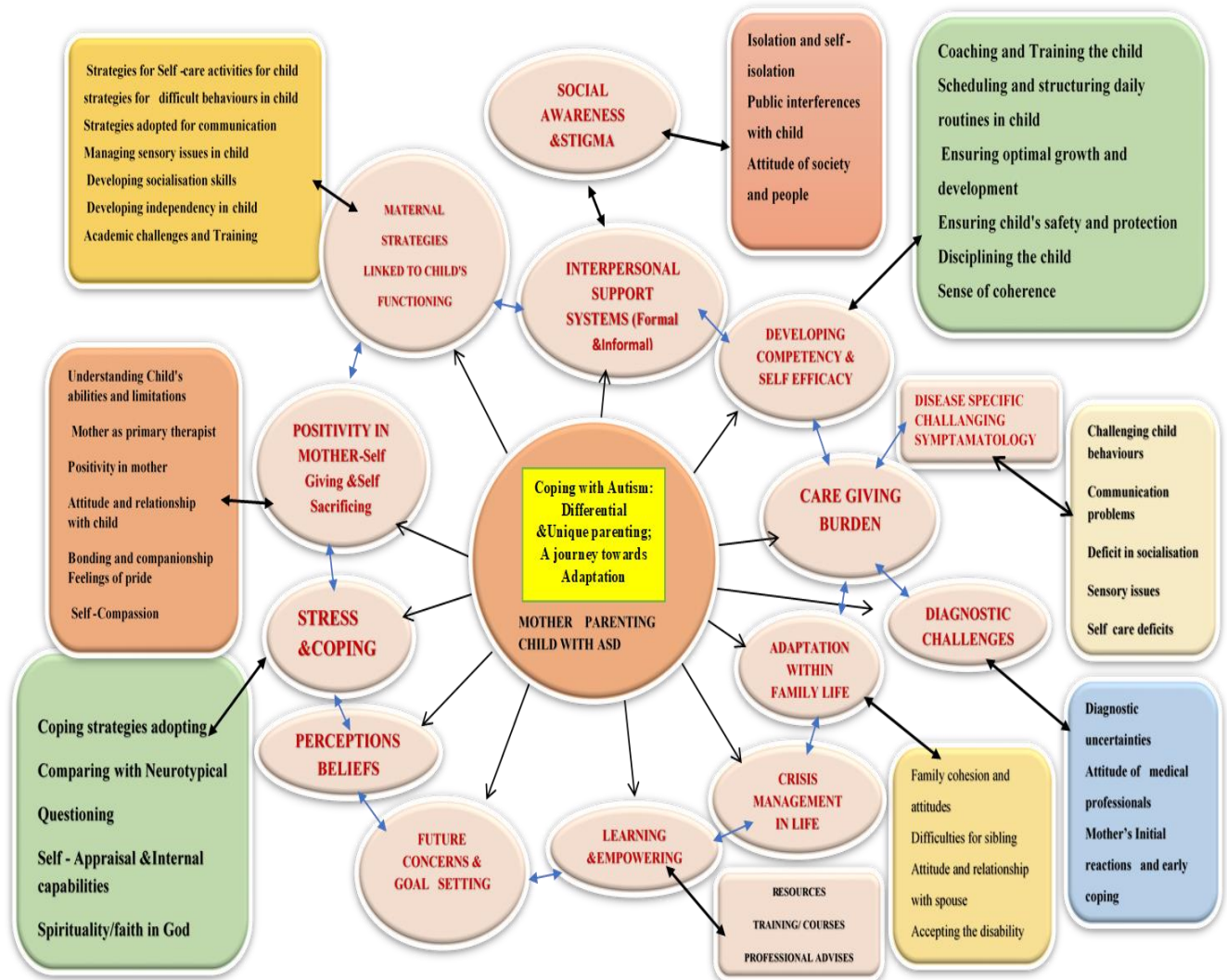


Figure 2 : Conceptual Model of “Coping with Autism: Differential & Unique Parenting; Mother’s journey towards Adaptation”

Figure 2:- The conceptual Model illustrates the breakdown of categories and subcategories surrounded by a core category which explains the parenting experiences of ‘mothers of children with Autism Spectrum Disorder’. The concepts are connected and formulated a model for parenting a child with ASD. After reviewing the existing literature and models about parental experiences of children with ASD. The interactions and connections with the concept derived are represented by the bidirectional arrows present in the conceptual model.

