

**EXPLORE THE CHALLENGES IN DAILY LIFE AND QUALITY
OF LIFE OF MOTHERS WITH AUTISTIC CHILDREN:
MOTHERS' PERSPECTIVE**



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Abstract

Rational: Autism is a neurological disorder and the prevalence of this disorder is increasing day by day. Due to their challenging behavior and interest those child need always high supervision and care-giving. As mothers are the primary care-giver, they have to fulfill all responsibilities regarding their special child's needs, domestic tasks and needs of their other children, spouse and other family members. Moreover, they have to face different social stigma due to their child's disability. Thus their own daily life and quality of life become impacted in many ways. It is important to know about mothers' challenges in daily life and quality of life with autism child.

Objectives of the study: The objectives were to identify mothers understanding about the condition of autism and the amount of time to perform their ADL's besides taking care of their child, it also explore if there any challenges in physical, social, psychological and family for mothers of children with autism.

Methodology: The study was an ethnographic study under qualitative design. The study was conducted in the paediatric unit of Centre for the Rehabilitation of the Paralyzed (CRP) at Savar, Proyash at Savar and Beautiful Mind School at Uttara, Dhaka. By using convenient sampling method about 10 mothers of autistic child were identified by the respected study settings. Semi structure open-ended questioners with face to face interview were used for data collection. Data was analyzed by using qualitative content analysis.

Result and Conclusion: From the finding of the research, it was seen that the mothers have lack of understanding about the condition of autism. After having a child with autism mothers' can't perform their ADL's properly, due to time limitation for care-giving demands of the child. Most of the mothers are also facing physical, social, psychological challenges but they are getting enough support from family members and spouse, but most of the mothers reported that they are unable to make time balance with their other children.

Key word: *Quality of life, Care-giving, daily living activity, Mothers of autistic children.*

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Key abbreviation

ASD: Autism Spectrum Disorder

ADHD: Attention deficit Hyperactivity Disorder

PDD-NOS: Pervasive Developmental Disorder Not Otherwise Specified

AS: Asperger's Syndrome

CDD: Childhood Disintegrative Disorder

CDC:Centers for Disease Control and Prevention

EEG: Electroencephalography

ADL:Activities of Daily Living

QOL: Quality Of Life

BHPI: Bangladesh Health Professions Institute

CRP: Centre for the Rehabilitation of the Paralysed

NGO:Non Government Organization

PWD: Person with Disability

SARPV: Social Assistance and Rehabilitation for the Physically Vulnerable

USA: United States of America

UK: United Kingdom

CHAPTER 1 INTRODUCTION

The term ‘disability’ broadly describes impairment in a person's ability to function, caused by changes in various subsystems of the body, or to mental health. Nowadays, Disability is a major concern in Bangladesh as well as all over the world. The prevalence of disability is increasing day by day. Autism is one kind of disability and now-a-days the prevalence of this is increasing day by day. Autism is a general term used to describe a group of complex developmental brain disorders. It is typically diagnosed in childhood and has a wide range of symptoms. It has stated by Hartmann (2012) that, these symptoms consist of communication, socialization, behavioural and interest impairments, as well as minimal social skills. Due to these symptoms, a child with autism may have trouble relating to peers and forming meaningful relationships. According to Rakib (2013), statistics show that 1 in every 100 individuals in the world suffer from an autism spectrum disorder. Autism in a child affects not only the child's life but also the life of the family especially the life of the mother. Mothers of children with autism lead a more stressful life than the fathers. They sometimes leave their own daily and productive life in order to provide care and to spend large amounts of time with their children. Moreover, they also don't get enough support from family and society. If a child is born with a disability, the mother is usually held responsible (Pathappillil, 2011). Sometimes they become the victim of social stigma and social shame. Dzubay (2011) mentioned that, they feel guilty, and blame themselves because they do not have clear enough knowledge about their child's disability so they think they are responsible for it. Sometimes a child's disability impacts on marital life, siblings, the financial condition, cultural beliefs and attitudes in the society. There are no studies about how mothers with autistic children are thinking, feeling, or understanding about their child's disability or about the challenges they face therefore, this study is to find out the impact on mothers quality of life due to having a child with autism.

1.1. Background

Bangladesh is a developing and densely populated country. Most of the people live here below the poverty line and literacy rate is also lower in the country. Disability is a major concern in Bangladesh as well as all over the world. The number of people with disabilities in Bangladesh is high enough to merit special attention. According to

Titumirand Hossain(2005), Action Aid-Bangladesh and Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV) put number of persons with disabilities at 8.8% of the total population. BangladeshProtibandhiKalayanSamiti records 7.8% and according to the current survey 5.6% of people in Bangladesh have a disability of one kind or another.

According to World Health Organization (2006), currently around 10 percent of the total world's population or approximately 650 million people live with a disability. Females have a higher rate of disability than males.

Autism is one kind of developmental disorder. It is caused by a combination of genes and environmental influences. The situation is different from other disabilities because Autism spectrum disorders have multiple characteristics of behaviour and neurological mechanism. According to CDC, children who are meeting the criteria of autistic disorder range in number up to 12 per 1,000 children worldwide. A current report stated that 1 in 110 children are diagnosed with autism in the world (Kopetz and Endowed, 2011).In Bangladesh just a few years back, people were merely aware about the disability of Autism.According to Rahman (2010), in Bangladesh nearly 10.5 lakhs individuals have autism. However, there is no national epidemiological study on autism in Bangladesh. Due to the increase in the rate of prevalence of Autism, many researchers have studied the mental health of parents who have children with autism. Caring for the child with autism is very challenging and produces a huge stress for parents. It has reported by Hartmann (2012) that mothers of autistic children reported having more stress than father, particularly about their educational issues as mothers are usually the primary care givers of these children. Mothers continuously have to provide high supervision to children's needs that's why they become less aware about their own daily and productive life and about their own health and careers. In addition, parents of children with autism reported as showing significantly lower levels of quality of life than parents of children with other disabilities. In particular, it has stated by Kamei(2013) that mothers of autistic children showed lower physical health, difficulties in social relationships and lower psychological well-being than mothers of children with other disabilities. Sometimes mothers are not aware enough about their child's problems therefore, they feel guilty and think them responsible for their child's disability. Moreover, there is little awareness about a disability like autism and its causes among the general population

in Bangladesh and many 'traditional' views on this issue still exist. That's why the burden of the mother is also related to social stigma or social rejection. Mothers typically have the major caretaking responsibility and they have to face the challenges associated with their child's disability (Ekas, 2009).

The researcher wants to carry out this study to explore the challenges quality of life of mothers with autistic children. This study will examine the mothers understanding about their child's problem, and their experiences and challenges as they face raising an autistic child.

1.2. Significance

At present autism is a current subject and after having an autistic child the mother's life changes. As mothers are main care-giver, therefore they have to manage all duties regarding their children rather than father. Thus mothers' own daily life activities maximum time remains unfulfilled and it can also influence their quality of life. On that purpose, only mothers had chosen for this study. It is important to conduct the study because it will provide a better awareness about the impact on the mother's life of having an autistic child. This awareness is very necessary to understand their problems and their needs. The result of the study can be beneficial for those mothers who have children with this disability. This research study is particularly necessary for occupational therapists so that they could be able to understand the needs and expectation of mothers and how mothers' daily life and QOL are impacted after having an autistic child. It will also help therapists to provide effective family education to mother and carer by increasing their knowledge about autism, and changing their attitudes towards autism.

This study will also help therapists to explain others about the challenges faced by mothers with autistic children. It will also help other health professionals such as social workers, counselors, and Psychiatrists on this topic. The mothers need to be able to fight for their children's well-being, without receiving complaints, thereby demonstrating self-denial, patience and concern. The nature of this study is an exploratory, qualitative approach in order to better capture the degree and complexity of the experiences being studied.

1.3. Aim of the study

- The aim of the study is to explore the challenges in daily life and quality of life of mothers with autistic children.

1.4. Objectives

- To identify the mothers understanding about the condition of autism.
- To explore the amount of time mothers can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their autistic child.
- To explore if there are any challenges (physical, family, social and psychological) for mothers with a child with autism.

CHAPTER 2 LITERATURE REVIEW

Family is the basic and important unit in any society and children are central part of family. When a child born in a family the role of parents is also become changed. The birth of a child is normally an eager expectation for parents. Parents always expect a healthy baby who will give lots of happiness and peace. However, when a child born with a physical disability or a developmental disability, parents become shocked, anxious and also become frustrated for the child's early recovery. It is really an unexpected event for parents. After having a child with disability, it has a strong impact on the lives of parents. Autism is one kind of complex developmental disorder rather than from other kinds of disability of children. After having a child with autism the life of parents specially mothers become more stressful. They faced numerous challenges after having a child with autism. Moreover, society and community people are not enough aware about this disorder and this is a matter of regret now-a-days.

2.1. Autism

Now-a-days Autism spectrum disorders are an urgent concern. Autism is a neuro-developmental disorder which is characterized by impaired and abnormal social interaction and communication, stereotypical behavior and restrictive interests. Usually the symptoms of autistic behavior appear earlier to age three. Pathappillil (2011) mentioned that in 1940's; Leo Kanner a psychiatrist and physician said that,

'Autism is a collection of differences in social interaction, communication, and focused interests'.

According to Pathappillil(2011), it generally change the way of nerve cell and synapses connect and organize information and thus affects the normal processing in the brain. In addition autism is called pervasive developmental disorder. It has suggested by Bashir *et al.* (2014) that,autism is one of the five pervasive developmental disorders. The pervasive developmental disorders include: Autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Asperger's Syndrome (AS), and Rett's Disorder and Childhood Disintegrative Disorder (CDD). All the disorders called together "autism spectrum disorders" (ASDs). However, In case of ASD's it is common characteristics that they have long-term impairments

within the domains of social interaction, communication, play, imagination, and a restricted range of behaviors or interests.

2.1.1. Prevalence of autism

The prevalence of autism spectrum disorder has increased world-wide. According to Elfert(2014), recently in 2014, the world-wide prevalence of autism was 1 in 68 children and the male: female ratio was approximately 4.5:1. Hartmann (2012) agrees with this that in USA approximately 1 child in every 110 children has autism and per year the rate is increasing at a rate of 10% to 17% and it has been seen that the prevalence is extremely higher in case of boys (1 in 70) rather than girls (1 in 315). According to Rakib (2013), the prevalence rate of autism is also increasing in other countries in the world such as the current prevalence rates of autism are 1 in 160 children in Australia, 1 in 100 in United Kingdom and 1 in 250 in India. In Bangladesh, there will be around 76,000 children under the age of five with ASD. It has been stated by Ma(2012) that there is no relation between occurrence of autism with race, ethnicity and socioeconomic background. Autism is found in all ethnic, racial groups and socioeconomic classes.

2.1.2. Etiology of Autism

The cause of autism is generally unknown. According to Ma (2012), there is usually no known single cause for autism but some multiple factors may be responsible for this. Rakib(2013) agrees with this that many genetic, environmental, infectious, immunologic, metabolic and neurological conditions are responsible for occurrence of autism because those generally affect the normal functioning of the brain. In an epidemiological study, it has been mentioned by Pathappillil (2011) that five teratogens are responsible for autism, those are: maternal rubella infection, ethanol, thalidomide, valproic acid, and misoprostol. Some environmental factors are also responsible for causing autism include certain foods, infectious disease, heavy metals, solvents, diesel tire out, phthalates and phenols used in plastic products, pesticides, alcohol, smoking, illegal drugs, vaccines and prenatal stress.

2.1.3. Diagnostic criteria for autism

Autism can be identified in early stage of child's development. According to Pathappillil(2011), it is usually identified as early as 18 months or sometimes even earlier. There is no physical abnormality in autistic children that's why parents

generally can't identify their child's problem. Most of them may show early motor skills such as sitting, crawling and walking on time that's why parents can't notice their problem of delays in social and communication skills. It has stated by Pathappillil (2011) that some common features usually have seen in case of them. Those are: (a) lack of gestures to express social interest/engagement or lack of pointing out to an object of interest within the environment, (b) poor eye contact, (c) limited communicative babbling, (d) limited understanding of spoken language, (e) failure to respond to being called by one's own name (f) sensory problems. According to Rakib (2013), some other characteristics of autism may include- Problems of facial expression, poor toilet skills, eating disturbances, preference of playing alone, Self-injuries behavior, learning difficulties, aimless moving with no fear of getting lost, climbing on dangerous and inappropriate objects such as (kitchen, roofs, railings), sleep disturbances, little or no communication, echolalia is quite common.

2.1.4. Prognosis

Generally autism has no cure. Woodgate, Ateah and Secco (2008) mentioned that it is a chronic, life-long condition and it has may be no known cure. However, early implementation of interventions may cause the better outcome for the quality of life of child with autism (Pathappillil, 2011). According to Dzubay (2011), it is a lifelong disability and it has impact on not only the individual with autism but also the family too. Rakib (2013) agrees with this that, general people have lack of knowledge about this condition that's why they are careless about their treatment. Bashir *et al.* (2014) suggested that at early stage parents often feel shame, fear of discrimination and stigma to share it to others and don't want to go to receive diagnosis for their children.

