Parenting Children with Autism Spectrum Disorder (ASD): Explore the Experiences in Different Social Levels in the Context of Bangladesh

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Erasmus Mundus Master's Programme in Social Work with Families and Children (MFamily)

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September, 2021

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Abstract

In English:

Title: Parenting Children with Autism Spectrum Disorder (ASD): Explore the Experiences in Different Social Levels in the Context of Bangladesh.

Author: Tania Saha

Keywords: Parenting, Children with ASD, Social Level, Role, Relation, Challenge, Coping Strategy, Support.

The study aimed to explore the various dynamics of experiences in parenting children with ASD and how these experiences live in different social levels in the context of Bangladesh. The study selected participants through purposive sampling. Total ten families - both parents/ nineteen parents participated in the study from two social levels. The qualitative research design was employed since the study intended to understand lived reality of parental experiences intensively. Data was collected using online and face to face interviews, and through thematic analysis, the study presented the findings. The study revealed diverse experiences in perceptions, relations, gender roles and challenges in parenting, along with the gaps in the state's initiatives to curtail these challenges in Bangladesh. Data showed parents took various coping strategies to lessen their hardship; in this case, adequate formal and informal supports work as strength and stress reliever to parents. Besides, parents identified essential requirements for themselves and their children that are possible to fulfill by proper policy measures and implementations. By looking at different parenting experiences dynamics, the study highlighted the relationship between parental experiences and their social levels. In this case, the study reveals various commonalities as well as diversity in experiences between social levels. However, the study revealed that parents from the high social level have more access to different resources than parents from low social status.

In Portuguese:

Título: Parentalidade de Crianças com Perturbação de Espetro do Autismo: A Exploração das Experiências em Diferentes Níveis Sociais no Contexto do Bangladesh.

Autor: Tania Saha

Palavras-chave: Pais, Crianças com Perturbação do Espetro do Autismo, Nível Social, Papel, Relação, Desafio, Estratégia de Coping, Apoio.

O estudo visava explorar a dinâmica das experiências vividas com crianças com Perturbação do Espetro do Autismo em diferentes níveis sociais no contexto do Bangladesh. Através da constituição deuma amostra não probabilística foram selecionadas dez famílias, num total de 19 progenitores, divididos por dois níveis sociais O desenho da investigação qualitativa foi utilizado dado que o estudo pretendia compreender a perceção dos pais sobre a realidade vivida. Os dados foram recolhidos utilizando entrevistas online e presenciais, analisados através de análise temática. O estudo revelou diversas experiências em perceções, relações, papéis de género e desafios na parentalidade, juntamente com as lacunas nas iniciativas do Estado para reduzir estes desafios no Bangladesh. Os pais adotaram várias estratégias para atenuar as suas dificuldades, nomeadamente, os apoios formais e informais adequados funcionam como uma força e um alívio do stress para os pais. Além disso, os pais identificaram requisitos essenciais para si próprios e para os seus filhos que são possíveis de cumprir através de medidas políticas e implementações adequadas. Ao analisar a dinâmica das diferentes experiências parentais, o estudo destacou a relação entre as experiências parentais e os seus níveis sociais. Neste caso, o estudo revela vários pontos em comum, bem como a diversidade de experiências entre os níveis sociais. revelando que os pais de alto nível social têm mais acesso a diferentes recursos do que os pais de baixo estatuto social.

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List of Abbreviations

ASD- Autism Spectrum Disorder

BES- Bronfenbrenner's Ecological Systems

BSMMU -Bangabandhu Sheikh Mujib Medical University

COVID-19 – Coronavirus Disease 2019

CRC- Convention on the Rights of the Child

CRI- Center for Research and Information

CRPD- Convention on the Rights of Persons with Disabilities

NGO- Non-Governmental Organization

NSPS- National Social Protection Strategy (Bangladesh)

QoL- Quality of Life

UK – United Kingdom

UNICEF **-**United Nations Children's Emergency Fund

Dedication

I dedicate this master's dissertation to my beloved father. I lost him long before but his love and inspirations are always with me in every success and achievement of my life.

Upendra Kumar Saha (1940-2006)

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I am truly indebted and thankful to many who helped me from the beginning to ending for the completion of this Master Dissertation.

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1 CHAPTER ONE- INTRODUCTION

1.1 Background

Autism spectrum disorder (ASD) is a lifelong disability (Rahman et al., 2016) that is becoming major concerning issue nowadays (Hasan, 2020). The number of children with ASD, has increased dramatically in the last two decades in the whole world, with a significant impact on both parents' and child's participation in their daily life (Begum, Islam & Rahman, 2020a). Usually, children with disabilities are a marginalized group in the world; they face massive social discrimination in society, family, community and national level to global ground (Murshid & Haque, 2020). Besides, these children need much parental attention to fulfill their requirements (Algood, Harris & Hong, 2013). Parents who have children with ASD need to confront very different parenting demands than the parents with typically developing children due to the unique demand of their children (Downes & Cappe, 2021). Thus, parents of autistic or disabled children need more inner strength not only to take care of their children but also cope with the challenges of everyday life (Di Giulio, Philipov & Jaschinski, 2014). As a result, to understand the practical scenario of the children and their parents, parenting children with ASD has become an area receiving considerable research attention in different parts of the world (e.g., Woodgate, Ateah & Secco, 2008; Pisula, 2011; Clauser et al., 2021).

Parents are the voice for their children with ASD as well as themselves. Moreover, for the management of children with ASD, their parents are the most important factors and primary caregivers, where ensuring parental wellbeing is also important (Akhter, 2021). Thus, parental experiences become immensely important to understand both children and parents' condition and their needs. However, due to socio, cultural and medical perspectives and understandings about these types of children, parents may need to go through different sorts of parenting experiences according to their contexts (Green, Darling & Wilbers, 2016). Thus, this research is an attempt to understand parenting experiences with their children with ASD in different social levels in Bangladesh.

In the culture of Bangladesh, there is a strong family bond among parents and children where parents are the main responsible persons for rearing their children and their overall wellbeing (Hamadani & Tofail, 2014). However, in the context of Bangladesh, children with ASD are enormously neglected, and both children with ASD and their parents are victims of the social negative perception and stigma (Ackerman, Thormann & Huq, 2005; Soron, 2015), which may cause challenges and even influence the parental acceptance about their children with autism (Zechella & Raval, 2016). Thus, parental personal experiences and their views can be significantly influenced by their circumstances. According to Bronfenbrenner (1989), children are nested by their parents and families, and their parents are also nested in their particular circumstances and culture where both micro and macro-level interaction occurs. Mostly, from the growing number of research, it came up that culture shapes parental involvement and their roles in parenting their children with developmental disabilities/ASD (Acar, Chen & Xie, 2021). Moreover, different research shows parents try to cope up with the challenges they face in rearing their children with ASD (Woodgate et al., 2008; Begum, Rahman & Islam, 2020b), and in this case, support systems and networks may play a big role (Islam, 2020; Shepherd et al., 2020). In addition, this study attempts to see if there is any relationship between parenting children with ASD and their social level. Unlike many studies, this study focused on detail understanding by looking at different dynamics of parental experiences that are interlinked in a particular context and time.

1.2 Statement of the problem

Disability is a significant social and economic phenomenon in Bangladesh, where children with ASD is one of the most vulnerable groups (UNICEF Bangladesh, 2014). A recent report from Bangabandhu Sheikh Mujib Medical University (BSMMU) confirmed that in Bangladesh, the number of children with ASD is increasing day by day; almost 2 in 1000 children have been suffering from ASD (Hasan, 2020). However, there is a lack of reliable and comprehensive research available to understand their condition and the necessity to protect them (UNICEF Bangladesh, 2014; Islam, 2020). On the other hand, parents are the primary caregivers for their children with ASD in Bangladesh (Akhter, 2021). Children with ASD are not able to raise their voice to protect their rights, so parents are their strong voice, advocates, effective activists to ensure their needs and rights (Carey, 2009; UNICEF Bangladesh, 2014; Green et al., 2016). Thus understand parenting experiences from their voice considering different dynamics is vital for getting clear scenario about the practical condition of both parents and children with ASD and taking protective initiatives for them. Persons with Disabilities Rights and Protection Acts (2013) of Bangladesh mentioned the importance of parental role and experiences in rearing children with disabilities and special training and education for the parents. However there are very little practical researches have been done on parenting children with disabilities/ASD and their experiences or challenges in the context of Bangladesh which has made it difficult to proper implementation of these acts and policies.

When it comes to parenting children with ASD, further research done in different country contexts indicates that parents of children with ASD experienced significantly greater hardship than other parents (Downes & Cappe, 2021; Hayes & Watson, 2013). Through reviewing different literature, Heiman (2002) discussed that parents of children with disabilities experiences greater more significant challenges, restriction and depression, and some parents experiences inadequate support, financial assistance, and lack of coordination between social service agencies. In fact, “Parents of children with autism spectrum disorder (ASD) describe their parenting experiences as difficult, intensive, time demanding, ongoing, and with no apparent finality to their role” (Altiere & Kluge 2009; Marsack & Samuel 2017, cited in Shepherd et al., 2020, p. 4331). However, these mentioned researches are done in the western context not able to describe cultural and social differences in parenting experiences of the other parts of the world like in Bangladesh. Moreover, “from a cross-cultural perspective, parenting behavior and its influence on child development outcomes are different across societies and cultures” (Lai et al., 2000; and Gonzalez-Mena, 2007, cited in Zhu, 2015 p.14) even parenting practice can be varied in the different social level in the same culture. Researchers in the western world cannot explain the parenting experience with their children with ASD in Bangladesh. It is crucial to understand parenting experiences from the context of Bangladesh to understand the real situation and take proper initiatives. Mainly, this current research is an endeavor to fill the research gap in this field of Bangladesh.

Hatton and Emerson (2009), through their research demonstrated that the socio-economic position might play an essential part in parenting children with disabilities, but parenting research is frequently conducted without a thorough examination of socio-economic characteristics where parental education and family income can have a direct impact on parenting (Azad, Blacher & Marcoulides, 2014, p.509). Ignoring parental social level in parenting experiences with autistic children may pose a problem getting clear and holistic views in this regard. The current research intends to focus the relationship between parenting experiences and their social level, through this, the study attempts to highlight the way parental experiences exist at different social levels. Furthermore, a general lack in the research with parenting experiences with their children with autism is the use of the traditional mother's focused model (Rudelli, Straccia & Petitpierre, 2021). However, this current research includes both father and mother to obtain clear parenting experiences and role-related dimension of both parents in the context of Bangladesh.

1.3 Objectives of the study

This research aims to explore the parental experiences with their children with ASD in terms of relations, roles, challenges, coping strategies, and supports in different social levels. Furthermore, through this exploration, the study attempts to figure out requirements for both parents and children to protect and ensure their rights in the context of Bangladesh. However, it is not possible to ignore the pandemic situation of Corona and its impact on parenting children with ASD. Thus, the impact of Corona also has been included in the above-mentioned dynamics of experiences. The general and specific objectives of the study are-

General objective

The general objective of this research is to understand the parental experiences with their children with ASD that are lived in different social levels considering different dynamics and necessities.

Specific objectives

1. Explore the relationship between social level and perceptions of parenting experiences.
2. Analyze different dynamics of parental experiences (relations, roles, challenges, coping strategies, and support systems also includes the impact of the corona pandemic in these dynamics).
3. Moreover, figuring out the necessity for the well-being and mitigating hardship and vulnerabilities for both parents and children.

1.4 Research Question

In order to stay focused on the objectives, the following research questions will be answered-

Main question

How do the parental experiences with their children with ASD are lived in different social levels in terms of relations, roles, challenges, coping strategies, supports and requirements?

Supporting questions

1. What are the parental perceptions towards their children with ASD in different social levels?

2. What is the scenario in relationship of children with their parents, siblings, and others from parents' experience?
3. What are the roles of father and mother in parenting children with ASD?
4. What are the main challenges and coping strategies in the parenting process?
5. What are the formal and informal supports available for ensuring needs for their children and themselves?
6. What are the crucial steps that should be taken to mitigate both children's and parental hardships?

1.5 Significance of the study

Autism is a comparatively new concept in Bangladesh, and the knowledge about the condition of children with ASD is highly inadequate here (Alam et al., 2020). Through the parenting experiences, this study will help to fill the existing knowledge gap regarding the practical condition and needs of both children with ASD and their parents. Besides, this study will help to open a number of avenues for future research in this field in Bangladesh and enrich the knowledge in this research field and literature done in the different parts of the world.

Furthermore, in the field of social work with families and children, it is undoubtedly very relevant to know the family condition, parenting experience and practice with the children with ASD in different social contexts to receive a deeper understanding of it and to take initiatives. In addition, this study is significantly beneficial for the families, parents, children, professionals and policy-makers, because the study explores valuable information for the policy-makers and service providers, which helps to design effective policy plan and its implementation to protect vulnerabilities and ensure rights for the children, parents and families.

1.6 Structure of the studies/ chapter

The study has been presented in six (6) chapters. The first chapter is the introduction of the study, highlighting the background of the study, research problem, research objectives, research questions, and the study's significance. The second chapter is about literature reviews, this chapter reviews previous relevant literature related to the research topic and purpose of the study. The third chapter presents the theoretical frameworks and concepts of the research that provide a clear guide and direction to the study. The fourth chapter is about the methodology of the study. This chapter discusses the strategies adopted to conduct the study by focusing on research design, methods, participant selection process, data collection, analytical process, ethical consideration, and the study's limitation. The fifth chapter presents the findings of the study and provides a detail discussion and analysis of the findings. The sixth chapter summarizes the main research findings and draws a conclusion. Moreover, the chapter makes recommendations and discusses the implications of the study.

1.7 Definition of keywords

Parenting

"Child-rearing that focuses on parents or caregivers practices of promoting scaffolding and supporting the optimum physical, emotional, social, and intellectual development of a child from infancy to adulthood" (Davis, 2000, cited in Hamadani & Tofail, 2014, p.123).

Different dynamics of parenting in the study

Parenting Role: A set of activities that father and mother play in rearing their children often indicate socially defined gender perspective (e.g., Acer et al., 2021).

Relation: Connection, communication and interaction between two or more people.

Challenges: Problems faced by parents in rearing their children which needs great psychological and physical effort to handle.

Coping Strategies: "Comprise procedures in which individuals can manage undesirable events and simultaneously control the internal tension created by the resultant stress" (Begum et al., 2020b, p.614).

Support: Refers physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support also formal support from professionals and organizations (Dust et al., 1986, cited in Pisula 2011).

Children with ASD

Children, who are suffering from the neuro-developmental disorder, with communication challenges, lack of social interactions and repetitive behavior (Begum et al., 2020b).

Social Level

In this study, social level refers to parental social status based on their professional and educational ground.

2 CHAPTER TWO – LITERATURE REVIEW

This chapter aims to review relevant earlier works to support and generate an understanding of the research topic. Literature review is critical to know what is already known in a particular research topic and, through this, developing arguments for the significance of research (Bryman, 2012; McGinn et al., 2016). This chapter intends to give a comprehensive and critical overview of the previous studies on the study topic, considering the purpose of the study. In addition, the time and context of the previous studies have been taken into consideration to understand the current study.

2.1 Understanding children with ASD and a brief overview in the context of Bangladesh

To start with, Autism is a developmental disability, a syndrome of autistic disturbances first described by Dr. Leo Kanner from the Jhon Hopkins hospital in 1943 (Rahman et al., 2016). "Autism spectrum disorder (ASD) refers to a group of complex neurodevelopment disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction" (Rahman et al., 2016, p.7). Mainly three deficits are noticeable such as social interaction, communication, and repetitive or stereotypic behavior (CRI, 2014) refer to social skill, behavioral problems, speech and non-verbal communication, that indicate how you view the world and how you interact with other people (Akhter, 2021). Moreover, ASD affects individuals differently and to varying degrees (CRI, 2014; Rahman et al., 2016). According to the description of the University of Iowa, autistic children are probably delayed in learning communicative behaviors and social interaction skills, share information with others, sometimes they prefer to be isolated as they have their own world, and they are not conscious about their surroundings. Furthermore, autistic children may behave aggressively, like biting, screaming, hitting, kicking etc. if they are confused (Rahman et al., 2016). It is a lifelong disability, the term "spectrum" refers to the wide range of symptoms, skills, and levels of disability (Rahman et al., 2016, p.7) and symptoms mainly appear between 18 to 36 months of age (Hasan, 2020).

By examining the global trend, it has been estimated that 1% of the world population suffered from autism (Rahman et al., 2016). The global prevalence of autism has increased twentyfold to thirtyfold since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s (CRI, 2014). According to the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network report, in 2014 approximately 1 in 68 children in the United States has ASD, which is thirty percent higher than the previous data reported in 2012 (CRI, 2014).The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism which means over 695,000 people in the UK may have autism (CRI, 2014). The number of children with ASD is dramatically increasing all over the world, and in this case, Bangladesh is not the exception. There is no exact statistical data of the number of children with ASD in Bangladesh, as there is no national epidemiological study on autism in Bangladesh. According to the Ministry of Social Welfare, nearly 1.4 million individuals may have autism in Bangladesh (Rahman, et al., 2016).

Only 12 children with ASD attended the centre for Child Development and Autism at BSMMU in 2001, which increased to 105 children in 2009 suggesting probable 10 prevalence. A study of BSMMU showed that the prevalence of autism in Bangladesh is 8.5/ 1000 population. Though in Bangladesh, no intensive or exact research has been carried out to understand the prevalence of autism, however, it is assumed that about 3, 00,000 children are affected, with one case in every 94 boys and one in every 150 girls (Rahman, et al., 2016, p.10). However, a recent report of BSMMU showed that almost 2 in 1000 children have been suffering from ASD in Bangladesh, wherein the urban prevalence is higher than the rural areas (Hasan, 2020). In addition, the number of trained professionals is low with other facilities. Most of the time, the children with ASD are detected by a general pediatrician and sometimes misdiagnosed and sent to psychiatrists (Rahman, et al., 2016). In addition, negative attitude to children with ASD is common in Bangladesh, where autism is still considered a curse (Rahman, et al., 2016).

2.1.1 Brief of Government activities and other initiatives in Bangladesh

Bangladesh was among the first countries to ratify two most significant global treaties that protect the rights of children with disabilities, one is the Convention on the Rights of the Child (CRC), in 1990, and another one is the Convention on the Rights of Persons with Disabilities (CRPD), in 2007 (UNICEF Bangladesh, 2014). The National Parliament of the Government of Bangladesh has also taken a number of legislative and policy actions. As a result, two important laws have been enacted, one is the Disability Right Law 2013 to protect dignity and rights to education, physical and psychological improvement, participation, get the national identity card, employment inherited property rights etc. and another one is the Neuro-Developmental Disability Protection Trust Act, 2013, mainly to provide physical, psychological and economic assistance, security and rehabilitation etc. (CRI, 2014). Though these acts are enacted to protect the rights of persons with disabilities, there is a gap in the implementation and mechanism of these acts in the practical field of Bangladesh to the improvement of person with disabilities as well as ensure and protect their rights (Murshid & Haque, 2020). Besides, the Bangladesh Government provides disability allowance or child disability grants to the children with disability from the low-income family. This disability grant is managed by the Bangladesh Ministry of Social Welfare (NSPS, 2014). In order to improve social protection and security, the Ministry of Social Welfare gives stipends for students with disabilities from lower-income families. In this program, the number of beneficiaries is 18,620[1]. It seems limited and not mentioned the criteria of children with disabilities. Basically, social protection mechanisms taken by the Government and some Non- Governmental Organizations (NGOs) to support parents and children are yet to reach a large number of families and parents, still, there are many gaps with these initiatives as well as challenges to get access to these services (UNICEF Bangladesh, 2014).

