

Specific Needs and Demands of Girls with Autism Spectrum Disorder: Parents Perspective

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Abstract:

The paper focused on exploring the specific needs and demands of girls with Autism Spectrum Disorder (ASD). By using a qualitative research approach, the case study method was adopted, and a semi-structured interview schedule was used as a tool of data collection. The Sylhet city corporation was the area of the study. As ASD girls were not fully cooperative for giving information, the parents of ASD girls were the participants of the study. The thematic analysis was considered for data analysis and interpretation. The study reveals that girls with ASD have some special needs or behaviors different from boys with ASD. Parents talked about such issues and also shared their struggle to meet those needs. One-fifth of them noticed the behavior of their girls, which is not usual. They like to stay alone and face difficulties in interacting or making friendships with other girls. Even they are not habituated to social gatherings and often try to avoid such environments. Parents shared their needs and also informed about the changes of needs related to their change of age. Some behavior and needs have been unchanged, but a few of them have changed as they are growing up. Even if it depends on the gender of the child, many of them are not able to understand it. One-sixth of the parents stated that their child has modified her behavior and needs due to the influence of motivation, following her friends and close persons. It happened as they have been going to school, and thus they have developed the concept of gender. Their parents viewed it positively, though some difficulties have arisen.

Key Words: Need, demand, behavior, Reaction, Menstruation.

1. INTRODUCTION AND REVIEW OF LITERATURE

Disability is an umbrella term, multifaceted and contentious and there is no universally approved definition (Nokrek, Alam and Ahmed, 2013). This phenomenon has come from Western societies (Coleridge, 2000) but it is important to measure and for policy formulation (Grech, 2009). Usually it is widely use to focus on individual functioning, including various types of impairment somewhat similar to the three-tier concepts of 'impairment', 'handicap' and 'disability' defined by World Health Organization (WHO). It has not only strong cultural relationship (Coleridge, 2000), but Metts (2004)

focused on the different and multiple dimensions of the ASD. He argued that it is closely related to medial, social and environmental factors though it is necessary to understand it first. Disability has been getting international and national attention but failed to provide a unique definition of it. Generally it limits the person's full and effective access and participation in social arena which is rightly focused by United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and WHO (2011). Disability is not only physical limitation, it could be mental and thus it invites similar obstacles as mentioned in Americans with Disabilities Act (ADA), 1990 (cited in Sultana, 2010).

Disability can be categories in different ways based on the impairment resulting disability. Physical, visual, hearing and more types of disabilities have been seen throughout the world. Even there are some special types of disabilities like Autism Spectrum Disorder (ASD) which have distinct features and lifelong consequences over one's life. Autism is a global phenomenon with local implications (Ehsan, et. al., 2018). The word "spectrum" indicates those characteristics which often face by person having ASD (DSM-5; APA, 2013). ASD is considered as a neurodevelopmental conditions where persons cannot make proper social interaction and communication, rather they show repetitive and control behavior (Tobing & Glenwick, 2002; Shu, 2009). Such deficits restrict them to communicate with others (Kanner, 1943). Contribution of genetic or environmental factors is not strongly examined and understood. Generally it occurs at early childhood but in most of cases parents could not understand at the initial stage. There are some wrong notions and understanding which often causes ASD before taking medical intervention. The accurate cause of ASD is still unidentified but may have connectivity with genetic tendency, or natural or even factors yet to be known. Despite having development of medical and biological science, genetic connectivity to ASD is still unrecognized (Chaste and Leboyer, 2012; Freitag, Staal and Klauck, 2010; Losh, Sullivan and Trembath, 2008).

ASD is a lifelong, usually constant condition that occupies regular impairments in language, social interactions and regular functions (Miranda, et. al., 2019). It was first mentioned by Leo Kanner in 1943. ASD could be diagnosed at early ages though there are no fixed markers to detect it (Anagnostou and Taylor, 2011). Initially it was viewed as person's own problems as a result of social and environmental factors. After series of study, relation with neurological malfunction was established (Huq, Rahman and Mahbuba, 2017). Generally ASD child creates troubles in family environment and produces special needs which are essential for their development (Altieri, 2006; Baker et al., 2005; Shu, 2009; Smith, Hong et al., 2010). Thus it is difficult to identify their behavior but some common characteristics are seen among ASD child including problem in social interaction, proper response and both verbal and non-verbal communication (APA, 2013). Apart from such common behavior, they might have some special behavior patterns like aggressiveness, hyperactivity, sensory and intellectual disability which help to detect ASD (Novaes, Pondé and Freire, 2008).

Evidences show that the heterogeneous features are common in ASD (Anagnostou & Taylor, 2011) though variations may be seen in secondary characteristics (Aman et al., 2009; Baranek, 1999). Even in many cases poor attention may show some ASD characteristics in early childhood (Baranek, 1999) or may affect by a short attention span (Aman and colleagues, 2009). ASD can change communication and

interaction pattern which forces them to show attacking behaviors including self-damage (Souders, Freeman, DePaul, & Levy, 2002). Not only verbal communication, they may have limitations in nonverbal communication and expressions etc (APA, 2013; Cowen, Harrison and Burns, 2012; Sadock, Sadock, and Ruiz, 2015). Majority of them have difficulty in talking to people (APA, 2013; Cowen, Harrison and Burns, 2012). Even they cannot use the right words or maintain the rhythm of words and sentences. Often they fail to understand the body language, tones or fail to interpret the meaning of symbolic interaction (Sadock, Sadock, and Ruiz, 2015).