Birth of an autistic child in a family, usually becomes a stressful event for the family. Mothers are the main care-giver of autistic child and they have to manage burden of their own family responsibilities as well as care-giving needs related to the child with autism. Thus Mother's QOL is affected in many ways after having a child with autism.

2.2. Quality of life:

According to Mohammadi *et al.* (2014), quality of life of the individual is defined by World Health Organization (WHO)-

‘The recognition, the individuals gain from their position in their lives in terms of their culture, value systems in which they live, goals, expectations, standards, and priorities’.

Kheir, Ghoneim, Sandridge, Al-Ismael (2012) suggested that physical, psychological and social domains of health are involved in QOL as it is a multidimensional concept. When a child is diagnosed with autism, it often creates great burdens on the family and they have to modify their daily lives in addition to manage the different and challenging behaviors of the child. It has stated by Mohammadi *et al.* (2014) that the parents with autistic children, especially the mothers have to spend large amount of time and energy to take care of their autistic child, therefore their individual expectations and standards would not be realized as a result, it affects their QOL. Mothers’ are usually impacted in all domains of quality of life after having a child with autism. Maternal care-giving burden and adverse QOL is usually occurs due to lack of functional independence, maladaptive behavior of the child with autism. According to Kheir, Ghoneim, Sandridge, Al-Ismael (2012), in many research researchers reported that mothers of children with autism faced different psychosocial problems like stress, depression, anxiety, restrictions of activity, and strain in marital relationships and diminished physical health.

QOL of mothers who have children with disability means how mothers are passing their everyday life along with their special children. Mothers are often sacrifices their own personal well-being in order to spend extended amounts of time to care for their children. They are always face different problems in different way. Sometimes they become unconscious about their own live and due to surrounding difficulty they remain in stress and anxiety and that has an adverse effect on their quality of life. In the study, researcher wants to find out mothers physical, psychological, family and social problems that they faced due to having an autistic child and the amount of time they can spend in performing ADL’s with taking care of their child.

2.3. Impacts on quality of life of mothers with autistic children:

2.3.1. Impacts on mother’s daily life

Rearing an autistic child is very challenging for every parent specially mothers. According to Hartmann (2012), taking care of those children is highly challenging

and stressful for parents. However, it takes some times for a new born baby to adjust with new circumstances but in case of child with disability and specially autistic child the situation become more difficult because they show unusual social behavior and difficulty in communicating in the society. Hartmann (2012) agrees with this that after having a child with autism the normal dynamics of a family become changed because parents need to give lots of time to take care of the special child that's why parents feel difficulties. Mothers take the major care-giving responsibility of the child and that's why they are more vulnerable in this perspective. It has mentioned by Abou-Dagga(2013) that Mothers have to tolerate more care-giving burden rather than father. Mann(2013) reported that, now-a-days mothers are maintaining numerous roles and involving themselves in job sector but due to majority of childcare responsibilities, they may be most impacted by having a child with special needs.

Care giving is a normal duty of mothers but an autistic child is needed high level of care which has a burdensome effect on the normal lives of mothers including physical, mental and social. According to Mann(2013), they can't expend time for their leisure and experience significantly more stressful events than mothers of typically developing children because of more care-giving responsibility. It has suggested by Motaghedi and Haddadian(2014) that mothers expend large amount of time with their children thus it hinders their possibilities to work outside for contributing to maintain family expenses. Sometimes mothers also leave their job for taking responsibilities of the special child. According to Karasavvidiset *al.* (2011), in case of Turkey mothers lose their jobs and usually work part-time because they are the only responsible for taking care of the special children. On the other hand, mothers also have to spend a large amount of time for receiving medical care for their children with autism that takes extra time and affecting their employment status. Sometimes mothers become insensitive about their own daily life activities to fulfill the needs of their special child. Finally, mothers have a lot of challenges in ADL's that affects their psychological aspects.

2.3.2. Mothers' psychological quality of life

Mothers of children with autism are always remaining in stress. According to Elfert (2014), they have to face high levels of parenting stress, depression, and anxiety. It is stated by Martins, Walker and Fouche(2013) that this ongoing stress has impact on mother's health. Poor mental health and lower level of well being of mother is mainly

occurs for intense depression and stress. However, mothers have to face different mental health problems. According to Dehnaviet *al.* (2011), mothers of children with disabilities have experienced different mental illness problems. It has suggested by Martins, Walker and Fouche (2013) that mothers of children with autism remain in more stress rather than mothers with non-autistic child. They usually remain in stress due to child's maladaptive behavior, lack of educational opportunities and dark future. According to Ogston-Nobile (2014), mothers have to manage their child's challenging behavior, physical disabilities, inability to perform daily living skills, sleep problems, eating disturbances, those are very time consuming and thus mothers' become stressed. Moreover in Canada, mothers are experienced high level of stress than father. It has reported by Elfert (2014) that mothers are highly involved in child rearing then father that's why it may be the reason of elevate stress on mother. On the other hand, mothers are not enough aware about the reason of their children's disability therefore they strongly feel guilty on themselves for their children's disability. According to Ma (2012), many parents reported that they often feel intense anger, guilt, depression and anxiety. They are found low on ability to cope by maintaining their social system, self-esteem and psychological and physical stability.

2.3.3. Mothers' physical quality of life

Mothers have to maintain high level of responsibility and have to spend lots of time with her special child that's why they always remain in mental stress that often affects their physical health. According to Abou-Dagga (2013), stress can become cause of many physical problems like headaches or backaches, muscle tension and stiffness, constipation, nausea, dizziness, insomnia, chest pain, rapid heartbeat, weight gain, loss of sex drive, frequent cold, lack of immunity and other health complications. Another study has reported that mothers have mental distress due to burden and stress of responsibility of their special children and this usually affect the physical health. Generally like other kinds of disabilities a mother with autistic child feel more stress. Ma (2012) agrees with this that physical health problems are more common in case of mothers with autistic children than mothers of non-autistic children.

2.3.4. Mothers' family quality of life (spouse, siblings and other family members)

Mothers have to spend high amount of time with their child with autism to provide extra care and manage their challenging behavior that's why it creates an impact on

their relationships with spouse and siblings. They often need extra close supervision from care-giver and also need to provide specialized medical care, and therapeutic interventions. According to Petrongolo(2014), mother as a primary caregiver, have to give much effort to fulfill the extra needs for their child with autism and make a balance between the demands of autistic children and other non-autistic children. Sometimes mothers can't provide enough care towards the other child due to her child with autism. It has stated by Bashir *et al.* (2014) that sometimes mothers face difficulties to balance time between their other children and autistic children and that's why the siblings may feel that they are ignored or less important for parents. According to Hartmann (2012), siblings feel jealous towards their brother/sister diagnosed with autism because a large amount of time mothers spend with them. This behavior by siblings can create problems in family and create difficulties for mothers as they are already passing through trauma and stresses. This is an impact on relationship of mothers with their other children. Not only sibling's relationship sometimes marital relationship is also impacted in some cases. According to Martins, Walker and Fouche(2013),mothers' care-giving role also affect their marital relationship. Bashir *et al.* (2014)stated that parents of children with disabilities have experienced more marital stress than parents with normal children, it is due to fulfill the extra demands of an autistic child, parents can't get enough time to spend personal time as a result problems creates in relationship between parents, they remain depressed, and even it may leads to occur divorce. According to Elfert(2014), the prevalence of divorce is significantly higher in case of parents of children with ASD. In Asian culture, Sometimes father's involvement in care-giving of the special child is less then mothers so that mothers become frustrated. Moreover, mothers have also faced different troubles from society people too. They also show negative attitude towards those children's and their mothers.

2.3.5. Mothers' social quality of life

Mother of a child with autism has to face difficulties in society due to their child's challenging behavior. According to Ma(2012), they always cope not only with their child's problems but also with stressful responses from others towards the child's behavior, as they have lack of knowledge about autism. Mothers are often become the victim of social stigma and rejection due to society people are not aware and not supportive towards child's disability. Dehnavi *et al.* (2011) stated that in Iran,

Australia, and USA it is showed that social stigma is one of the main problem of mothers with autism. Dehnavi *et al.* (2011) reported that there is a natural tendency of society people to blame mothers for misbehaviors of children with autism. According to Altieri(2006), the parents often describe that their relatives are generally unhelpful towards them. The unhelpful attitude from family members and the stigma felt from members of the community increases the burden of mothers of a child with autism. Dzubay (2011) reported that mothers become psychologically depressed when they don't get enough support from society and lose the opportunity for social communications. When mothers feel stressed and cannot get enough support from society, then they began to use maladaptive behavior strategies such as avoidance. According to Johnson *et al.* (2011), mothers usually try to take their child with autism out in the community. Mothers also feel shy to take their kids into friends or relatives houses because of the child's challenging behaviors and thus sometimes mothers become isolated from their friends, family and the community reported by Hartmann (2012). It has stated by Dehnavi *et al.* (2011) that social avoidance and isolation may lead to mental health problems of mothers. Social support is very important for the mothers of autism. Martins, Walker and Fouche (2013) mentioned that social support helps to reduce negative stress effect on mothers of children with autism.

At the end of literature review, it could be said that mothers are more vulnerable position and their quality of life is affected after having a child with autism. They usually quit their own daily living, productive and leisure activities to give extra care and spend maximum time in care-giving to the child with autism. Moreover, they also don't get enough support from family and society. Sometimes they become the victim of social stigma. They also have not enough clear knowledge about their child's disability so they feel guilt and think they are responsible for their child's disability. Due to this reason, mothers feel different physical, psychological challenges. The relationship with family members, siblings and husband is also affected in many ways. By doing this study researcher wants to find the challenges mothers faced in daily life and overall quality of life after having a child with autism and their understanding about their child's disability. This will be very helpful and will become important written evidence on this perspective.

CHAPTER 3 METHODOLOGY

The methodology that was used in this study has discussed in this section. The aim of the study is to explore the challenges in daily life and quality of life of mothers with autistic children. The qualitative method has selected to conduct the study as it is an exploratory research. In order to do this study different study settings has selected and from those settings study participants has collected by using the convenience sampling method. During the data collection session, data has collected through face to face interviews by using semi-structured questionnaires. The data gathered was then analyzed through the qualitative content analysis method.

3.1. Study design

The ethnographic approach of qualitative research design has used to explore the study.

‘Qualitative research is a systematic scientific inquiry which seeks to build a holistic, largely narrative, description to inform the researcher’s understanding of a social or cultural phenomenon’ (Astalin, 2013).

It is usually conducted to gain an understanding of a situation. This method was selected for doing this research because qualitative methods help to explore the experience of participants. Ethnographic research is the study of culture and society. Culture includes attitudes, beliefs, and values held by a certain group of individuals.

According to Reeves, Kuper, and Hodges(2008), *‘Ethnography is the study of social interactions, behaviors, and perceptions that occur within groups, teams, organizations, and communities’*.

The design has used to focus on the experience of people as they engage in their everyday worlds. It also helps to identify the beliefs people hold and the perception of them from different perspectives. The researcher thought that this design was appropriate for this study because the mothers of children with autism are a specific group of in society and the study aim is to explore the challenges in daily life and the quality of life of mother’s with autistic children. The researcher collected the information of participant’s opinions because each participant’s opinion is unique.

3.2. Study area or setting

The qualitative study was conducted in the following settings-

Centre for the rehabilitation of the paralysed (CRP), at Savar. CRP is a non-government organization (NGO), which treats and rehabilitates people with disabilities regardless of their socio-economic status and aims to improve the quality of life of Persons with Disabilities (PWD) in Bangladesh. CRP has outdoor unit facilities for PWD such as a paediatric unit, neuro-musculoskeletal unit, stroke rehabilitation unit and hand therapy unit. In the paediatric unit treatment is provided by therapists to different types of children with disabilities like Cerebral Palsy, Autism, Down syndrome, ADHD, congenital deformity, muscular dystrophy etc. The paediatric unit provides two services an inpatient service and an outpatient service. Autistic children are mainly treated in the outpatient service. Autism therapy group is also conducted by the therapists of CRP (crp-bangladesh.org, 2010). From this paediatric unit the researcher has collected data from mothers with autistic children.

Proyash is a Special Needs school situated in Savar. It is an institute run under the patronization of the Bangladesh Army and dedicated to the wellbeing of persons and children with special needs. The main objective of this school is to educate and train children and youths with special needs (Proyash.edu.bd, 2014). At the present, there are 55 special needs children at the school, with Cerebral Palsy, Autism, hearing problems and intellectual disabilities and 47 of them have been diagnosed as autistic.

The Beautiful Mind Autism School is a private organization registered under the Ministry of Social Welfare, Bangladesh. It is situated in Dolipara North of Uttara Model Town, Dhaka. It is a sensory immersion school for children with autism, developmental delay and sensory integration issues (Motin, 2014). In an interview attached in (Appendix-6), it has mentioned that they offer a wide range of flexible programs for autistic children and mentally challenged children. At this time there are 150 special needs children at the school and from them near about 80 children's have autism.

For data collection the researcher used places which were recommended by the participants and where the participants feel comfortable to give data.

3.3. Participants

A main concern of accomplishing a research study is finding the subjects or sample to study. In order to get valid findings, it is not necessary to collect data from everyone in a community. It depends on the study objectives and the characteristics of the study population that determine which and how many participants should be collected.