Discussion:-

Unlike the common perception that raising child with Autism Spectrum Disorder creates negative life experience, life with challenges and burdens, the mothers in this present study clearly articulated that their mothering experience was a mixture of positive and negative experiences. In the present study, the mothers expressed their positivity for parenting a child with ASD. They stated they are having a positive attitude and relationship with their children in terms of understanding their abilities and functional limitations, adopting the role of a therapist at home, developing a bonding and companionship with child. Moreover, they expressed self-compassion and a feeling of pride for parenting a child with ASD.

Parenting a child with ASD is demanding and stressful (Dabrowska. A., & Pisula. E, 2010). However, all participants in this study revealed, through their words in the interviews, a positive approach to parenting their children. Specifically, they were described more attachment, love, warmth, responsiveness and sensitivity and an overall positive quality of their relationship with their autistic children. Recent research has documented that parental warmth, sensitivity and communication and opportunities for cognitive stimulation, which mothers in the current study display, are influential in shaping the cognitive and social skills of children with ASD (Conti, 2015; Smith, Greenberg, Seltzer and Hong, 2010). These positive parenting behaviours can be linked to more positive-parent-child relationships, a decrease in children's problem behaviour and more optimal child-developmental outcomes (Lambrecht's et al, 2011).

Participants in this study were facing ongoing challenges for parenting their child with ASD such as physical and mental exhaustion, feeling stressed and overwhelmed, dealing with difficult behaviour, managing alone, and feeling blamed and judged by others. This theme is incongruent with the study findings of (McGrew, J., Melissa, S. 2009) reported that greater the symptoms of autism, the higher the burden for the parents, and the families in general. Another interesting aspect of maternal struggles is child's behaviour challenges which Bourke Taylor, et al (2010) discuss in their study, is the fact that mothers dealing with their disabled child's behavioural challenges also talk about the stigma they face from their communities, and show these negative attitudes further exacerbate their daily pressures. The authors also discussed about the findings that suggest the correlation between maternal stress and challenging child. A qualitative study conducted by (Ludlow et al, 2012) to identify the daily challenges of parenting children with autism spectrum disorder, revealed that, most of the time challenging behaviour of the child created frustration and anxiety in them. Most of the parents were lacking adequate support from the society. A lot of them reported that social isolation and thus the study emphasize the need for more societal support systems.

The current study findings showed that participants were developing competency and self-efficacy for parenting by various strategies such as coaching and training their child, ensuring optimal growth and development for child, maintaining a routine and structure in life, disciplining the child positively, providing safety and protection for the child. These findings are supported by the study findings of various studies. Gargiulo (2006) reported that parents of autistic children need to realise the necessity of interventions and intensive training at home and outside and that should be monitored by parents. In the present study participants reported difficulties to identify the problems in their child before getting a formal diagnosis. The findings indicated that parents were satisfied after they got a proper diagnosis for their child. The study findings of (Altieri, M.J. and von Kluge, S. 2009) were consistent with this theme. They conducted a study to explore the perspectives of the parents regarding the struggles and successes while taking care of a child with ASD revealed that most of the parents were confused regarding their child's behaviour and they have a feeling of lost and devastation after the diagnosis of their child. But it was observed that despite of hardships most of the parents were ready to mobilize every possible source to help their child.

Participants in this study reported need for more family adaptation for child care. They reported that they were facing difficulties to balance their family. The mothers perceived that they were getting good support from their spouse for care giving. Also, they reported that siblings of autistic kids were facing difficulties and they were affecting badly. This study findings are congruent with the findings of several studies (Gray, 1994; Hutton and Caron, 2005; Myers, Mackintosh and Goin-Kochel, 2009). A study done by Sruthy (2017) to explore the perspectives and experiences of Indian parents and to examine various coping strategies adopted by them for their children with autism Spectrum Disorder. The findings revealed that the diagnosis of the child with autism was not acceptable for the family members and more often it created a shock or a feeling of grief in the family, The diagnosis itself created psychological changes in the parents and along with that unpredictable behaviour of the child such as repetitive behaviours and temper tantrums were found to be challenging for some parents. At the same time few parents

reported that they eventually learned to accept the fact and they were involved in planning daily routines of the child. Ooi et al (2016) did a meta synthesis on parenting a child with ASD with an aim to explore the parent's perspectives in parenting a child with ASD with a view to examine the adaptations and beliefs of parents towards a child with autism and their family and social experiences. The results of the review showed that parents were facing many challenges in various aspects of child care and had an impact on parent's stress and adaptation. The study highlighted the importance of family centred care, in order to enhance the wellbeing and "quality of life" of families of children with ASD.

