

**IMPACTS ON THE DAILY LIFE OF MOTHERS OF CHILDREN
WITH DOWN SYNDROME: THE MOTHERS' PERSPECTIVE**



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Except where is made in the text of the thesis, this thesis contains no materials published elsewhere or extracted in whole or in part form a thesis presented by me for any other degree or diploma or seminar.

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The ethical issues of the study has been strictly considered and protected. In case of dissemination the finding of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

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Abstract

Rational: Down syndrome is the most common genetic chromosomal condition. The children with Down syndrome (DS) experience delay in their cognitive and physical development which causes difficulties to perform in self work for the DS children. The mothers of children with DS have to provide more care to their children. They face challenges to maintain the time schedule in their daily life. They also face stigmatize attitude from the community due to have the children with Down syndrome. This study is important to know about the daily life of the mothers of DS children.

Objectives of the study: To explore the experiences of mothers in self care, productivity, leisure and social participations with Down syndrome child; to find out experiences about family and community supports and financial status with Down syndrome child.

Study design: The study is an ethnographic study under qualitative research design. Through the convenient sampling method about 10 mothers of child with Down syndrome were selected as participants for this study. Data was collected by using face to face interview with a semi-structured questionnaire. Data was analyzed by qualitative content analysis.

Result and Conclusion: The study findings reported that the DS mothers face challenges to perform their own self care activities, productive works and leisure due to spend much time to look after their children. These mothers get enough positive supports from their family members and they can participate in different social functions. However, they don't get enough supports from their community and their expenses become increased which affects their financial condition due to have the children with Down syndrome. This study is important for the Occupational therapist to work with mothers having children with Down syndrome. The Occupational therapist can promote the mothers' coping strategies in managing the Down syndrome children.

Key ward: *Down syndrome, the daily life, Mothers Perception.*

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Key abbreviation

DS: Down syndrome.

ADL: Activities of Daily living.

CRP: Centre for the Rehabilitation of the Paralyzed.

BHPI: Bangladesh Health Professions Institute.

QCA: Qualitative Content Analysis.

OT: Occupational Therapy.

WMT: William and Marie Taylor.

BM: Beautiful Mind.

CHAPTER 1

INTRODUCTION

Bangladesh is one of the world's most densely populated countries. The population of Bangladesh is about 160 millions. There is no accurate data or information on the exact number of persons with disabilities in Bangladesh. However, 15% of the population in Bangladesh are persons with disabilities according to the World Bank estimates (Universal Periodic Review of Bangladesh, 2013). Every year there are a lot of babies born with disabilities, due to various poor conditions of the country, such as poor maternal health care, lack of nutrition and lack of education. According to Disability in Bangladesh (2014) the prevalence of disabilities in children below 18 years can be estimated at 6%, and for the age group above 18 years the prevalence at about 14%, or corresponding to 3.4 million children with disabilities and 10.2 million adults with disabilities. There are many conditions of children with disabilities in Bangladesh, such as Autism spectrum disorder, cerebral palsy, Down syndrome, deaf-blindness, hearing impairment, intellectual disability, physical impairment, speech impairment, visual impairment and multiple disability. Down syndrome is a common disorder in Bangladesh. Down syndrome is a genetic disorder that causes life-long intellectual disabilities, developmental delays and other health problems. Down syndrome varies in severity. It is mentioned (Hsiao, 2013) that Down syndrome affects not only children but also their families, especially in non-western countries. Family demographics, family demands and social supports appear to be important factors that may play a vital role in how families respond to the birth of a child with Down syndrome. Having a child with Down syndrome has a negative effect on a mother's daily life. These mothers dedicated more time to child care and less time to their own self-care, productive activities, leisure and social participation. They are stigmatized by the society due to having children with special needs. This study has identified the impact on mothers' daily life because of have a child with Down syndrome.

1.1. Background

Down syndrome is the most common chromosomal disorder. It caused by an error in cell division those results in an extra 21st chromosome. According to National Down syndrome Society, (2012) the cause of extra chromosome is still unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome. Incidence of Down syndrome according to the mother age is 1 in 2000 pregnancies for the mothers about age 20 years and 1 in 100 pregnancies for the mothers about 40 years. Babies and children with Down syndrome experience some delay in all aspects of their development- physical, social, language, play and emotional. They also have some physical features such as low muscle tone which may impact on their development and fine motor and self-care skills. Children with DS learn to sit walk, talk, play and toilet train and do most other activities later than their peers without Down syndrome. Families are usually unprepared for the birth of child with DS and for the impact of it will have on their lives. Caring for a child with special needs can be a stressful job for parents. According to Wayne and Krishnagiri (2005) the parents who have children with special needs face challenges to maintain balance among work, leisure and activities of daily living. It have shown (Barnett and Boyce, 1995) that mothers of a DS child dedicated more time to child care and spent less time in social activities. They face difficulties to maintain their own self care activities, productive activities such as house hold works, leisure activities, social participations due to spend more time to child caring. They get less social supports due to have the children with Down syndrome. According to Home (2002) families of the special needs children face stigmatizing attitudes from the communities. These negative views of the society towards the mothers caused for self-blame among these mothers. It has mentioned (Shelley, Vivian and Nadia, 2009) that these mothers of DS children experience symptom of depression. It is very important for a mother to get support from family and community who have a child with special needs. Mother is the main care giver of a child. The mothers who have children with DS suffers more than the father or other family members.