3.3.1. Study population

In this study, mothers of autistic children were the Participants or study population. These were selected from the 3 organizations previously described, using the convenience sampling method. Three different study areas had selected in order to get opinions from different cultural groups. This was necessary to achieve a study with a solid foundation.

3.3.2. Inclusion criteria

- Mothers of autistic children who are interested to become a participant of the study.
- Age range of mothers (20-50) years. This age range is preferred because usually in Bangladeshi perspective, according to the department of Health & Family Welfare (2014), total fertility rate of women 15-49 years.
- Mothers who have minimum primary education will be eligible for the study because they will easily understand the purpose of the study and will be able to give valuable data according to the questionnaire of the research.
- Participants who are able to communicate and had no hearing problems will be selected for the study. Clear communication is required to provide answer during the interview session.

3.3.3. Participants selection procedure

Participants are the main things to conduct a research. For the study, 10 mothers had selected, who have children with autism. The sample had selected by convenience sampling method.

According to Koerber, and McMichael(2008), a health care researcher defined that, Convenience sample is a method by which participants are selected who are readily available and easy to contact for the researcher.

In this technique the participants can select those who are convenient to the researcher. Data can gather swiftly and begin the calculation. Very little preparation is needed to effectively use convenience sampling for data collection. This technique had used in this study because it is fast, easy, readily, available and cost effective. Moreover, it is very useful in time sensitive research. A list of mothers who fulfilled the inclusion criteria had made, then invited them to become a participant in the study. Those mothers have available time and also involuntarily interested to involve in study were selected as participant.

3.3.4. Field test

Before beginning the final data collection, it is necessary to carry out a field test which will help to refine the data collection plan. It gave a practical knowledge about the application of questionnaires for the study population and gave opportunities to rearrange the study questionnaires again. By field test researcher can find out that the questionnaire is fulfilling the purpose of the study or not. The questionnaire will not be sensitive and it will be culturally appropriate. Field test had done with one mother of autistic children and according to the field test the questionnaire had also modified by researcher.

3.4. Data collection:

Interviewing is one of the techniques used to gather data in survey and ethnographic research. Researcher had used semi-structured open-ended questionnaire and taken face to face interview to collect data from the mothers with autistic children. According to Bailey(1997), face to face interview are more intimate, by using this interviewer can interact directly and develop rapport with the interviewee. It also may be important if sensitive issues are need to be explored.

3.4.1. Data collection tools

- Semi-structured questioners had developed to collect data and it had used in interview session [semi-structured questionnaire both Bangla and English was attached in the Appendix- [(3.2.) and (4.2.)].
- Consent form had used to take permission from the participants for data collection.
- Pen, paper and clipboard had used to take notes and write down observations, general information of the participants.

- Recorder had used to record the data of the participants during data collection session. According to Isaac(2013), recording is used to capture qualitative data in thesis or dissertation research and ensures descriptive validity. While taking notes and writing down observations is important but it's more likely have possibilities to miss out on some details. An audio recording of an interview allow the researcher to refer back to the interview and take a fresh look at the interview data. A clear recording of an academic interview makes transcription of the interview easier and faster.

3.4.2.Ethical Consideration

The research had to maintain ethical consideration in all aspect of the study. This study research following issues should be considered:

- Researcher had taken approval from supervisor and head of the Department of occupational therapy of Bangladesh Health Professions Institute (BHPI) an academic institute of CRP.
- Researcher had taken permission for data collection from the authority of paediatric unit of CRP, Proyash, and Beautiful Mind School.
- Researcher had maintained confidentiality about service information of those institutes.
- Informed consent had collected from the participants.
- All participants had informed about the aim and objectives of the study by the researcher.
- The researcher had promised to the participants that all information provided will be kept confidential and will not expose their identity.
- Subjects or sample had full rights to withdraw themselves from the study without any hesitation.

3.4.3. Data collection procedure

Semi-structured face to face interview had done with open ended questionnaires and had taken in-depth information. Semi-structured interview is in the partial pre-planning of the question. It is mentioned by Keller and ketharina(2010)that semi-structured interview is conducted with a fairly open framework which allows focused, conversational, two-way communication. It is mainly used in qualitative research. This method had used in this study because by using this method in-depth information

had gotten and participants felt freedom to express their views in their own terms. It has stated by Cohen and Crabtree (2006) that it gives reliable, comparable qualitative data. Researcher thought that it was most effective method for this study. At first some standard questions had made which were matched the objectives. Researcher had collected data by own self. At first a quiet and suitable place had arranged in the respected study setting by communicating with the regarding authority and spent some time building rapport with the participants. Then researcher had explained the details of the study, for example- aim, objectives and purpose of the study. Then the opinion of the participants had taken by using a consent form. After completing these primary steps, questions had asked for data collection according to the purpose of study. All questions and consent form were translated into Bangla. Interviews were conducted in Bangla and recorded by MP3 recorder. Duration of interview was approximately 20 minutes. Beside recorder paper and pens had also used during interview for writing the extra information from the participants.

3.4.4. Data analysis

Data analysis is the most complex and most vital aspect of qualitative research. It has mentioned by Thorne (2000) that it is a part of generating findings that alter raw data into new knowledge. Researcher had analyzed the data by qualitative content analysis. According to Hsieh and Shannon(2005), qualitative content analysis has been defined as, '*a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns*'.

This method had used in this study because it is readily understandable and it provides an appropriate result in a scientific way. At first, it included systematic organizing of the field notes, transcripts of interviews and other associated materials to ensure the research question was addressed. Then data was transcript from the interviews of audio recording. Each of the transcripts were translated into English by 3 different individual, one was the researcher another 2 were such people who are not involved in the study. Then the researcher verified the accuracy of the data. Data analysis had started with reading all data repeatedly word by word to derive the code. Codes are derived from participants' answer. Data had organized according to the categories. Researcher had found some question categories. In Appendix-(4.2.), question no.(1-5) detected understanding of mothers about the condition of autism, question no. (6-8)

detected the amount of time mothers can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their autistic child and question no. (9-17) detected if there any challenges (physical, family, social and psychological) of mothers with a child with autism. Under those categories, all the information had coded from participants' interview. The coding was different from each participant and after finishing the coding; some important codes had detected that reflected the themes of the study findings. Therefore, the data had analyzed in 3 stages:

Coding → Categorizing → Generating themes

3.5. Rigor of the study

The rigorous manner was maintained to conduct the study by the researcher. This study was conducted in a systemic way by following the steps of research under supervision of an experienced supervisor. During the interview session and analyzing data, the researcher never tried to influence the process by own value, perception and biases. The answer of the questions had received whether they were of positive or negative impression. During the data analysis the researcher did not try to submit his own perspectives. The transcripts were translated by another 2 individuals to avoid biasness and researcher checked it several times with his own translation and recording to reduce any mistake and compared it with the Bangla transcript. The participant's information was coded accurately and checked by the supervisor to eliminate any possible errors. All the information and documents related to participants' had always tried to keep confidential. At last in the result section, scientific manner had used and didn't interpret the outcomes of the result.

Summary table of the study

Objective	Question no.	Category	Theme
(1) To identify the mothers understanding about the condition of autism.	Question no. (1-5)	<ol style="list-style-type: none"> 1. Mothers understanding about the condition of autism. 2. Mothers concept about the cause of autism. 	<ol style="list-style-type: none"> 1. Most of the mothers have lack of understanding about the condition of autism but some of them are aware about it after involving their children in special care.
(2) To explore the amount of time mothers can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their autistic child.	Question No. (6-8)	<ol style="list-style-type: none"> 3. Mothers concerned about performing their self-care activities. 4. Amount of time for mothers to perform self-care activities. 5. Mothers concerned about performing their productive activities. 6. Amount of time for mothers to perform productive activities. 7. Mothers concerned about performing their leisure activities. 8. Amount of time for mothers to perform leisure activities. 	<ol style="list-style-type: none"> 2. Most of the mothers can't able to perform their ADL's properly due to not getting enough time to perform those besides taking care of their autistic child.

<p>(3) To explore if there are any challenges (physical, family, social and psychological) for mothers with a child with autism.</p>	<p>Question No. (9-17)</p>	<p>9. Mothers experience about physical challenges</p> <p>10. Mothers quality of life in social interaction</p> <p>11. Mothers experience about psychological challenges</p> <p>12. Mothers' QOL in family relationship (other children)</p> <p>13. Mothers' QOL in family relationship (husband)</p> <p>14. Mothers' QOL in family relationship (other family members)</p>	<p>3. Most of the mothers are facing different physical challenges (tension, headache, high blood pressure, sleep disturbance, joint pain and sickness) and psychological challenges (frustration, grief, fear and self-blame) but it is a matter of hope that most of them don't blame themselves for child's condition and it is helpful to empower their mental health.</p> <p>4. Most of the mothers are facing different social challenges like stigma and lack of support from neighbors on the other hand some of them oppose with this.</p> <p>5. Most of the mothers are not facing family challenges because they are getting support from spouse and family members, but they are unable to provide enough time for their other children. But some of them complained that they are getting lack of support from spouse and family members.</p>
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CHAPTER 4 RESULT AND DISCUSSION

Discussion section is a very important part, where the researcher can add her explanations to the work. According to Shuttleworth (2009), in this critical part of the research paper, the researchers start the process of explaining any links and correlate those with findings of the study. The findings and discussion have been presented together with the necessary literature support. Each of the tables below represents the collected data. The tick was given only for those columns where the mothers spoke about those issues. Here 'P' was used for participant.

4.1. Findings at a glance

Theme-1: Most of the mothers have lack of understanding about the condition of autism but some of them are aware about it after involving their children in special care.

Theme-2: Most of the mothers can't able to perform their ADL's properly due to not getting enough time to perform those besides taking care of their autistic child.

Theme-3: Most of the mothers are facing different physical challenges (tension, headache, high blood pressure, sleep disturbance, joint pain and sickness) and psychological challenges (frustration, grief, fear and self-blame) but it is a matter of hope that most of them don't blame themselves for child's condition and it is helpful to empower their mental health.

Theme-4: Most of the mothers are facing different social challenges like stigma and lack of support from neighbors on the other hand some of them oppose with this.

Theme-5: Most of the mothers are not facing family challenges because they are getting support from spouse and family members, but they are unable to provide enough time for their other children. But some of them complained that they are getting lack of support from spouse and family members.

Category 1: Mothers' understanding about the condition of autism.

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Don't know about autism		✓	✓				✓		✓	✓	5
Know about autism after the child is born but no idea previously	✓				✓						2
No idea, but believe that the child's condition is going to improve through special care				✓		✓					2
Others have negative attitude towards autism								✓			1

Table 1: Understanding about the condition of autism

Most of the participants have no knowledge about the condition of autism. The Mother said that, *'no... no, I can't tell anything about autism'*.

Some participants said that they only knew about autism after their child was born. Before that they had no idea about autism. Mothers said, *'when my son had become autistic then I had known about autism, before that I had never known about what is autism'*.

According to Rakib(2013), it's found that in Bangladesh 1% children's are estimated as autistic around 1.5 lakhs. There is a lack of understanding about autism among the general public and parents and they are careless about treatment of autistic children until it is too late. It has reported by Baba (2014) that in a study in Nigeria, there is lack of understanding and awareness about autism in the community, in different ethnic groups and economic classes.

One participant said that these special children don't get enough affection from relatives or enough opportunities like a normal child. Nobody ever respects these children.

According to Dehnavi *et al.* (2011), in Iran it is found that public education and publicity is necessary to increase awareness about autism in society to modify public stigmatic attitudes. Lam (2013) mentioned that in Asian, American and Indian families, mothers has lack of understanding about autism and they get less social support from society and it was very stressful.

This study found that most of the participants have lack of knowledge about the condition of autism and the general public has lack of knowledge about the disorder too. In published studies it is also found that mothers and society people generally has lacked awareness about this disorder.

Category 2: Mothers' concept about the cause of autism.

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Don't know the specific cause	✓	✓			✓			✓	✓	✓	6
Late conception				✓							1
Seizure problem						✓					1
Sickness and Mental pressure of mother			✓								1
Feeling of fear							✓				1

Table 2: Concept about the cause of autism

Most of the participants have no idea or concept about the cause of autism. One mother said, *I don't know*. Another mother said, *'most of the people say many things but I don't know it exactly'*.

Based on the literature, medical sciences also can't discover the exact causes of autism. The cause of autism is still unknown. It has reported by Rakib(2013) that due to this lack of clarity, 48.89% of mothers were confused about the causes of autism of their children in Bangladesh.

One participant mentioned that due to late conception, her child became the sufferer of autism. The mother said, *'I think I had conceived late that's why my child had become the victim of autism'*.

It has stated Rakib(2013) that there is evidence that the risk of developing autism in a child is related with the age of the mother and father at the time of the child's conception. The possible reasons for this are: increased risk of pregnancy complications, lower maternal autoimmunity and increased risk of chromosomal abnormalities. Risk factors for developing autism can be the father's age, mother's age or both.

Another one participant said that seizure is responsible for her child's autism. Mother said that, *'when I had done his EEG test then his seizure problem is identified, when*

he was fall down at the age of seven month then seizure occurred and he had got severe trauma in brain. Now for which reason it is occurred, but in EEG test seizure problem is identified so I think that may be the reason’.