On the other hand, Saima Wazed Hossain, a school psychologist and global advocate for autism who is also the daughter of the Prime Minister of Bangladesh, has been actively engaged in global and domestic advocacy of mental health disabilities along with the autism (CRI, 2014). Furthermore, the Bangladesh government has taken some initiatives to protect children with autism, such as the Global Autism Public Health Bangladesh initiative that started in July 2011 with unanimous ratification of the Dhaka Declaration on Autism Spectrum Disorders. Moreover,

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[1] http://www.mof.gov.bd/en/budget/13_14/gender_budget/en/05%20Chapter%2005_29_Social%20Welfare_English.pdf

this initiative is working to address issues related to autism and other neuro-developmental disabilities and to promote access to quality health services both regionally and globally (UNICEF Bangladesh, 2014). Another major initiative is the establishment of *Shishu Bikash Kendra* (Child Development Center) in government tertiary medical colleges for early assessment, diagnosis and intervention for children identified with potential developmental delays. These centers also offer training and support for parents of children with various disabilities. The Child Development Centers are now located in ten government medical hospitals with trained multidisciplinary teams, where three centers are located in capital city Dhaka, and the rest seven are located outside Dhaka (UNICEF Bangladesh, 2014). However, the situation analysis report of UNICEF (UNICEF Bangladesh, 2014) did not provide any information about the practical scenario of these initiatives and how they work. Moreover, Soron (2015) discussed some government initiatives for the children with autism such as, the Ministry of Primary and Mass Education has developed a short episode of 'Meena' cartoon to raise awareness of autism, staged a popular interactive theater in 158 sub-district level on autism, the government initiated 73 Disability Service Centre in district and Upazila (sub district) level with a special "Autism Corner", besides autism incorporated in the education curriculum and children with autism will get extra 20 minutes in the exam, a 'One Stop Mobile Service' program has been implemented for the families who live in rural areas with lack of accessibility to medical services. According to Soron (2015) this kind of government initiatives help to reduce the stigma associated with autism and autistic child in Bangladesh. However, the author did not discuss the function of these initiatives in the practical field or if these initiatives brought any difference for the children with ASD or, any practical example of experiences of parents and child. Besides, Akhter (2021) discussed that since 2010 Bangladesh Prime Minister and her daughter are trying to create awareness regarding autism by taking various steps. However, still, achievements are limited since knowledge is very inadequate, and there is still many misconceptions surrounding its management, such as simple medicine will cure the child. Moreover, there is no alternative training and research to deal with the gap (Akhter, 2021). Furthermore, Alam et al. (2020) mentioned, there are lots of challenges regarding children with disabilities or autism in Bangladesh, and the knowledge about their general condition is shamefully inadequate.

2.2Parental experiences with their children with ASD

Parenting a child with a developmental disability influences a person emotionally, physically, socially, financially and it is a mix of emotions and experiences altogether (Carroll, 2013). According to Ackerman et al. (2005), a disabled child of any variety requires more intensive care than any non-disabled child and being a parent of a child with any disability is often a full-time occupation in Bangladesh along with the severe test to a family's economic and psychological stability. Interestingly, it is evident that there is no generalized set of parenting practices for children with disabilities (Ackerman et al., 2005). When it comes to reviewing literature on parenting children with autism, most of the literature in the context of Bangladesh is on disability in general, with very little of it focused on autism (Alam et al., 2020). To understand parenting experiences here, I review related and relevant literature according to the study topic and purpose from the different parts of the world along with the Bangladesh context.

2.2.1 Parenting stress and different dynamics of challenges

The experience of parenting a child with a disability/ASD is undeniably stressful (Carroll, 2013; Hayes & Watson, 2013; McStay et al., 2014; Enea & Rusu, 2020). Altiere and Kluge (2009) found after discovering the reality that their child has autism, every parent experienced despair, sadness, denial, confusion, and anger or feeling of loss. Moreover, the growing and developmental process of an autistic child is very stressful and challenging for the parents (Begum et al., 2020b). Hayes and Watson (2013) found that parents of children with ASD experience more parenting stress than those who have typically developing children or children with other disabilities. According to Smith, Oliver & Innocenti (2001), family, functioning resources and the level of child disability are the two essential elements that are related to parental stress. The severity of the child's disability had a notable impact on stress related to the parent-child relationship; basically, a child's social skill is one of the predictors of parenting stress. Algood et al. (2013) mentioned that much parental attention for disable child can increase parental stressors, besides multiple factors such as socioeconomic status, family rules, rituals, routines, lack of adequate insurance coverage, and inaccessible community resources compromise the quality of parenting and increase stress.

Pisula (2011) figured out the main reasons for parental stress, where the first reason is children's behavioral symptoms and problems. Second is lack of professional support and limited access to necessary services and the unsatisfactory relationship between parents and professionals, and finally, negative social attitude and lack of understanding about the problems of child and their families. Parental stress is also related to the child's regulatory difficulties. These problems affect a number of areas, including emotional and affective regulation as well as circadian rhythm, some children with developmental disabilities have irregular sleeping problems causes' parental stress, fatigue and other physical disorders (Pisula, 2011; Hoffman Sweeney & Lopez-Wagner, 2008). Pisula (2011) also mentioned that not only the lack of knowledge of professionals and the inadequate services and support but also this kind of limitation impacts the relationship between parents and professionals pose extra burden of stress to parents. Severe stress experienced by parents of children with ASD has profound consequences for their interactions with the child and family life (Pisula, 2011). Shepherd et al. (2020) discussed that parenting stress could be classified as either objective stress (financial difficulties that lead to the degradation of physical health) or subjective stress (parents' emotional response, negative perception about their parenting abilities that manifest other feelings of inadequacy).

Regarding social perception and parental stress Green et al. (2016) mentioned not only child, parents are also disabled by cultural narratives that devalues their children's life and their parenting. Furthermore, Parents who have children with autism face huge social stigma (Woodgate et al., 2008; Gray, 2002). According to Soron (2015), parents of children with autism or any other mental illness face social discrimination and stigma in Bangladesh. Even government has a negative and stigmatized view of burden and no use in investing in this sector. These kinds of negative social views contribute to increasing parental stress, moreover, parental increased stress lessens the father-child relations and interactions and father's feelings of responsibilities instead raise substance abuse among fathers (Soron, 2015).

Moreover, parents need to protect their children with disabilities from society's hostile attitude in Bangladesh (Ackerman et al., 2005; Rahman et al., 2016). According to Ackerman et al. (2005), in the context of Bangladesh, parents who have children with any kind of disability have to face challenges in economic, social and educational dimensions. The authors also mentioned, rejection from education systems is visible because; from the common perception in Bangladesh children with disability are not welcomed to the education systems. They are treated as hopeless to teach and reason of harm to other students, which is also can be seen as common parental perception in many cases, where parents also think this child cannot learn (Ackerman et al., 2005). In fact, the child could learn and perform if appropriate training, support, and materials were available for them (Ackerman et al., 2005). Moreover, when parents come to know the disability of their child, their first thought is "What have I done to deserve this?" but eventually, they accept the child's problems and try to help (Ackerman et al., 2005, p .53). In addition, sometimes cultural values may influence the attitude of a family toward a child's disability, the family may choose the child with a disability as a family secret and hesitate to report requirements and support (Acar et al., 2021).

Again, social perceptions in developing countries like Bangladesh; girls are subordinated to boys in almost every sphere of their lives (Jowel, 2014). As a result, girls children with disabilities are at more risk and often victims of physical, emotional and sexual abuse in Bangladesh even sometimes parents perpetuate this kind of abuse (Ackerman et al., 2005). Basically, the gender of the child can be seen as a critical factor in the context of Bangladesh since girls with disabilities are less likely than boys to receive food and care (UNICEF Bangladesh, 2014). In addition, the gender of the child causes parental stress and worries for both mother and father. Similar to mothers, fathers of daughters with ASD reported higher levels of stress and worries than fathers of sons (Rivard et al., 2014).

Moreover, another challenge is that parents of children with autism live in a world of isolation due to their child's disruptive and anti-social behavior and the social stigma (Woodgate et al., 2008 – research in a Canadian context). Woodgate et al. (2008) described it as a "being in their own world" for the parents, and the reason for the isolation of parents is lack of familial (include extended family member and relative) and social understanding about the challenging nature of autism of their children as well as their parental suffering. Common social perception is to give less value to the children. Again due to the intensive care of the children, parents feel a missing usual way of life. In addition, parents have to face challenges to access different systems due to a lack of training and knowledge of professionals (ibid).

Besides, severe stress experienced by parents of children with ASD has profound consequences for their health and well-being (Pisula, 2011). Parents of children with disabilities have to face a high level of depression and other health problems with shocks denial, self-blame, guilt or confusion (Heiman, 2002). Benjak et al. (2011) found in Croatia that parents of ASD had poorer health and quality of life because parents are only in the focus of support for the needs of the child with ASD, not for parents' need or suffering. Therefore, Benjak et al. (2011) emphasized to include close monitoring of parents' health and well-being for treating children with ASD properly in the system, which is enormously neglected and the main reason for parental challenges of poorer health and quality of life. According to Mumbardó-Adam, Barnet-López and Balboni (2021), due to the unique characteristics of parenting children with ASD, parents have to face higher levels of parental stress and lower levels of family quality of life.

2.2.2 Gender role in parenting

Mother commonly plays the primary parental role by tradition and unspoken law in Bangladesh where siblings play the role of second caregiver. Often mothers need to leave their job for their parental role for the child with a disability (Ackerman et al., 2005). Similarly, Green et al. (2016) explained that mother of a child with a disability has powerful gender expectations from a society where it is counted normal for a mother to sacrifice other aspects of life in order to provide proper care for their child with a disability. Acar et al. (2021) discussed through a systematic review of literature how culture may affect parental involvement in the context of Mainland China, Taiwan, and Turkey. Across all three cultures mother plays the role of primary caregiver for their children with developmental disabilities, and mothers are expected from their culture to play this role. Moreover, mothers are involved in diagnosis and services for their children with developmental disabilities and the role of communication with professionals.

Rudelli et al. (2021) presented the father's role in the development or education of their children with ASD. They described father's satisfaction, self-efficacy, care giving burden from the perception of the father in the context of Italy, where fathers' role is not monolithic rather, their experiences are complex. In their study findings, fathers expressed their positive feelings and satisfaction with their parental role. Father enjoys spending time with their children, and they do their best care of the child as well as consider themselves successful seeing improvements in their child situation. Moreover, the authors show, fathers are capable of managing their behavior when it is necessary. A father, who is aware of his role and gets actively involved in the day-to-day parenting activities (meals, washing, play, etc.), is likely to be more active in decision-making and discussions concerning the upbringing of his child. Father who is satisfied with the social support is less prone to feel overburden in their parenting (Rudelli et al., 2021).

Parental stress is viewed as a complex set of non-specific, persistent and significant challenges associated with the most essential roles of a parent. Since mothers take most of the care of their child, hence mothers are under huge stress with their children with developmental disabilities (Pisula, 2011). Different research showed fathers also face significant challenges due to their child with autism; however, the knowledge is still limited about how they experience their problems. From some studies, it was found that fathers of children with autism faces more stress than the father of typically developing children (Baker-Ericzén et al., 2005, cited in Pisula, 2011).

Furthermore, co-parenting came as beneficial in the work of Downes and Cappe (2021). According to Downes and Cappe (2021), to mitigate the challenges of raising a child with ASD, parents must understand their roles and responsibilities where co-parenting is beneficial for both parents and child outcome. They mentioned co-parenting relationship works as a central process of family functioning with multiple influences on parents and children. Through analyzing nine different studies Downes and Cappe (2021) mentioned, though mothers require to play the main role of parenting but supportive co-parenting is beneficial to less the parenting stress and a better sense of parental efficacy.

2.2.3 Understanding support network

According to Shepherd et al. (2020) parents seek out social support to cope up with the challenges and stress with their raising child with ASD. In this context, support is divided into two sources one is informal support consisting of friends, family and other elements within social networks, dominant providers of emotional support. Another one is that formal support comes from organization and Government primarily assists through the provision of financial, informational or tangible support. The important thing is to understand the operationalisation of social support, and it's relationships in the autistic children parenting context where social supports work as protective measures.

Islam (2020) demonstrates through his study in the context of Bangladesh that parents with intellectual disability have less social network (smaller number of close friends and relatives for sharing problems, seeking help or consulting while making an important decision) than the parents with a child without disabilities. And in this case, multiple factors work, such as the number of friends and relatives and how many of them live close to support. Numerous extent of the social network works as a source of social support and influences parenting performance, coping capacities and relational adjustments, which means social support derives from social network can be instrumental, informational and emotional (Islam, 2020). He also mentioned that there is the relationship between social support and ecological context, but very few researches have addressed the issue from the context of Bangladesh. Parents of a child with a disability are lonely and less satisfied with their social support and network (Islam, 2020). According to Putnam (2020), physical health problems, depression and other mental health problems can be visible risk factors for a person with a limited social network. Social support gives relief of stress and burden in parenting (Rudelli et al., 2021). Social support is a protective factor for the adaptation of the parents with a child with autism. Informal support (from family, friends, and relatives) is a more critical source of social support that provides invaluable emotional and instrumental help (Pozo, Sarriá & Brioso, 2011).

2.2.4 Parental positive point of view, success and support

To understand parenting success with their children with a disability, it is important to understand ecological systems and their influence in parenting. Mainly successes occur when proper supports are in place at the micro-, meso-, and macro-levels and these supports are culturally sensitive to the needs of the child, family and parents (Algood et al., 2013). Altiere and Kluge (2009), in the context of Michigan, demonstrated, despite struggles, some parents described their parental experiences positively where parents take it as positive learning experiences, way to personal improvement (patience, compassion, and acceptance), friendships strengthening of the family, and love of their child. From their findings, Altiere and Kluge (2009) elicited- with their positive mindset half of the couples noticed an increase in compassion and empathy towards each other. For these parents, parenting a child with autism worked as a transition that changes their life views positively. It also helps to get social support and to know true friends. They found new friends through the support group. Some parents get support from extended family networks. Besides parents experienced hope and joy with their child through their positive acceptance and child's improvement.

2.2.5 Parents' 'social level' and their experiences

Parental financial position impacts their parenting with their children with disabilities. Parents in poverty are unable to provide the environment for growth and development and necessary assistive device (UNICEF Bangladesh, 2014). The economic cost of raising children with any kind of disability is one of the main considerable parenting issues and reasons for vulnerability for both parents and children in the context of Bangladesh (UNICEF Bangladesh, 2014). Extra monetary investment is needed to raise a child with a disability (Islam, 2020). Besides, the parents are strong advocates for ensuring their child's need and protect rights, but in this case, parental socio-economic level and education is vital to realize their situation and advocate for their children (UNICEF Bangladesh, 2014). Knestrict and Kuchey (2009) mentioned, familial and socio-economic status is important to get access services for the child with disabilities, if one is struggling with basic needs cannot be reflective about their child with a disability.

Azad et al. (2014) examined mothers' parenting behaviors and investigated the relationship between parenting behaviors and socio-economic conditions (education, income, status). Through their study, authors mentioned, parental socio-economic context and education level have a direct or indirect impact on their parenting, mothers who reported more education as well as who reported more family income had a significantly higher level of positive parenting. Authors also mentioned mothers with more education are better able to understand the depth of factors related to their child development. As a result, positive parenting practices in early childhood. In addition, higher family income means more access to resources (e.g., opportunities to attend classes, read on the topic, and hire a babysitter).

Mainly, the lack of education of parents is a challenge as higher educated parents give more support to help their child with autism in their special needs (Begum et al., 2020b). Moreover, Ackerman et al. (2005) discussed that due to lack of knowledge about their child's disability, sometimes parents do not understand what to do and how to deal; however, if parents are given a chance for knowledge or education, they will become energized and active. Therefore, they are a receptive population for educational and medical intervention. The world health organization has given priority to parental education in autism because such parental education (PE) can increase parental understanding; improve quality of life, efficacy and copying; as well as reduce anxiety and stress. However, access to this kind of education is still limited and unavailable in many regions of the world (Stošić, Frey Škrinjar & Preece, 2020).

2.2.6 Regarding Covid 19 pandemic

According to Mumbardó-Adam et al. (2021) the Corona-virus pandemic affects the lives of children with ASD. They mentioned during the new social situation of the pandemic, children and adolescents with ASD benefited from more time spent with their parents due to quarantine. As a result, children were more communicative, learning some new skills and participating in the family routine. Parents are also benefited from this extra time as they spend more time with their children to help them to teach new skills related to their autonomy and communicative interactions. Moreover, parents appreciated online school and psychological support and maintained online contact with relatives during quarantine.

2.2.7 Understanding coping strategies

Woodgate et al. (2008) present the parental perception of sustaining and coping through their research. The authors mentioned that a strong sense of self and family would enhance protective measures for the child with autism. Therefore, parents found it important to work towards a healthy balance to obtain well-being for themselves, child and their family with the recognition that their meaning of life is not only to focus on helping their child development, rather to create a balance between their focus on parenting and other aspects of life. Parents also mentioned cherishing different milestones of their child helps to preserve parent's sense of hope and in sustaining the self and family. Besides, parents need to learn to let it go when the situation is not possible to change. Furthermore, learning from other useful sources and other parents who have similar experiences is helpful. Again parents have to fight for their voice to be heard; thus, it is vital to educate others to respect children with autism and their parents.

Begum et al. (2020b) pointed out that parental education has an impact on coping strategies in raising a child with autism in the context of Bangladesh and the authors analyzed their data and findings through eight groups of coping strategies, such as: confrontive coping, distancing from a problem, seeking social support, self-controlling, accepting responsibility, planful problem-solving, escape-avoidance, and Positive reappraisal. The authors discussed that person with higher education has greater executive ability to manage their problems. They found education has an impact on coping strategies with accepting responsibilities through taking the situation with a positive attitude. In Bangladesh, there is still lake of opportunities for seeking professional help for their children with autism, in this case, parental acceptance of the situation through self-controlling strengthen their mental ability to support and manage their child. Mainly, parents of autistic children need more social support and education to cope up with the situation and manage their children (Begum et al., 2020b).

In research on families of children with ASD, four factors have been shown to be significantly involved in the adaptation of parents: a) characteristics of the child with ASD – namely, the severity of disorders and behavior problems; b) social support; c) perception of problems; and d) coping strategies (Pozo et al., 2011, p.108).The severity of disorders of the child influences the parental stress and the adaptation strategy of parents (Herring et al., 2006; Lecavalier et al., 2006; Tomanik et al., 2004, cited in Pozo et al., 2011). Another thing is social support from family, community, school or other organization that can alleviate the parental stress, improve coping strategies and develop a parental response to child's needs (Bristol, 1984; Dyson, 1997; Sharpley et al., 1997 and Dust et al., 1986, cited in Pozo et al., 2011). In addition, parental positive perception and aspects help them adapt to their situations (Pozo et al., 2011). Usually, parents take different strategies to cope with their parental stress (ibid). Grant and Whittell (2000) found that problem-solving strategy is more effective when particular problem is possible to change for the better. If problem-solving strategy does not work in particular situation then cognitive strategy through managing the situation is effective. However, the circumstance can arise when neither problem solving nor cognitive strategy work. As a result, parents need to deal with the consequences of the challenges to cope (Grant & Whittell, 2000).

Resilience is very important to understand coping strategies, adjustment with a particular situation, self-esteem, various aspect of social life, along with social support (Dumont and Provost, 1999). Heiman (2002) found three main factors that enable parents to function in a resilient way, such as open discussion and consultation with family, friends, and professionals, positive bond between parents which supports and strengthens each other, finally, continuous and intensive educational, therapeutic, and psychological support for family members. On the other hand, stable socio economic status is essential to focus child with a disability and establish meaningful rules, rituals and routines for resilience (Knestrict & Kuchey, 2009).

2.3 Chapter summary

This chapter discussed relevant literature related to the study topic and purpose in the context of Bangladesh and international to understand previous knowledge and research on parenting experience with their autistic children. The literature review started from understanding the autism and the brief overview in the context of Bangladesh then discussed other literature relating to dynamics of parental experiences.