Kuhaneck et al (2010) also reported in their study that mothers were using different coping strategies to deal with parental stress. Mothers had the opinion that planning ahead, self-learning, and seeing things in a more positive light, and working in coordination with the spouse and family members are some effective ways of dealing with stress. Participants in this study were adopting similar coping strategies such as planning ahead, self-learning and positivity in parenting. Kartilini et al (2016) did a qualitative study on "Wellbeing of mothers of children with Autism" in Malaysia. The methods used was interpretive phenomenological analysis using in-depth interviews with 8 Malaysian mothers from different ethnic backgrounds. The findings also revealed that parents were adopting coping strategies, including acceptance, proactive mindset, character growth, spirituality, parent support networks fostered the wellbeing of parents. Gour and Pandey (2016) on "coping and parental relationship in the families of children with ASD in India". The findings revealed that parents were adopting more coping strategies like depended on household help and collecting information from the internet, receiving advices from professionals and spiritual methods like reading scriptures, support from family and support from the society. Brezis et al (2015) did a study to explore the experiences of parenting a child with Autism Spectrum Disorder in India, revealed different ways used by the parent to deal with the daily stressful environment. Most of the parents conveyed their relationship with family members and society in relation to the child and it was found that most of them were worried about diagnostic procedures and treatment. These findings are supporting the theme of stress and coping in this study.

Tan et al (2011) reported that mothers perceived the child with ASD as punishment from God and some others believed that it was their duty to care the child and perceived as a gift from God. These findings were incongruent with the findings of (Mahmood, D.H., Saleemi P., Riaz DH., Hassan Y., Khan F, 2015) reported that mothers adopting positive method to deal with every day challenges in life. Avoiding coping and religious coping were the two main coping strategies mostly used by the parents. In this study participants were believed that the disability was coming from God and so they left all the problems to the love and the infinite wisdom of God. Participants reported that a passive nature of dependence and trust with God. Participants in this study were adopting various coping in order to manage stress in their life. 'Coping with autism' identified as a major core category in this study, Mothers were constantly coping with the diagnosis of autism in their child and with stressful parenting. Beliefs and perceptions" of mothers for parenting a child with ASD derived as one of the categories in this study. This domain of parenting mainly included their beliefs and perceptions about different areas of 'caring a child with ASD'. A study by (Kayfitz, Gragg and Orr, 2010) reported that mothers of children with ASD having more positive experiences than fathers.

Participants in this study reported that the awareness of autism is lacking in India. They expressed as a result of less awareness they were facing isolation and stigma from the society. They felt that the unique psychosocial problems present in these children causes more difficulties for the public to understand their situations. The findings of this theme is supported by a qualitative study done by Pathappillil (2011). The findings indicated that lack of awareness regarding autism causes stigmatization associated with any form of mental illness. The present study findings revealed that participants were learning more about autism by undergoing training and they were interested to learn and empower by themselves in order to train their children with ASD. Since this study was conducted in a setting where more educational and training services were providing for mothers in autism to better equip them with facing future challenges. This theme is supported by the study done by Minhas et al (2015), the findings revealed that Special services were rare and most often they were located in urban areas and most of them were inaccessible to the general population. The study strongly demands the need for more family support networking system and capacity building and more training in this area.

Limitations and Recommendations for future research:

The small sample size of the study makes generalisation of the study limited to other settings. Also the cultural diversity in India which indicates that even greater sample size do not immediately guarantee generalizability or representativeness for parenting experiences.

The conceptual model developed in this study provided empirical evidence for mothers experiences in parenting a child with Autism Spectrum Disorder in Indian context and the construct developed can be used for testing various hypothesis related to parenting a child with ASD after comparing with existing parenting theories using quantitative paradigms. The parents of autistic children also need psychological support in a better way especially in crisis situations in family and the mothers of these children need support and realistic reassurance from health care facilities. The health care people can render this support in a better manner through early identification, appropriate referrals etc. A protocol for the parents on the early identification and of autism in infants can be prepared and evaluated. A protocol on the home care management and training for mothers parenting children with ASD can be prepared and evaluated. The findings of the study will help the future researchers to explore other aspects of ASD in children and use of various interventions to improve their quality of life. The findings of the study can be used to develop strategies for interventions like building community and family support networks to provide respite services for the main carer and training for specialists, community members such as community health workers in order to provide evidence-based interventions.

Conclusion:-

The findings of this qualitative data analysis revealed a core category “Coping with Autism: Differential and unique parenting; mother’s journey towards adaptation” based on the experiences of mothers parenting a child with ASD derived from major categories. The goal for the current study was to gather the data while having little influence on the participants’ accounts of their reality thereby assuming an objectivist position by the researcher. The researcher reflected on his role as a researcher throughout the data collection and interpretation process. Recommendations are made for practice considerations, policy development and future research.