According to Adamo *et al.* (2011), it is found that there is high degree of clinical overlap occur between autism and epilepsy. In autism the risk of seizures is reported the range 5% to 46% and the prevalence of autism in epileptic population are reported at 32%. Though this relationship is confusing until now but it provides evidence that, possibly common genetic and molecular mechanisms are responsible for both the seizures and ASDs.

Further one participant said that she was sick and was in mental pressure after her marriage to adjust with a new family due to her sickness and mental pressure her child becomes autistic child.

In a study, it has reported by Atharia, Ghaedia and Kosnina(2013)that the effect of depression and stress during pregnancy can lead to autistic disorder or increase the symptoms of autistic disorder to the child after pregnancy.

Another one participant mentioned that, doctors said due to feel fear the child become autistic before that he was well.

There are many controversial opinions about the etiology of autism. According to scientists, different factors are responsible for the etiology of autism. There are many misconceptions among parents and general people in the society. Parents have those types of misconceptions due to lack of knowledge about exact cause of autism.

Based on their participants’ opinion it’s clear that most of mothers have not enough knowledge about the cause of their child’s autism. But some of them have little idea and a few of them has misconceptions about the cause of autism.

Category 3: Mothers’ concerned about performing their self-care activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Not able to perform properly	✓		✓		✓	✓		✓		✓	6
Can do it with lack of interest				✓							1

Can do but feel stress and challenge		✓							✓		2
Able to perform							✓				1

Table 3: Concerned about performing self-care activities

Most of the participants mentioned that besides take care of their special child in home they are not able to perform their self-care activities properly and timely. Mother said that, *‘no, I have to give high amount of time comparatively high amount of time for my child, as I do service so it is very tough for me to get time’*.

According to Lam(2013), mothers of autistic children experienced higher levels of care-giving stress and had gained less time for their own self-care and other pleasurable activities.

Another one participant said that she doesn’t feel interest to perform self-care activities. Further two participants said that she does her self-care activities but feel many stresses and challenges to do those activities.

In a study of Asian American families, Lam(2013)statedthatin 90% cases, mothers act as a primary caregiver and takes all responsibilities of rearing of children with autism, while fathers play the financial role. According to Altieri (2006), some families’ think that fathers aren’t responsible to do childcare and household chores, those are the responsibilities of mothers. That’s why a large burden falls on mothers by maintaining all duties and thus they are getting little time for themselves or the others children in family.

Another one participant said that she is able to perform self-care activities with taking care of her child in home.

According to Barbera(2007), mothers’ present situation is going to change due to less aggressive behavior of their children.

In this study it is found that most of the participants can’t perform their self-care activities properly with having a child with autism. On the base of literature, it has been seen that due to mothers is the main care-giver of children with autism so they need to bear all care-giving responsibilities of them and also maintain house-hold responsibilities. Finally, thus it becomes challenging for them to perform their self-care activities.

Category 4: Amount of time for mothers to perform self-care activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
1-2 hours		✓		✓			✓				3
2-3 hours	✓					✓		✓	✓	✓	5
1 hour			✓								1
Half an hour					✓						1

Table 4: Amount of time to perform self-care activities

Most of the participants mentioned that they are getting 2-3 hours to perform self-care activities. Some participants mentioned that they are getting 1-2 hours to perform those activities. Moreover very few of them stated that they are getting less time than those mothers. The mother said, *'this is right I can't but I try and after trying I get half an hour for myself'*.

According to Plant and Sanders(2007), mothers are responsible for doing all the work related to child care. These are: the child's own self-care activities, completion of in-home therapy, attendance at medical appointments, therapy sessions, educational programs, and management of child's challenging behavior. Ebrahimi*et al.* (2013) mentioned that mothers continuously have to balance between meeting the children's needs and having a normal life, but it is very difficult to keep this balance. According to Dehnaviet *al.* (2011), mothers have to spend more than thirty hours every week providing care for children with autism in Iran. It has also reported by Kerenhappachu and Sridevi(2014) that mothers tend to give little time for themselves due to care-giving demands of their children with autism.

In this study, it is found that mothers get less time to perform their own self-care activities, as the literature has indicated. This is due to continuous care-giving demands and mothers leave their own daily life needs, and become unconscious about their own self-care activities and how it impacts on their quality of life.

Category 5: Mothers' concerned about performing their productive activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Not able to perform properly				✓			✓	✓		✓	4
Doing a medium amount		✓									1

Can do but feel stress and challenge									✓		1
Able to perform	✓		✓		✓	✓					4

Table 5: Concerned about performing productive activities

Most of the participants mentioned that they are not able to perform their productive activities like house-hold activities and official activities properly, besides taking care of their child in home. Mothers said that, '*I am not able to perform properly*'.

A few participants said that they are performing their house-hold activities quite well as well as taking care of their child, and very few participants said that they were doing their house-hold works besides take care of their child, but at the same time they feel very trouble.

According to Ogston Nobile (2014), mothers of autistic child experienced a greater risk of stress and depression than the father, because they are more involved in caring for their children and managing their household responsibilities. Moreover, mother's careers are also disrupted. It has mentioned by Altieri (2006) that they wanted to work outside the home but can't seek employment due to the high level of care-giving demands of their children with autism. According to Dehnaviet *al.* (2011), many mothers have to give up their careers which increased the financial burden on the family and created stressful situations for them in Iran.

Some participants said that they are able to perform their productive activities besides taking care of their child in home.

In the literature it is found that, most of the mothers with autistic children always face career problems due to the less working time they have, because of the care-giving needs of child. According to Barbera(2007), the mothers' situation can be better if the child has less aggressive behavior.

In this study it is found that most of the participants can't perform their productive activities properly after having a child with autism. On the basis of the literature, it has been seen that mothers bear all the rearing responsibilities of autistic children. Due to this high care-giving burden mothers face difficulties in performing their productive activities.

Category 6: Amount of time for mothers to perform productive activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
2-2.5 hours		✓									1
2 hours			✓		✓						2
2 -3 hours						✓	✓	✓		✓	4
3-4 hours									✓		1
1.5-2 hours	✓			✓							2

Table 6: Amount of time to perform productive activities

Most of the mothers mentioned that they are getting 2-3 hours to perform productive activities. Some of them mentioned that they are getting only 2 hours and a very few of them mentioned that they are getting 3-4 hours to perform those activities besides taking care of the child in the home. Moreover very few of them stated that they are getting less time than all those mothers.

According to Ogston-Nobile(2014), mothers have the responsibilities of child-related care giving needs and the domestic tasks. Those responsibilities make the mother's life stressful. The less involvement of fathers makes more stress for the mothers. It has mentioned that, mothers have to provide care-giving for twenty-four hours, seven days a week and this becomes a continuous job for mothers throughout the child's entire lifetime (Altieri, 2006). All of this work is very time constraining for mothers with autistic children. It has stated by Obaid and Al-kadoumi (2012) that mothers who work outside the home, when they have an autistic child, they can no longer manage this, due to having less time.

In this study, it is found that mothers are usually getting less time to perform their productive activities like household or official works or both. As much of the literature indicates, due to care-giving demands, most mothers can't perform their productive activities properly. The result of this study contradicts other studies, because some of the mothers stated that they are able to manage their productive work besides taking care of their children.

Category 7: Mothers' concerned about performing their leisure activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Not able to perform			✓		✓			✓		✓	4
Get very little amount of time		✓							✓		2
Able to perform	✓			✓		✓	✓				4

Table 7: Concerned about performing leisure activities

Most of the participants mentioned that they are not getting leisure time because of taking care of their child in the home. Mother said that, '*don't get any time to spend as leisure time*'.

According to Lam (2013), mothers of children with autism have to spend a high amount of time for care-giving, therefore there remains little or no time for their pleasurable activities and this is very stressful. It has reported by Rakib (2013) that in case of working mothers with children with disability, they get even less time for their own care and leisure, than mothers raising a typical child.

A few participants said that they are getting a little amount of leisure time besides taking care of the child in the home.

According to Johnson *et al.* (2011), the mothers' stress may be linked to the high level of time demand of their children. They have to provide child care and do all the household chores and thus they don't get time for leisure activities in comparison with mothers of children without disabilities.

A small number of the participants mentioned that they are able to perform their leisure activities as well as taking care of their child in the home. The mothers said that, '*yes, getting time to perform leisure activities*'.

It is found that some also reported positively that they think the present situation is better than it had been a decade earlier (Barbera, 2007). The mothers of autistic children who are less aggressive feel more relief. These mothers can manage their work and can also spend some leisure time.

In this study it is found that most of the participants are unable to enjoy leisure activities, or are getting very little time to spend as leisure time when they have a child with autism.

Category 8: Amount of time for mothers to perform leisure activities

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
1 hour or less	✓	✓	✓		✓				✓		5
1 or 1.5 hours								✓			1
2 hours							✓				1
10-15 or No time for leisure				✓						✓	1
3-4 hours						✓					1

Table 8: Amount of time to perform leisure activities

Most of the participants mentioned they are getting 1 hour per day or less to spend as leisure time, besides taking care of their children with autism. Few of them said that they are getting only 1 or 1.5 hours to spend as leisure time. Some of them also mentioned that they are not getting any time to spend as leisure time or getting very little time.

Providing physical assistance for daily living to children with disabilities can be very time consuming for the parents. According to hsieh and Puymbroeck(2013), in a study of Taiwan, many parents reported that they had no time for themselves. Time was a major leisure restriction for them. Even when those parents participated in leisure activities, they were continuously anxious about their child's condition. They reported that they were not able to enjoy the leisure activity because they were not fully engaged in it.

In this study, as well as in the literature, it is found that mothers are not getting enough time for their leisure, and this causes stress.

Category 9: Mothers' experiences of physical challenges

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Feel tension		✓	✓	✓	✓	✓		✓			6
Sickness and physical stress			✓			✓	✓		✓		4

High blood pressure			✓		✓		✓				3
Diabetes					✓						1
Headache		✓		✓						✓	3
sleep disturbance				✓						✓	2
Become old in early age					✓						1
Joint pain			✓			✓				✓	3
No impact on any physical condition	✓										1

Table 9: Experience about physical challenges

All the participants shared their experiences of the physical challenges of the extra care-giving needs of their children. To explain about their physical challenges most participants admitted to tension, sickness, physical stress, high blood pressure, diabetes, sleep disturbances, headache, joint pain, feeling old in early age. Mothers said that, *'problems are like I become sick, my pressure becomes increased, and that type of problem'*.

According to Rakib(2013), autism has an indirect impact on the physical health of family members in Bangladesh. Continuous anxiety, depression, and tiredness from care-giving, all have an impact the physical health of mothers of autistic children. Tension or stress can be the cause of a lowered immunity and sleep deprivation, thus it may result in difficulty in concentrating, memory impairment and other health complications. It has reported by Alhusieni(2012) that due to the high level of care-giving needs of the autistic child, 31.3% of mothers felt different physiological responses such as crying, loss of appetite, cold, sweat, trembling, physical pain, rapid heartbeat and physical breakdown in Saudi Arabia. A high level of care-giving is associated with poor physical health which increases as the children grow up.

Another one participant said that by giving lots of time with their child and giving special care for them, it has no impact on her physical condition.

That is much deviated result found from this study. All literature said that the mothers are facing lots of challenges in their physical aspects. According to Barbera(2007), children who are less aggressive behaviors, their mothers feel more relief. For that sometimes they can manage their works and less impact on their physical condition.

In this study, it is found that most of the mothers are facing different physical problems due to care-giving burden like headache, sleep disturbance, high blood pressure, joint pain, sickness. Very few of them reported no experience of facing any physical problems. Based on Literatures, mothers of child with autism faced different physical problems due to high level of stress of care-giving.

Category 10: Mothers quality of life in social interaction

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Neighbors are not enough sympathetic towards mother and child	✓	✓			✓				✓	✓	5
Experiencing stigma like blame mother for child's condition		✓	✓	✓			✓		✓	✓	6
Sympathetic toward mother and child			✓	✓		✓	✓	✓			5
Not experiencing any stigma	✓				✓	✓		✓			4
Neighbors avoid to mix with the special child and often ill-treat them as mad	✓		✓	✓							3
Look at the child at different way and feel irritate towards them		✓			✓					✓	3
Isolated from neighbors									✓		1

Table 10: Quality of life in social interaction

Half of the participants mentioned that their neighbors are not enough sympathetic towards them. Mother said that, *'actually some of them may sympathetic or some of them laugh and tease. I think myself that they may laugh and may look differently towards the child when they can understand that the child is no normal completely. Therefore I feel sad'*.

It has stated by Kerenhappachu and Sridevi(2014) that the mothers of mentally handicapped children experienced higher level of social burden rather than mothers of the physically handicapped children. woodgate, Ateah andSecco(2008)reported that parents reported that society give less value on the lives of the children with autism and felt stigmatized, thus adding to the feelings of isolation. According to Fairthorneet al. (2014), poor levels of social support and perception of stigma against their children with autism hampered maternal quality of life.

Most of the participants of the study mentioned that they are experiencing stigma like blaming themselves for their child's condition and so on. Mother said that, *'they say that it may be your fault. You have fault otherwise why the child is in this situation. Most of them say like that'*.