3 CHAPTER THREE- THEORETICAL FRAMEWORK

The importance and relevancy of theory in qualitative research cannot be overlooked. According to Bradbury-Jones, Taylor and Herber (2014) "theory in qualitative research has numerous functions, for example, it can provide rationalization or justification for the methodological approach used, it can offer a comparative context or an organizational framework for the interpretation and representation of data or it can serve as a scheme for representing findings" (p.136). This study considers two main theoretical aspects, one is Schalock and Verdugo's quality of life theoretical frameworks, and another one is Bronfenbrenner's ecological system theory. Both these theoretical frameworks explain the direction of the study and guide to conceptualizing findings gathered throughout the research. Along with these theoretical frameworks, this chapter discusses the concept of 'social level' theoretically.

3.1 Schalock and Verdugo's Quality of Life (QoL) approach

The QoL theoretical model pays attention to the individual perception of their life position in a particular socio-cultural context in which they live and in relation to their expectations, standards, concerns, physical and psychological state and relationship (Van Hecke et al., 2018). Schalock and Verdugo's QoL model (2002) has been extensively documented due to its formulation and validation in both conceptual and measurement frameworks (Van Hecke et al., 2018). Besides, the QoL model has significantly impacted the research of the field of intellectual and developmental disabilities (Schalock et al., 2016) also in social welfare and social service along with other fields (Van Hecke et al., 2018). According to Schalock and Verdugo (2002) QoL is the set of factors or multi-element framework that reflects life as a whole. The eight core domains of this quality of life model are as follows: material wellbeing, physical wellbeing, emotional wellbeing, social inclusion, interpersonal relationships, self-determination, personal development and rights. These eight core domains reflect three levels of systems; micro- (individual), meso- (organizational) and macro level (societal) in which people live (Schalock & Verdugo, 2002). According to the QoL theory, these three levels are unavoidable as people's activities and quality of life are intensively connected with these three levels of systems (Schalock & Verdugo, 2002). The main characteristics of this theoretical model is to focus the holistic approach of a person's life where cultural relativism that socio-cultural issues and contexts of social values are always taken under consideration (Van Hecke et al., 2018). In this case, individual perception and their experiences receive proper attention to understand their lives by going thoroughly their socio-cultural condition, personal experiences of challenge, joy, success, failure, stress, relationship and support. Also the model focuses on person's physical and mental health, self strength, resilience, coping strategies as well as personal development, policy and rights (Schalock et al., 2016; Van Hecke et al., 2018).

Thus, "the etic (universal) and emic (culture-bound) properties of this QoL-construct have been cross-culturally validated in terms of domain structure and stability" (Bonham et al., 2004; Jenaro et al., 2005; Schalock et al., 2005; Wang et al., 2010, cited in Van Hecke et al., 2018). According to Schalock et al. (2016) QoL is ''a multidimensional phenomenon composed of core domains that constitute personal wellbeing. These domains are influenced by personal characteristics and environmental factors. One's QoL is the product of these factors. It can be impacted positively through quality enhancement strategies that encompass developing personal talents, maximizing personal involvement, providing individualized supports, and facilitating personal growth opportunities''(p. 4–5). Schalock and Verdugo's QoL framework focuses on objective living conditions, but people have own perceptions about these conditions (Verdugo et al., 2005, cited in Van Hecke et al., 2018). Moreover, Schalock and Verdugo (2002) see QoL as a dynamic theoretical model that may change overtime as people's perceptions and satisfaction about their lives are changeable in their different life stages.

The concept of this theoretical framework is very relevant to this current research objective since this research focuses on parental perceptions and narrations of their parenting children with ASD in their socio-economic contexts, including different dynamics of experiences. This theoretical model gives a direction of this study that the interconnectedness among individual, organizational and societal levels is important to understand parenting experiences. Moreover, the QoL theoretical model guides to use holistic approach to understand parenting experiences that the study intends to do through looking at different dynamics in experiences in a particular time and place. Besides, the theoretical framework reminds us that context and time are significant; things can be changeable over time and different life situations. Furthermore, the dynamics (challenges, support, relationships, roles coping strategies, future plan and requirements) of the parental experiences that this research intends to explore, indicate the purpose of eight core domains of the QoL theoretical model as the dynamics of the research reflects on the situations related material, physical, emotional, social, relationships, self-determination, personal development and rights considering wellbeing and the reality in a particular context.

It is needed to mention that "the most appropriate kind of QoL-measurement format may vary according to the specific goals of the assessment" (Van Hecke et al., 2018, p.339) but "QoL-measurement based on a conversation format has been suggested as well" (Claes et al., 2009 cited in Van Hecke et al., 2018). In this case, proxy reports are not valid generally, but the family persons and other people who know them well can give information or report. It involves methodological pluralism by taking perspectives and the combination of subjective and objective indicators (Van Hecke et al., 2018). However, this current research is not exclusively intended to figure out the quality of life of the parents and their children following the measurement model and application of the core domain of the QoL framework rather, it's conceptual model works as the focus of this research by emphasizing different dynamics of the experiences of parents that are lived in different social levels. Mainly, the theory of QoL starts with a conceptual model and is based on a clearly defined and described concept, compatible with other accepted theories, and integrated into current trends (Schalock et al., 2016, p.2). The conceptual model of the theory not the measurement model, is considered as the guide to understanding the findings of the research.

3.2 Bronfenbrenner's Ecological Systems theory (BES)

Ecological system theory is developed by Urie Bronfenbrenner in order to understand human growth by focusing on ecological systems and human's interactions (Bronfenbrenner, 1979). This theory identifies five environmental systems (micro-family, peers, school, neighborhood, meso-interrelationship of two or more micro-systems, exo -family social network, mass media etc., macro - culture, nature and chrono- pattern of the environmental events and transitions over time) with which an individual's development and growth interact (Bronfenbrenner, 1979).

These five systems are interconnected; the change in one level affects other systems directly or indirectly. Guy-Evans (2020) mentioned the influence of one system on a child's development depends on its relationship with the other systems.

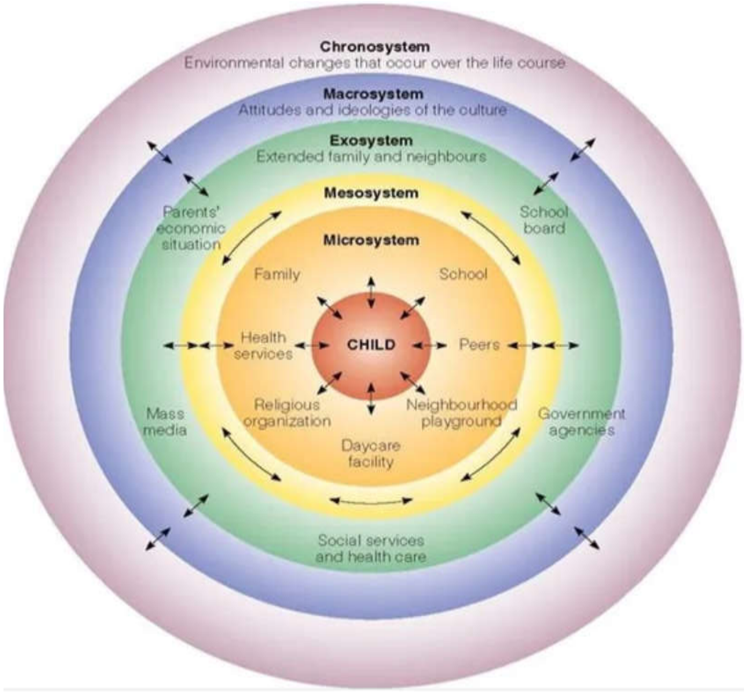

Figure 1 Bronfenbrenner`s Ecological systems theory (Source: Guy-Evans, 2020)

Following the previous QoL theory to understand parenting children with ASD it is important to obtain clear idea of an individual, organizational and societal interactions or connectedness. In this case, the Bronfenbrenner`s Ecological systems theory is an ideal model for understanding the interconnectedness of micro to macro interactions. It is not possible to ignore the impact of border context in parenting. In our, every behavior and attitude have an impact of micro to a macro system, for example, family support, education and socio-economic context (Begum et al., 2020b; Islam, 2020). According to Algood et al. (2013, p.128), individuals move through a series of life transitions, all of which demand environmental support and coping skills, so social issues involving parenting children with disabilities, family relations, income, health issues, education, and so on can be subsumed under the ecological model that helps to access factors relevant with these issues.

Micro system is the first level of Bronfenbrenner's Ecological Systems. "Bronfenbrenner (1977) described the micro-system as a pattern of activities, social roles, and interpersonal relations experienced by the individual or a group of individuals in a natural setting (e.g., family, school etc.). "Factors at the micro-system level can directly affect care giving for children with disabilities, such as parenting practices and parent-child relations" (Algood et al., 2013, p.128). People who are living in a family are interconnected with each other. The existence of a child with ASD may bring challenges, stress and other changes in the family (e.g., Begum et al., 2020b & Islam, 2020). Besides, parental and other family interactions and suitable support may greatly impact the child (e.g., Algood et al., 2013; Islam, 2020). Thus understand parental responses and experiences from the micro-level or individual parent with their children with ASD is the main motto of this research. Moreover, through micro-system of BES theory, child condition, parenting role, child-parent relationship, along with other familial issues possible to conceptualize.

Similarly, meso-system depicts the interaction between different micro systems such as, family and religious beliefs, parents and school and so on. According to Bronfenbrenner (1994) this system "comprises the linkages and processes taking place between two or more settings containing the developing person" (p.40). Understanding meso-system help to obtain a clear idea of how one micro system influence another regarding factors that associated with parenting children with ASD in their daily life experiences and involvements, for example, school may give some relief or good support to the parents by providing the right direction that helpful for the child development and parenting process. On the other hand, the exo-system includes the parent's workplaces, parent's friends and the mass media. These do not have direct involvement with the children, but this surrounding has an indirect impact on them such as work pressure of parents may impact on parenting negatively, or supportive workplace is helpful for parents to get more facilities and time to take care and spend more time with the child, consequently influential for the child. In a word "Parents' personal social network ecology such as their relatives, neighbors, co-workers, and other friends influence their parenting attitudes and behaviors" (Cochran & Walker, 2005 cited in Islam, 2020, p.3).

Besides, the macro-system is another level of ecological theoretical perspectives that reflects on how cultural elements impact the development of a child (Bronfenbrenner's, 1977) such as, cultural belief, values, laws, customs, social policy, health care systems, ethnicity etc. which influence the operation of micro, meso and exo systems. Negative social perceptions towards children with ASD, such as social stigma, may increase pressure in parenting, where the good social policies in a country can reduce the financial and psychological pressure of parents. In addition, the final level is chrono-system that includes environmental changes or major life transition, is not much related in this study; however ongoing Corona situation and its impact on parents, parenting techniques and their children with ASD cannot be overlooked. Current Corona situation and its impact can be seen as a transition for the parents and their children.

Thus, this theoretical perspective gives a direction to understand parenting experiences with their autistic children in different social levels in terms of parent's views, their daily life interaction with different environmental factors. Furthermore, the theoretical model focuses how different systems, interactions, relations and options are helpful to manage and cope up with daily life challenges in a particular time, place and context.

3.3 Theory to conceptualize 'social level'

Marxism conceptualized different social levels based on purely economic phenomena and discussed social division as classes. This theory mentioned about working class and petty bourgeoisie, where the petty bourgeoisie is the dominant class, and the state is the direct agency of the repressive power of the dominant class, and this is the way how society consists and makes the reason of conflict (Giddence & Held, 1982). Social complexity is a reflection of the nature of class formations and is primarily structured by capital/wage labor relations which reflected overall institutional form of the society but "class relations are influenced by what

Althusser called ‘conjunctures’ refer to the specific circumstance of history, limited in time and place” (Giddence & Held, 1982, p.94). Althusser rejected the way Marxism defined classes based on only economic phenomena instead he mentioned “every class society consists of three ‘levels’ combined differently in varying types of society. These levels are the economic, the political and the ideological”(Giddence & Held, 1982, p.94). Heyman (2013) discussed the approach ‘political economy’ that recognizes that the economy is central to everyday life but he contextualizes economic relations within state structures, political processes, social structures, and cultural values. Therefore culture, values and social structures are needed to take into consideration, still, in this world; there are some societies where the social level or status is not dependent on income instead on the number of cattle they own. For example, some Bantu speaking community in the Kalahari desert in Botswana[2]. It needs to clarify that, in this research social levels of the parents are not classified by the only economic phenomena or the relations in a capitalist society mentioned in the Marxist theory rather in this research, income is important in consideration of social level with the ideological (concerning the economic or political situation and policy in a society) perspective of the different job position, status, respect, education and amenities due to their positions in particular circumstances or organizational surroundings.

In this case, Magee and Galinsky’s (2008) work is relevant. They used the term social hierarchy to conceptualize different social levels focusing on two important elements such as power and status. “Power, related to one’s control over valued resources, transforms individual psychology such that the powerful think and act in ways that lead to the retention and acquisition of power. Status related to the respect one has in the eyes of others generates expectations for behavior and opportunities for advancement that favor those with a prior status advantage” (Magee & Galinsky 2008, p.2).

Magee and Galinsky’s (2008) mentioned that hierarchy is a fundamental feature of social relations prevalent in various forms where a pattern of this social level may minimize in some context but always exist in society. The signs of hierarchy or level formalization can be showed in job titles also develop informally in groups (Magee & Galinsky, 2008). Besides, giving focus on the relation between status and power is also important to understand social level through the concept of hierarchy in a particular circumstance. According to Thye, (2000, cited in Magee & Galinsky, 2008, p. 20) “Power, more than status is a property of the actor where status more than power is a property of co-actors and observers. Powerful individuals also have high status if respect is conferred on them for having asymmetric control over valued resources, and high-status individuals also have power if the respect others have for them increases the perceived value of their resources”. Moreover, power and status can lead each other.

Therefore, to understand parenting experiences with their children with ASD in different social levels above mentioned notion such as ideological perspectives, status, power or social hierarchy is helpful to get a clear idea about social levels. This understanding is undoubtedly vital in this research since certain circumstance has been selected to see the relationship between social level and parental experiences. The methodological part of this research clarifies more about the population and area selection of this research.

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[2] https://www.britannica.com/place/Kalahari-Desert/People-and-economy

3.4 Three theoretical contents as a model of analysis

These three contents of Schalock and Verdugo's Quality of Life (QoL) approach, Bronfenbrenner`s Ecological systems theory (BES) and theory to conceptualize social level are worked as interconnected phenomena to give direction to the study as well as guide to conceptualize and analyze the findings. Mainly, all these contents indicate a different level of systems that are interrelated with each other that helps to understand human life from a holistic way considering broader context through the individual parental experiences. Therefore, it is clear that the main focus of the study is the micro level or individual parent's experiences which interacts with other systems and levels. As a result, these individual parenting practices, perceptions and different dimensions of experiences refer to both QoL and BES theoretical perspectives, and both theoretical perspectives involve the relations of social level of the parents in their experiences through understanding differences and commonalities or how experiences live. This interconnectedness that is described in this part is more clearly visible in the following figure-

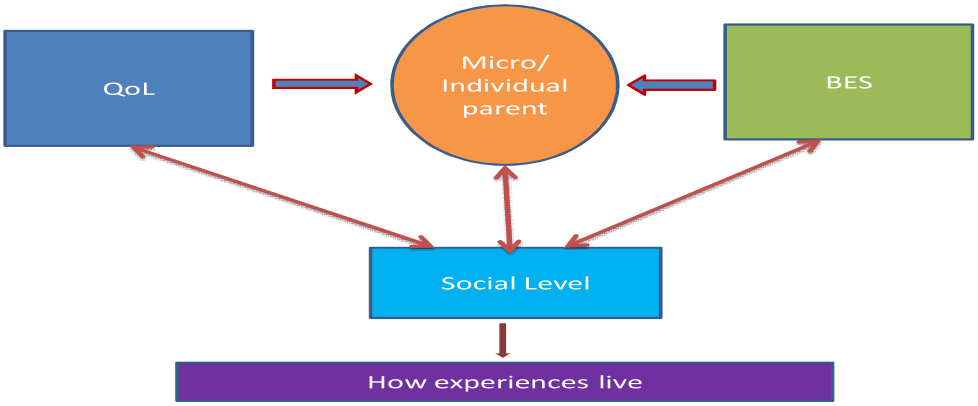

Figure 2 Interconnectedness of three theoretical contents as a model of analysis (Source: Author)

3.5 Chapter Summary

This chapter mainly discussed two theoretical frameworks- (1) Schalock and Verdugo's Quality of Life approach and (2) Bronfenbrenner`s Ecological Systems theory which guided the conduct of the study and helped to conceptualize the findings. Along with the theoretical frameworks, this chapter conceptualized the concept of social level theoretically, which is one of the critical concepts of the research. Besides, this chapter discussed the interconnectedness of all these three contents and how this interconnectedness guides the analysis of the findings and quarry of the research.

4 CHAPTER FOUR-METHODOLOGY

This chapter explores the research strategies that used for conducting this study by discussing the epistemological and ontological position, research methods, research design, research participant's selection process and category, research area, tools for data collection, analytical process and techniques. Along with these, it also has included the ethical consideration as well as the limitations of the study.

4.1 Literature search technique

Searching for earlier literature is an essential part of research to understand related previous researches. In this case, it is necessary to use some technique such as keywords for different databases then database allows to finding out relevant articles (Bryman, 2012). According to McGinn et al. (2016), literature searching strategies may include hand searching, searching of trials, registers, or consultations with experts. However using an electronic database for searching literature is helpful in accessing the available evidence and evidence-based practice in social work. The general question of the literature search was, "what are the parental experiences with their children with ASD? Then different dimensions of the study were elaborated, like how these experiences lived in different social levels, in terms of their challenges, supports, relations, roles, coping strategies and requirements? Therefore, according to the research questions and research plan, "parenting", "parents", "family", "children", "autism", "special child", "social class", "challenges", "success", "support", "strategies", "gender" were used as keywords. McGinn et al. (2016) discussed "test search" in the different database with keywords to find out potential databases. First of all, several databases were searched, and then Scopus, ProQuest Sociology Collection and Google Scholar were found as the potential databases for the literature search. Boolean algebra (OR, AND, NOT) and ''search syntax'' to link concepts as a searching method were used following the rules of databases. Through these databases, related literatures from different parts of the world were found and the relevancy of the literature was figured out by reading the abstract. First of all, by searching Scopus, ProQuest Sociology Collection, and Google Scholar, the first set of literature were figured out and then related literature as well as bibliography or reference list of pertinent articles was used to find out other more relevant literature. Moreover, some related literatures were searched and collected from the library.

4.2 Methodological Choice

4.2.1 General research approach along with epistemological and ontological position

In this study, the general research approach is qualitative, and the epistemological position of this study is interpretivist, what Bryman (2012, p.380) mentioned as "understanding of the social world through an examination of the interpretation of that world by its participants". This qualitative study addresses parental experiences with their children with ASD in different social levels, through the individual perception and the voice of the parents. Creswell (2014) narrates epistemology as a process of "knowing what we know". Participants' specific social context or participants own background shapes their interpretation (Creswell, 2013). The current study intends to understand parental experiences by considering their socio-economic background in the context of Bangladesh.

Creswell (2013, p.20) asserts ontology as the nature of reality. This research embraces the idea of multiple realities in parenting children with ASD through the parent's experiences. Which are based on parental individual perspectives and nature of personalities, their children's condition and social perspectives, parental family background and social level as well as other circumstances that they are embedded in. The ontological position of the study follows the constructionist approaches. In this study, through the interview process and data collection, the researcher and participants construct the reality of the subjective meanings of parents' experiences. Bryman (2012) asserted, "Constructionist which implies that social properties are outcomes of the interactions between individuals, rather than phenomena 'out there and separate from those involved in its construction" (p.380). Mainly following the social constructivism ontological approach, this research focuses on how parental experiences are lived at different social levels. It points to the subjective meanings of parents' experiences to understand the complexity of views rather than narrow the meanings into a few categories or ideas (e.g., Creswell, 2013).On the other hand, Both Kanuha (2000) and Pillow (2003) discussed ontology and epistemology in research, which are considered crucial for understanding research journey and selecting method in the field of social work. Following this part, the research method and design are discussed in the next part.