Parents often showed negative reaction upon receiving an ASD diagnosis (Divan, et al., 2012). Although receiving a diagnosis allowed initial release, helps to aware them to understand greater needs and access to special services for their child (Calzada, Pistrang and Mandy, 2012). Current international and local research highlight resource limitations for healthcare and schooling, and foreseeable changes within the family unit (Fewster, 2014; Vassallo, 2016; Schlebusch, 2015; Bashir, Bashir, Lone, and Ahmad, 2014; Fletcher, Markoulakis and Bryden, 2012; Matenge, 2013). Changes included, but were not limited to, catering to the ritualistic needs of the child (Dawson 2011; Johnson and Rodriguez, 2013), vocational changes of parents to accommodate the child (Dawson, 2011; Fletcher, Markoulakis and Bryden, 2012) and social isolation of the family (Divan, et. al., 2012). Children having ASD show similar behavior and curiosity (APA, 2013) and often do repetitive acts like inattentiveness, anxiety and troublesome behaviors (Hartley, Sikora, & McCoy, 2008; Simonoff et al., 2006). Different studies indicated that parents had little or no knowledge about it before diagnosis of their kids (Preity, et. al., 2017). The unusual behavior patterns cause significant difficulties (Cullen & Barlow, 2002). Having a child with ASD is a source of more stress for Parents and they are nearly three times vulnerable with compare to others to become psychologically ill (Brobst, Clopton, & Hendrick, 2009; Dillenburg, et. al., 2010; Gau et al., 2012;). It negatively impact parents' mental health status but reduces over time as their child's behavior improved (Gray, 2006; Hoffman, et. al., 2009). Such symptoms and behaviors are closely influence the mental condition of the parents (Abbeduto et al., 2004; Lecavalier et al., 2006).

Kiami and Goodgold (2017) showed that the majority of the cases, it produced stress among the parents. Even such parents face serious stress than the parents having disabled child (Barroso et al., 2018; Craig et al., 2016; Davis and Carter, 2008; Giovagnoli et al., 2015; Gupta, 2007; Hayes and Watson, 2013; Hoffman et al., 2009; Rao and Beidel, 2009; Watson et al., 2013;). Different studies have examined the marital satisfaction, conjugal crises and related issues among the parents having children with ASD. Gau, et. al. (2012) showed that such situation reduces marital pleasure and thus it can invite divorce (Hartley et al., 2010). But these are similar to all (Freedman, Kalb, Zablotsky, & Stuart, 2012) as opposite findings are also reported. In many cases it helped to produce additional satisfaction and sustainability of conjugal life (Gau et. al., 2012; Hartley, et. al., 2011). Karney & Bradbury (1995) explained parental problem using the vulnerability-stress-adaptation model. In one side, vulnerabilities decrease their capacity to hold positive couple interactions and stress obstructs partners to adapt. This model has wide range of use to explore parental stress (Cutrona et al., 2011; Doss, Rhoades, Stanley & Markman, 2009). Hartely, et. al. (2016) focused that this model has been using to get a valuable skeleton to explicate the interactions of parents who have such child.

Having a child ASD can create uncertainty among parents (Karst and Hecke, 2012) and form anxiety and depression (Almansour, et. al., 2013; Estes, et. al., 2013; Ou, Cha, and Wang, 2010). In this situation parents need social support may assist them to adjust with the reality and to concentrate to their children with ASD (Machado, 2016). Mothers are the vulnerable here as it produces stress and negative emotional, physical, economic or marital experiences (Cullen & Barlow, 2002; Dardas & Ahmad, 2014; Higgins, Bailey & Pearce, 2005; Kring, Greenberg, and Seltzer, 2010; Lecavalier, Leone, & Wiltz, 2006; Lee, 2009). Gradual increase of depression and parenting stress is revealed by Ingersoll and Hambrick (2011) and mothers are more vulnerable than fathers (Davis and Carter, 2008; Ekas, Lickenbrock & Whitman, 2010). Caring a child with ASD is very difficult and stressful. In many cases, parents faced stress, anxiety and depression which negatively influence their mental condition (Gau, et. al., 2010; Hoffman et. al., 2009). Negative mental condition invites negative mood and parenting stress (Pottie and colleagues, 2009). Moreover, parenting stress low emotional supports that lead marital difficulties (Pottie et al., 2009). Caring ASD child often disrupt daily activities that mostly hamper mothers (Larson, 2006). Though disruptive behaviors of such child determine parents' mental health, but become lower when their child's behavior improves over time (Gray, 2006; Hoffman, et. al., 2009). Caring and raring such child makes Parents vulnerable (Benjak, et. al., 2011; Olsson & Hwang, 2001).

There are many factors which produce parental stress. Studies of Bebko et al. (1987) and Moes (1995) showed that stress level is associated with the behavior pattern of child. Supporting their opinion, Baker-Ericzen et al. (2005) focused on the skill of social interaction is linked with such stress. If the ASD child fails to interact then it produces additional stress to parents. Different studies have explored the factors which invite sever stress for parents (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Aneshensel, & LeBlanc, 1997; Pearlin, 2000). Parents need more social and spousal support (Kersh, et. al., 2006; Saloviita, Itälänne, & Leinonen, 2003) to provide adequate support to their ASD child. In many cases, absence of necessary support and negative consequences reduces fathers' responsibility considering the negative consequences (Barbarin, Hughes and Chesler, 1985; Bristol, Gallagher and Schopler, 1988). Such situation seeks valuable time, resources and energy of parents (Seltzer et al., 2001) that result physical exhaustion and fatigue (North American Nursing Diagnosis Association, 2001; Ream & Richardson, 1996) and create gap between father and mother (Aylaz, Yilmaz, & Polat, 2012). It promotes bitterness between parents, especially among mothers (Gray, 2003; Luong, Yoder, & Canham, 2009) and encourage parents to blame each other for this situation (Fletcher, Markoulakis, & Bryden, 2012). But having a child with ASD has some positive influence and help to strong and improve relationships, family functioning, understanding and tolerance (Havens, 2005) and develop commitment to continue conjugal life (Bayat, 2007; Davis & Gavidia-Payne, 2009; Pakenham, Sofronoff, & Samios, 2011; Pelchat, Lefebvre & Perreault, 2003). Such cases help to strong family bondage, understand the positive meaning of life and develop their level of communication (Bayat, 2007; Zubrick, Williams, Silburn, & Vimpani, 2000).