According to Lam(2013), stigma and shame is always faced by parents who have children with disabilities such as autism in Asian communities. Lack of knowledge about this disorder influenced the society people to blame mothers for their child's condition. They are believed that mothers have violated some cultural rules for that they get children with disability. In a study in Bangladesh reported that, especially the aged one in family members blames the wife to given birth of a child with disability (Rakib, 2013).

Half of the participants mentioned that their neighbors are sympathetic towards them. Mother said, *'yes sympathetic'*.

According to Rakib(2013), it was found that 48.89% neighbors are showing positive attitude towards autistic children, also taking part in care-giving the child in Bangladesh. It has stated by Tarabek(2011) that mothers who get available social support had faced fewer physical and psychological issues than those who are getting less support.

Some of the participants of the study mentioned that they are not experiencing stigma due to having a child with autism.

According to Shpigelman(2014), mothers reported that after getting child with disability they have learned to think positively and how to cope with difficulties. Sometimes they don't worry about that stigma. In Bangladeshi perspective, sometimes mothers don't want to share their problems to outsider, which can be another reason of this.

Very few participants said that usually the neighbors avoid mixing with their child, and also doesn't allow their children to mix with autistic child and they often ill-treat them. Small number of them said that neighbor's look at the child at different way and feel irritate towards them. Isolation from neighbors are also stated by a very few participants.

It has mentioned by Lam(2013) that autistic children show maladaptive behaviors and those behaviors appear strange or inappropriate among many Asian communities as they have lack of awareness about autism disorder, thus it increase difficulties for mothers because community people blame themselves for their children's behavior. It has found by Rakib (2013) that sometimes neighbors do not want to interact with the autistic family members. Rakib(2013) reported that sometimes mothers want to interact with the neighbors but they can't due to the child's maladaptive behavior as 35% parents stated this in a study in Bangladesh.

In this study, half of the participant mentioned that society people are not enough sympathetic towards child with autism and their mothers and half of the participants mentioned that society people are sympathetic towards them. Moreover most of them are experiencing social stigma from society for their child's condition and some also contradict with this. Literatures also indicate that social support is very important for mothers to cope with the adverse situation. Some study reported society people sympathetic and some indicated not. So results can vary from society to society but most of the study indicated negative attitude is common from society toward disability.

Category 11: Mothers' experience about psychological challenge

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Feel prolong frustration and grief	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10
Always remain in fear for child			✓								1
Have no blaming for their child's condition	✓	✓	✓	✓		✓	✓	✓		✓	8
Self-blame for the child's condition					✓				✓		2

Table 11: Experience about psychological challenges

Most of the participants said that they always remain in frustration and grief for the child due to think about the future of the child after their death, society people's attitude towards the child is a common stressor for them and sometimes they feel guilt for their child's condition so they feel frustration. A very few participant said that they always remain in fear for them because it is not possible to keep them alone in home or allow them to go outside alone.

Mothers of children with autism always remain in depression and faced other psychological issues rather than mothers of typically developing children. According to Lam(2013), stress is mainly for the severity of the disorder and high level of care-giving demands for them. Stress and frustration is also due to the insecure future of their child. Tarabek (2011) mentioned that parents may worry about who will provide care for their child after their absence. Families of children with disabilities often reported that public reaction is judgmental, stereotypical and negative toward them. It is stated by Pathappillil(2011) that people have lack of awareness about this disorder; therefore they may simply blame a child's inappropriate social behaviors as lack of discipline. This is also providing negative psychological impact on mothers with autism in India. According to Lam (2013), sometimes mothers feel a sense of self-blame on themselves due to their child's disability and believe that they have done something wrong during pregnancy or violate cultural rules therefore they have this child. They think they are responsible for child's disability, thus it creates impact on their mental health. Moreover, according to Fairthorne *et al.* (2014), mothers feel grief to a loss. They reported that losing their expected healthy child to autism.

Many participants said that they don't think them responsible for their child's condition.

It has reported by Yousafzai, Farrukh and Khan (2011) that caring for a child with disability enables mothers to move beyond traditional boundaries and thus they change their wrong beliefs and think positively and seek health and education service for their children. Some doesn't blame themselves for their child's condition.

In this study, it is found that most of the mothers are always remain in frustration and grief to think about their children with autism and this may lead negative psychological outcomes for mothers. Some of them provide self-blame on them for their child's condition. This has an adverse effect on their mental health. But it is a matter of hope that most of the mothers don't think them responsible for their child's condition. Literatures reported that, self-blame, anxiety, depression, frustration are common in mothers of children with autism. But the situation is now changing, mothers become empower and their concept become changing towards children with disabilities.

Category 12: Mothers' QOL in family relationship (other children)

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Not able to give enough time and care to other child		✓		✓	✓			✓	✓	✓	7
Able to give enough time and care to other child			✓			✓	✓				4
Can't able to help in study of the other child		✓		✓	✓						3
Other child are getting less care									✓		1
Other child feel lonely and bored										✓	1

Table 12: Quality of life in family relationship (other children)

Most of the participants mentioned that they are unable to give enough time and care to their other child due to providing extra care to the special child. They mentioned that they are facing problems like they are unable to help their other children in study purpose, other children are getting less attention and care and they are often feel lonely and bore due to get less time and care.

A special child requires high needs, which consume the parents time. Hartman (2012) reported that, it may be difficult for parents to make balance with their child with autism and other children. According to Vliem(2009), siblings of children with autism remain in stress and feel jealousy for getting less time from parents. It has also found that, they also feel neglected and remain lonely (Ma, 2012). This is very alarming issue for mothers to make time balance between their children and it impacts their relationship with other children.

Some of the participants said that, they are able to give enough time and care to their other child due to providing extra care to the special child. Mothers said, *yes, I can do.*

It has stated by Rakib(2013) that sometimes it is found that a maturity and a sense of responsibilities become develop in many siblings and they take pleasure in the activities of their brother and sister. Then negative psychological thinking doesn't appear on them. Mothers also feel fewer problems to maintain balance between their children.

In this study, most of the mothers face difficulties to maintain care-giving balance between their children but some mothers can able to make balance between their

children. But literature said that, maintaining the high needs of a child with autism most of the mother feels hesitant to fulfill the needs of other children thus negative psychological impact fall on siblings.

Category 13: Mothers' QOL in family relationship (husband)

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
No impact fall on relationship with husband	✓	✓	✓			✓	✓	✓		✓	7
Impact fall on relationship with husband				✓	✓				✓		3
Unable to give enough time to husband				✓					✓		2
husbands can't understand the reason of child's problem and blame their wife					✓						1

Table 13: Quality of life in family relationship (husband)

Most of the participants mentioned that there is no impact on their relationship with their husband due to having a child with autism.

It has reported by Hartley *et al.* (2011) that better quality marital relationships influence better quality parent–child relationships. If mother get spousal support then it becomes very helpful to cope with adverse situation. Kuhaneck *et al.*(2010) stated that mothers feel relief to get spousal support to think that there has someone to support them. It is found that marital distress is common problem faced by mothers of child with autism. According to Doron and Sharabany(2013), some studies reported that there is a positive affect fall on the marital relationship because they have found proper ways to communicate and improve physical and mental cooperation, after getting a special child.

Some participants said that due to having a child with autism, little impact fall on their relationship with their husband. They reported that they are unable to give enough time to their husband, that's why problems increasing in their relationship. One participant said that sometimes her husband can understand the problem but sometimes can't understand the problem and usually blame herself for child's condition.

Marital conflict is more common in parents of children with disabilities rather than parents with normal children (Bashir *et al.* 2014). As mothers are the primary care-giver, therefore they have to spend large amount of time to provide care-giving to their child, that's why they may get little time for herself or her husband. Thus negative impact falls on their marital relationships. According to Rakib(2013), the divorce rate is in the 80% range in families of children with autism in Bangladesh. Pathappillil(2011) stated that many mothers reported that marital conflict occurred between husband and wife as a result of having a child with autism in India.

In this study most of the mother's opinion is there is no impact fall on their relationship with their husband. Researcher thinks that due to cultural perspective, most of the people of our country are restrictive and as the topic is so personal therefore they usually don't want to share their internal matter with the outsider. But some of them share their opinion with the researcher.

Category 14: Mothers' QOL in family relationship (other family members)

Codes	P-1	P-2	P-3	P-4	P-5	P-6	P-7	P-8	P-9	P-10	Total
Sympathetic towards mothers and child's	✓		✓		✓	✓		✓	✓	✓	7
Not enough sympathetic towards mothers and child's		✓		✓			✓				3
Treat the child at different way and criticize them.		✓					✓				2
Don't like to allow the child in their home				✓							1

Table 14: Quality of life in family relationship (other family members)

Most of the participants said that their family members are sympathetic towards the child and themselves. Mothers said that, 'yes, *sympathetic*'.

The attitudes of extended family members vary from family to family. Sometimes they seem like supportive, well-meaning but sometimes they seem like judgmental, negative and ignorant. It has mentioned by Fairthorne *et al.* (2014) that almost half of the mothers are benefitted from helpful and supportive family members in Australia. According to Wolf(2009), it is also found that 61.5% of parents are having other family members help in child care in Kentucky. Mothers

coping skill is increased those who are having sufficient support from spouses, family members and other parents.

Some participants said that their family members are not sympathetic towards the child and themselves. Some of them said also that family members usually treat the child at different way and criticize them and a very few of them mentioned that family members don't like to allow the child in their home.

According to Dehnaviet *al.* (2011), the main sign of autism is behavioral problem; therefore easily people ignore their neurological problem and blame parents for their children's misbehaviors. According to Previous studies family members showed different kinds of stigmatic and discriminative behavior towards children with Autism. Some parents reported that extended family members blame parents for their children's disorders (Tarabek, 2011). It has stated by Altieri(2006) that sometimes extended family members may reject the child with autism or distance themselves from the family. The parents often describe relatives as cold, distant, and generally unhelpful. Low family support decrease maternal quality of life and increase burden for mother to cope with critical situation.

In this study, most of the mothers reported that their family members are supportive and sympathetic towards them. But some of them oppose it. Usually family members attitude vary from house to house. It also depends on the knowledge of the family members about disability. In literature the evidence said that some study indicates family members are supportive and some study indicates negative attitudes are common from family members.

Finally, researcher thought that after having a child with autism mothers' quality of life is hampered. They can't balance time with their own ADL's and also their other family members specially spouse and other children due to high care-giving demands of the special child. It also impacts their physical and psychological aspects. Moreover, lack of societal and family support is also responsible for their increasing burden. It's mainly due to lack of knowledge about this disorder among society people, they usually show stigmatic attitude towards children with autism and their mothers. Mothers have lack of awareness too about this disorder therefore sometimes they feel guilt and self-blame on themselves for their child's condition. Overall

mothers' daily life and quality of life is decline after having a child with autism and they faced different challenges physical, psychological, social and family aspects.

4.2. Limitation

It is the first time for the researcher to conduct this study as a part of course curriculum. So there is limitation on researcher's skill to conduct the interviews. If the researcher is a skilled person in conducting interview then she may be obtain more in-depth information. During data collection, there was not enough time to build rapport with participants and researcher therefore, sometimes in-depth information had not come out. There are many studies in the world about autism but in the Bangladeshi context there have very few. The researcher had to use many secondary sources assessed by internet. It was difficult to discuss the finding in the Bangladeshi context. The researchers always tried her best to consider these limitations. Though there are some limitations but still the study contains enough information about mothers' way of life.

CHAPTER 5 CONCLUSION

Autism is a neurological disorder. They usually show maladaptive behavior and interest therefore they have to provide constant supervision. In Bangladeshi perspective, mothers have to maintain major care-giving responsibilities of their children and also have to manage their household responsibilities. As caring a child with autism is very challenging therefore mothers have to remain in ongoing stress. It often impacts their daily life and overall quality of life.

The study has been conducted to explore the challenges in daily life and quality of life of mothers with autistic children. This study would be helpful to identify specific problems area and challenges of mothers to provide appropriate emotional support and education to increase their self-esteem coping skills. From the result of the study, it has found that mothers have lack of understanding about the condition. They usually don't get enough time to perform their ADL's properly due to high care-giving burden. Moreover, they also faced different physical, psychological, family and social problems after having an autistic child and thus their daily life and quality of life is decline greatly. It is also true that some mothers take their child's related works positively and reported that they don't facing any problems and also it is a matter of hope that most of them don't blame themselves for their child's autism as well as they are getting support from society and it is very helpful to reduce negative psychological outcomes of them.

This study is important for occupational therapists as they can work with mothers to increase awareness about autism among mothers and society people, they can give motivation and education to the mothers to increase their mental stability and coping skills. They also can run home visit and arrange open discussion with society people to reduce their stigmatic attitude towards autistic child. Schools those are working with autistic child may arrange mothers' session, self-help group session, sharing session to raise awareness and empowerment of mother and occupational therapist can organize those sessions. Government should come forward to help in organizing awareness raising and promotional program about autism and its intervention to increase awareness in community people about autism and its treatment.