4.2.2 Research method and research design

In this study, to answer the research questions, the qualitative method has been used. The study focus is to understand how reality evolves depending on individual parenting experiences. In this case, a subjective approach and acknowledging multiple realities is essential to gain an in-depth understanding of parenting experiences. Therefore, the qualitative research method is perfect to understand parental experiences and their context. The findings are always linked to the context, and this kind of logic most commonly should be associated with qualitative research, also called inductive reasoning[3]. In addition, there is an option to capture emotion and feelings in qualitative research to understand people's views. Moreover, qualitative research helps the researcher deeply analyze the socio-cultural reality through the practical parental experiences. According to Shank (2002), qualitative research is a form of systematic empirical inquiry into meaning. Here, the word 'systematic' means "planned, ordered and public" and 'empirical' means this type of inquiry is grounded from experience. This dissertation is qualitative in nature and exploratory in design.

Research designs demonstrate the type of inquiry and the suitable framework for the research (Bryman, 2012). In this research, qualitative research design has been chosen as the research explores the experiences of the parents rearing children with ASD, so this research design is more like exploratory, and this exploratory approach enabled the researcher to get a deeper understanding of lived experiences of parents concerning their contexts (e.g., Creswell, 2014). In addition, Creswell (2014) pointed out that exploratory qualitative studies begin with questions like "how" and use verbs like 'explore', 'understand' or 'discover' that I used in the research questions. Therefore, the exploratory research approach enabled this study to answer the research questions of how the parental experiences are lived in different social levels and explore how parents cope up with their challenges. Also how do the parental roles, family relationships and support networks work in parenting in the context of Bangladesh.

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[3] https://www.youtube.com/watch?v=hCOsY5rkRs8

4.3 Purposive Sampling and participant selection

Since the research aims to explore how parental experiences with their children with ASD are lived in different social levels in a context of Bangladesh, thus according to the goal and research questions of the study, purposive sampling has been used to select participants. According to Bryman (2012) purposive sampling enables researchers to select participants according to their research goal and relevance to the research questions. In this research, the participants are Bangladeshi parents who have children with ASD from two different social levels.

4.4 Study area, access to the field

This research is about parental experiences with their children with ASD in different social levels, which is significant in Bangladesh to know the practical situation and take necessary steps for both parents and children. However, due to Corona situation, it is restricted and hard to move and work in a broader context that is why nearby university residential area of the researcher has been selected as research area, which is situated in Savar under Dhaka district in Bangladesh. The area has been selected because there is a school (to protect the privacy of the children and their parents, the name of the university and the school are not mentioning here) for the children with ASD. Initially, the plan of this school was started with the initiative of the university's teacher and other staff who have children with ASD and then this school was established in 2009 with the collaboration of the university, government and an NGO. Now, this NGO is not involved anymore with the school.

Currently, this school is running with the special fund, and monitoring of the university, and the teachers of the school are not permanent there, but they are working here for 8 to 10 years. This school has 18 students from 5 to 18 years old from different social levels. To ensure confidentiality and protect the participants from any kind of harm, both the participants' names and the school have been anonymised in this study. The school was selected to get information about the parents and reaching out to them. With the help of previous university teacher, researcher got access to the school Principal and explained to her about the study as well as obtained information about the school and their activities. Due to Corona, school activities are going on online and teachers typically come once a week to do administrative work. A declaration letter was given to the school Principal from researcher current university (ISCTE_IUL, included in the appendix), as the formal requirements of the school, and then the school Principal gave the necessary information (name, address contact number and profession) of the parents of the enrolled children in the school. Moreover, the principal suggested researcher to use her reference to get access to the participants of this research. This way researcher reached out to the parents. Participants of this research are living nearby residential area of the school. They prefer to live in this area mainly because of their children's wellbeing. The natural environment of this area is good with open space, park, botanical garden and enough fields of playing and walking along with the school facilities for the children.

4.5 Study population and sample size

This study investigated the parental experiences that are lived in different social levels considering different dynamics of experiences and the necessities for both children and parents. Therefore both Bangladeshi fathers and mothers of children with ASD were selected as study populations or participants in this research. In this study parents were selected from two different social levels regarding their professional and educational backgrounds. The study involved total of ten families with both parents. In this case five families were selected from higher education and first-class job holders background with a particular status, amenities enjoyed due to their profession (standard house rent, health insurance, transportation facilities are some categories of conveniences that they have and due to their status they have good social capital and communication). In this category there are families with university teachers, high ranked officials with the education level of PhD/ masters (given in details in the demographic section). Another five families were chosen from the 4th-grade job position (according to Bangladesh government policy) or a very small businessman with lesser educational background with limited living facilities. In this category, there are families of peon, office assistant, cleaner and attendant (given details in demographic part) with the completion of 6th to 10th grade/secondary school certificate. Families were called by the researcher one by one, looking at the documents serial given by the school's Principal. Some of them had severe family and personal issues, and they were not ready to give time for the study. Moreover, in the list, there were only five 4th grade job holder families whose children are enrolled in this school. However, luckily all those five families were interested in being participants in the research. Other five families were selected from higher education and professional background based on who responded first to participate. Prior to started, the study plan was to talk total of 20 participants (10 families, both parents), but data was collected from 19 participants as there was a single parent (mother) family (her husband died a few years ago). Single parenting experiences gave some different insights into parenting in this research. The intention of this research is not to compare, rather see in detail how experiences are lived in different social levels in the case of parenting in a particular context. Participants have been chosen for this study from two grounds of social level one is socially influential because of their education, job position and knowledge and another represents a vast number of people and their life in Bangladesh.

Since the plan of the study is to work with the parents to know their daily life experiences intensively in parenting children with ASD, thus the sample size of the study is not big. In fact, for a qualitative study, it is not necessary to have a significant sample size that is likely to quantitative research since quantitative research typically needs a big sample size for generalization. Thus ten families and 19 interviews are enough samples for this research (e.g., Bryman, 2012).

4.6 Demographic information of the respondent

In this research, a total of 10 families were selected, and the target was to know in detail about both parents' experiences through in-depth interviewing and intensive participation. Interviews were conducted with both parents separately to understand both parents' perceptions separately and how gender role works in parenting experiences with children with ASD. A total of 19 parents from two different social levels participated in the study. Demographic information of participants is given in the following table1. Here to protect the confidentiality of the participants, their original names have been anonymized into pseudonyms and other information is kept the same they were given during data collection.

Participating parents' name and age (years)	Gender of children with ASD	Age of children with ASD	Number of Other children	Occupation	Education
Family 1 Father (F) : Roni, (41 years) Mother (M) : Rina (37 years)	Daughter	8 years	one younger daughter (4 years)	F:University teacher M: Housewife	F: PhD M: Master Degree
Family 2 Father (F) : Hasan (63 years) Mother (M) :Hena (57 years)	Daughter	18 years	One elder daughter (28 Years)	F: University teacher M: Housewife	F: PhD M: Master Degree
Family 3 Father (F) : Anjan (40 years) Mother (M) :Sefa (39 years)	Son	11 years	Na	F: University teacher M: School teacher	F: PhD M: Master Degree
Family 4 Father (F): Sofiq (40 years) Mother (M): Era (37)	Son	10 years	One younger daughter (5 years)	F: 1st grade officer M: Housewife	F: Master Degree M: Master Degree
Family 5 Father (F): Alam (53 years) Mother (M): Aliya (51)	Daughter	18 years	Na	F: 1st grade officer M: University teacher	F: PhD M: PhD
Family 6 (Single parent) Father (F): Akter (Deceased) Mother (M): Alifa (45)	Daughter	17 years	Na	M: Attendant in a ladies hostel	M: Secondary school certificate Exam (SSC)
Family 7 Father (F): Sipon (46 years) Mother (M): Ruma (36 years)	Daughter	13 years	2 daughter One is 20 years and another is 5 years	F: Peon of a dean office M: Housewife	F: 10th Grade M: 6th Grade
Family 8 Father (F): Eshak	Son	12 years	One elder daughter	F: Office Assistant	F: SSC M: 5th Grade

Participating parents' name and age (years)	Gender of children with ASD	Age of children with ASD	Number of Other children	Occupation	Education
(46 years) Mother (M): Popi (37 years)			(19 years)	M: cleaner in ladies hostel	
Family 9 Father (F): Robi (47 years) Mother (M): Mim (43 years)	Daughter	16 years	One elder son (22 years)	F: Small business M: Housewife (Arabic/religious tutor but mostly volunteer)	F: 10th grade M: 8th grade
Family 10 Father (F): Rafiq (40 years) Mother (M):Manika (34 years)	Son	11 years	One elder sister (17 Years)	F: Office Assistant M: Housewife	F: 10th grade M: 6th grade

Table 1 Demographic information

In Table1, information about the number of other children has been put as well because it helps to understand the family structure, support system, interaction and relation of autistic children with their siblings and how parents organize time for caring for other children as a part of parenting experiences. Besides, this research intended to see how parental experiences are existing in various social levels. Therefore, parental professional and academic backgrounds have been given in the table.

Need to mention that higher academic and professional positions bring these families or parents special life facilities with better living conditions. For example, university teacher and 1st-grade government employees have some facilities which are not only always their standard income, but they also have special values and high respect in Bangladeshi society (e.g., Sultana & Motalab, 2014; Magee & Galinsky, 2008). Their salary is given through Bangladesh government's pay scale, which is equivalent to the middle to upper-middle class according to their experience, promotion in their job and familial situation depend on one or both parents' earning members in their families. On the other hand, parents from fourth-grade job holder' have low range of salary with low facilities and social status but able to fulfill their basic needs.

Participants Rina and Hena were both working women before they came to know the autism of their children. They left the job for the sake of taking care of their children. Era wanted to work but sacrificed for his son. On the other hand, Alifa did not do any job because she preferred to give her time to her daughter however; she had to start a job when her husband passed away. As her husband was an employee in this university (research area), so university administrator gave her this job as an attendant so that she can be independent and take care of her child.

4.7 Data related method

This part describes the data collection methods and tools, along with the data management and analysis.

4.7.1 Data collection methods

After getting the contact number and address, researcher made the first phone call to the parents to briefly introduce the project and invite them to participate in the study. When they confirm participation, researcher made the second call to decide the time of the interview and the place or the way of interviewing according to participants' preference. Due to Corona situation, we needed to be more strategic about the interview process. In this case, the priority was health and safety for all. The following parts will uncover the data collection method, time and place/way.

4.7.2 In-depth interview process

The data was collected through in-depth interviews, which helped get detailed information about parental experiences with their children with ASD. The interviews were carried out in a semi-structured way and more unstructured interaction. That means using open-ended questions that allowed participants to discuss and talk about their experiences in detail in their own way. This kind of interview helps this research to explore participants' thoughts, feelings, and perceptions about their experiences in parenting as well as understanding their personal and emotional issues. Semi-structured and open-ended questions helped to obtain participants own interpretations instead of following predetermining formalized set of questions (Patton, 2002; Bryman, 2012). According to Creswell (2013, p.48) "the more open-ended the questioning, the better, as the researcher listens carefully to what people say or do in their life setting". An interview guide (included in appendix) was designed by following research questions and objectives that guide the researcher throughout the interview session, as well as supported to not overlook any important point to ask. Moreover, the interview guide helped to ask participants the same type of questions and acquire data according to the research objectives. The data collection process through open ended questions and in-depth interviews made participants free to share their stories and voice, as a result obtained rich information that executed the research objectives.

On an average, each participant was interviewed for fifty minutes (without including flexible break time). Since the research field was in Bangladesh the interview language was Bengali because most of the participants are not use to or comfortable to speak in English and they prefer Bengali to speak thereby they expressed information freely and in detail which helped me to obtain rich data about their experiences. With the permission of participants, all interviews were recorded. Besides the record, researcher also took some notes as a backup.

4.7.3 Procedure of taking interview

Multiple procedures were taken to conduct interviews in this present research. Due to the Corona situation, interviews were taken, focusing on and considering participants' health issues first and how they prefer to participate. Therefore, 13 out of 19 interviews were taken by video call, and in this case, participants decided the media of the interview. According to the convenience of the participants, I took seven interviews by Zoom (Zoom is a cloud-based video conferencing service you can use to virtually meet with others - either by video or audio-only or both, all while conducting live chats - and it lets you record those sessions to view later[4]). And five interviews

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[4] https://www.pocket-lint.com/apps/news/151426-what-is-zoom-and-how-does-it-work-plus-tips-and-tricks

by WhatsApp (used for message and either one-on-one or as groups and can also be used to make video calls and telephone calls using your data or WiFi instead of your minutes. It can also be used to send photos and videos to people on your contacts list[5]) since all participants were not comfortable with zoom.

Another point was notable that regardless of their social level, each family has at least one smartphone because their children need to attend online classes due to Corona. In both cases, I used an extra recorder which worked as a backup. And this way, interviews were finished through video calls. In addition, six interviews were conducted face to face according to the wishes of the participants, where all safety measures and distances were strictly maintained to avoid any kind of harm. For ensuring safety face to face interviews were not conducted inside of participants' houses relatively open places beside their house in a natural and secluded environment were selected where there was no public gathering or crowd. All these interviews were recorded with the permission of Participants. Both video call interviews and face to face interviews help researcher to observe parental expression while they were talking about their challenges, support, success, necessities. Researcher also had the opportunity to see their children because during conducting interviews with parents, their children came and showed some interaction and activities in both types of interviews that helped to get some necessary visual impression even in technology-dependent interview in pandemic situation.

4.7.4 Data transcription and translation

As the interview was done in the Bengali language thus, data was transcribed in Bengali by the researcher. During transcription, pauses, stutters, silence, involuntary actions and repetition of words that seemed habitual were all removed. The focus was more on the content and information, rather than how it was said without causing any missing of data. However, some expressions like crying while talking about their pain were recorded in the bracket in the transcriptions. After transcription, the researcher translated data into English with correct words and grammar to make it clear in proper meanings and interpreting exactly what participants mentioned about their life situation and experiences.

4.7.5 Data analysis

According to Creswell (2013, p.180) "data analysis in qualitative research consists of preparing and organizing the data" Bryman (2012) described data analyzing as managing and interpreting the data. In this research, data is managed and analyzed through thematic content analysis.

Braun and Clarke (2006, p.79) mentioned thematic analysis as a method "identifying, analyzing and reporting patterns (themes) within data" which organize data as well as describe data set in detail. As the first part of the thematic analysis, I read data for several times (e.g., Bryman, 2012; Creswell, 2013). During these steps I made the observation alongside the text and take some notes of a common pattern in the data set. Moreover, I identified the event, description by participants, which is essential for this research investigation and relevant to the research questions as well as the research objective to identify the theme. Coding each transcript by putting points with the key words alongside the information written each line/paragraph one of the main elements of identifying of themes for analyzing (Bryman, 2012). Line by line coding is

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[5] aga.co.uk/magazine/technology/internet/communications/what-is-whatsapp-and-how-do-i-use-it#:~:text=WhatsApp%20is%20used%20for%20messaging,people%20in%20your%20contacts%20list.

essential to avoid losing important perspectives given by participants (Charmaz, 2004, cited in Bryman, 2012). Braun and Clarke (2006, p.82) assert, "a theme captures something important about the data concerning the research question, and represents some level of patterned response or meaning within the data set". Therefore, through this process, themes were identified manually, and then data was taken from each transcript under the particular theme in another file with the mark of different interviews. Afterwards, themes were divided into various subthemes to do the analysis. Table 2 demonstrated some themes and subthemes identified from data by coding-

Theme	Subtheme
1. Parents' experiences when they came to know about their child's autism	o Parental Knowledge about autism o Shocking with a feeling of lose o Swift to seek help
2. Relations and interactions	o Deep relation and good interaction with mother o Interaction and relation with father o Relation and interaction with siblings o Relation and interaction with peers, teacher and others
3. Perception of parents with their child	o Positivity o Acceptance with time o Feeling of Burden
4. Parental experiences of challenges and struggling	o Stressful experiences and parents' health o Challenges in understanding the child o Challenges to get access in health education and other necessary services o Challenges due to social perception o Challenge with child's destructive behavior o Conflicts between parents o Challenges due to Corona
5. Gender role of parents and activities	o Role of Mother o Role of Father o Role during COVID
6. Coping Strategies	o Diverse strategies in parenting and understand the relation with social level o Personal stress management o Future plan for the children with ASD
7. Support	o Informal Support o Formal support
8. Identified Requirements and recommendation	o Ensure security and minimum respect o Get quality services according to the need o Residential and institutional facilities

Table 2 Pattern of some identified theme and subtheme by coding

4.8 Ethical considerations

In a qualitative research design, ethical issues should be considered strictly. As it is mentioned in the introduction, children with ASD are marginalized groups in Bangladesh who face different forms of vulnerabilities. In this case, parents are direct or indirect sufferers of their children with ASD. Thus, the study topic was sensitive for the parents, and researcher needed to be very aware of their rights and sensibility. Ethics has been strictly maintained at every stage of the study, beginning to the end. This study was guided by the ethical principles discussed by Bryman (2012). The four primary areas of ethical principle were considered in the study, which includes harm to participants, informed consent, invasion of privacy and deception (Bryman, 2012).

First of all, data collection was done with great sensitivity. According to Bryman (2012), before starting data collection, the researcher needs to simply illustrate the study's purpose and participants' rights. In this study, from the onset, participants were informed about the purpose of the study, procedure, benefits and risks, participants' rights, a clear idea about the researcher's position and the use of information. They were also informed about their voluntary participation in the research, their rights to withdraw from the study. According to Hammersley and Atkinson (2007, p.210) "it is often argued that people must consent to being researched in an unconstrained way, making their decision on the basis of comprehensive and accurate information about it; and that they should be free to withdraw at any time".

Besides, a detailed consent form explaining their rights as participants were designed and sent to the participants. Consent was taken from each participant about their participation and the way they prefer to participate since, due to Corona, most of the interviews were taken by video call. Moreover, ensuring the confidentiality of participants' is vital to protect them from any kind of harm and feel free to share their experiences. In this study, participants were assured of the confidentiality of their responses, and their anonymity was maintained throughout the study. The name of participants and their children, the name of their living place and school name kept anonymous in this study to keep their rights and prevent harm. A relationship was developed between the participants and researcher based on respect and trust. With the permission of participants, the interviews were recorded to avoid the chance of misinterpretation and cross-checking of information and in this case to ensure confidentiality, all the recorded interviews and transcript was kept in a safe and secured file in the computer of the researcher and only used for the intended purpose of the research. The data was collected in the preference of participants' time, place and way they feel comfortable as well as can maintain privacy. Interview of father and mother were taken separately so they can speak freely about their individual experiences regarding roles, relations, challenges, supports and other issues without any hesitation or biasness. In the case of face to face interviews, safety measures for Corona were adequately maintained to ensure health safety.

4.9 Quality assurance of the study

Reliability is vital in social science research to understand the consistency and trustworthiness of the research, as well as validity, helps to understand the method in the investigation of the research (Kvale & Brinkmann, 2009). Though, validity and reliability are mostly used for assessing the quality of quantitative research however becoming increasingly relevant in qualitative research (Bryman, 2012; Creswell, 2013). The validity of research involves the data collection process. Besides, to establish the "trustworthiness" of a qualitative study, Lincoln and

Guba (1985, cited in Creswell, 2013 p. 246) use unique terms, such as credibility, authenticity, transferability, dependability, and confirmability for internal validation, external validation, reliability, and objectivity. Eisner (1991, cited in Creswell, 2013 p. 246) discusses the credibility of qualitative research instead of using term validity. In this research, data were collected by following ethically accepted standards, so the findings are credible. Again, in this research, to see the scenario of parenting experiences from different angles, data was collected from different social levels and both parents through in-depth interview using a guideline and proving questions. In addition, previous literature and theoretical framework validated the findings, and analysis of the study.

The study is authentic because, through the parental voice, experiences are interpreted and explored. Regarding transferability, the sample size of the research is enough (e.g., Bryman, 2012) as the research aim was not to generalize, rather the findings of the research gave rich information about parenting experiences with their children with ASD, including different dynamics and diversity in different social level. Dependability refers complete record of the various stages in the research (Bryman, 2012). The research clearly outlined all the processes from the problems statement, theoretical choice, methodological choice and other pertinent parts. Moreover, the research ensures the confirmability as the collected data or finding was not biased by the researcher's personal values because this study on parenting with autistic children was a completely new experience for the researcher where research ethics, reliability, and authenticity were strictly maintained.