Supporting data:

Funding:

The authors received no financial support for the research

Conflict of Interest:

No conflict of interest has been declared by the authors.

Acknowledgement:-

The author acknowledge the support provided by Action For Autism (AFA), National Centre For autism, New Delhi, India for conducting the main study. The investigator would like to thank Dr. Deepak Gupta, Centre For Child and Adolescent wellbeing (CCAW), New Delhi, India for his considerations to conduct a pilot study .

Ethical Considerations:

Informed Consent from participants (mothers of children with ASD) were obtained before the beginning of the study, all the participants completed written informed consent forms and were assured that their information would remain confidential. Ethical clearance obtained from Institutional Review Board (IRB) of Action For Autism (AFA) New Delhi, India (AFA is the National advisory and training Centre in India). The protocol of this study was registered in clinical trial registry India. (No: REF/2017/12/016488).

References:-

1. Sharma, A., Nandini, G., Sane, H., Biju, H., Shetty, A. (2015). Parent and Teacher Guide Book For Autism: 2nd Edition. Neurogen Publication, Mumbai, India
2. Al-Oran, H.M., AL-Sagarat, Ahmad Yahya (2016) . Parenting Stress of Children with Autistic Disorder. *Open Access Library Journal*, 3:e2791. <http://dx.doi.org/10.4236/oalib.110271>.
3. Altieri, M.J. and von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies*, 18, 83-92. doi:10.1007/s10826-008-9209-y
4. Baghdadli, A., Picot, M., Michelon, C., Bodet, J., Pernon, E., Burstezjn, C., et al. (2012). What happens to children with PDD when they grow up? prospective follow-up of 219 children from preschool age to mid-childhood. *Acta Psychiatrica Scandinavica*. 115(5), 403-412
5. Bessette-Gorlin, J., McAlpine, C. P., Garwick, A., Wieling, E. (2016). Severe Childhood Autism: The Family Lived Experience. *Journal of Pediatric Nursing* , 11 ;31(6):580-597
6. Bourke-Taylor, Sylvia Rodger, Jill Ash burner & Linda Cart mill Helen.(2010). Helping Children with autism spectrum disorders and their families: Are we losing our occupation-Centred focus? *Australian Occupational Therapy Journal*. doi: 10.1111/j.1440-1630.2010.00877.x