Reference list

(Harvard Referencing Style- 2014)

- Athari, P, Ghaedi, L, & Kosnin, A.B.M. (2013) 'Mothers' depression and stress, severity of autism among children and family income', *International journal of psychological research*, 6(2), pp.98-106. Available at: https://www.google.com.bd/search?q=Mothers%20%99+depression+and+stress,+severity+of+autism+among+children+and+family+income%20%99,+International+Journal+of+psychological+Research,+6%282%29,+pp.+98106.&ie=utf8&oe=utf8&rls=org.mozilla:enUS:official&client=firefox-a&channel=fflb&gws_rd=cr&ei=DX3cVNbIHsT0mwWH4oDICg [Accessed 20 January 2015].
- Astalin, P. K. (2013) 'Qualitative research designs: a conceptual framework', *International journal of social science & interdisciplinary research*, 2 (1). Available at: <http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCQQFjAB&url=http%3A%2F%2FIndianresearchjournals.com%2Fpdf%2FIJSSIR%2F2013%2FJanuary%2F13.pdf&ei=pXzcVJ2fMYLYmAXEqYK4Dg&usg=AFQjCNE5vupjIaxdTFRPHPxpI6NNPiA1TA&bvm=bv.85761416,d.dGY> [Accessed 20 January 2015].
- Altieri, M.J. (2006) *Family functioning and coping behaviors in parents of children with autism*. Master's theses and doctoral dissertations. Eastern Michigan University.
- Alhusieni, H.M. (2012) *Level of perception of significance of support groups among mothers of autistic children*. Partial fulfillment of the practical training in field of counseling psychology. Effat University.
- Abou-Dagga, S.K. (2013) *Psychological stress and resilience among parents of autistic children in Gaza Strip*. Partial fulfillment of the requirements for the degree of Master in Community Mental Health (nursing science). The Islamic University of Gaza.
- Adamo, M.C.D, Moro, F, Imbrici, P, Martino, D, Roscini, M, Santorelli, F.M, Sicca, F, & Pessia, M. (2011) 'The emerging role of the inwardly rectifying K⁺ channels in autism spectrum disorders and epilepsy', *Malta medical journal*, 23 (03). Available at:

<http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.um.edu.mt%2Fumms%2Fmmj%2FPDF%2F327.pdf&ei=RXzcVIilK6XwmAW0toGYBw&usg=AFQjCNHmzwcVJ3H3RveEfjy4ZTikmHSw&bvm=bv.85761416,d.dGY>[Accessed 20 January 2015].

- Bashir, A, Bashir, U, Lone, A, & Ahmad, Z. (2014) ‘Challenges faced by families of autistic children’, *International journal of interdisciplinary research and innovations*, 2 (1), pp. 64-68. Available at: https://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CBwQFjAA&url=http%3A%2F%2Fwww.researchpublish.com%2Fdownload.php%3Ffile%3DChallenges%2520Faced%2520by%2520families%2520of%2520Autistic%2520Children-153.pdf%26act%3Dbook&ei=hUy7VMY1D8mXuATzk4HICw&usg=AFQjCNHQJ6qoJMWnLZQ_xB1p7cr96LMGSA&bvm=bv.83829542,d.c2E [Accessed 4 September 2014].
- Barbera, M.L. (2007) ‘The experiences of "autism mothers" who become behavior analysts: a qualitative study’, *Journal of speech - language pathology and applied behavior analysis*, 2(3). Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&cad=rja&uact=8&ved=0CDAQFjAC&url=http%3A%2F%2Fbarberabehaviorconsulting.com%2Farticles%2Fmom_bcba.pdf&ei=kFoFVajwMdiVuATg2IKgCg&usg=AFQjCNF8KPNlytSGPJDmrjwUSy7vwuoPNw[Accessed 4 September 2014].
- Bailey, D. (1997) *Research for the health professional: a practical guide* 2nd edition, Philadelphia: F.A Devis Company.
- Baba, P.N. (2014) ‘Living and dealing with autistic children: a case study of a Nigerian family in Cincinnati, Ohio, United States’, *Research on humanities and social sciences*, 4 (8). Available at: <http://www.iiste.org/Journals/index.php/RHSS/article/view/12479/12808>[Accessed 4 September 2014].
- Cohen, D, and Crabtree, B. (2006) *Qualitative research guidelines project*. Available at: <http://www.qualres.org/HomeSemi-3629.html>[Accessed 15 July 2014]

- crp-bangladesh.org (2010). *Occupational Therapy*. Available at:
http://www.crpbangladesh.org/index.php?option=com_content&view=article&id=80 [Accessed 15 July 2014]
- Dehnavi, S.R, Malekpour, M, Faramarzi, S, & Talebi, H.(2011) ‘The Share of internalized stigma and autism quotient in predicting the mental health of mothers with autism children in Iran’, *International journal of business and social science*, 2(20). Available at:
<http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CBwQFjAA&url=http%3A%2F%2Fblogs.longwood.edu%2Fkandicebrown%2Ffiles%2F2013%2F03%2FArticlesonAutismProject.docx&ei=etplVMn6INHhuQS6r4EQ&usg=AFQjCNG4GWzL2Ko8u78IBPh0W9gJxtlgQ&bvm=bv.79142246,d.c2E> [Accessed 4 September 2014].
- Doron, H, & Sharabany, A, (2013). ‘Marital patterns among parents to autistic children’, *Psychology*, 4(4), pp. 445-453. Available at:
http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CBsQFjAA&url=http%3A%2F%2Fwww.scirp.org%2Fjournal%2FPaperDownload.aspx%3FpaperID%3D30167&ei=inrcVK-UN-GNmWz44GQAg&usg=AFQjCNH7s3XUi9xBLwmlkcwRx_E_1akwQ&bvm=bv.85761416,d.dGY [Accessed 20 January 2015].
- Dzubay, S. K. (2011) *Parental grief, coping strategies, and challenges when a child has autism spectrum disorder*. Partial fulfillment of the requirements for the Master of Science Degree in family studies and human development. University of Wisconsin-Stout.
- Department of Health & Family Welfare (2014) *Health bulletin 2013*. Dhaka: Directorate general of health services. Available at:
http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=13&cad=rja&uact=8&ved=0CFgQFjAM&url=http%3A%2F%2Fhpncconsortium.org%2Fadmin%2Fessential%2FHB_2013_final_Full_version_1March14.pdf&ei=zFMFVaSCKY6xuQTgxYKoDg&usg=AFQjCNHnHwmxd84ozc0HPJy_PEWBSKkEZQ&bvm=bv.88198703,d.c2E [Accessed 20 January 2015].
- Ebrahimi, H, Malek, A, Babapoor, J, & Abdorrahmani, N. (2013) ‘Empowerment of mothers in raising and caring of child with autism spectrum disorder’, *International research journal of applied and basic sciences*,

4(10),pp. 3109-3113. Available at:

http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.irjabs.com%2Ffiles_site%2Fpaperlist%2Fr_1112_130816234934.pdf&ei=8nncVNrEDaHbmgWQ4L4Bg&usg=AFQjCNFmNwum3GZz_12X1c6HejGzSPRekA&bvm=bv.85761416,d.dGY [Accessed 7 September 2014].

- Elfert, M. (2014) *Fathers of children with autism: the impact of a support group on fathers' stress, depression, coping, and marital satisfaction*. Partial fulfillment of the requirements for the degree of doctor of philosophy in the faculty of graduate and postdoctoral studies (special education). The University of British Columbia.
- Ekas, N.V. (2009) *Adaptation to stress among mothers of children with autism spectrum disorder: the role of positive affect and personality factors*. Partial fulfillment of the requirements for the degree of doctor of philosophy. University of Notre Dame.
- Fairthorne, J, Fisher, C, Bourke, J, & Leonard, H. (2014) 'Experiences impacting the quality of life of mothers of children with autism and intellectual disability', *Psychology research*, 4(8), pp. 666-684. Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=9&cad=rja&uact=8&ved=0CF8QFjAI&url=http%3A%2F%2Fwww.davidpublishing.com%2Fdavidpublishing%2Fupfile%2F9%2F10%2F2014%2F2014091071411065.pdf&ei=_VLLVK7hH4SNmwWfx4FA&usg=AFQjCNFD2K_L3w6OllvIxKoDIxQBRfd1pw&bvm=bv.84607526,d.dGY[Accessed 22 January 2015].
- Hartmann, A. (2012) *Autism and its impact on families*. Master of social work clinical research papers. St. Catherine University.
- Hsieh, H, & Shannon, S.E. (2005) 'Three approaches to qualitative content analyses', *Qualitative health research*, 15(9), pp.1277-1288. Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCIQFjAB&url=http%3A%2F%2Fwww.iisgcp.org%2Fglssn%2FSupplemental%2520Reading%2520on%2520Coding%25202.pdf&ei=0IPcVMW_EoXbmgXqoCICA&usg=AFQjCNEbiwoxalZQSsjCWLduwxgGjLyvg&bvm=bv.85761416,d.dGY [Accessed 4 July 2014].

- Hsieh, P., & Puymbroeck, M.V. (2013) 'Leisure as a means of coping: the experience of Taiwanese parents of adult children with disabilities', *Recreation and society in Africa, Asia and Latin America*, 4(1). Available at: <https://journal.lib.uoguelph.ca/index.php/rasaala/article/view/2714/2824> [Accessed 12 January 2015].
- Hartley, S.L, Barker, E.T, Seltzer, M.M, Greenberg, J.S, & Floyd, F.J.(2011) 'Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism', *American association on intellectual and developmental disabilities*, 116(1), pp. 81-95. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3059595/> [Accessed 4 July 2014].
- Isaac. (2013) *3 Tips for recording research interviews*. Available at: <http://www.academictranscriptionservices.com/3tipsforrecordingresearchinterviews/> [Accessed 31 August 2014].
- Johnson, N, Frenn, M, Feetham, S, & Simpson, P.(2011) 'Autism spectrum disorder: parenting stress, family functioning and health-related quality of life', *Families, systems, & health*, 29(3), pp. 232-252. Available at: <http://hinarilogin.research4life.org/uniqueSIGpsycnet.apa.org/uniqueSIG0/index.cfm?fa=buy.optionToBuy&id=2011-21122-003> [Accessed 4 September 2014].
- Kheir, N, Ghoneim, O, Sandridge, A, L, Al-Ismail, M. (2012) *Quality of life of caregivers of children with autism in Qatar*. Undergraduate research experience program. Qatar national research fund.
- Keller, s, and Katharina, c. (2010) *Semi-structured interviews*. Available at: <http://www.sswm.info/category/planningprocesstools/decisionmaking/dicision-making-tools/gathering-ideas/semi-structure> [Accessed 15 July 2014].
- Kopetz, P. B, & Endowed, D. L. (2012) 'Autism worldwide: prevalence, perceptions, acceptance, action' *Journal of social sciences*, 8 (2). Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA&url=http%3A%2F%2Fthescipub.com%2FPDF%2Fjssp.2012.196.201.pdf&ei=_njcVIqiLYTEmwWV3IKwAg&usq=AFQjCNH1CzBuZqcAfXMfF7R5QOQI8ygECA&bvm=bv.85761416,d.dGY [Accessed 14 August 2014].

- Kamei, A. (2013) *Perceptions and experiences of mothers who have children with autism spectrum disorders: cross-cultural studies from the US and Japan*. Partial fulfillment of the requirements for the degree doctor of philosophy. The University of North Carolina.
- Kerenhappachu, M.S,&Sridevi, G. (2014) ‘Care giver’s burden and perceived social support in mothers of children with mental retardation’, *International journal of scientific and research publications*, 4(4). Available at: <http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCIQFjAA&url=http%3A%2F%2Fwww.ijsrp.org%2Fresearchpaper0414%2Fijsrpp2881.pdf&ei=93DcVIyoJoTWmAXY9YLoBQ&usg=AFQjCNFZCjsfsCk58rAC29LDWLHT5nikw&bvm=bv.85761416,d.dGY>[Accessed 4 September 2014].
- Karasavvidis, S, Avgerinou, C, Lianou, E, Priftis, D, Lianou, A,&Siamaga, E. (2011) ‘Mental retardation and parenting stress’, *International journal of caring sciences*, 4(1). Available at: http://internationaljournalofcaringsciences.org/docs/Vol4_Issue1_04_Karasavvidis_Abstract.pdf [Accessed 4 September 2014].
- Kuhaneck, H.M, Burroughs, T, Wright, J, L, &Darragh, A.R. (2010) ‘A qualitative study of coping in mothers of children with an autism spectrum disorder’, *Physical & occupational therapy in pediatrics*, 30 (4), pp. 340-50 Available at:http://digitalcommons.sacredheart.edu/ot_fac/6/?utm_source=digitalcommons.sacredheart.edu%2Fot_fac%2F6&utm_medium=PDF&utm_campaign=PDFCoverPages[Accessed 4 September 2014].
- Koerber, A, &McMichael, L. (2008)‘Qualitative sampling methods’, *Journal of business and technical communication*, 22(4), pp. 454-473. Available at: <http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=19&cad=rja&uact=8&ved=0CFUQFjAIOAo&url=http%3A%2F%2Fcourses.johnmjones.org%2FENGL605%2Fwpcontent%2Fuploads%2F2012%2F05%2FKoerberandMcMichaelQualitativeSamplingMethods.pdf&ei=v3XcVMnwBuHAMwXNnYKQDw&usg=AFQjCNGncc9q7KpPflaS1HR5BxK69DcSbQ&bvm=bv.85761416,d.dGY>[Accessed 4 September 2014].