4.10 Limitation of the study

Firstly, the limitation causes due to the pandemic situation (COVID 19) limited the motilities of the researcher or collect data from a broader context. Thus, the study field was selected nearby a place centering the school.

Secondly, the study attempts to focus on various dynamics of a child’s and parents' situation, including various aspects. However, the research did not focus intensively on the impact of child’s level of autism (mild or high) in parenting experiences. According to Smith et al. (2001) level of child, disability is an important element to understand parental stress. Moreover, the level of autism may influence coping strategies and other treatment-related experiences of parents, which was not included separately in the study.

Thirdly, this research focuses on parental voice and experiences to understand different dynamics regarding both parents and children since the parents are directly involved with their children with autism. However, including the perception of some experts relating to the field could have added some more observation about the actual condition of policy and their implementation in Bangladesh as well as what can change the situation in the context of Bangladesh.

Moreover, a certain timeline of the research can be included in the limitation. However, the limitation of the study will open the scope of new researches in this field and fill the knowledge gap.

4.11 Chapter Summary

The chapter discussed the methodological approaches of the study. The chapter included interpretivist epistemological and constructionist ontological approach, systematic literature search techniques, participant selection, demographic information of the participants, data collection process, thematic analysis of data along with ethical standard and limitation of the study.

5 CHAPTER FIVE: FINDINGS AND DISCUSSION

This chapter presents the findings of the study collected from the field through interviews. Findings are analyzed based on themes according to research objectives and questions. The findings answer the research question of the study; the main research question of the study is- How do the parental experiences with their children with ASD are lived in different social levels in terms of relations, roles, challenges, coping strategies, supports and requirements? Mainly, this chapter explores and discusses the findings to comprehend different dynamics of parental experiences with their children with ASD in Bangladesh. To obtain a clear idea of parental experiences, this chapter intends to discuss from the first impression to the present state of parenting experiences concerning research objectives and questions.

Besides, in this study, data were collected from 2 different social levels (meticulously discussed in the methodology part). For the convenience of presentation and discussion of the findings, FSL or first social level has been used for the parents from higher status, education, and professional background and SSL or Second social level has been used for the parents from lesser status, education, and professional background. Here, 'First' and 'second' are just two words using for the convenience of the research.

5.1 Parents' experiences when they came to know about their child's autism

This section presents parental experiences, knowledge, reaction and immediate action when they came to know about their child's autism.

5.1.1 Parental Knowledge about autism

The study reveals that initially, parents found some interaction, communication, or behavioral problems in their child, then they take them to a health specialist. In most of the cases, autism was identified when their child was 1 to 3 years old. It disclosed from the findings that irrespective of their social level, parents did not know about autism prior to get experiences with their children. In other words, regardless of their educational qualification parents did not have any clear idea about autism, why it happens, how long it may continue, or if there is any variation of severity among the children with ASD.

"*more or less within two years, we came to understand that she does not speak…there is an institute in Mohakhali (Dhaka) where they do some tests with the help of different types of noises in the ear. We went there, and they did some tests. A branch related to this problem in Shishu (Child) Hospital confirmed it later on. We heard the term 'autism' first from them in the Shishu Hospital"* (Hasan). A mother said, *"My husband did his PhD from North-America, but none of us had any idea about autism or anything regarding this"* (Aliya)

Moreover, from the lack of knowledge and understanding, some parents thought the child would be cured. A parent mentioned, *"Normally, people's general knowledge about autism is very low in Bangladesh. I am educated, and I am a Master's pass as well; still, I did not know anything* *about autism…., I thought that if we can take care of her and provide her with therapies, then she will be cured soon"*(Rina).

The quotes mentioned above from the participants elicit the general knowledge of mass people or parents about autism in Bangladesh, which is very low (e.g., Ackerman et al., 2005; UNICEF Bangladesh; 2014; Soron, 2015; Alam et al., 2020).The above-cited data was collected from the highly educated and respected people who have more significant contribution in education and awareness (the first two examples have taken from university teachers with completion of PhD). However, they had no knowledge or idea about autism before getting experiences with their child, just as the parents from a lesser educational background. From their lack of knowledge and understanding, the parents initially thought that their child would be cured soon. This fact expressed that autism is a kind of untold or un-discussed topic in Bangladesh even though the government has taken initiatives to increase the awareness and knowledge about autism (e.g., Soron, 2015). Moreover, data in the study demonstrated the gaps of the awareness initiatives because the knowledge about autism is still very low.

5.1.2 Shocking with a feeling of lose

It was shocking after getting a clear idea through discussing with the doctor to every participant because parents desired to have an average child, not a disabled one. Carroll (2013), in the context of the United States, explained that most families desire to have an average child, not the one with a developmental disability, which is consistent with the research finding.

"Not having a normal child was very unfortunate for me .I cried a lot after learnt about his condition, I had a dream of a son, and Allah has given him, but I wanted a normal baby" (Monika).

"Actually, at that time, we could not even believe this. In a sense, our whole family became autistic then" (Roni).

"I was emotionally broken with the feeling of loss from the moment I came to know about her condition because society neglects such children. I felt a fear of uncertainty to raise the child with my earning" (Sipon).

From these statements of the participants, it can be said that it was a shocking experience with the feeling of loss for the parents (e.g., Altiere & Kluge, 2009) and hard to believe initially because of their expectations of average child and the fear of future unknown journey and uncertainty. Moreover, the social context and opposing views in society overwhelmed them (e.g., Ackerman et al., 2005; Rahman et al., 2016; UNICEF Bangladesh, 2014). In addition, the cost of raising this kind of child also came immediately as a part of a parental shock, especially parents from the SSL (e.g., Islam, 2020; Knestrict & Kuchey 2009). This analysis indicates the interaction from micro to macro level discussed in both QoL and BES theories where parental desire (micro) relates to social values (macro) as well as express the relations between parental uncertainty and social level (Schalock & Verdugo, 2002; Bronfenbrenner, 1989).

5.1.3 Swift to seek help

The study reveals that parents became so restless after knowing about the autism of their children that they lost focus from other aspects of their life except thinking about what they can do for their children and became desperate to seek help in any possible way.

"In the beginning, I always used to feel restless thinking what should I do, what will happen by doing anything as my child is like this. I sometimes thought that if selling everything we had could completely cure my son, we would do that too. I lost my focus from my study and stopped communication with my friends" (Sefa).

Regardless their condition, parents took the initiative instantly to try if there is any possibility of curing their child. They tried from the doctor, therapists to traditional healers.

"*We took our child immediately to a psychiatrist after the child specialist. We tried everything, doctor, therapist and traditional healer"* (sofiq).

Financially capable parents did not stop after trying treatment inside the country; rather, they took their child abroad for getting better treatment.

"We tried our best, not only in our country but also we took her to India to get a clear idea and to check if there was any way of curing her (Rina).

A study of Altiere & Kluge (2009) showed in the context of southeast Michigan that after knowing their child's autism, parents are swift to seek help and mobilize their resources, sometimes in any possible way, which is consistent with the result of the current study.

In addition, it reveals in data that parents from FSL are likely to get access more option to seek help than parents from SSL (e.g., Knestrict & Kuchey,2009- in the context of Holand), such as, taking their child to abroad, suggests relations between parents' financial status and access abilities.

5.2 Relations and Interactions

The data, it reveals that the degrees of intimacy, relation and interaction of autistic children with their parents and other members are varied. Generally, they have better intimacy with their mothers.

5.2.1 Deep relation and good interaction with mother

In the study, in every case, mother claimed that they always stay close to their child so they understand better their child, and there is good relation, interactions and communication between child and mother. Not only mothers but also most of the fathers indicated that children have good relations and communications with their mother than them. In addition, mothers expressed deep understanding and relationships when they share their experiences which is absent in fathers' cases.

"I have an excellent interaction with my child. Our understanding is such that I understand everything she wants to express; not even her father understands that. May be for some reason, she is trying to disturb you or grab/hold you; I know why she is doing so. She will try to hold you

because of your mobile phone. I understand when she wants to go to the toilet through her facial expression. Even she comes to me if she needs something" (Rina).

Thus, generally, mother and child have good relation and interaction. Furthermore, in the findings of the study, another critical thing came up that parents' personality and their experiences as a child has an impact in relation and interaction with their child that refers to both QOL and BES theoretical model of individual personality and micro-level interactions (Schalock & Verdugo, 2002; Bronfenbrenner, 1979; 1989).

"I always wanted that I will have a daughter who will have many conversations with me. I could not do this with my mother as I have much distance from her. My philosophy of persistence is different from my mother. My mother has particular thinking about me…This does not satisfy me, and thus, a distance came between my mother and me. So, the relationship that I could not build with my mother, I always wanted to build that with my daughter. And I talk a lot with my daughter, and maybe I talk with her without any reason. Maybe this is creating confidence inside her for which she never felt left alone. I know she can understand everything. This is a relationship of the soul which I cannot make anyone understand, she in fact, knows everything of mine, and I understand that. In fact, I understand all of her moves. I cannot express this feeling with words. It is not possible. This is very interesting for me, and I enjoy this very much. She likes gestures, she likes voice tone, she understands these if I ask her that, 'what have you eaten today dear?' she replies joyfully that she had singara (a kind of snacks). But if she was asked this purposefully, then she would not give any reply. If we can make her understand something which is very funny for us, then she also enjoys that. She laughs a lot then and we need to make her understand this by drawing figures, and I understand how to tell her something so that she can grab the fun inside. Moreover, I inform her, my plan or when I go out" (Aliya).

The statements mentioned above of a mother demonstrated a depth understanding of and the soul's relationship between mother and child. This understanding and relation help a mother to know how her child understands and interacts or communicates better. Moreover, findings of the study demonstrated the impact of a particular personality, childhood development as well as childhood experiences of a parent in the relationship with their children with ASD.

5.2.2 Interaction and relation with father

The field data reveals that in most cases, children have good relations and interaction with their fathers. Fathers take care of their child and their needs. The child also adores their father, communicates with them and waits for coming back of their father, for instance-

"*His bonding with me is such that he cannot live without me, I cannot spend a lot of time with him but he waits for my coming back home, he is a father's fan, he loves to spend time with me, play with me"* (Sofiq).

"*Though this daughter of mine has issues, but she understands if I am sick, she hugs me tightly and adores me, she kisses me"(Sipon).*

"We have a very good relationship that I understand what my daughter needs just by looking at her eyes" (Anjan).

All these above-mentioned quotes indicated good relation and interaction between father and children with autism. However, there is some exception as well. One father said, *"She does not interact with me that much, and I even do not try to interact with her. Most of the time I am busy with my work, focus the finance of the family, she stays her own and mostly interacts with her mother"(Roni)*

Above mentioned father's statement shows that father's interaction and relations varies and do not always they have good interaction and relation with their autistic child. Sometimes father's interaction and relations depend on their focus of interest and their job and finance-related involvement. In addition, during Corona in some cases intimacy of relation between children with ASD and their father increased as their father stay home long time than before- "*her all relation is with me now, this has increased in this pandemic situation as I stay longer at home, she likes to stay with me, annoys me whole day to take her out, for a car ride, or to bring foods that she likes, she talks with me whole day as well"* (Hasan).

5.2.3 Relation and interaction with siblings

It is clear from findings that relations and communications with siblings of the autistic child is noticeable. They cannot always express themselves and their feelings, but child with ASD interact with their siblings in different ways. For example, one mother uttered about her two daughters-

"They have an excellent interaction as well. She (child with autism) has no interest in fighting; rather the younger one beats her. She is the one who sacrifices. But they cannot express their bonding with each other, like, adoring younger sister, she cannot express like this. But she does not dislike her younger sister. One day, I climbed up the stairs and told my two daughters to climb slowly. As I was not there, my elder daughter held her younger sister to climb up the stairs safely" (Rina).

It reveals in parental experiences that siblings contribute as support, playmates and interactional development for their brother and sister with ASD (given in detail in the support part). In some cases, it is hard for siblings to adjust and interact with their brother or sister with ASD- *"Her younger sister does not want to play with her that much because she does not understand and try to hit her younger sister all the time"* (Ruma).

5.2.4 Relation and interaction with peers, teacher and others

The study showed that children with ASD interact less or more with peers, teachers, and others, especially whom they see frequently or the people who generally take care of them on different occasions.

"She has good interaction with her cousins, she loves to stay with them, play with them, moreover, she has a good understanding with her grandparents, uncle, aunt and teacher whom she knows and who looks after her and takes care of her in different times when I was busy with other jobs" (Aliya).

However, it always varies depending on the child and other parties where it is clear that interest of both parties is important in relationship and communication, such as, one parent narrated, *"He does not have any good interaction with any of our relatives, he wants to get close, but they like to stay away"*(Sofiq).

5.3 Perception of parents with their child

In this part, mainly I intend to focus on general parental perceptions of their children and how they perceive having a child with ASD. The study reveals that regardless of their social level majority of the parents mentioned the religious aspect of having a child with ASD that they have this child with the wish of almighty, so they cannot pass through their child. Since having a child with ASD is their reality, some parents perceived it very positively. Again some parents try but cannot carry the positivity about their child rather accept it with the time as their fate and leave it to the almighty.

"She is a human being like us. She loves us. I never feel sad or ashamed for her. Allah gifted me this child. Everything happened with the wish of Allah. Allah likes her, so why I would not like her. I must like her. I think the Almighty Allah has given me happiness through her, that is, if I do not get heaven after my death, then I may get heaven only because of her"(Mim).

Jegatheesan Miller and Fowler (2010) demonstrated that religious belief in Asian Muslim immigrants' parents in USA helps to perceive their child with ASD positively. Thus parents consider having such a child as a blessing because Allah made this decision for them for good reasons. In these cases parents cannot question instead accept it positively and do their best for their children. These religious beliefs and positive perceptions mentioned in Jegatheesan et al. (2010) echoed in the statement mentioned above of Mim. However, not every parent in this study can follow religious beliefs this way and perceive their child positively. Again, different perceptions can come in different life stages-

"Actually, what should I say, he is a gift from the Almighty Allah, we cannot throw him away. When he was small, I really used to think that it would have been better if he had lost; maybe because I was very young then, I had less patience then. And I actually was not introduced with these things. I was the youngest daughter of the family, and my father was a government official. I never understood what is a struggle and never seen this type of thing in Dhaka. One day, even I told my husband that we were going to a Kabiraj (traditional healer) riding on a car, while returning, I saw a jungle, I was telling him that, "Let us leave him alone in the jungle and go away." Then he got astonished and said, "What are you saying!" This, too, has happened…Now the situation is such that it is impossible to live without him" (Era).

The above-mentioned quote expressed that perceptions and feelings of parents with their autistic children can depend on parents' previous experiences, level of maturity and patience, degree of involvement and capacity of handling this kind of child and so on. Moreover, parental perceptions may be fluid that changes over time, once she wanted her child to be lost, but now she cannot even think of living without this child. Moreover, some parents from SSL, in their experience, perceive their child as a burden due to their financial hardship to bear the requirements of the child (e.g., UNICEF Bangladesh, 2014; Islam, 2020).

"She is a human, we cannot throw her away, sometimes we get angry, then we scold her a lot, sometimes we beat her as well, but she is our child however she is. Nevertheless, she is burden for a family like us. Actually, the Almighty Allah has given us by mistake; this child is not for us" (Sipon).

However, the finding reveals that positive perceptions in parents about their children with ASD, such as focusing their behavior, hope for improvements or positive changes in parents due to their child etc., help parents to mitigate hardship in parenting. This finding is consistent with the study of Altiere and Kluge (2009).

"I know having this kind of child is not easy, but I am happy with my daughter, my son is normal, but he disobeys me, and his behavior sometimes hurt me. I know my daughter does not understand like my son, but I hope her improvements even I dream of her marriage one day. With my limited ability, I try to give her best, she also loves me. That is why I never feel any burden" (Robi).

"I always perceive my daughter as a blessing because she has made me a different person, who is strong and perceive life differently. I do not prioritize anything unnecessary anymore. Besides, I see many old people whose children do not look after them so they are alone and have no work to do. This reality makes me realize that I am fine, and my daughter will live with me as long as I am alive. Even I will have work at my old age since I have to take care of her. I take it positively, which keeps me very strong" (Aliya).

Parental perception varies about their children with ASD because parents are not the monolithic group. However, in the study, every parent acknowledges their child as human first of all. Some parents do not perceive their child positively rather accept it as their fate; however, some parents, with all of their hardship, perceive their children as their reason for happiness and blessings where their positive perception helps them to be hopeful and strong. Besides, parental perception may change overtime. One thing is recognizable from the discussion that parental perception and viewpoints can be created in different ways based on their growing environment, personality, financial issues and other influences they come to contact with, which are recognizable through the Bronfenbrenner's ecological theory (1979) that explains person's interaction in micro to the macro level and its influence on them and their perceptions.

5.4 Parental experiences of challenges and struggling

Parenting a child with a disability is a mixture of different experiences (Carroll, 2013) where the challenge is one of them. In this study, every parent mentioned their experiences of challenges and struggling from different aspects, which started from the early age of their child and continuing. These challenges influence both child's and parents' quality of life (Begum et al., 2020a). Though challenges are interrelated to one another, here to obtain a clear idea challenges are described and analyzed by following subthemes.

5.4.1 Stressful experiences and parents' health

In this study, all parents mentioned that rearing, handling, take caring of this kind of child is very stressful, which is undoubtedly challenging for them (e.g., Carroll, 2013; Hayes & Watson, 2013; McStay et al., 2014; Enea & Rusu, 2020). Generally, every challenge they face causes less or more stress to the parents which may differ from person to person. Mainly, parents need to give more care for the child with ASD than the "normal" child which is stressful (e.g., begum et al., 2020b; Hayes & Watson, 2013; Algood et al., 2013).

"It is very stressful to bring up such a child because you need to think more, give more attention and time. So, much energy is needed with more resources. I passed a lot of depressing time, but I never stopped taking care of her or never have I ever neglected her" (Hena).

Therefore, from the findings, it is clear that parents need to give more attention, thought, energy and more patience to take care of the child with ASD, as well as more resources are required, which is stressful. However, parents have to continue their duty of taking care of their autistic children with their overwhelmed stress as they are the primary caregiver in the context of Bangladesh (Hamadani & Tofail, 2014).

One mother mentioned, *"Though I am a mother, sometimes it seems unbearable for me but nothing to do, he is my child"*(Manika).

However, their parenting stress with their child with ASD never leaves them without cost; rather often lead them to low quality of life with different mental and physical health challenges (e.g., Heiman, 2002; Pisula, 2011; Benjak et al., 2011).

"Then a time came when I realized that I am getting sick gradually from over work and stress, sometimes I feel like I have become a half-autistic. Everyone's life history is more or less similar who has a special child. At a certain point in their life, all of them become mentally sick" (Era).

"Thoughts of her have increased my blood pressure. Till now, I have stroked twice. I could not sleep at night. I used to wake up suddenly and start crying loudly. I used to have a lot of headaches then. My husband also has become very sick with high diabetes, and he needs to take insulin" (Ruma)

Therefore, the stress of parenting children with ASD can cause serious psychological and physical health challenges for parents in the context of Bangladesh, which has a negative impact on both parents and child daily life quality and participation (Begum et al., 2020a).Therefore parent's good health is important to ensuring quality of life for both parents and children with ASD. Benjak et al. (2011) emphasized to include close monitoring of parents' health and well-being for treating children with ASD properly in the state system and policy measures which is neglected most of the cases.

5.4.2 Challenges to understand the child

The study findings express that parents faced challenges understanding their autistic child, mostly initially because the child used to get hyper suddenly but did not understand the reason. Parents felt helpless thinking about how to handle the child and what could help children to communicate better. Many parents mentioned that it took a long time to understand their child, and gradually they understood. On the other hand, some parents said they are still facing some difficulties understanding their children in some situations even though they are taking care of their children for more than twelve years.