Parents have to face unfavorable consequences and public comments in social arena (Farrugia, 2009; Gray, 2002; Lasser & Corley, 2008; Ludlow, Skelly, & Rohleder, 2011; Midence & O'Neill, 1999; Neely-Barnes, Hall, Roberts, & Graff, 2011; Safe, Joosten, & Molineux, 2012; Woodgate, Ateah, &

Secco, 2008). It can weaken marital happiness, produce disturbances (Higgins et al., 2005), increase anger, anxiety and depression (Gray and Holden, 1992), reduce social outings (Kraijer, 2000). Mothers often feel loneliness when making decisions (Larson, 2006) and produce stress in families (Seltzer, et al., 2001; Smith et al., 2010) resulting in a high rate of divorce among parents having a child with ASD (Hartley and colleagues, 2010). As an ASD child often fails to obey social norms that bound the families to seek different ways to adjust their daily life (Bristol, 1984; Dunn, et al., 2001; Altieri & von Kluge, 2009), even parents like to withdraw their children with ASD from society to avoid unfamiliar situations (Glazzard and Overall, 2012). It affects family functioning, limits leisure activities (Myers et al., 2009). As a consequence, families may lose social support (Bromley et al., 2004; McConnell, Savage, & Breitkreuz, 2014) and socio-economic status (Georgiades, et al., 2008).

Parents have to play multiple roles and responsibilities, from care to education and struggle to ensure those essential needs (Klein & McCabe, 2007; Lutz, Patterson, and Klein, 2012; Woodgate and colleagues, 2008). Not only care, financial ability is also important here to arrange needs. Financial cost is higher, sometime three times (Järbrink et al., 2003) and may invite a negative impact over their life (Järbrink et al., 2003; Sen & Yurtsever, 2007), or even change their financial status and face difficulties to manage expenditure (Altieri and von Kluge, 2009; Aylaz and colleagues, 2012; Fletcher and colleagues, 2012; Sharpe and Baker, 2011; Thomas et al., 2016; Vohra et al., 2014; Zablotzky et al., 2014). Not only that, parents had to change their employment or work place only to manage the situation (Fletcher et al., 2012; Järbrink et al., 2003; Gray, 2003). Interestingly, parental commitment to secure their child with ASD encouraged them to extend their working hours (Gray, 2003) to earn more but diverse thoughts and feelings were seen who had to stop working (McCabe, 2010).

Autism has been increasing rapidly since 2002, has become the global health issue (Action and Desmond, 2012) and approximately 1% of the global population affected by ASD (Pervasive, Disorders and Korea, 2012). But the prevalence rate of autism depends on many factors including age of children, investigation mechanisms and techniques, geographical area, etc. (Williams, Higgins and Brayne, 2006). However, it is assumed, in Bangladesh nearly 10.5 lakhs individuals may have autism. Statistical data is not adequate to understand the prevalence rate of ASD in Bangladesh though Haque (2015) claimed it 0.84%. Statistics of the center for Child Development and Autism at Bangabandhu Sheikh Mujib Medical University (BSMMU) clearly show the rapid growth rate of ASD cases (Faras, Ateeqi and Tidmarsh, 2010). Country wide study of 2013 showed that the prevalence rate is 1.5 per 1000 where the rate is much higher in urban areas. Generally it is estimated that one child among 500 has ASD and thus the total number is nearly 280,000. Different studies have showed that the general knowledge, awareness and parental attitude towards autism in Bangladesh is not positive. Over 95% of the parents had very little or even no knowledge of autism before diagnosis of their kids. Social stigma and barriers are also found as one of the key challenges in rural Bangladesh. Even parents felt hesitated and the social environment restricting them to go outside with their children, especially in the social gatherings (Preity, et al., 2017). People often fail to understand it, ignore the needs of such child and thus try to focus it differently. Sometime people like to view it from religious grounds, understand it as the punishment of God or devil related issue (Preity, et al., 2017; Zerin, 2015).

In Bangladesh, autism is still a concept to academicians. Studies on parenting challenges, stress and their coping are not adequate to focus it. Before diagnosis, parents have little or no idea about autism and this is the prime challenge for parents. In one side, parents often fail to give proper attention and care. In other side, it very difficult for them to tolerate their child's pain which produce depression among parents (Preity, et al., 2017). Their struggle starts from diagnosis and continues till throughout the life. Some studies have explored the parenting stress of Bangladeshi parents (Akter, et al., 2020; Preity, et al., 2017) but their challenges are still hidden. Though stress is related to challenges but it has multiple implications which needed to be explored. Even how do parents cope with the challenges is also unexplored. Challenges are not only to manage their child, rather they face challenges to manage their own responsibilities, anger and depression. Even challenges could be different based on rural urban setting, family support, economic capacity to manage, family structure, etc. These areas are yet to be investigated to understand the issue properly. Such studies are not uncommon in other countries but rare in our country. Government has been trying to pay necessary attention to the needs of autistic children but we need to think it as an integrated way. As the parents have to manage everything, so their struggle, coping techniques are essential to explore.