- Lam, J. T. (2013) *The experience of Asian American mothers raising children with autistic disorder*. Partial fulfillment of the requirements for the degree of doctor of psychology. John F. Kennedy University.
- Mohammadi, Z. D, Yazdezadeh, H, Bassaknejhad, S, &Daghagheleh, R. (2014) 'Effectiveness of group training program relevant to stress management on the quality of life and its dimensions using a cognitive- behavioral approach in mothers of children with Autism', *Jundishapur journal of chronic disease care*, 3(1), pp. 1-10. Available at: http://www.sid.ir/en/VEWSSID/J_pdf/5060720140105.pdf [Accessed 4 September 2014].
- Mann, A.R. (2013) *The experiences of mothers of children with autism in Jamaica: an exploratory study of their journey*. Graduate school theses and dissertations. University of South Florida.
- Motaghedi, S, &Haddadian, M. (2014) 'The effect of growth appraisal & individual assessment of stress on mental health of autistic children's parents', *Life science journal*, 11(9s), pp. 32-37. Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCUQFjAA&url=http%3A%2F%2Fwww.lifescience.com%2F%2Flife1109s%2F005_24680life1109s14_32_37.pdf&ei=rFIVNbbBI2uASWxILwCA&usg=AFQjCNFeFe67ar014x6ZISAz9IL3cEcN8Q&bvm=bv.79142246,d.c2E [Accessed 5 September 2014]
- Martins, D.C, Walker, P.S, &Fouche, P.(2013) 'Fathering a child with autism spectrum disorder: an interpretative phenomenological analysis', *Indo-pacific journal of phenomenology*, 13(1). Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CBwQFjAA&url=http%3A%2F%2Fwww.ajol.info%2Findex.php%2Fipjp%2Farticle%2FviewFile%2F99652%2F88935&ei=dJIVNaYJYKiuQTj_oLgAg&usg=AFQjCNFVnNwws4bpcRTV6sghf7UISgY8kg&bvm=bv.79142246,d.c2E [Accessed 5 September 2014]
- Ma, P. S. (2012) *Children with autism in Taiwan and the United States: parental stress, parent-child relationships, and the reliability of a child development inventory*. Dissertation for the degree of doctor of education. University of North Texas.

- Matin, S. (2014) *School profile of Beautiful Mind*. Available at: <http://www.beautifulmindbd.net/profile.php> [Accessed 16 July 2014]
- Obaid, M.A.S, & Al-Kadoumi, K. (2012) 'Family member needs of autistic children', *American journal of health sciences*, 3(4). Available at: <http://www.cluteinstitute.com/ojs/index.php/AJHS/article/view/7323/7391> [Accessed 6 September 2014].
- Ogston-Nobile, P.L. (2014) *The division of family work among fathers and mothers of children with an autism spectrum disorder: implications for parents and family functioning*. Partial fulfillment of the requirements for the degree of doctor of philosophy. Virginia Commonwealth University.
- Pathappillil, J.S.J. (2011) *Through our eyes: a qualitative study of Indian mothers and their perceptions of autism*. PCOM psychology dissertations. Philadelphia College of Osteopathic Medicine.
- Plant, K.M, & Sanders, M.R. (2007) 'Predictors of care-giver stress in families of preschool-aged children with developmental disabilities', *Journal of intellectual disability research*, 51 (2), pp. 109-124. Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCAQFjAA&url=http%3A%2F%2Fspace.library.uq.edu.au%2Fview%2FUQ%3A94420%2FUQ_AV_94420.pdf&ei=rnLcVlriGqa3mwWW7oDABQ&usg=AFQjCNHG7II_HmQY5z_UORvziEodQyX5Zg&bvm=bv.85761416,d.dGY [Accessed 16 January 2015].
- Petrongolo, M. (2014) *Stress in mothers of newly diagnosed children with autism spectrum disorders: barriers to care use of support services and child behavior*. Partial fulfillment of the requirements for the degree of doctor of psychology. Philadelphia College of Osteopathic Medicine.
- proyash.edu.bd (2014). *Proyash*. Available at: <http://www.proyash.edu.bd/> [Accessed 15 July 2014].
- Reeves, S, Kuper, A, & Hodges, B.D. (2008) 'Qualitative research methodologies: ethnography', *BMJ (clinical research) ed.*, 337. Available at: http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCMQFjAB&url=http%3A%2F%2Fwww.allgemeinmedizin.unijena.de%2Fcontent%2Flehre%2Fequip_summer_school%2Fequip_2009%2Fe4100%2F2008010_Reevesetal_Qualitativeresearchmethodologies

ethnography.pdf&ei=w37cVN70JIqOuATf8ICIBw&usg=AFQjCNEcKop26C3slfCdd5j5Ex0Y5qRxA&bvm=bv.85761416,d.c2E [Accessed 15 July 2014].

- Rakib, A. (2013) *Problems of autistic children and their families: a study in the urban areas of Bangladesh*. Partial fulfillment of the master's degree of social sciences final examination. University of Dhaka.
- Rahman, M. (2010) 'Autism spectrum disorders', *Journal of Bangladesh college of physicians and surgeons*, 28(3), pp. 143-144. Available at: <http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=10&cad=rja&uact=8&ved=0CFYQFjAJ&url=http%3A%2F%2Fwww.banglajol.info%2Findex.php%2FJBCPS%2Farticle%2Fdownload%2F6506%2F4992&ei=2KMGVe6DOIrHuATG1oGoBA&usg=AFQjCNHoGi7NAqDMsaKLRVuQ3K69ynkung&bvm=bv.88198703,d.c2E> [Accessed 15 July 2014].
- Shuttleworth, M. (2009) ***Writing a discussion section***. Available at: <https://explorable.com/writing-a-discussion-section> [Accessed 15 January 2015].
- Shpigelman, C.N. (2014) 'How to support the needs of mothers with physical disabilities?' *Disability and rehabilitation*, 7, pp. 1-8. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/25098594> [Accessed 15 January 2015].
- Tarabek, J. (2011) *Relationship satisfaction and mental health of parents of children with autism: a comparison of autism, ADHD, and normative children*. Partial fulfillment of the degree of Master of Science in human development. Virginia Polytechnic Institute and State University.
- Throne, S, (2000). 'Data analysis in qualitative research' *Evidence based nursing*, 3(3), pp. 68-70. Available at: <http://ebn.bmj.com/content/3/3/68.full> [Accessed 2 August 2014].
- Titumir, R. A. M. & Hossain, J. (2005) ***Disability in Bangladesh prevalence, knowledge, attitudes and practices***. Available at: <http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CCEQFjAA&url=http%3A%2F%2Funnayan.org%2Freports%2FDisability%2520Prevalence%2520and%2520KAP%2520Study.pdf&ei=Tg0IVYizBIKLuwTG5oCABg&usg=AFQjCNENMwNjFFbOsuYgWKKNGkWKKeYfyhA&bvm=bv.88198703,d.c2E> [Accessed 2 August 2014].

- Vliem, S.J. (2009) *Adolescent coping and family functioning in the family of a child with autism*. Partial fulfillment for the degree of doctor of philosophy (nursing). The University of Michigan.
- Wolf, R.N. (2009) *Social support domains for parents of children with autism spectrum disorder: assessing perceived needs and stress levels*. Masters theses & specialist projects. Western Kentucky University.
- World Health Organization (2006). Promoting access to healthcare services for persons with disabilities. Available at:
http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&cad=rja&uact=8&ved=0CDAQFjAC&url=http%3A%2F%2Fwww.who.int%2Fnmh%2Fdonorinfo%2Fvip_promoting_access_healthcare_rehabilitation_update.pdf.pdf&ei=t2cFVdPZE8mNuAT2z4L4Cw&usg=AFQjCNE5bWaHULUCxPSGue_3OdafFVaYA [Accessed 2 August 2014].
- Woodgate, R.L, Ateah, C. &Secco, L. (2008) ‘Living in a world of our own: the experience of parents who have a child with autism’, *Qualitative health research*, 18(8). Available at:
http://www.google.com.bd/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&cad=rja&uact=8&ved=0CCsQFjAC&url=http%3A%2F%2Fparented.wdfiles.com%2Flocalfiles%2Fautism%2FLiving%2520in%2520a%2520world%2520of%2520our%2520own%2520%2520Autism.pdf&ei=NtlVP6tN4HbuQSWt4LIBw&usg=AFQjCNElCIr477_d0li4UO8Okz69jIkdaA&bvm=bv.79142246,d.c2E [Accessed 4 September 2014].
- Yousafzai, A.K, Farrukh, Z, &Khan, K. (2011) ‘A source of strength and empowerment? an exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan’, *Disability and rehabilitation*, 33(12), pp. 989-998. Available at:
<http://www.ncbi.nlm.nih.gov/pubmed/20874447> [Accessed 15 January 2015].

Appendix-1

(Permission letter for conducting the research)

Date: 20.07.14

The Head of the Department,
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, savar, Dhaka-1343.
Through: Research Supervisor.

Subject: Prayer for seeking permission to conduct the research project.

Madam,

I am Lipika Ghosh, 4th year student of Bachelor of Science in Occupational Therapy program at Bangladesh Health Professions Institute (under the medical faculty of Dhaka University), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). As I am a student of 4th year, I have to do a dissertation for my academic purpose. My dissertation title is "*impact on quality of life mothers with autistic children: A perception based study*" and I will be trying to identify the impact on quality of life of mothers with autistic children. For my dissertation purpose, I need permission from you to continue my research project. So, I therefore pray and hope that you would be kind enough to give me the permission to continue the research project for my study.

Sincerely yours,

Lipika Ghosh (*Lipika Ghosh*)
4th year B. Sc in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Center for the Rehabilitation of the Paralyzed (CRP).

Permission will be approved by	Signature
Head of the department Nazmun Nahar Assistant professor & Head of the department Occupational therapy department BHPI, CRP, Savar, Dhaka	As per supervisor's comment it may allow her to conduct this study. <i>Nazmun Nahar</i> 24.07.14
Supervisor Md. Yeasir Arafat Alve Lecturer of Occupational Therapy Department Bangladesh Health Professions Institute (BHPI) CRP, Savar, Dhaka-1343	Recommended to conduct the study following the proposal. with best wishes. <i>Yeasir Arafat Alve</i> 29.07.14

Appendix-2

(Permission letters for data collection from the selected study area)



বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

CRP-Chapain, Savur, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206, Tel: 8020178, 8053662-3, Fax: 8053661

তারিখ : ১২.১০.২০১৪

প্রতি
ইনচার্জ
শিশু বিভাগ
সিআরপি, সাভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী লিপিকা ঘোষকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ১৪.১০.২০১৪ তারিখ থেকে ৩০.১১.২০১৪ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরণ করা হলো।

তাই তাকে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

Maz

নাজমুন নাহার
সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



*She will collect data from
paediatric unit. please help
her.*

*Thanks
H*

26-10-14
HOSNEARA PERVEEN
Incharge, Paediatric Unit
CRP, Savur, Dhaka



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178, 8053662-3, Fax: 8053661

তারিখ : ১২.১০.২০১৪

প্রতি
অধ্যক্ষ
প্রয়াস
সভার সেনানিবাস, সভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী লিপিকা ঘোষ তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ১৪.১০.২০১৪ তারিখ থেকে ৩০.১১.২০১৪ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

নাজমুন নাহার
সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



অধ্যক্ষ
প্রয়াস
সভার এরিয়া



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206, Tel: 8020178, 8053662-3, Fax: 8053661

তারিখ : ১২.১০.২০১৪

প্রতি
অধ্যক্ষ
বিউটিফুল মাইন্ড
উত্তরা ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী জিপিলা ঘোষ তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ১৪.১০.২০১৪ তারিখ থেকে ৩০.১১.২০১৪ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

নাজমুন নাহার

সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



Approved
10/23/14
Vice-Principal
Beautiful Mind

Appendix-3

(Consent form and questionnaires in Bangla)

Appendix: 3.1- সম্মতিপত্র

গবেষক, লিপিকা ঘোষ, বাংলাদেশ হেলথ প্রফেশনস্ ইন্সটিটিউট এর ছাত্রী যা পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সি.আর.পি) এর একটি শিক্ষা প্রতিষ্ঠান। তিনি অকুপেশনাল থেরাপী বিভাগে ৪র্থ বর্ষে অধ্যয়নরত আছেন। এই গবেষণাটি তার অধ্যয়নের একটি অংশ। গবেষণাটির শিরোনাম, “অটিষ্টিক শিশুদের মায়েদের দৈনন্দিন জীবনধারণের ক্ষেত্রে প্রতিবন্ধকতাসমূহ অনুসন্ধান করা।”

আমি.....গবেষণাটির উদ্দেশ্য সম্পর্কে যথেষ্ট অবগত হয়েছি। আমি যে কোন সময় যে কোন মূহুর্তে গবেষণা থেকে অংশগ্রহণ বাতিল করতে পারব এবং এর জন্য কারো কাছে জবাবদিহি করতে বাধ্য থাকব না।