"It was very challenging to understand her. Finally after a long challenge, I understood her personality. She does not find anything interesting until anyone let's her know why is that happening. I need to draw for her because she understands better by drawing. She sings when she feels like singing. If you ask her to sing a song, she will be immediately hyper. These are some examples" (Aliya).

"We really do not understand what his interest is; sometimes he likes school, sometimes he does not. We understand he is different, he often feels scared, but we do not know why? We went to

the doctor and traditional healer, but still, we cannot figure it out. It would be great if we could get some good help or learning" (Eshak).

Analyzing the above-mentioned quotes, it can be seen that generally understanding a child with ASD is challenging however, parents gradually understand from their daily life experiences. In this case, some parents understand better, and some parents understand less. Besides the above-mentioned two quotes, I have selected the first one from FSL and the second one from the SSL Background. It was noticeable from the observation that parents from FSL background show better realization and explanation capacity of their child's behavior. This observation is consistent with the study of Begum et al. (2020b); where authors discussed educated parents understand their children better because they have better cognitive functions and understanding capacity about how to manage. In the second quote parent mentioned that they need help and learning support to understand their child. In this regard, one parent mentioned-

"To handle this kind of child we need to know what and how to do, so we need training but, there is no training scope for parents in our country but only for the teacher and therapist. Those teachers who went for training write down what s/he learnt and gives training to other teachers as well. They keep some parents in their training as well so that it becomes easier for them to understand. But, from my observation, this does not benefit the parents who are less educated because they do not understand anything. Parent's education is crucial in order to get best out of the training. For example, my mother is not that educated, so she feels boring to spend time with my son. She does not understand him. Rather, she says that, my son is very disturbing. Again, when we used to go to our village, everyone would look at him surprisingly; they used to ask me if he is mad or if he has any problem because they are not educated. So, I needed to make them understand, but I do not face any problem here in our neighborhoods because all of our neighbors are university students or educated" (Sefa).

Thus, parental education came as vital in the findings not only for understanding their children with ASD but also for getting a good outcome from the training. In addition, from the participant's interpretation about the school training session, it is clear that this kind of training is mainly for the teacher. However, they include parents but ignore the individual parenting level of understanding, which poses another challenge. However, previous research demonstrated that parents can learn how to deal with their child with low academic level if they receive good training opportunities. For instance, Ackerman et al. (2005) discussed that due to lack of knowledge about their child's disability, sometimes parents do not understand what to do and how to deal. However, if parents are given a chance for knowledge or education, they will become energized and active. The world health organization has also prioritized parental education in autism to increase parental understanding (Stošić et al., 2020).

5.4.3 Challenges to get access in health education and other necessary services

Parents mentioned several challenges to getting proper treatment for their children with autism, leading them to be less satisfied with the medical system in Bangladesh. The study findings reveal that sometimes parents faced challenges receiving the correct information, therapy, or treatment they expected. Akhter (2021) discussed that, in Bangladesh, there is still limited training and knowledge among the practitioners, which reflects in the findings of the current study.

"Doctor said, there are many examples that this type of child has cured. For two to three and a half years, none told me directly that she will not get cured. I had tried everything and gave one hundred percent effort to get treatment. Then to be sure, we went to India and figured out the truth" (Rina).

"Due to regular communication problem we brought private therapy for our child but whoever came did not have any special education, just had a small training and just came to pass their time. Moreover, this private therapy is costly; you have to pay four times higher than the hospital. We see that in foreign countries there are treatments for this type of children, but unfortunately, we do not have those in our country" (Roni)

Besides, despite different government initiatives (e.g., UNICEF Bangladesh, 2014; Soron, 2015) the study findings expressed negligence in getting necessary treatment for the children with ASD in Bangladesh.

"*This type of child has many manifestations, such as convulsions, OCD, depression and different types of sexual issues, there is no treatment of autism, but there are treatments for these. But psychologists and doctors have sympathy for them, but they do not have any concentration regarding them. It is like, their life is not that much valuable"* (Aliya).

Thus, there is a lot of knowledge gap, skill gap, and ignorance are noticeable in the medical system of Bangladesh, and this information and awareness came from the educated parents/ FSL. Parents from SSL did not mention any gap in the treatment system, so it seems they are not aware of these challenges.

Furthermore, regarding educational services, parents expressed challenges due to lack of research, lack of proper monitoring systems, lack of skills and handling power of the teacher. Besides, the lack of individual child's requirement based activities in school came as one of the big challenges in data.

"A lot of complaints used to come to me daily from the school. But, she did not do anything at home that she used to do in school…. Then I realized that the teachers do not treat the children through understanding children's type and level, which ultimately makes the children hyper. Teachers have a lack of training, and they have a lack of intelligence. Still, they try to give their service as much as possible for them, they care the children, and my daughter would not stay with them if they did not care for her. Adoring someone is a different thing from handling someone with intelligence" (Hena)

"Her school facilities and systems are not up to the mark, and they do not do anything as per the requirement of a child, just maintained general activities. There is no research, and their monitoring system is not satisfactory. Those who are not concerned about their children, like, a shopkeeper, will keep his child here because he does not have any demand like us. They do not understand. Again, there are many normal schools in Bangladesh, if every school would take three or four children like this and provide them extra care, then this problem would not become this serious. Sometimes they take, but they do not provide with the extra care these children require" (Roni).

Parents from FSL described these challenges mentioned above where they also relate to parental education and social level to recognize school-related challenges for autistic children. Parents from FSL mentioned that they are concerned about special school services, but a parent with less education may not concern with these issues. Moreover, they indicated ways of dissolving academic challenges by the support of normal school. However, the opportunity and care in a normal school for autistic children are very poor which reflects the work of Ackerman et al. (2005).

In addition, research findings illustrate that every service is costly for children with autism, such as particular school, treatment and therapy. Moreover, they need some exercise instruments to improve their physical conditions, which are also expensive. Cost related issues mainly pose a challenge to the parents from SSL backgrounds of their low income. However, parents from FSL also face challenges with the expenses in their context because their income is standard but not always adequate to serve their children's needs instead cause financial stress and harassment.

"Cost of therapies and her school has become a burden for us" (Ruma, from SSL).

"We have to take him to India twice a year due to his health condition, and he is under a renowned doctor, so treatment is very costly. It is serious economic harassment which is not possible for everyone to bear, it is also hard for us, but we are managing it. In addition, this type of child is very choosy, I will not eat this, I will not wear this, somewhat like this. They like rich food and expensive clothes which are also costly" (Anjan, from FSL).

Therefore, the cost behind a child with autism creates challenges for parents from every level but parents from SSL have to face more challenges. Ackerman et al. (2005) described this challenge as a severe test of a family's financial stability.

5.4.4 Challenges due to social perception

Cultural narratives devalue children with disability and their parents (Green et al., 2016). Findings showed social perception towards autism in Bangladesh causes serious challenges for both children with ASD and their parents, also involved the impact of macro-level in individual parenting experiences (e.g., Bronfenbrenner, 1989).

Firstly, Findings showed social perception stigmatizes children with ASD as results of a sin done by their parents (e.g., Ackerman et al., 2005), where parents are treated as the sinners. This perception devalues both parents and child as a result, poses massive parental pain (e.g., Green et al., 2016).

"*The people from the society say that maybe we have done something very wrong for which the Almighty Allah has given us this punishment. These words hurt a lot. People do not understand. They think that I am the one who did something wrong, which is very painful"* (Manika).

Moreover, apparent ignorance from society to the child is noticeable in the research data where no one wants to interact with the child. *"Whenever we take her outside, everyone calls her an autistic, this hurts us a lot. We feel terrible, and no one wants to interact with her"* (Sipon).

For this stigmatization and ignorance, parents deliberately hide their child's condition until it recognized by others. *"Sometimes parents hide their child condition until it caught by others. The main reason is our social context; there are many parents who need to hear different types of negative things"* (Aliya).

According to Acar et al. (2021), cultural values may influence a family's attitude toward a child's disability; the family may keep the child with a disability as a family secret. Besides, sometimes parents need to hear something very annoying for them and make parents feel down even in the working place.

"My parents and relatives always blame me to take this child in Japan; they think this happened because of Hiroshima. In my workplace, if there is any problem or if someone cannot win an argument with me, they try to stop me by telling me something about my daughter like I have become mad because of my daughter. They try to attack my weak point; rub salt on my wound" (Roni).

Thus, parents face this kind of social stigma regardless of their social level, which is always challenging and makes them psychologically sick and down. Societal negative perception works here as a big challenge against parents and their children with autism.

Secondly, dominant gender perception in Bangladesh devalues girl child than the boys (e.g., Jowel, 2014). According to Ackerman et al. (2005), girl children with disabilities are at more risk to face physical, emotional and sexual abuse in Bangladesh due to particular social perceptions towards girls. Thus parents face more worries and challenges with their girl child with autism (Rivard et al., 2014) which is precisely echoing in this study where ensuring safety for the girl child is one of the main concerns or challenges for the parents.

"Half of our tension would get reduced if she were not a girl but a boy. Suppose, in news and portals, we often see sexual harassment towards women. Now, she is growing up, and that has become our main point of concern. We don't even leave her alone to a close relative; we feel insecure." (Roni).

*"Security concern is more for the girl children than that of boy children. We always need to have an eye on her, which tutor we are selecting for her, how everything is going on; we always need to take care of these" (*Hena).

Therefore, in Bangladesh, parents have to face challenges and worries ensuring safety for their girl children with ASD because they can be easy victims of vulnerability/sexual harassment if parents do not keep an eye on them since they are not able to understand and maintain safety issues for themselves.

Thirdly, in the findings, some parents reported, due to negative social perception with autistic children, parents have to face the challenge to maintain their regular social communication and attachment.

Actually, I do not go anywhere. It is forbidden for parents of special children like me to interact with other people, the matter is such in our society that we cannot talk about this problem. So, I live entirely alone. In the building I live in, my interaction with other people is only hi-hello-how are you when I meet someone on the stairs, but as like other people go to each other's home that actually does not happen with mothers of special children like us because I need to take my child with me. He can touch or grab anything without asking or can start disturbing someone. I mainly mix with those who have a child like mine (Era).

Another parent describes no relationship with relatives, "*We did not keep any relation with our relatives deliberately because they blame us for the child.*" (Ruma).

These kinds of social views and parental detachment also may lessen the option of social support (Altiere & Klog, 2009). Findings show, sometimes a parent who has a child with ASD can be neglected from the different social invitations. However, not everyone faces this negligence; findings of the research indicate parents with strong social status may face less discrimination in this case. Such as one parent mentioned, "*regarding getting an invitation, I face less discrimination because of my social status, I am a senior teacher, I have political involvement and different responsibilities in the university. That is why my family is not excluded in social invitations, but I think this happens with other people"* (Hasan). This quote linked relationship between parental social status and their experiences.

5.4.5 Challenge with child's destructive behavior

"*My child damage things a lot, I was never able to gather the courage to keep my son to someone else even when I was admitted in hospital he was with me*" (Era).

"She has a lot of interest in fire and kitchen we need to keep an eye on her until she sleeps" (Roni).

This kind of destructive behavior of their children with autism put parents in a huge challenge. Thus, they never feel the courage to leave their children alone or keep to someone else; instead always need to keep an eye to save them from any kind of physical harm as well as protect important staff from damage.

5.4.6 Conflicts between parents

Findings shows, parents face conflicts in their conjugal life because of their children with ASD. In this case, husband and wife blame each other a lot. As a result, face difficulty in their relationship for a particular time which is challenging. However, over time, it gets alright though sometimes they quarrel because of their different parenting opinions. Nevertheless, at one point, they realize that there all disagreement comes from the feeling of stress and well-being for their children with ASD.

"We used to have problems between us because of our child. It was like, I could not tolerate some works of him, and he also did not like some of my works. That means sporadic behavior. Later on, we slowly adapted to each other. Over time, everything got all right. But, there are these types of problems in every family. The husband blames his wife; again, the wife blames the husband and says that it all happened because of you. My husband thinks I am a failure because I do not understand many things for which our child is like this. Though still, we quarrel a lot but we know everything for his betterment" (Sefa).

5.4.7 Challenges due to Corona

Parents reported pandemic situation created some challenges, such as children with ASD face difficulty adapting with the online class, so they cannot learn from school and their academic activities are stopped now. Again, they disturb more to their parents as they stay all day at home.

"She disturbs more when she is at home, she cannot concentrate on online classes. She used to walk to school and this was her exercise, so she remains tired. Hence she sleeps well, but now

she does not go for a walk, she does not sleep at night and tries to hit me, cries all night and disturbs me" (Ruma).

5.5 Gender role of parents

This section focuses parenting role of both father and mother and its different aspects through their experiences.

5.5.1 Role of mother

Mothers play the leading parental role in Bangladesh for their children with disabilities (Ackerman et al., 2005), which is also commonly seen in many other cultural contexts (e.g., Green et al., 2016; Acar et al., 2021). Findings in this research show the same scenario where regardless of the social level mother plays the role of a primary caregiver who is responsible for all kinds of taking caring of her child with ASD. In most of the cases, mothers do not get enough time to take a rest and think about themselves since the mother has to handle all other household chores and professions (for job holders) along with parenting responsibilities. What's more, single mothers need to play both parents' roles which is a massive responsibility.

"About my daughter, I am the primary caregiver. Her father gives me an opinion on how one thing can be better and lot of mental support, but I need to play the role of an anchor. This was not easy all the time, I have to balance everything, work, family and child. But, in most cases, mothers need to play the role of an anchor" (Aliya).

*"I cannot enough sleep at night, even not in the morning. If I become tired after working for a long time, still I cannot take any rest, I do everything for her, she stays with me always, when she was younger than now I had to keep her in my laps every time while cooking and even while I went to the washroom, I have to take care all of her issues, feeding, cleaning, take her to school, help her in the study, to cook and other household chores as well as take care of other children" (*Ruma).

Besides, it is evident in the current study finding that in many cases mother has to sacrifice their dream career or working plan to raise family income because of their parenting role, also discussed in Ackerman et al. (2005). In this case, social expectation from the mother in the parenting role works as a key contributor that normalizes the mother's sacrifice for their child as a motherly responsibility. Both Acar et al. (2021) and Green et al. (2016) discussed that social expectation defines mothers' role in parenting from different contexts. From my observation of the study, I realized that social expectation normalizes mother's role and their sacrifice such a way that mother's personal pain or frustration for losing their dream life are got hidden under the socially defined gender role.

"I did my master's; I had some dreams too, which I buried underground. I did not attend any program at that time; I did not give time to my family, relatives, neighbors or anyone. I do not have that time to set aside for myself" (Era)

"*I actually need to sacrifice everything. I don't carry any different identity of my own now that I dreamed of. Because, if she was not like this, then I would do a job now, I also had a very beautiful music career which I could build-up more"* (Rina).

"*I had a sewing machine, and with that, I could contribute raising family income before, now I cannot because of her"* (Ruma).

5.5.2 Role of father

The field data demonstrated that the father's role in parenting mostly related to ensuring the financial security of the family, which reflects the traditional father's role in parenting in Bangladesh. In Bangladesh, fathers are usually considered the breadwinner of the family and, therefore, are not expected to participate directly in child-rearing regardless of their socio-economic status (Hamadani & Tofail, 2014). In the research findings, each father mentioned that they usually do not give much time to their children. Regardless of their social level, the contribution of the father in children's caring and development are very less. Father's main focus is to maintain financial security for both family and the child with ASD. Moreover, fathers try to spend free time with their children and bring what is needed or the child likes.

"The fact is I don't have many contributions to her development. Even I don't have at least a two percent contribution. 40% of the credit for her development goes to the private tutor, 50% of the credit goes to her mother, and the rest ten percent contribution is of school, therapy, relatives and me. I spend more time with my work for our economic solvency as her future is much uncertain, we want to keep something for her so that she doesn't become a burden to anyone"(Roni)

*"When I return, I pass the time with him, keep him beside me and try to interact with him, and his mother takes all of his care that needed, I bring things he like as per his mother's recommendation"(*Rafiq).

Hamadani and Tofail (2014) mentioned in some cases, norms are changing in Bangladesh regarding child-rearing generally; some fathers participate alongside their wives to take care of their child. Some try to spend quality time when they are home which is echoing in the findings of father's role in parenting children with ASD. In some cases of the study, fathers try to help in taking care or take their autistic children out for a walk or entertainment when they get time. However, in most cases, this kind of father's role is not regular or mandatory like a mother. Only one father mentioned that he takes care of his children during the weekend-

"I prepare breakfast for the children on Friday (holiday), I make them take shower then, at lunch time, I feed my son and my wife feed our daughter, sometimes I go out for a walk along with the children". (Sofiq).

However, fathers' roles are not monolithic (Rudelli et al., 2021). The study shows that father sometimes helps their child with autism in drawing, take them out or shopping or take them for treatment and always assist in making the decision for child's wellbeing by discussing with child's mother.

"When I am free, I help her drawing, (Alam), *"I take him out when I get the time and take him every program I join, moreover I always with him when we take him for treatment, I don't do much but always discuss with his mother"* (Anjan).

Though the mother plays the primary parenting role, it is also noticeable from the data that the father is capable of managing the situation if it is needed. Moreover, both parents generally face pressure with their child with autism.

5.5.3 Role during COVID

Parents' role has changed due to pandemics and lockdown. Both parents and child are spending more time at home sometimes it causes working load or more responsibilities for mothers. Mothers need to look after their children the whole day and take caring their studies as they are not going to school or spending time with their teacher.

"*As she stays at home during corona, she wants to eat all day so I need to cook a lot for her"* (Hena).

"Tutor and school all are closed so I give him about one hour to make him revise what he learnt from tutor or school" (Era).

Hence, the mother's role increased during corona pandemic. Moreover, mothers are contributing to developing the skill of their children (e.g., Mumbardó-Adam et al., 2021). *"As my job is closed so I spend more time, and I talk a lot with her than before which helpful developing her communication"* (Sefa).

Moreover, changes are noticeable in the father's role during the lockdown. Some fathers are also contributing to household chores and spending more time with their child, and try to teach different things to their child during the lockdown, which is helpful for the child development as well (e.g., Mumbardó-Adam et al., 2021).

"AS I do not have work now because of lockdown I spend more time with him and sometimes helps her mother in household chores" (Eshak). *"Since, I am free now, I teach her a lot of things as much as I can"* (Anjan).

5.6 Coping Strategies

Findings express that parents endeavor their best to make their children happy and cope up with their challenging situations through taking various strategies. Moreover, parents try to make some spaces for themselves to manage their stress as well as design some plans for their child's future wellbeing.

5.6.1 Diverse strategies in parenting and understand the relation with social level

In the study, parents pointed out various schemes that they follow to cope with their situation. It is clear from the findings that handling a child with autism is very challenging for the parents. In this case, to cope, parents used the strategy of learning from experts and other people who have experiences and applied this learning with their child. In their study, Woodgate et al. (2008) also mentioned learning from others as a parental coping strategy.

"It was very hard to handle her then I learnt how to behave with this child from the mothers who have children with ASD and other experts. We seek help from a psychologist who told us to speak with her but each word separately. We did it for her better understanding gradually; she learnt to make a sentence. We also learnt if she wants something, then we should give that to her

as soon as she asks for it so that she can understand that if she asks for anything, she will get that, and thus she will communicate, she will learn to ask. Whenever she asked for anything, we gave her that. No matter how difficult it is, I have always done what makes her happy. I designed what I will do for her, I kept her happy and thus I was happy too" (Aliya).

For the sake of the child's development and convenience of understanding, parents use the strategy of seeking help and learning from other people who have previous knowledge and experiences in this case. In the findings, it can be seen that parents from FSL have more options to seek help from experts or get trained from India or outside because of their rich networks and financial capacity, which is almost not possible for the parents from SSL. However, they try to learn from their possible networks to cope up and minimize the hardship of handling their child. For instance, one mother in the study learnt from two university students whom she gave sublet in her place to raise her family income. Also, some other parents mentioned they learnt some strategies from doctors and therapists. Azad et al. (2014), mentioned mothers' from financially capable families have more access to the resources, which is pertinent to the findings.