Autism is a developmental disability which has multiple dimensions included impaired social interaction and communication. Early detection could be helpful to minimize its serious effects and consequences. But due to many factors including stigma, misconceptions, absence of proper medical facilities, economic condition of parents and poor understanding often create barrier to diagnosis at proper time suggested by different studies. Even after diagnosis, parents often fail to pay proper attention, necessary care and continue medical intervention. Moreover, it invites huge parental stress, couple conflict and break normal family functioning. This is one of the growing health issues for the world as well for Bangladesh but its consequences over family is still less focused. From proper diagnosis to management, parents of our country have been facing series of obstacles including hostile religious, social and cultural practices prevailing here. Government has been showing respect and care to this issue but absence of necessary support and services, vast majority has to meet the medical expenses and care without external support. But the most crucial aspect is the care and management of the autistic children by their parents. Evidences based on the different countries suggest that parents have to struggle to meet expense, to maintain their work and working hours, to keep peaceful conjugal life. Though some studies explored some positive impact on conjugal life but generally it has wide range of negative impact over parents. Stress, couple conflict, economic crises, social isolation and many negatives consequences often create vulnerable situation for families having children with autism. Bangladesh is a developing country where rate of autism has been increasing. Literally people are less or no aware about autism and in most of the cases they simply fail to understand the situation. Even people often face social and cultural pressure that makes their life more critical. Absence of necessary medical service also acts as a barrier to get proper treatment and therapy. All these events put more and more pressure on parents and its consequences are nearly unknown. How do parents cope with the situation and manage, is necessary to know to take necessary policy and to initiate service delivery system. Though there are some initiatives have been taken by the government but not adequate to meet the needs.

Studies on the issue are rare and parenting experience is nearly uncovered in Bangladesh. Parents not only struggle to ensure care, they have to cope with the existing social system. Even social stigma and misconceptions are strong here which often create additional crises for such parents. Existing literature and studies are not enough to understand parental struggle and coping. The propose study is designed to know the parenting experiences of parents including the difficulties, challenges usually face in inside and outside the family. It will also try to find out the consequences over their life and coping mechanisms. As a developing country, Bangladesh has to prepare itself to meet the growing up challenges of autism to achieve sustainable development goals. To obtain such goal, area of health and health education must be properly addressed to provide adequate service so that people could live with security. As autism is one of growing health issues of the world, as well as for Bangladesh, so we need to take preparation and to arrange necessary services. Findings of the study could be helpful for the policy makers to know the situation properly and to rethink about the issue and about the existing service delivery system. Even, academicians and researchers could get new inside to learn and to initiate new study to understand the issue in our context.

2. METHODOLOGY

With the objective of understanding specific needs and demands of the children living with ASD a study was conducted by using qualitative research approach. Sylhet city was the area of the study. It is one of the important divisional cities of Bangladesh where people from different districts are living. There is no accurate or tentative statistics on ASD based on this city, so it is difficult to clarify the total population. First we have collected list from the District Social Services department. We also collected information from some special schools located in Sylhet city. Then we made a draft list of parents. As parents having girl child with ASD were the population of the study, so the research team made a separate list of such parents. There are around 112 parents found who have girl child with ASD. Except parents, service providers like teachers of special schools, doctors, government officials and medical service providers were considered as the key informants of the study. Based on the list developed by the research team, we tried to select potential participants. During initial contact with the parents, many parents did not show interest to participate. Even some parents found not reside in Sylhet city. Considering all the issues, we used purposive sampling technique to select participants. Based on the list developed by the research team, 26 parents were interviewed and 6 persons were selected as key informants. At the same 5 case studies were conducted considering the nature of the parents. The study used multiple data collection tools considering the nature of the study. Separate data collection tool was used for parent, key informants and case studies. A semi-structure schedule was developed and used to take in-depth interview of the parents. This schedule mainly focused on the parenting challenges and coping mechanisms. A semi-structured guideline was used to conduct case studies. We developed a semi-structured interview protocol for the key informant interview for the service providers. This protocol mainly focused on the issues to understand the parenting challenges, social reality, their crises, future initiatives. The protocol also used some questions to cross-check the issues as raised by the parents. After successful data collection, necessary editing and furnishing were made by the researchers. Collected data was coded and analyzed for themes. Necessary statements were incorporated and interpretations were done. Case studies were organized and presented in a separate way to develop a

clear picture of the cases which would help to understand the life, struggle and coping of parents. Thematic analysis has used to present the findings. Necessary interpretations have made carefully.

3. FINDINGS AND ANALYSIS

3.1 Demographic Information

The population of the study was the parents having girl child with ASD. As we have mentioned earlier that the process was difficult due to absence of proper information about the population. We have to collect information from various sources and thus we made a list. Among them we have interviewed 26 parents and 5 case studies were done. The vast majority of the parents were Muslim except few parents from other religions. Among 26 participants, 18 was mother and 8 was father. Most of the cases, it was difficult to reach father as they usually stay outside during day time for their livelihood. Except 6 mothers, rest of them were housewife. One of them is teacher, another one is engaged in private job, and rest of the 4 is paid worker. Except few, most of the fathers (participant) were low paid worker. But participants also shared that, their partners have business or private job or other sources of income. Even in few families, there were multiple earners who helped to maintain family expenditure. In terms of their economic status, majority of them (two-third) belonged to lower income group but few of them found have better economic condition as they have multiple earner or multiple sources of income. Average monthly income of the lower income group was range between TK. 12000-18000. On the other hand, monthly income of the few participants was more than 30 thousands. They have business or multiple earners in the family. More than two-third of the participants lived in single family. Few of them lived in joint or extended family. It is also observed that they have migrated from rural area for better life and thus live in single family. Few of them lived in joint family with their parents or they are supposed to bind to live with them for their support. Participants were asked about their educational status. One-third of them completed primary education, where another one-third of them completed secondary level. Among others, a number of graduates are very negligible portion. Even few of them can only read and write their name. Size of the family was also investigated under the study. Among the participants, nearly two-third of them family size is between 4-5 persons. On the hand, close to one-third of them family size is comparatively larger as they live in joint or extended family. They have 7-9 members including their older parents and siblings. Data also indicates that the ASD child is the first child of the nearly 40 per cent families. Only 20 per cent cases, more than one child found having disability but it is normal for the rest of the families. Even no parent was found having any form of disability.