উক্ত গবেষণায় অংশগ্রহণকারীদের উপকার নাও হতে পারে, তবে ভবিষ্যতে অংশগ্রহণকারীর মতো ব্যক্তিগণ গবেষণা থেকে উপকৃত হতে পারেন। গবেষক অংশগ্রহণকারীদের অনুমতি সাপেক্ষে সাক্ষাতের তথ্য সংগ্রহের জন্য মোবাইল ফোন ব্যবহার করতে পারবেন।

আমি অবগত হয়েছি যে, গবেষণার জন্য আমার দেয়া সব তথ্য নিরাপদ ও গোপন রাখা হবে এবং যদি প্রকাশনার কাজে ব্যবহার করা হয় তাহলেও নামহীনভাবে প্রকাশ করা হবে। আমার নাম, ঠিকানা এই গবেষণায় কোথাও প্রকাশ করা হবে না, এবং তা গবেষণার ৫ মাস পর নষ্ট করে ফেলা হবে।

উপরোক্ত সমস্ত তথ্যাবলী জেনে আমি সম্পূর্ণ স্বেচ্ছায় এ গবেষণায় স্বতঃস্ফূর্তভাবে অংশগ্রহণ করছি।

স্বাক্ষর

অংশগ্রহণকারীর স্বাক্ষরঃ	তারিখঃ
স্বাক্ষীর স্বাক্ষরঃ	তারিখঃ
গবেষকের স্বাক্ষরঃ	তারিখঃ

Appendix: 3.2- প্রশ্নপত্র

বাচ্চা সম্পর্কিত তথ্যঃ

বাচ্চার বয়স-

লিঙ্গ-

বাচ্চার কি কি সমস্যা হয়-

আপনার বাচ্চা কি স্কুলে যায়-

বাচ্চার মা সম্পর্কিত তথ্যঃ

মা'র বয়স-

শিক্ষাগত যোগ্যতা-

পেশা-

ধর্ম-

বর্তমান বৈবাহিক অবস্থা-

আপনার দৈনন্দিন জীবন কীভাবে কাটে- (১) খুব ভাল (২) ভাল (৩) মোটামুটি (৪) খারাপ (৫) খুব খারাপ

পারিবারিক তথ্যাবলীঃ

বাসায় কে আপনার বাচ্চাকে দেখাশুনা করে-

বাসায় বাচ্চার সংখ্যা কতজন-

পরিবারের মাসিক আয়-

কাজ বিষয়ক তথ্যঃ

- ১) কখন এবং কিভাবে আপনি আপনার বাচ্চার বর্ধনজনিত সমস্যা বুঝতে পারলেন?
- ২) কখন আপনি প্রথমবার জানলেন যে আপনার শিশুটি অটিস্টিক শিশু?
- ৩) আপনার শিশুটি অটিস্টিক শিশু জানার পর আপনার মনোভাব কেমন ছিল?
- ৪) অনেকের অটিজম সমস্কে বিভিন্ন ধারণা আছে। অটিজম সমস্কে আপনার ধারণা কি?
- ৫) আপনার শিশুটির অটিজম হওয়ার পেছনে কি কারণ আছে বলে আপনি মনে করেন ?
- ৬) ক. আপনার বাচ্চার যত্ন নেওয়ার পাশাপাশি আপনি কি নিজের দৈনন্দিন কাজগুলো (নিজের যত্ন) করতে পারছেন ?
খ. যদি পারেন তা হলে কতটুকু এবং এর জন্য কতক্ষণ সময় দিতে পারছেন দয়া করে বিস্তারিত বলুন।
গ. আপনি কি সময়টা যথেষ্ট মনে করেন, না হলে কেন যথেষ্ট নয় ?
- ৭) ক. আপনার বাচ্চার যত্ন নেওয়ার পাশাপাশি আপনি কি আপনার গৃহস্থালি কাজগুলো (ঘর পরিচর্যা) সঠিকভাবে করতে পারছেন ?
খ. এই কাজগুলো করার জন্য কতক্ষণ সময় দিতে পারছেন দয়া করে বিস্তারিত বলুন?
গ. আপনি কি সময়টা যথেষ্ট মনে করেন, না হলে কেন যথেষ্ট নয় ?
(চাকুরিজীবী মায়েদের ক্ষেত্রে)
ক. আপনার বাচ্চার যত্ন নেওয়ার পাশাপাশি আপনি আপনার অফিসের কাজগুলো সঠিকভাবে সময়মত করতে পারছেন কি ?
খ. এই কাজগুলো করার জন্য কতক্ষণ সময় দিতে পারছেন দয়া করে বিস্তারিত বলুন?
গ. আপনি কি সময়টা যথেষ্ট মনে করেন, না হলে কেন যথেষ্ট নয় ?
- ৮) ক. আপনি কি শিশুটির প্রতি যত্ন নেওয়ার পাশাপাশি অবসর সময় কাটানোর বা নিজেকে সময় দেওয়ার মত সুযোগ পান ?

- খ. আপনার মতে কতটুকু বা কতক্ষণ সময় পান দয়া করে বিস্তারিত বলুন?
গ. আপনি কি সময়টা যথেষ্ট মনে করেন, না হলে কেন যথেষ্ট নয় ?

শারীরিক

- ৯) ক. আপনার শিশুটির সাথে আপনার অনেক সময় অতিবাহিত করতে হয় এবং তার বিশেষ যত্ন ও নিতে হয়, এসব কাজ করতে গিয়ে আপনার বর্তমান শারীরিক অবস্থা কেমন?
খ. যদি ভাল না হয় তাহলে কি ধরনের সমস্যা অনুভব করছেন?

পারিবারিক

- ১০) ক. অটিস্টিক শিশুটির যত্ন নেওয়ার পাশাপাশি আপনি আপনার অন্য বাচ্চাদের সঠিকভাবে যত্ন এবং সময় দিতে পারছেন কি ?
খ. যদি না পারেন তা হলে এর জন্য কি ধরনের সমস্যা হচ্ছে দয়া করে বিস্তারিত বলুন।
১১) ক. অটিস্টিক শিশুটির জন্য আপনার সাথে আপনার স্বামীর সম্পর্কের উপর কোন প্রভাব পড়েছে কি?
খ. যদি সমস্যা হয় তাহলে কেন হচ্ছে এবং কি ধরনের সমস্যা হচ্ছে বলে আপনি মনে করেন ?
১২) ক. আপনার পরিবারের অন্যান্য সদস্যরা অটিস্টিক শিশুটির প্রতি কি সহানুভূতিশীল বা তাদের কাছ থেকে কি আপনি সহযোগীতা পাচ্ছেন?
খ. যদি সহানুভূতিশীল বা সহযোগী না হয় তাহলে এর পেছনে কি কারণ আছে এবং কি ধরনের সমস্যা অনুভব করছেন বলে মনে করেন ?

সামাজিক

- ১৩) ক. আপনার প্রতিবেশিরা আপনার এবং আপনার অটিস্টিক শিশুটির প্রতি কেমন মনোভাব প্রকাশ করেন, তারা কি সহানুভূতিশীল?
খ. যদি না হয় তাহলে এর পেছনে কি কারণ আছে এবং কি ধরনের সমস্যা অনুভব করছেন বলে মনে করেন ?
১৪) ক. আপনার বাচ্চাটি অটিস্টিক হওয়ার ফলে আপনি কোনো ধরনের অপবাদের স্বীকার হচ্ছেন কি ?
খ. যদি হয়ে থাকেন তবে কাদের দ্বারা হচ্ছেন এবং কি ধরনের অপবাদের স্বীকার হচ্ছেন বলে মনে করেন?

মানসিক

- ১৫) ক. আপনার বাচ্চার অটিজম হওয়ার জন্য আপনি নিজেকে কি দায়ী মনে করেন?
খ. যদি মনে করেন তাহলে কেন মনে করেন দয়া করে বিস্তারিত বলুন?
১৬) ক. আপনার বাচ্চাটি অটিস্টিক হওয়ার ফলে আপনি কি হতাশা অনুভব করেন ?
খ. যদি করেন তাহলে কেন হতাশা অনুভব করেন ?
১৭) ক. আপনি কি মনে করেন একটি অটিস্টিক শিশু হওয়ার ফলে মায়েদের জীবনে বিরূপ প্রভাব ফেলে-
খ. যদি মনে করেন তাহলে কেন মনে করেন ?

Appendix - 4

(Consent form and questionnaires in English)

Appendix: (4.1.) - Consent form

The researcher Lipika Ghosh, is a student of the Bangladesh Health Professions Institute (BHPI) which is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. She is studying in 4th year in Occupational Therapy department of BHPI. This study is a part of her course curriculum. The title of the study is, “Explore the challenges in daily life and quality of life of mothers with autistic children”.

In this study I am a participant or sample and I have been clearly informed about the purpose of the study. I will have the right to withdraw in taking part from the study at any time at any stage and I am not bounded to answer to anyone for this. This study may not give any benefit or impact on participant work at present but in future people similar to them may get benefit from the study. Researcher can use mobile phone to get information about meeting to the participants for study purpose according to the permission of the participants.

I also informed that, researcher will keep all my information safe and confidential and the identity of me and my child will not be disclosed in publication of the study. personal identity such as participant’s name and address will not be published anywhere of the study and The confidential document will be destroyed after five month of the study has been published.

I have been informed about the above-mentioned information and I am willingly agreed to be a participant of the study with giving my consent.

Signature

Signature of the Study Participant:	Date-
Signature of the witness:	Date-
Signature of the Researcher:	Date-

Appendix: (4.2.) - Questionnaires

Child's information:

Child's age:

Sex:

Child's problem:

Child's birth position in the family:

Is he/she goes to school:

Mother's information:

Age:

Level of education:

Occupation:

Religion:

Current marital status:

How you pass your everyday life: (1) Good (2) very good (3) medium (4) bad (5) very bad

Household information:

Who take care of the child in home:

Number of children in home:

Monthly income in the family:

Work related information:

(1) When and how did you understand your child's developmental problems?

(2) When did you know first time about your child's autism?

(3) What was your initial reaction after hearing about your child's autism?

(4) Many people have different opinion about autism. Please explain your understanding about autism?

(5) What do you think about the reason behind your child's autism?

(6) Are you able to perform your daily-living activities (take care of yourself) properly with taking care of your child in the home?

If you can then how much time you can spend for this please explain?

Do you think it is enough for you if not then why not?

(7) Are you able to perform your house-hold activities properly with taking care of your child in the home?

How much time you can give to perform those activities please explain ?

Do you think it is enough for you if not then why not?

(In case of working mother) -- Are you able to perform your official activities properly with taking care of your child in the home?

How much time you can give to perform those activities please explain ?

Do you think it is enough for you if not then why not?

(8) Do you get enough time to spend your leisure time?

How much time you can give to perform your leisure please explain-

Do you think it is enough for you if not then why not?

Physical

(9) You have to spend lots of time and have to give special care to your child. By maintaining this entire things how you feel physically?

If not good then please explain the problems you are facing physically?

Family

(10) Do you can give enough time and care to your other child along with taking care of your special child? (In case of siblings)

If not then please explain the problems you are facing because of it ?

(11) Do you face any extra stress or impact on your relationship with your husband due to your child's autism?

If you face problem then please explain the reason behind it and the problems you are facing because of it ?

(12) Do you think that your other family members are supportive and sympathetic towards your autistic child?-

If not then please explain the reason behind it and the problems you are facing because of it?

Social

(13) Do you think that your neighbours are supportive and sympathetic towards your autistic child?

If not then please explain the reason behind it and the problems you are facing because of it ?

(14) Have you face any stigma due to having a child with autism?

If you faced then by whom and what kinds of stigma do you faced, please explain it?

Psychological

(15) Do you think that you are only responsible for your child's autism?

If you think then why you think that please explain it ?

(16) Do you feel frustration because of having a child with autism?

If you feel then please explain the reason behind it?

(17) Do you think having an autistic child has an adverse effect on mothers life?

If you think then why you think that please explain ?

Appendix-5

(Demographic table)

Participants	Participants' Age (years)	Educational background	Occupation	Child's age (years)	Child's sex	No. of child in family
P1	48	Masters	Housewife	14	Male	2
P2	40	H.S.C	Housewife	7	Female	2
P3	44	B.Com.	Housewife	11 years	Female	2
P4	38	H.S.C	Housewife	9	Male	2
P5	37	B.A	Housewife	5 years 10 months	Male	2
P6	38	H.S.C	Housewife	7	Male	2
P7	30	S.S.C	Housewife	5 and half months	Male	2
P8	36	M.A	Professor (collage)	9	Female	2
P9	35	S.S.C	Housewife	6	Male	3
P10	35	Masters	Housewife	10	Male	2

Appendix- 6

Personal communication with occupational therapist of Beautiful Mind: A Special Center for Autistic and Mentally Challenged Children

Beautiful Mind : A special center for Autistic and Mentally challenged children is a private organization. In the school, there is an opportunities of education and as well as treatment of children with autism, down syndrome, developmental delay. At present in the school, there is 150 special need children are taking service from here and from them near about 80 children have autism. They usually offer different flexible and effective programs for autistic children and mentally challenged children.

Palash Saha. (2014). About Beautiful Mind : A special center for Autistic and Mentally challenged children. Lipika Ghosh [mobile phone] ERP, 14 July 2014.

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(Harvard Referencing Style- 2013)