Data reveals that parents cannot give enough time and care to their normal children due to their special child, so to balance their situation, parents focus on making their normal child more independent.

"I cannot give time to my younger one because of my special one, so I am trying to make my younger daughter independent. I have already taught her that she has to help herself. I have already trained a lot of things comparing her age. This is my strategy to make the balance" (Rina).

According to Begum et al. (2020b) Parents with higher education have a greater ability to understand and way out the challenges they face with their children with ASD. The current research finding also shows that some educated parents analyze their child's behavior to figure out a strategy that can work for them.

"*I tried to teach her alphabets when fog used to cover our windows because she used to find that interesting. She used to match the alphabet 'B' with spectacles. This means not an alphabet but objects attract her which must be meaningful"* (Hena).

Besides, in the parental experiences, children with ASD are very dependent on their parents, especially on their mother, which is very stressful. Thus, to release stress and decline dependency of their children, parents took the strategy of leaving their child with relatives, neighbors (who are supportive) or house tutors.

"I gave her enough space so that she could be handled by anyone but not only her mother; I developed this skill of her. Then there was a female student who used to give her time. I appointed her as my daughter's tutor, and she tried to teach a lot of things" (Alifa).

Moreover, some mothers expressed that they try to follow a routine to balance between other works and take caring of their children with ASD. Following a routine helps parents to make a plan to manage time for cooking, cleaning, take care of child, taking the child to school, outside, personal work and so on. However, sometimes they need to make changes in their routine.

"I have a target to follow a routine to balance life, but I cannot always maintain same, school days and lockdown routine are not same" (Mim).

Some parents also narrated that they take some strategies to calm the child when they are hyper or stubborn for anything or, if parents needed to concentrate on other things. In this case, parents give their children what they like, such as particular food that the child likes but takes a long time to finish or playing the music or dancing beat that child likes to listen to.

"Whenever she becomes stubborn, or someone comes to my place, I give her chanachur (spicy snack) and pickle, because she likes this thing and it also requires some time to finish this dish. So, she would peacefully eat then without causing any disturbance" (Monika).

"I don't allow her to listen to music always but only when her stubbornness starts to increase to make her calm" (Alifa).

Some children with ASD have the tendency to damage stuff, and in this case, parental strategy is to keep important things safe. *"I need to keep my books, notebooks, laptop and all other important things in a locker"* (Roni).

On the other hand, one mother said, *"I teach poor children Arabic, almost as a volunteer so that my daughter get company and improve. Different types of children come to me. Often I tell them to do something for me, like, making my daughter's hair, and putting makeup on her, having some conversations with her, or helping her in her studies. Interacting with them, she tries to imitate them in a lot of things. I allowed my daughter to play with these children. Even, I always allowed her to play with them if I am not at home. I do not ask for any fee. Whatever they give, being happy is enough. I do it only for my daughter's development; even I reared a neighbor's child till she was five years old as her mother did job. I kept that girl for my daughter's benefit. My daughter used to stay with her and play together, so she cried and disturbed me less* (Mim).

From this statement of Mim it is evident that parents can do their best from their level. This mother is not much educated, and her financial condition is not so good, but she teaches religious education or Arabic to poor children without making any demand for many years. She does it only for her child's development because when her daughter was very little, she did not interact so doctors and some other people suggested her to involve her child with more children to develop her interaction. Therefore, she started to rear a neighbor's child along with her child as well as this Arabic teaching to give company to her child. According to Mim these strategies worked well because communication skill of her daughter is much better than before as well as child's disturbance to her mother got reduced.

Besides, in the study, some parents mentioned that their children with ASD are choosy, they like an expensive dress, shoes and rich foods which are a financial burden for some parents especially who are from SSL however they try to cope up and manage the situation through compromising their needs. Parents stated that they prioritize their children with autism because these children are helpless, and they do not know what will happen when they will not be there.

"He likes to travel and buying expensive dresses and shoes, I take him shopping, he chooses by himself and everything is expensive for me, but I always buy what he chooses. In this case, we buy very minimum for us, or we compromise buying for ourselves. We always give him the priority so that he can feel comfortable, and this is the same for food. Moreover, whenever we

have an official program, they give rich food packets to me, I never eat it, as he likes rich food, I always bring it for him" (Eshak).

Moreover, one parent said, *"we shared everything about her along with the medicine to our close friends and relatives, so that if I am sick or anything happens to us, they can take care"* (Aliya). Thus, sharing works here as a strategy for the parents to ensure caring of their child in any challenging time of parents.

In addition, parents mentioned engaging their children in different works to develop their communication skills and help them become self-dependent.

"*I always ask him to bring this or that for me and also I send him nearby shop. I call shopkeeper from the balcony to measure stuff I need, and I send my son to bring it from the shop, I do these things deliberately so that he can learn how to interact with other people"* (Era).

"For me, the most important thing is to make these special children self-dependent, I focus on teaching him wearing cloths, eating food and using washroom by himself" (Sefa).

Again, about coping up with menstrual issues, mothers mentioned they become alert and prepare five days before the date. They teach their children with ASD about menstruation and help them to manage it. "I set everything for her, and I taught her how to manage it" (Mim).

Cherishing different milestones of their child helps to preserve parent's sense of hope and in sustaining the self and family (Woodgate et al., 2008). According to Poso et al. (2011) parental positivity helps them to adapt. The current study presented the same result of the parental experiences in Bangladesh where parental positive views and capacity of focusing improvements and success help them reduce their stress and adapt to challenges.

"She has improved and calmer now, she learnt to wear her clothes, using the washroom and some other things, I consider it as success. She has an interest in dancing and drawing. I encourage her in her interest, and I am hopeful, which makes me happy and satisfied about her and help me to relieve the stress of parenting" (Rina).

Apart from these strategies, parents need to cope with the ongoing Corona Situation. Children with autism do not understand corona or lock down. Thus they disturb their parents to take them out like a pre-corona situation. To manage autistic children with the pandemic circumstances, parents use some alternative options as strategy, such as-

"She wants to go out a lot; we say that everything is closed now, but she does not understand it always, so we take her to the rooftop, she plays with the instruments she has. Also, I buy the foods she likes; arrange her birthday party every Saturday, make her busy with music and other things so that she stays calm and disturb us less" (Hasan).

Furthermore, the study shows that parental personal experiences and education have a relation in coping strategy and manage their challenges in parenting which is also reflected in the work of Begum et al. (2020b). According to Begum et al. (2020b), educated parents can cope up better in parenting children with ASD through accepting responsibilities and taking the situation with a positive attitude. Moreover, self-controlling capacity helps parents to accept the situation and manage their child.

"When I was a student, I was a national badminton champion, and I used to do a lot of cultural activities along with debate. As I was a sportsman, I learnt to lose. I think this is a great quality to accept defeat. All these things give me strength for being a mother. I know how to face" (Aliya)

"Less-educated people do not know that this type of children is manageable. They may think that their children are mad at which they are doing so. They think, what will happen with him/her! But giving that child some time can make him/her social which those families do not know at all" (Sefa)

Both Aliya and Sefa are educated parents as well as job holders. Their above-mentioned statements refertotheir personal experiences, education and involvement helps them to accept, self-controlling and learn how to face and manage their children with ASD.

5.6.2 Personal stress management

In the research findings, parents shared different personal stress management strategies that help them get released from parenting pressure. In this case, parents try to do what they love, like singing; involve them with more professional work; spend some time alone with themselves and stay away from negative people etc. Moreover it is noticeable from the findings that majority of the parents involve themselves with religious activities to manage their stress which resembles with the study of Jegatheesan et al. (2010).

"*For personal stress management, I practice singing sometimes, after they fall asleep at night; I spend one and a half hours for myself. Maybe I do something or pass the time in social media or listen to music"* (Rina).

For relieving from stress, my biggest support is my works; if I have works in my hand, then I am fine (Alam).

"If I wear a saree with a wooden earring, a tip, then I feel very good and my mood becomes good completely. This is such a simple thing but yet gives me a lot of pleasure, I feel very joyful. Again, I require some space from my daughter or my husband; I love to spend some time alone with only myself. I keep myself away from negative people because this gives me a lot of stress" (Aliya).

"Performing religious activities everyday makes me peace-loving and help me to manage my stress" (Robi).

Another point in stress management came up from the parents that fathers usually go out to get fresh air and feel relieved when they feel stressed, because of their children with ASD. This seems impossible for the mother due to their socially determined gender role where mothers are expected to stay with their children as much as they can so they cannot leave their child behind alone and go out like a father.

"Gender is a huge issue. If I am disturbed, or if I am feeling bad, then I can go outside anytime, but her mother cannot if she feels the same too" (Roni).

However, some parents stated that they do not do anything to manage their stress. They accept their stress as their fate, and sometimes their child's happiness works as their stress manager.

5.6.3 Future plan for the children with ASD

The research findings demonstrate that parents are very worried about the future of their autistic children as they are not going to live forever. Consequently, most of the parents have already taken some future plans, strategies and initiatives that will support their children with ASD in their absence.

"We eight families with special children have bought a piece of land; we have a plan to live in the same building so that we can help each other in our old age. If we make a six storied building, then each family will take one flat, and two floors/4 flats will remain empty, we will make a gym setup and occupational therapy on one floor, and there will be teachers' campus in another. There should be a cooking space or common kitchen or some social programs like a music room. When I will die, the day my dead body will be taken out of that house, but I will be tension free because there will be someone, maybe a teacher besides my daughter" (Aliya).

Aliya is a professor, and she made this plan with the family from the same status and is capable of making this plan successful in the next few years. According to Aliya and her husband Alam, this is a very stable and realistic plan for their child's future because all of the parents who will live in the buildings are their friends and have the same category children and helpful for each other. Moreover, there will be trained staff along with all kinds of facilities needed for these children. Moreover, some parents from FSL narrated that they made their house as a part of the future plan for their special children.

"I made this house for the future of my special daughter. In my absence, my elder daughter will live in here with her family and look after her younger sister" (Hasan).

Not everyone from FSL can think of such a big plan because of their other responsibilities. Besides, some parents from SSL have a plan to make a small house for their children with ASD. However, parents from both social levels have taken the endeavor to save some money for ensuring the future security of their special children. In addition, some parents have taken another child hoping that; this child will look after their special child in their absence.

"Her dad's pension allowance is deposited in the post office; for now, that is what I saved for her, I also try to keep aside some money from my small income (Alifa).

"We took another child so that she can take care of her elder sister but I am saving money for our elder daughter so that she won't be a burden to her younger sister" (Roni)

Furthermore, parental plans to arrange a marriage for their special child came up in the findings, so that someone can look after their children in future.

"She needs someone to look after her so our plan is to arrange her marriage when she would be twenty with a poor good guy if we could find one, we are searching. Then if she got pregnant, we would rear her child for her, and in the future, if her husband left her, then the child will look after his/ her mother. I saw a family like this and is inspired by the idea" (Mim).

Both Mim and her husband Robi expressed the same opinion. These parents are from SSL and are very religious. In their opinion, since, according to Islamic Hadis, arranging daughter's marriage is Farz (Obligatory) for the parents, they are planning this way.

Besides, regardless of social level, every parent wishes that their special children at least can learn to handle their personal works. Parents are constantly helping their children through school, different strategies, and plans to overcome challenges and ensure their wellbeing.

5.7 Support system (informal and formal)

Parents of children with autism seek social supports in order to cope up with their parenting challenges which work as protective measures for the parents (Shepherd et al., 2020). The research findings present both formal (institutional), and informal (family, relatives, neighbors and others in social networks) supports in the case of parenting children with ASD from parental experiences. One mother said*, it is not possible for a mother alone to take care of a child like this on her own. In this case, social support works as a stress reliever but, in this individualistic era, no one wants to take care of other children, so lack of support causes more stress in my case* (Rina).

Statement of Rina is consistent with the work of Shepherd et al., (2020); Islam (2020) and Rudelli et al. (2021), where they highlight the fact that social support helps parents to get relieved from stress, on the contrary, lack of support is the reason of more stress. According to Algood et al. (2013), parenting success occurs when proper supports are in place in micro, meso and macro levels which reflects through the informal and the formal support experiences of parents in the current research.

Firstly, regarding, **informal support** parents expressed different dynamics. According to the mothers in the study, since they have to play the primary parenting role, helpful husband or mental support from husband works as a great support, stress reliever and encouragement to do more for their children with ASD. Specifically when the husband gives time and helps to make the decision for the child's wellbeing as well as caring about the child's condition and mother's parenting stress.

"My husband tries to give time to my child and me as much as he can. Besides, he tries to give support mentally in every way that I need, helps me to feel relax in my works, decisions and parenting. Actually, If the fathers are supportive and helpful, then a lot of strength can be gathered, a lot more can be done" (Hena).

However, two mothers stated that they did not get any supports in parenting from their husband except basic financial needs. Only financial help from the husband do not satisfy them rather, they feel a lack of care from their husband, which is frustrating and stressful. *" It's frustrating that he never realizes that I keep him all day long, he should take him for some time, I never get support from him that I expect, only income cannot be all support"* (Manika).

Moreover, about extended family support networks, some parents mentioned that everyone from both paternal and maternal sides of the child gave them support in different ways, such as, treatment; take caring, financial issues etc. According to the parents, these kinds of supports were incredibly helpful in parenting children with ASD.

"I received support from everyone from my family. I can easily go for work even abroad because I can keep my daughter to my mother or to her paternal aunties" (Aliya).

"I have been staying with my sister for the last one year. After her father's death, my brother, sisters and other family members helped me their best in financial needs and other issues. I do the job but I feel great reliance because of them, they care about my daughter's need" (Alifa).

Besides, it reveals in the data that getting a great deal of informal support not only helps in the parenting process and material needs of both parents and their special children, but also helps to improve child's understanding skills.

"Actually, the Almighty Allah has given me such luck that I even received support from my landlord, from my neighbors, my brother, husband, in-laws, parents, everyone supported me always. There are eighteen to twenty students among us. There is no one who received support like me. They also say that my daughter understands everything very quickly for this support" (Mim).

Some parents from both social levels mentioned that they did not get any support from the extended family networks, which made their life much stressful (e.g., Shepherd et al., 2020; Islam 2020; Rudelli et al., 2021).

"We never get support from my relatives and parents made our life more stressful as we have to manage by ourselves even when we are sick. In this case our only support is our elder daughter (Rafiq).

In fact, in this study, siblings support came as an essential informal social support. Siblings play a significant support role in the development of their autistic brother and sister. However, support from siblings seems gender-biased since caring support primarily comes from sisters where brother's support is irregular. In Bangladesh, girls or women generally do care work or household chores (e.g., Hamadani & Tofail, 2014).

"He does not give complete concentration to his sister as he is a boy. Sometimes he does and sometimes he does not" (Mim).

"My elder daughter helps me a lot in taking care of my autistic daughter. She gave her younger sister enough time besides her studies. Many people say that it would be impossible for me to bring up my autistic daughter if I did not have my elder daughter by my side. If I had to go anywhere on any purpose, she used to take care of everything in the house" (Ruma).

Even during COVID situation and lockdown sister's contribution to behavior development of their autistic sibling is noticeable.

".. during the Corona situation, when he started passing the time at home with my daughter, I realized he is following my daughter what he did not do during school. I observed that he is not that much restless as before and does not annoy me like he used to do" (Era).

Furthermore, findings showed parents from FSL have good social networks and social capital because of their academic and professional background as well as various involvements. They know many people who work as support in different needs, such as child's treatment, managing suitable accommodation and learning.

"*I know many people because of my various involvements. Some of my friends are in a very good position that helps me give information about where to go, which doctor is good for this child, and help me make networks with higher governmental authority to advocate for school and accommodation for these children. These kinds of networks give me strength and support (Hasan).*

"My friend made a home where he takes care of 16 orphan girls. He always tells me that he has kept a room for my daughter. He asks me not to worry. He ensures me that one of the girls from his home will take the responsibilities of my daughter someday. It's a big support for me"(Aliya).

This kind of network and support is not noticeable in parents' experiences from SSL in this study. They do not have this kind of supportive social network or friends. In addition, parents from FSL can afford maid for assisting household chores; as a result, a mother can give much time to their children.*"We have two maids to help still I do not get time to take rest because I give full time to my children"* (Era).

Secondly, regarding **formal support** majority of the participants pointed out that they received some sorts of support from school and teachers. The school helped them to get respite from their parenting role for more than three hours. Moreover, due to school support child's dependency on the mother got decreased.

"Due to school, her dependency on me has decreased a lot, and that was my only relief time" (Rina).

However, according to parents' opinion, institutional or daycare support is inadequate in Bangladesh and initiatives that are taken by the government are mainly media coverage.

"Institutional support for this child is very limited in Bangladesh. We see that the Bangladesh government is doing a lot of things for the media focus, and they do this for show. The reason why the Bangladesh government is doing these things is that PM's daughter works with these. But there is nothing like structural development here" (Roni).

It is evident from data that formal support is insufficient. Nevertheless, parents from SSL received disability allowance from the government according to the legislative rules (e.g., NSPS, 2014).

"She receives six hundred taka (6 Euro) per month. They don't give the monthly allowance every month but altogether after six months" (Alifa).

5.8 Identified requirements and recommendations

Identifying requirement and recommendation from parents help to understand the gap, what is essentially needed, or what is yet to be done to ensure rights and well-being for both the children and parents. Undoubtedly parents are the voice for both their autistic children and themselves to identify their requirements to protect rights. Findings of the research reveal that to mitigate the hardship of parenting children with ASD and child's vulnerability, parents identified some requirements considering their contexts in terms of personal and social challenges, child's developmental needs, state capacity of Bangladesh and ensuring minimum rights and security for both parents and their children with ASD.

Collected data of the study expressed that changing social perception towards the children with ASD and ensuring their security is the crying need for the parents regardless of their social status or positions. Parents want their children to get security and minimum respect as human beings from society and people. According to parents, these changes in society will be a great help for parents to deal with their challenges. In this case, Government should take more awareness initiatives to raise awareness among the mass people.

"People's attitude towards them should be changed; this is the first requirement for both children and their parents. They did not do anything wrong; in fact they did not do anything. People should behave well with them. We get hurt when people say, "That mad girl had a child", and this actually hurts a lot. The girl is autistic, and anyone from our society did something bad with her. Let people's humanly qualities wake up, don't say they are the result of a curse. At least, respect them as human" (Hasan).

"We parents want our children to be secured. This type of child cannot express their feelings, unlike healthy children. If we get this security from the society that no one harms them then this will be our biggest achievement, Government should take awareness initiatives to ensure their rights" (Alifa).

Changing social perception, ensuring security and governmental responsibilities in this case came as important requirements in the findings. Besides, parents mentioned others need to ensure child's rights, safety, development and consequently wellbeing of the parents. Such as-

- *"Most schools are actually business-oriented and general for all; schools should be according to the level of the children which we don't have. But we need this kind of good school for our children's proper development"* (Rina).
- *"We need more research and more expertise not only to know what actually needed for this kind of child and their parents but also getting necessary quality services"* (Roni)
- *"It could be better if we could receive training"* (Popi).
- *"There is no home day-care system in our country. We need daycare center with trained caregivers then the working mothers or the mothers who are just housewives will keep their children in the daycare. By this, she will get relieved" (*Sefa).
- *"If there was a government institute, we need one, this is very important for us where children can live happily, especially after our death. We would remain tension free that there is someone to take care of our daughter after us. If there was such an institute at every district level for the special children that would be very good. Government can do this by taking help from a rich person or foreign donation, and this is very important. This is more important than schooling. They can continue schooling besides their residential institute. I think it is for government to do that"* (Anjan).
- *"The number of schools should be increased with low cost for these children"* (Eshak)
- *"His treatment is also costly, it could be better if government open some special free treatment services"* (Manika).
- *"The most important thing for a family is money. If any of their parents or siblings has a good permanent job, then that is enough. And the allowance they receive is not enough for a special child to be very honest. If the government would give a permanent job to a member of the family who has autistic children in consideration autism could be better"* (Mim).