3.2 Specific and Unique Needs, Demands and Reactions

3.2.1 Unusual Behavior Pattern

Needs and demands of child with ASD are unique but many parents face difficulties to understand it. As they often fail to express their needs and desires, so parents need to know their behavior. Such child often creates mental pressure for parents as their demands are not similar. Even in case of a girl child with ASD, parents have to face acute difficulties considering the social context. In this case, it is the responsibility of the parents to understand their needs and act accordingly. Majority of the participants informed that they faced difficulties to understand their needs and demands due to their complex expression. Though many parents are now habituated to understand their body language but not always

easy to know it. Most of parents said that their child fail to express their food demand. Two-third of the participants informed that, their child never asks for food or they only want particular food they like. One of them shared like,

“How will there be demand because she does not understand what demand is. Even if she is not given food even for 7 days, she will not come and ask for food. Sometime she holds my finger and takes me to the certain place where we store food. It helps to know that she needs food. Now she is 7 years and still we are facing such problem.”

Another parent shared like,

“She likes certain food items and always like to eat those items. We have been trying to make her familiar with other food items but she never shown any interest. Now she is nearly 10 years but her growth is not like a 10 years old girls because of her food habit. She needs additional nutritious food for her physical development but we have failed to change it.”

Many parents expressed their tension about their physical growth and nutrition. At least two-third of them has been facing such problem as they mentioned. In some cases, changes are visible but not adequately. Most of the cases, they like to eat those foods which are not healthy. One of them shared like,

“She likes to eat junk food and she never makes any demand about other food items. When she becomes hungry, she shows some body language and we react accordingly. Sometime we take her at restaurant or similar places just to make her familiar with various foods but result is not satisfactory.”

Not only food related problem, parents have been facing some other challenges as mentioned by them. Vast majority of them reported that their child often make such demand and show aggressive behavior to get it. Though there are some common features among child with ASD like different food habit, toy selection, repeated behavior, making noise or play with those things which are not suitable for them. One-fourth of them complained that their child often like to play with kitchen utensils and make them dirty. They like to cook with paper or even with vegetables and that become their regular activities. One of the parents explained like,

“She likes to cook with kitchen utensils and always take them to her own playground. Even she takes vegetables and does whatever she likes. If you want to restrict her from doing so, she starts crying, even she hurt herself. We always hide vegetables but she tries to find it out.”

Similar problems have been facing by few other parents as they mentioned and they also explained their problems. One of them shared like,

“She wants knife to cut vegetables though we never allow her to get it. But she is very clever as she knows how to get it. We have to lock our kitchen always but sometime she gets access and creates problems. One day she took knife and then cut her middle finger badly. We had to take her hospital and doctor was very angry to see it. We store all Sharpe kitchen items over the self so that she can’t get it.”

Some other unique features were noticed by parents during the interviews which seemed not common to all. Taking shower frequently is another unique problem as mentioned by three parents. One of them explained like,

“My daughter likes to take shower frequently. If she gets door open, she enter into the bathroom and open the water tap and does what she likes. It does not mean that she does it in summer only, she does it any time. For this reason, she often faces cold related health issue but we could not change her attention.”

Some children show different attitude and maintain special characteristics which are not common among others. At least five parents shared the similar behavior pattern of their children different from others. These ASD children show crazy behavior to get their desired things in any setting. One of the parents explained like,

“My girl always likes to make-up herself and she does it when she gets such opportunity. When she was only 5 years, she often did it with any color material like lipstick, color pencil or even with paint. Still she has similar habit though some changes have made.”

Another parent shared like,

“She likes to break ceramic items and she enjoys it very much. It was a favorite game for her. We have brought plastic and metal plate and other utensil and always keep ceramic items in a safe place. We have been trying to develop her understanding but changes are very slow.”

3.3 Unique Needs or Behavior as a Girl with ASD

Child with ASD show different behavior and demand different from normal child. Different studies have explored such behavior and demand and the present study also attempted to know it. Along with their different behavior we also wanted to know their unique behavior, need and demand which are rare among ASD child. Different studies indicated that, gender based needs and demands are in many ways not similar though there are some common features they usually show. Participants were asked about the unique needs as girl with ASD and they shared their experiences. Majority of the participants shared their child’s behavior and need but few of them shared some unique features of their ASD children which get attention to us. Interestingly few of the parents shared that their girl child never demands anything. They like to do what they like and pass hours without asking anything to anyone. Even they never ask for food, mostly remain silent and play alone. This is the problem for parents as they can’t understand her need and demand. One of them explained like,

“How will there be demand because she does not understand what demand is. Even if she is not given food even for 7 days, she will not come and ask for food. We have to ask her again and again but she does not response. She talks only when she likes to talk but uses only few words. We have been visiting doctor and therapist but development is very slow.”

Another parent said somewhat similarly,

“She is ten years but can’t do her own work. Can’t go to the toilet, can’t take shower, and even can’t wear her dress properly. She is growing and we are very anxious about her safety, decency and moral learning. Sometime she does not like to wear dress and does it in front of anyone which invite embarrassing moment for us.”

Also, in some cases, some autistic children show different needs which are not common to all. One of the parents shared her experience like,

“She screams all day, shows temper for any reason. She beats all the kids at school. She doesn't understand anything without me, I can't leave her anywhere, just cry. She likes her elder aunt a little bit. Every day she has to eat ice cream or cake. Not all children have to do this. Not a single day goes by that she doesn't sneak into the house for cake and ice cream.”

Similarly, another parent highlighted her daughter's diverse needs and said,

“My eldest daughter wakes up in the morning and sits on a particular place of the house. She spent the whole day there and at night I pick her up from here and take her to sleep. In between, I feel like listening to her order all day long. She does not even take a glass of water herself. But can do everything including walking. Other children are not like that. At least it works on its own.”