7. Brezis R, Weisner T, Daley T, Singhal N, Barua M, Collera S.(2015)Parenting a child withAutism in India:Narratives Before and after a parent-child Intervention Program.*Cult.Med Psychiatry..* 39(2): 277
8. Bonis, S.A., Sawin, K.J. (2016). Risks and Protective Factors for Stress Self-Management in Parents of Children With Autism Spectrum Disorder : An Integrated Review of the Literature. *Journal of Paediatric Nursing, 11* ;31(6):567-579.
9. Conti, R. (2015). Compassionate parenting as a key to satisfaction, efficacy and meaning among mothers of children with autism. *Journal of Autism and Developmental Disorders*,1- 11 DOI: 10.1007/s10803-015-2360-6
10. Dabrowska, A., &Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*, 266-280.
11. Dunn, M., Burbine, T., Bowers, C., &Tantleff-Dunn, S. (2004). Moderators of stress in parents of children with autism. *Journal. Community Mental Health, 37* (1), 39-51.
12. Gargiulo, R. (2006). *Special Education in Contemporary Society*.Belmont,CA: Thomson Learning, Inc
13. GourSmriti and Pandey Neelam. (2016). Coping Mechanisms and Parental Relationship in the Families of a Child with Autism Spectrum Disorder. *The International Journal of Indian Psychology, 3*(3) ,83-93. DIP: 18.01.069/20160303
14. Gorlin, B J., McAlpine, C. P., Garwick, A., Wieling, E. (2016). Severe ChildhoodAutism : The Family Lived Experience. *Journal of Pediatric Nursing. 11* ;31(6):580-597.
15. Gray. DE. (2006). Coping over time : the parents of children with autism. *Journal of Intellectual Disability Research. 31*(2): 77-86
16. Gyun-Young Kang, Cha-Soon Choi, and Se-JinJu . (2016) .Parenting Experience of Mothers with Children with Autism Spectrum Disorder: An Analysis of the Mothers’ Diaries *Indian Journal of Science and Technology, 9*(20), DOI: 10.17485/ijst/2016/v9i20/94698,
17. Hoogsteen, L., & Woodgate, R. (2013a). The lived experience of parenting a child with autism in a rural area: Making the invisible, visible. *J. Pediatric Nursing, 39*(5), 233-237.
18. Hutton,A.M, &Caron,S.L. (2005).Experiences of families of children with autism in rural England.Focus on Autism and other Developmental Disabilities.20, 180-189.
19. Karst, J.S., & Van Hecke, A.V. (2012). Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Journal of Clinical Child and Family Psychology Review, 15*, 247-277. <http://dx.doi.org/10.1007/s10567-012-0119-6>
20. Kartilini I, Cornish K ,Kummar, A.S., Park, M.S & Golden, K.J . (2018). ParentingStress and Resilience in Parents of Children with Autism Spectrum Disorder (ASD) inSoutheast Asia: A Systematic Review. *Journal of Frontier Psychol. 9*:280.doi:10.3389/fpsyg.2018.00280
21. Kayfitz, A. D., Gragg, M. N., & Orr, R. R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 337-343. doi:10.1111/j.14683148.2009.00539
22. Kristin D. Neff, Daniel J. Faso. (2014). Self-Compassion and Well-Being in Parents of Children with Autism .*Mindfulness .Springer Science*.4-10. DOI 10.1007/s12671-014- 03592
23. Kuhaneck Heather Miller, Tajhma Burroughs, Jamie Wright, Theresa Lamanczyk&Amy Rowntree (2010).A qualitative study of coping mothers of children with Autism Spectrum Disorder, *Physical and Occupational Therapy in Pediatrics*.30(4). 340-350,DOI: 10.3109/01942638.2010.1662
24. Lambrechts Greet, Karla Van Leeuwena, Hannah Boonenab, Bea Maesa and Ilse Noens.(2011). Parenting behaviour among parents of children with autism spectrum disorder.Research in Autism Spectrum Disorders 5, 1143-1152. doi:10.1016/j.rasd.2010.12.011
25. Ludlow, A., Skelly, C., Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychol, 17*(5):702–711
26. Mahmood.D.H.,Saleemi P., Riaz DH., Hassan Y., Khan F.(2015). Coping strategies of mothers with ASD children .*The professional Medical Journal*.22(11). 1454-63
27. Minhas, A., Vajaratkar, V., Divan, G., Hamdani, SU., Leadbitter, K., Taylor, C. (2015).Parent’s perspective on care of children with autism Spectrum Disorders in South Asia –views from Pakistan. *Journal of Intellectual&Developmental Disability .42*(1) -<https://doi.org/10.3109/09540261.2015.1049128>
28. Myers, BJ., Mackintosh, VH., Goin-Kochel, RP .(2009). “My greatest joy and my greatest heart ache”: Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *J.AutismSpectr Disord*;3:670–84.
29. Ooi, K L., Yin sin Ong, Anne, SJ.,&Khan,TM. (2016). A metasynthesis on parenting a child with ASD. *Journal of Neuro Psychiatric Disease and treatment, 12*, 742-765.

30. Pathappillil, Sara, JJ. (2011). Through Our Eyes: A Qualitative Study of Indian Mothers and Their Perceptions of Autism. PCOM Psychology Dissertations. Paper 195.
31. Pushpalatha.R, Shivkumara. K. (2016). Stress, Burden and Coping between Care givers of Cerebral Palsy and Autism Children. *International Journal of Indian Psychology*. 4 (1). 80.DIP:18.01.112/20160401.
32. Sinha, D., Verma, N., Hershe, D. A. (2016). Comparative Study of Parenting Styles, Parental Stress and Resilience among Parents of Children Having Autism Spectrum Disorder, Parents of Children Having Specific Learning Disorder and Parents of Children Not Diagnosed With Any Psychiatric Disorder. *Annals of Internal Medicine*. Den. Res, 2(4):106-11.
33. Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010b). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167–178. doi:10.1007/s10803-009-0844-
34. McGrew, J., Melissa, S. (2009). Care giver burden after receiving a diagnosis of autism spectrum disorder. *Research in Autism spectrum disorders*. 3 (1). 86-97
35. Stroke (2007). Autism Spectrum Disorders (Pervasive developmental disorders). Bethesda: National Institute of Mental Health (NIMH);
36. Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Journal of Pediatrics*, 119 .114-21.
37. Sruthy J. (2017). Perspectives and Coping strategies among parents of children with Autism Spectrum Disorders. Master of Public Health Dessertation. MAHE, ManipalStrock, M. (2007). Autism spectrum disorders (pervasive developmental disorders) Bethesda: National Institute of Mental Health (NIMH).
38. Tan H. M, Wilson A, Olver I, Barton C. (2011). The experience of palliative patients and their families of a family meeting utilized as an instrument for spiritual and psychosocial care: A qualitative study. *BMC Palliative Care*. 10(7):1–12. <http://dx.doi.org/10.1186/1472-684X-10-7>.