Therefore, apart from changing social perception and ensuring security, parents identified requirements relating to good quality school, more research and expertise, training for parents, daycare center, Government residential institute, more number of schools with low cost, free treatment facilities and ensuring secured income sources in the family. However, last three requirements mentioned above, mainly came from the parents of SSL where getting financial support is one of their main requirements. Besides good quality schools, more research and expertise are recommended by the parents from FSL. These requirements related variations may indicate some relationship between the social level of parents and their requirements. However, changing social perception, ensuring security, scopes of parental training and residential facilities were rolled up as vital requirements from both levels.

5.9 Need of proper policy measure and its implementation

It is evident from the above-mentioned parental experiences and its discussion/analysis that proper policy and its implementation is a crucial need to minimize parenting challenges and ensure their requirements. According to Canary (2008), the policy indicates the connection between macro-structures and micro-practices where formal support by proper policy implementation is vital to ensure the quality of life and well-being for both parents and children. Here well-being indicates adaptability, family functioning, material satisfaction, empowerment, self-esteem and child development (Canary, 2008, p.417). Necessary legal acts and policies contribute as counteract the negative consequences for the parents and their children with disabilities, also ensure financial supports, service related needs and social inclusion (Di Guilio et al., 2014). Moreover, proper monitoring systems and considering problems of parents and children with autism in every aspect of life is essential (e.g., Di Guilio et al., 2014). Following the guideline of CRC and CRPD the Bangladesh Government also enacted laws, developed different policies and initiatives to protect rights and ensure social inclusions of children with disabilities (UNICEF Bangladesh, 2014; CRI report, 2014; NSPS, 2014; Soron, 2015). However, there is a gap in this policy implementation in the practical field (Murshid & Haque, 2020; UNICEF Bangladesh, 2014) which is also evident in the data mentioned in this chapter. However, parents reported limited knowledge about these policies and support. In this case, Nuri et al. (2020) mentioned that low coverage of these governmental supports is the main reason behind parents' limited knowledge. Several factors can prevent parents from fully realizing the benefits of policy and program intervention such as, cultural norms, lack of information about available services, cost, time, demands, lack of professional sincerity and so on (Canary, 2008). Also NGO can play an important role in this respect (Di Guilio et al., 2014). In the study, parents mentioned they know about the state capacity of Bangladesh, so they only focus on essential requirements for the children with ASD and themselves, which is possible through the attention of the governments by making proper policy and its proper implementation. In this case, parental participation in the policy process and its proper monitoring along with professional transparency will be helpful to ensure rights for both parents and children with ASD in Bangladesh (e.g., Canary, 2008; Di Guilio et al., 2014).

5.8 Chapter summary

This chapter analyzed and discussed findings to answer the research questions. Here findings are presented from thematically analyzed data. Mainly this chapter discussed data by using theoretical model (details are given in chapter three- QoL and BES theoretical frameworks) of the research as a guide, and by reflecting previous relevant literature where individual parenting experiences with their children with ASD have been explored, through different dynamics and interaction in a particular context and time. In addition, this chapter presented findings and discussion simultaneously, unlike some studies that use independent chapters for discussion.

6 CHAPTER SIX- CONCLUSION

This qualitative research aims to explore parental experiences in parenting children with ASD in the context of Bangladesh, considering different core dimensions and dynamics in experiences, as well as how these experiences lived in different social levels. The main research question that the study searched for is- How do the parental experiences with their children with ASD are lived in different social levels, in terms of relations, roles, challenges, coping strategies, supports and requirements? Through this research question, the study investigated parenting perception with their autistic children, different dynamics of relationships, gender role in parenting, parenting challenges, adopted coping strategies, available support networks and the crucial requirements that should be fulfilled, through the experiences of parents in two different social levels (FSL and SSL, please see the page, 33). The research attempted to understand if there is any relationship between parenting experiences and their socio-economic status. The study has been done in the context of Bangladesh to obtain a clear idea about the practical situation and necessity for both parents and children with ASD. This study is very significant in the social work field with families and children in Bangladesh. The study highlighted the experiences from the beginning to still now to understand the overall situation from a holistic approach. Moreover, the impact of current Corona pandemic situation added to the experiences.

Following the research objectives, the study explored the relationship between social level and parenting experiences by analyzing different dynamics. The study revealed diversities and commonalities in parenting experiences in two different social levels. Regarding dynamics, firstly the study demonstrated that, general knowledge about autism is still very low despite various government initiatives in Bangladesh. It was a shocking experiences to parents regardless their social level to know about autism and the unknown journey of parenting their children with ASD. However, it was noticeable that every parent took the immediate initiative from their level of capacity to help their children with ASD. Secondly, the study has found that parental perception with their children with ASD is diverse depending on parents' growing environment, previous experiences, personality, degrees of maturity and involvement, level of faith in religion, financial issues, etc. Again parental perception can change over time with their level of acceptance and maturity as well as other issues they came into contact.

Thirdly, the study has revealed good relations and understanding between mothers and children with ASD in every case, mother spends much more times than others. In this case parents' childhood experiences, background, personalities have an impact on their understanding and relationship. Moreover, various degrees are visible in the relationship between children with ASD and other family members (father, siblings) or related people. In addition, in a relationship, both parties' interests and endeavors came as significant issues. However, good relationship and better understanding are helpful handling the children with ASD. Fourthly, the study found that role and experiences in parenting are gender biased where mother has to play the primary care giver role in Bangladesh. For their role mothers often do not get enough scope to think about themselves rather have to sacrifice their personal desire and dream career. This kind of sacrifice is normally treated in Bangladesh's society as a part of their maternal responsibilities where mother's frustration got hidden under the socially defined gender role. However, good social support and systems for both the child and mother can minimize this hidden frustration and psychological stress. On the other hand, fathers' role in child's caring and development of autistic children is notably less. Fathers' role mostly related to ensuring financial security for both children and family represented the traditional breadwinner role. However during Corona lockdown father spends more time with children and helps them more in skill development along with their mothers which is beneficial for both parents and children with ASD.

Fifthly, the study has found that parenting children with ASD is a very stressful experience for the parents, and they have to face various challenges daily. This parenting needs more attention, more time, more take caring and more resources, which pose colossal stress that leads parents to various physical and psychological challenges. Disturbance of children with ASD has increased during Corona as the child always stays at home. The study demonstrated that it is challenging to understand an autistic child's mood; however, education of parents is important since educated parents could better understand and analyze their child's behavior, thus able to manage well their child and their situations. Moreover, the study has found challenges and negligence in getting accurate information and treatment from professionals due to their lack of skill and knowledge. Again in education systems, there is a lack of specialized schools with proper research, individual child's need-based program, monitoring and skills of professional. These challenges indicate the gaps and requirements in systems. These kinds of awareness regarding systems came from the parents from FSL connect the diversity in parenting experiences with daily life challenges in different social levels. Moreover, cost of necessary services and instruments causes challenges to parents from both social levels; however parents from SSL have to face more challenges due to their limited income. Besides, negative social perceptions stigmatize both parents and their children with autism cause social devaluing and negligence towards both parents and children. As a result both parents and their children with ASD have to face various discrimination and challenges in daily basis. However in some cases parents with vital social status face less discrimination which demonstrated relationship between experiences and social levels. Moreover parents of girl children with ASD have to face more stresses in ensuring safety for their children due to the existing gender perspectives in Bangladesh.

Sixthly, the study found that parents take various coping strategies to mitigate their challenges, such as learning from others, using different tactics to decline dependency of children on parents, managing child by giving their favorite things, taking different schemes to manage their personal stress and through arranging different safety measures for now and future. The study has revealed that parents do their best for their children from their levels such as voluntary teaching to the poor children and reared neighbor's child to get company for the child with ASD to develop interaction and learning capacity and so on. These kinds of schemes and willpower help parents to mitigate their challenges, also, showed parental mental strength and capacity of adaptation. Besides, the study revealed that the parental educational level, background, and self-controlling capacity can influence parents' ability to face challenges and cope with their situations.

Seventhly, the study has found that adequate availability of social support helps parents to better cope up and get relieved from parenting stress and various challenges. Besides, adequate support helps to give a proper growing environment and chance of need fulfillment of children; as a result, child development. In this case, both formal and informal support came as a strength and stress reliever in parenting. On the contrary, lack of support from informal networks causes colossal stress and frustration in parenting. Support from siblings seems gender-biased in the study where care based support mainly comes from sisters reflects the traditional gender role in

Bangladesh. In addition, the study has found that parents from FSL have better social capital and support networks due to their academic, professional background and various involvements, which are helpful in getting proper information and ensuring different needs for children. Besides, the study reveals inadequate institutional and formal support for both parents and their children with ASD in Bangladesh.

According to research objectives, requirements for both parents and children with ASD have been identified in the study through parents' voices. In this case, requirements came up considering personal and social challenges, child's development needs and state capacity of Bangladesh. Parents mentioned only those crucial and possible requirements to fulfill by the goodwill of governments and society. Ensuring social security and minimum respect towards child and their parents came is the most important need. In this case, government-initiated formal supports and awareness programs came as requirements. Besides institutional and residential facilities, the parents' scope of getting information and learning came as requirements from both social levels. Moreover, more schools with low cost, accessible treatment facilities and ensuring secured income sources in the family came as vital requirements from the parents from SSL, where good quality school, more research and expertise to ensure the quality in services are recommended by the parents from FSL. These findings also connect the relationship between requirements and social levels. Through analyzing the data the study highlighted that proper policy measures and their implementation in this field can ensure parents and their autistic children's needs, rights and wellbeing.

Therefore by exploring above mentioned dynamics the study concludes that parental experiences are diverse in parenting children with ASD. These experiences are connected with micro to macro level interactions. Through theoretical guidance and previous literature, the study presented different aspects of parents and their children's life situations through parenting experiences. In the case of an understanding relationship between parental experiences and their social levels, the study reveals various commonalities as well as diversities in experiences between social levels, which also include other social and personal dimensions. However, the study reveals high parental levels of status, education, and professional background open more scope of social capital and access to different resources in the context of Bangladesh. In addition, good support systems and proper policy measures are vital to fulfill the requirements and ensure rights for both parents and their children.

6.1 Implication and recommendation

The study expresses parents' experiences in parenting children with ASD in different social levels, including different dynamics to get a clear scenario about parents and their children's situations, vulnerabilities, existing supports, gaps, requirements and so on. Undoubtedly, the study has big implications in policy and their practice. The study revealed different gaps in the existing program intervention of governmental and non-governmental organizations. Moreover, parents' daily life challenges and their different impacts on both child's and parent's quality of life have been well uttered in this study through practical experiences of the parents. Besides, the study expressed requirements through parental voice to ensure both parents and child's rights. These requirements focus on formal support intervention for mitigating hardship and protecting rights for them. Therefore knowledge of this study will contribute to promote good policy measures and their implementation, rethink existing policy intervention, and remove its gap. In this case, proper monitoring, parents' participation in program intervention and practitioners' goodwill and transparency are recommended.

Moreover, the study contributes to understanding the practical scenario in parenting children with ASD and their vulnerabilities, strategy, strength and other dynamics in Bangladesh. Besides, the study contributes to filling the existing knowledge gap in this field in the context of Bangladesh. The study encourages this field to come into focus in future research where future studies should contribute other aspects of this population because this population is vulnerable in social perception and various contexts.

Besides, the study is relevant in the field of social work with families and children because, the study included socially marginalized and vulnerable populations (parents and their children with ASD), and their practical situations in different social levels/contexts in Bangladesh. Furthermore, the study has figured out what is needed to mitigate their vulnerabilities, also contributes to the social work practice through policy measures. In addition, the study reveals parents' coping strategies that reflect parental strength of handling their situation, also very relevant in social work practices as it focuses people's participation and strength on handling their situation by taking diverse actions.

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APPENDIX I – CONSENT FORM

Consent Form

Dear Sir/ Madam,

You are being invited to participate in an Erasmus Mundus Master Dissertation research project under the Institution named, ISCTE- University Institute of Lisbon, Portugal about parenting children with Autism Spectrum Disorder (ASD). You would be asked some questions related to your regular individual parental experiences with your children with ASD. The information given below will present you the basic idea about this research project and your rights and responsibilities as a participant. Please read this form carefully and feel free to ask if you have any question regarding this project. Once you agree to participate, please sign in the end according to the given instruction.

Research Objectives: The main objectives of this research is to explore the parental experiences with their children with ASD in terms of relations, roles, challenges, coping strategies, and supports in different social levels. Furthermore, through this exploration, the study attempts to figure out requirements for both parents and children to protect and ensure their rights in the context of Bangladesh. Moreover, the impact of current Corona pandemic situation will be focused in the above mentioned dynamics.

Research Goal: This research is a part of the master program and the master's degree is fully funded by Erasmus Munsus Scholarship. Therefore, the general purpose of the study is educational along with the contribution as a future research reference, and policy reference. The findings of the study may be used for national, international publications and conferences as well as other useful avenues available.

Research Procedure: Once you agree to be part of this research, you would be expected to engage an in-depth interview. Due to the Covid-19 situation and the government's policy on a lockdown, interviews will be conducted in your convenient time through video call or the way you prefer by focusing health/safety issues. The interview will be tape-recorded with your permission, so that no chances to miss any data but you have right to request stop recording at any time if you do not feel comfortable. Data will be transcribed by researcher in its original (Bengali), translated to English language and saved in the locked file with password. And the transcription would be share with you for the accuracy check.

Risks and Benefit to Participation: There is no identified risk to participate in this study but, if you do feel uncomfortable with any question you have rights to refuse answer of that question or withdraw your participation. No cash or material reward will be given for participation in the research.

Confidentiality: In this research identities of the participants will be anonymous to prevent any kind of harm of the participants and researcher would use pseudonym instead of the real name. All the record and electronic information would be kept in locker and secured place, no one would listen your response unless you permit them.

Voluntary Participation and Withdrawal: Your participation is voluntary, that means you are free to leave the consent and withdraw the study anytime if you feel so.

Further Contact and Questions: The researcher of the project is Tania Saha, Mobile number: +8801827789529, email- taniasaha777@gmail.com, you can contact with these number and ID if you have any further quarry about this study. The name of the supervisor of the study is Maria João Pena, email- Maria_Joao_Pena@iscte-iul.pt . You may also contact with her if you have any further concern regarding this research project.

Statement of Consent:

I have read carefully the contents of this consent form and I understand about the study.

So, here, I, Participant's Name ________________/ Signature______________ give my consent to be a participant in the study. Date_____________________.

Researcher's name___________________/ Signature__________________,
Date____________________.

APPENDIX II- INTERVIEW GUIDE

"Parenting Children with Autism Spectrum Disorder (ASD): Explore the Experiences in Different Social levels in the Context of Bangladesh"

Guideline for In-depth Interview (IDI)

Metadata

Name of Respondent	
Age	
Education	
Occupation	
Number of children	
Address	
Mobile No	

Theme	Main Question	Probing
General information and identification of ASD	Please tell me about your children.	• Name, Gender, Age • When and how did you identify that your child suffered from ASD? Tell me the event please.
Relation and interaction of Children with ASD	Tell me about your child's communication, interaction, daily life activities, and relations.	• Tell me about your child communication and relation or interaction with his parents (Mother and father), other family members, teachers, classmate and others. • What type of activities they normally do in their daily life? • Do you notice any changes of your children in terms of communication and other developmental issues in current pandemic situation? If yes then please explain it in detail. • What are the strength and weakness of your child behaviour? Tell me from your perception.
Parenting experiences and strategies	Please tell me about your parenting experiences including your strategies in details.	• What types of role do you usually play for your child with ASD? • How much time do you usually give your children? • What are the impacts on other siblings (age of your other child)? • How do you maintain your child's meal?

		• How do you maintain your child's medication/treatment? • How do you maintain your child's schooling and education? • How do you spend leisure time? • How do you manage your child's demand? • How do you manage your child in any social gathering like marriage, birthday party etc? • How do you manage your child's schooling, medication and demand in current pandemic situation? • How do you perceive ASD of your child? Please explain? • Do you feel that ASD of your child is a blessing/burden/curse for your family?Why? • Do you need to make any kind of changes or strategies in your daily life to rear your child? • What are the satisfaction/success and dissatisfaction in your parenting that you would like to mention?
Challenge of parenting and coping mechanism	Please describe your challenges regarding parenting. Please describe how do you cope up with these challenges?	• Do you face any personal challenges regarding rearing your child? If yes, please explain. • Do you face any challenges in family level regarding rearing your child? If yes, please explain. • Do you face any socio-cultural challenges in regard to up bring your child? If yes, please explain. Is there any impact of your child's gender? • Do you face any economical challenges/ constrain regarding upbringing your child? If yes, please explain. • Do you face any challenges to get access the necessary services? If yes? What are the main reasons behind these challenges? • What are the challenges do you face in current pandemic situation regarding rearing your children? • Do you think is there any relation between your social level and the challenges that you may face or not face? • What do you do to cope up with these challenges that you mentioned? • How do you manage your personal stress? What are the strategies do you take to deal with this challenges and stress?
Formal and informal support	What are the formal and informal supports that	• Have you got any support (economic, parenting, medical, social security) from

systems	available for you and your child?	Government or any social work organizations? If yes, then explain it in detail please. - Do you think co-parenting is supportive? - Do you get any support from your extended families, kin, friends or neighbour? How do these support networks work for you? - What kind of resources do you think you have access and you need for the betterment both of you and your child?
Recommendation	What are the crucial steps that should be taken to mitigate both children's and parental hardship?	- How do you define you and your child's quality of life? - What kind of support is needed to ensure rights and quality of life for both of you? - What are the steps that should be taken from Government to mitigate both children's and parental hardship? - What type of steps can be taken to support the parents of ASD children? - As a parent of a Child with ASD, what type of support do you expect from your family member as well as society?

APPENDIX III – DECLARATION LETTER

iscte INSTITUTO UNIVERSITÁRIO DE LISBOA

DECLARATION

This is to certify that TANIA SAHA, from Bangladesh, passport number EA0565255, is currently enrolled in the Erasmus Mundus Master's Programme in Social Work with Families and Children (MFamily), 7th edition 2019-2021, coordinated by the University of Stavanger (Norway) and in which Iscte University Institute of Lisbon (Portugal) is a partner institution. The student is the recipient of a Partner Country scholarship from the European Commission under the Erasmus Mundus Programme - Action 1 (EMMC) to attend the MFamily Master, covering the full duration of the programme.

An Erasmus Mundus Joint Master Degree (EMJMD) is a prestigious, integrated, international study programme, jointly delivered by an international consortium of higher education institutions. EMJMDs award EU-funded scholarships to the best student candidates applying under annual selection rounds.

As part of the mobility path of this programme, Tania Saha successfully completed her first semester at Iscte University Institute of Lisbon, the second semester at the University of Stavanger (UiS) and the third semester at the University of Gothenburg (UGOT - Sweden). The student is currently enrolled at Iscte for the 4th semester that started in January 2021 and will end in October of this year, during which she will complete her thesis.

The student is going to do a study on the topic of parenting experiences with their children with Autism Spectrum disorder in a context of Bangladesh. Therefore, we wish your maximum cooperation for her data collection process.

Please do not hesitate to contact me should you need further information or clarification.

Kind regards

Lisbon, April 13th 2021

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Pedro Vasconcelos

Coordinator of the MFamily Master at Iscte

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APPENDIX IV-NON-PLAGIARISM DECLARATION

I hereby declare that the Dissertation titled . . . Parenting Children with Autism Spectrum Disorder (ASD): Explore the Experiences in Different Social levels in the Context of Bangladesh . . . . submitted to the Erasmus Mundus Master's Programme in Social Work with Families and Children:

- Has not been submitted to any other Institute/University/College
- Contains proper references and citations for other scholarly work
- Contains proper citation and references from my own prior scholarly work
- Has listed all citations in a list of references.

I am aware that violation of this code of conduct is regarded as an attempt to plagiarize, and will result in a failing grade (F) in the programme.

Date (dd/mm/yyyy): ....17.09.21.......................................

Signature: .... Tania Saha.................

Name (in block letters): ……
TANIA SAHA...…........................