There are some other cases as mentioned by the parents whose have unique needs and demands which often invite difficulties for parents. They neither accept it nor reject it. One of them shared his experience like,

“My child likes to shower in the rain and she does it for long time. We can’t restrict her from doing it. If the sky becomes cloudy she becomes happy and waiting for rain. Now she is growing and needs to maintain decency but she is unable to understand it. We pass hard time in rainy reason.”

Not only have that, few children had some other unique needs and behavior as mentioned by their parents. One of them shared like,

“She is very crazy and likes to buy anything she desired. We hardly take her to market just to avoid embarrassing situation. If she gets chance, she grabs anything and we have to buy it, whether the price

is beyond our capacity or not. Interestingly, she uses this thing but you can't take away it from her room."

Compare to male ASD child, some parents identified differences in terms of their needs and demands as well as their behavior pattern. One of them explained like,

"She does not like to share her room or even bed with my other kids. If they enter into her room, she becomes angry and attack them. We have been trying to develop her understanding but she is not ready to change her attitude. During her monthly cycle, she keeps distance from us; even she does not allow her mother."

Girls with ASD also have some special needs or behavior different than boys with ASD. Parents talked about such issues and also shared their struggle to meet those needs. One-fifth of them noticed about the behavior of their girls which are not usual. They like to stay alone, face difficulties in interaction or making friendship with other girls. Even they are not habituated in social gathering and often try to avoid such environment. One of them shared like,

"As she grew older, her behavior changed. She doesn't want to go to social events. Because, she doesn't like to talk to everyone. She likes to play with kids but kids think she's big."

Nearly similar problems were shared by few parents. One of them explained like,

"She is now 14 years and her physical growth is normal. She likes to play or talk with boys but we can't allow it. Even she likes to wear male dress which often invites embarrassing moments for us. If we want to restrict her from doing so, she become crazy and starts shouting."

Three parents shared very interesting needs and behavior of their girls which are different from others. They have some special needs and behavior and they like to do it frequently. Parents have been trying to change it but failed to do. One of them shared like,

"My daughter likes to follow her father and imitates his behavior. One day we found that she was shaving his check like her father. We thought she was doing just to know it. But she has been doing it and we can't restrict her. As result, her father threw away all the shaving kits and from that day, he has been doing it at outside. But my daughter still tries to do it with cream or other things she gets."

Two of the parents shared special need of their girls. One of them shared like,

"My daughter likes to draw picture and she does it always. She draw picture not only on paper, she does it on wall, or other places of house. She uses color pencil, pen, and if she does not get it, then use anything suitable for drawing. Now our house is a painted house."

Parents have to straggle to meet the needs and demands of their girls with ASD in many ways. In one side, their unique demands invite embarrassing moments, in other side they have to spend additional money to meet it. In some cases parents have to use force to control their daughters not to do the act which make the girls crazy. Moreover, such needs invite danger or health issues for the girls as described by the some parents. One of them described like,

“Certainly you would not allow your child to play with those things which are dangerous or harmful her. Like other parents I do not like to allow her to do it as she often hits her head on wall. If she becomes angry, she starts to do it and continue it. We have to go to doctor two times for her injury. Doctor always advises us to keep her safe but it is not easy as you can say.”

3.4 Gender based Needs

The study is aimed to explore the challenges of parents having girl with ASD. So we focused on the issues related to the title. To understand their challenges, we tried to know the needs, demands and challenges of girls with ASD with compare to male. Parents were asked about to share to those challenges or needs that are unique and associated with girl. Parents shared their needs and also informed about the changes of needs related to their change of age. Some behavior and needs have been unchanged but few of them have changed as they are growing up. Even it depends on the gender of the child though many of them are not able to understand it. Parents shared about their physical changes along with their mental changes which influence them to change their needs and demands. One-sixth of the parents informed that their child has modified her behavior and needs herself due to influence of motivation, following their friends and close persons. It happened as they have been going to school and thus they have developed the concept of gender. This parent viewed it positively though some difficulties have arisen. One of them shared like,

Now she could understand the differences between male and female and she tries to response accordingly. Like her dress, behavior, distancing, attitude and other behavior have been developing but still she is not fully aware due to her autism. But she faces problems in managing her monthly cycle.”

Understanding physical growth and social expectation is a great challenge for autistic child as well as their parents. In some cases, they become habituated by observing friends behavior but many of them remain unaware. It depends on their ability to understand, socialization and teaching by parents. Such cases, they need continuous motivation, instructions and supervision as mentioned by many parents. One of them shared like,

“Teaching them about gender and gender difference are the major challenges for parents of teen girl with ASD. Most of them can’t understand it, even they often make mistake to differentiate between male and female. It increases mental pressure for parents and they pass very hard time. Always they have to keep an eye on them so that they can’t make any mistake.”

Keeping an eye on their ASD girl is not the solution. They need to make aware and habituated about social expectation, physical changes and their safety as mentioned by the majority of the participants. All the parents found very aware but passing tense time due to it. Most of the parents faced challenges to teach them about physical changes. Even they (child) often show negative reactions or avoid their advice. One of the parents shared like,

“We had to spend nearly 3 years to teach her about gender difference, even she was not ready to accept it. Still she sometime makes mistake as she likes to play with boys. She often asks, why difference?”

Another parent shared like,

“My daughter often asks me about gender difference and she does not find any difference. She likes to wear boys dress and ignore our suggestions. We have been trying to make her aware but she becomes angry. She compares with her brothers and does what she likes. Inside the home, we can manage somehow but it is very difficult at outside.”

Parents discussed that both the boys and girls with ASD have unique needs and demands but dealing with a teen girl with ASD is totally different as mentioned by nearly all of them. As they have been facing such situation, so they explained teen age needs and challenges. One of the parents shared like,

“When her first monthly cycle was started, she was extremely scared and we had very hard time to make her understand. It has changed her mood, she often keep distance during this time. Even she does not allow us to talk or share her toilet. But she could not maintain confidentiality and sometime ask about it in front of other family members.”

Not only that, some parents have different experiences due to their daughters' needs and demands. Parents whose daughters have already experienced monthly cycle, vast majority of them reported about the mood disorder of their girls. They do not like to talk, share, go to school or even do not allow family members to come closer at that time. One of them shared like,

“She keeps distance, remain silent and stay far from all. Even she imposes food restriction and eats only selected food at that time. We can't talk as she becomes angry and most of the time stays at her room. It seems that she is very scared of monthly cycle and passes hard time.”

Parents also shared some other needs and changes of behavior of teen girls based on their experiences. Few of them reported that, their girls like to hear songs and they do it frequently. They only hear those songs they like and do it when they wish. Even few of them also informed that, their liking and disliking have changed. Moreover, changes in their daily routine, activities and interactions are noticed by the parents. One of the parents explained like,

“My daughter has been changing her daily routine and activities, even her liking and disliking which make us puzzle. By the change of time, she now near some selected songs but does not like to interact with family members like past. We like to give her access but we can’t impose anything. If her younger brother wants to talk with her, sometime she allow but most of the time she does not show any interest.”

Observing male child with ASD or hearing their needs and behavior parents under the present study have compared the gender based needs and demands as well as their changes in behavior. But parents who have both male and female child with ASD, they have great opportunity to compare it. Only 5 parents under the study have such opportunity and they discussed the differences. Most of the parents informed that, usually they have common needs and behavior based on their mental ability and understanding capacity. They also shared that it is difficult to differentiate their needs and behavior before the age of 9 to 10 years. Though some of them could not differentiate due to their weak mental ability. One of the parents who have both male and female child with ASD, shared her experiences like,

“I think, both the male and female child with ASD show nearly similar needs and behavior before they reach to the age of 10 years. When their physical appearance change, hormonal changes taken place, then they change some of their needs and behavior. My daughter started to change her mood and behavior after the age of 11 years. Shyness and keeping distance are the main two symptoms are seen and still she is doing so. Even her mood has changed and she often stays at her room.”

Another parent also shared the changes by observing her daughter changes. He explained like,

“I have been observing that changes are faster among girls than boys. She does not like to allow anyone to use her personal things to use, or even touch. From her teen age, she has been suing separate glass, plate or even towel and she becomes seriously angry if someone uses it accidentally. If it is happens she washes thing again and again. During her monthly cycle, she does not allow anybody to sit on her bed, even her mother. It seems to us that she passes very uncomfortable time during her monthly cycle.”

Physical growth of girl is faster than boy and in many ways girl can adjust and learn social interaction than boy. It is also happens among girls with ASD as reported by parents though not adequately. But emotional expression and reactions to any situation are high among them as mentioned by parents. They have some common traits but these have been changing by the time of their age. Parents informed that, many of them show different behavior as well as needs and demands after they reach at age of 10 or above. Due to hormonal change, bodily change and social learning often create dilemma among them to react properly. In some cases, they cannot adjust with the expected social responses and thus they create a hard boundary around them. One of the parents shared like,

“What she was and what she is-difference between two stages are remarkable to us. Now she could understand some social behavior and expectations but at the same time she often fails to adjust with the social reality. It hampers her behavior; she reacts and burst into tears when she fails to response. She does not like to hear any fun about her. She behaves like a woman or sometime does it like a child. I

know, she is serious to response but her mental capacity often works as barrier. It has been changing her attitude, behavior and needs. Now she tries to pass most of the time alone and remains busy in reading books.”

Nearly similar experience was shared by another parent whose girl is now 15 years old. She explained like,

“Now she does not like to welcome any guest at our home. She keeps distance and hardly talks with them. Because she feel discomfort in presence of guests as she often fails to behave properly. I think, she remains worried about their reactions and she does not like to hear negative words from them.”

3.5 Reactions to Unmet Needs/Demands

Various studies and case studies explored that the children with ASD often show reactions if they fail to get desired things or their needs are not meet. In some cases, they become violent or aggressive and do what they like. The study also aimed to know the reactions of such children in case of needs or demands are not meet. Parents shared about their reactions and differences, and opinions are not same. Most of the cases, when the parents are unable to meet the demands or needs of the autistic child, the child becomes very aggressive. Due to excessive anger, they not only hurt others but also themselves. Moreover, breaking furniture and crying are also part of these reactions. A parent said about her daughter's reaction like,

“After asking for something and not getting it, she gets very angry, stubbornly throws everything away. Even she bites her own body sometimes.”

Such reactions are common among many girls as mentioned by parents. Though girls become social and nearly normal by observing social interaction and others behavior but their socialization process is not easy like normal child. They take additional time, spend long time to observe other and then try to imitate or follow it. But their reactions are different as they become emotional quickly. Another parent said,

“She becomes crazy when I do not allow her to going outside. She throws things in the house, beats the sisters, and throws down the bed sheets and pillows, especially the books and notebooks of her sisters. That time she does not want to understand the situation.”

Besides, 4 other parents described similar experiences. In some cases, autistic girls do not have any such needs, so they do not get upset even if the needs are not met. A parent said,

“In the case of many children, if something is asked for and not given, then staying at home becomes a liability. Reaction of my daughter is different as she keeps silence if she fails to get her demanded things. But it is not good; it might produce anger in her mind.”

Reactions of few of them are totally different as mentioned by their parents. These girls show their reactions by avoiding food and doing their regular activities. They stay at their room and pass hours after hours without moving from same place. It is the sign of their reaction. One of the parents explained like,

“My daughter does not show anger, craziness or breaks anything like many other girls with ASD. Her symptom of reaction is different as she keeps silence, avoid food and sit on the same place for hours. Usually she does not show negative attitude or attacking manner but she is very emotional which is very harmful. She does not like to express her pain but her reaction tells us many things.”

Few of them have distinct demand and desire as they like to behave like a mature person. They want to work at home but often they fail as they have little or no understanding about it. Problem is here that they do not like to hear their criticism and if so, they show angry behavior or unwanted reactions. Few of the parents shared about the reactions of their girls when they do not get their desired things or acts. They even like to cook like their mother though they have little or no idea about cooking. But if their parent forbids them then they become angry or feel insult. At least five parents have been facing such problems and they also shared their experiences. One of them explained such situation like,

“My 11 years old girl like to cook but she does not know how to cook. Sometime I give her access to observe but she wants more. If I restrict her then she becomes angry and show negative reactions. One she put water into boiled oil and it was a terrible moment for us. Fortunately she had minor injury but she still likes to do it.”

Few of them show harmful tendency when their needs are not meet by parents. Usually they do not destroy things like many girls but show reactions over their body and life. Though they have no idea of the consequences of such reactions but they often do it to show their dissatisfaction to parents and to family members. Parents noticed that such situation often disturb them but they have no alternate to avoid it. In some cases, parents force them but results are not comfortable for them. Rather it invites additional tension for them. One of the parents shared like,

“If we can't meet her demand or we do not try to meet it considering her safety, she shows harmful reactions. She often demands for new dress which is not possible for us due to our limited income. I try to keep her busy so that she forgets it but she does not leave her demand. Then she entered into bathroom and take shower for long time. She comes out when she desires.”

Emotional reaction is common among girl with ASD though forms are different. Crying, shouting, keeping silence, breaking things or other forms are mentioned by parents. But such reactions are depending on the individual attitude and mental ability. Few of them usually cry silently whereas many of them do it loudly. On the hand, few of them show their dissatisfaction by keeping silence, but many of them create sound. One of the parents told,

“My daughter starts crying but silently and she continues it for hours. That time we stay from her as she does not like our company. After hours she becomes normal and does her activities. But it does not mean that she forgets her demand. She does it again and again and we are habituated. In some cases, we try to meet her demands but not always.”

Keeping silence may be tolerable for parents but opposite situation invites embarrassing environment for them as mentioned by ten of them. Their children cry loudly and people around their house become disturb. These girls view it as negligence to them and their attitude and expression are very aggressive as mentioned by their parents. Sometime they make arguments and speak in way which is not polite. One of them shared like,

“My daughter views that we do not love her and ignore her demand. She does not try to understand our condition or for what reason we can’t meet her demand. She starts crying very loudly and nearest people can hear her cry. Even few of our neighbors come to our house though they are well aware about it. Few of them try to take her with them but she shows no interest.”

Parents have to show patience when their child becomes crazy and have to manage the situation by providing support and positive manner. As they have limitations to control their emotion, so they need supportive attitude and reactions from their parents. Key informants also discussed about the issue and they explained the possible solutions or focus on the role of the parents in those situations. They talked about the mental ability of the children and their failure to control their emotion. They suggested to give time, take them out for visit and to make their time funny or constructive. They complained that, many parents do not try to understand their child, rather they treat them as normal and thus they behave accordingly. It is not the solution, rather it makes them crazy. All most all of them suggested to keep patience and to behave like a friend. Parents must have to remember their daughter’s mental and thinking ability. Such child often shows some demands which may not comfortable for parents. Even many parents can’t meet such demands due to their limited income. But they should not ignore their demand, rather they should follow alternate way to manage them. One of them explained like,

“Parents must have to consider their mental ability and they should not react always. We know it is not always easy for parents to keep patience as they have to face it regularly. But their negative attitude or reactions may invite additional problem for them. It may make the girls crazier. They need to talk their girls continuously, try to develop their ability to understand and to change their behavior. Such efforts are important not for the girls, it is also important for the parents to get relief of such pain.”

One of the teachers said like,

“They need continuous support, motivation and also need good companion. Social interaction may help them to observe and to learn excepted behavior. We should not impose anything over them; rather we should try to give them positive environment. Many parents ignore it and thus they often face such demands and make the situation complex.”

Key informants also talked about the formal education and therapy which are very important for their mental development. They can learn socially expected and accepted behavior, norms, and values, and thus they could understand their role. Even it could help them to reduce their negative reactions. Such children can develop their maturity which helps them to restrict from frequent demands. Parents should try to continue their education as well as their counseling therapy.

4. CONCLUSION

Rate of autism has been increasing in the world due to many reasons. This issue has been getting priority in the many countries. Parenting challenges are diverse and coping mechanisms of parents are depended on the many factors. The study explored the multidimensional challenges of the parents having girl child with ASD. But the most crucial challenge is to manage support for the child and their social security. Gender is a vital factor as female with ASD has to face acute problems, challenges and barriers in many ways. Not only financial limitations, parents have to face social challenges. Insecurity and exploitation are other forms of challenges as many parents have to face it. We have law, policy and services but gender based focus is not visible. We need to give special attention focusing the gender based challenges and limitations. Government should pay attention to gender based challenges and thus incorporate it in law, policy and services. Even we need to provide additional facilities to girls with ASD and to their parents. Gender based insecurity needs to be considered and need to take initiatives to reduce it. Parents should get support and services as they have to face challenges. Our policy should focus on the conjugal issues, family management and financial support properly. Even it is important to introduce counselling service for parents. Similarly our service providers may work as change makers by providing advice and mental support to parents. It is also important to broadcast information about existing services so that parents may inspire to get it. Parents like to get it easily, so special call number may be introduced to get necessary information. We need to focus on the parents who reside far from the city and in rural setting where services are absent or very limited. Government should take initiatives to incorporate different groups of people to provide wider services to them. Still now people are less interested about autism, even it is unknown to many people including parents. This area need to get importance to make change. Service and quality life of girl child with ASD depends on the positive social and family environment, awareness of parents and support system. Our law, policy and service should focus on the issues properly. Thus, parents will get mental support and girl child with ASD will get desired services.

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