The mothers who have children with DS face some problem to maintain their daily life more than a mother who have a typical developing child. They face difficulties to maintain their self care, productive work, leisure activities and social participation beside care giving their DS child. They also face challenges to get family and social

supports. The financial conditions also become negative change to have the children with DS due to the cost of medical care of the children. In Bangladesh there are no findings about the daily life of mothers with DS children. This is important for the special needs schools to know about the impact on the daily life of the mothers, because these special needs schools and organizations only focused on the care of the children. They have no appropriate arrangement of different educational and awareness programs for the mothers. In this study the impact on the daily life of mothers who have DS children has found out on the basis of mothers' experience.

1.2. Significance

This study helps to find out the impact on mothers' daily life of having children with Down syndrome. Mothers of the children with DS face challenges to maintain their own self-care, productive works and leisure activities. They give up other roles in society due to their increased responsibilities for childcare. Reeja and Sujatha (2013) conducted study in India and mentioned that in comparison with fathers of DS children, mothers spent more time in providing care, offered more types of support and perceived more care giving burden. The behavior and health of the children had a greater impact on mothers than on fathers. An occupational therapist can use this study as evidence of the impact on the mother daily life with a DS child. When Occupational Therapists come to know the difficulties of a mother with her DS child, then they could provide appropriate interventions, for example: recommendations, modifications and suggestions to minimize if they have any challenges, and help them to lead a better daily live. According to Ramisch *et al.* (2005) psychological problems such as depression and anxiety disorders are higher among mothers with special needs children. This study can help other professionals such as psychiatrics or counselors to know about the psychological condition of the mothers of the children with Down syndrome through these mothers' experience of daily life.

The participants have taken from two organizations, the William and Marie Taylor Inclusive School and the Beautiful Mind School. Through this study these organizations have come to know about the impact on mothers' daily life to have the children with Down syndrome. Mother is the primary or main care giver of a child. If the mothers have negative experiences in their daily life this must affect their child caring. These organizations are working for the well being of special needs children. Moreover, it is very important to know about the coping strategies of the mothers of

DS children which help the organizations to ensure the children' well being. The organizations may also arrange educational sessions to provide information or awareness programs for the mothers, and other people in the community. It could also arrange counseling programs which will help to gain a better life for the mothers and their children.

In this study the strengths and weaknesses of the mothers about their families has been identified and also find out whether they are supported by their local communities or not. This study can help the new mothers with the children with DS to learn about the living conditions of other mothers of DS children, and this will help them to know how to prepare or cope with it in future. Through this study they may also learn about the strengths of other mothers which will help them to form a support group by themselves.

1.3. Aim of the study

The aim of the study is to find out the impacts on the mothers' daily life of having children with Down syndrome.

1.4. Objectives of the study

- To explore the mothers' experiences of maintaining their self care, productive, leisure activities and social participation, at the same time as caring for their DS children.
- To identify the mothers' experiences in case of supports from family and society as well as if they have any changes in financial conditions due to have a DS child.

CHAPTER 2

LITERATURE REVIEW

Down syndrome is a common disorder in Bangladesh. There are a number of children with disabilities in Bangladesh. The children with DS are less in proportion than the other disorders such as autism, cerebral palsy, deaf-blindness, hearing impairment, intellectual disability, physical impairment, speech impairment, visual impairment in Bangladesh. There are some impacts on the families who have the DS children; specially, the impact on the daily life of the mothers of DS children. In this chapter the different studies which are related about Down syndrome and the impacts on the daily life of the mothers of DS children has been used as evidence.

2.1. Down syndrome

Down syndrome is the most common chromosomal malformation in newborns. According to Weijerman (2011) it caused by an error in cell division results in an extra 21st chromosome. The condition leads to impairments in both cognitive ability and physical growth that range from mild to moderate developmental disabilities. Children with Down syndrome also have an increase risk of congenital defects and organic disorders such as congenital heart and gastrointestinal defects, celiac disease and hypothyroidism. There are gender differences in Down syndrome, with slightly higher numbers of boys than girls. Throughout the world, the overall prevalence of Down syndrome is 10 per 10,000 live births, although in recent years this figure has been increasing. Shelley, Vivian and Nadia (2009) mentioned that - In the Netherlands, the birth of a child with Down syndrome is estimated to occur in 14 per 10,000 live births annually which are increased in recent years. The other study has been shown (Weijerman, 2011) that in the Netherlands, the most recent measure of Down syndrome prevalence was 16 per 10,000 live births. In the United Kingdom, the prevalence of pregnancies affected by Down syndrome has increased considerably and there are 6,000 babies with Down syndrome are born in the United States each year. However, the prevalence of Down syndrome depends on socio cultural variables. In countries in which abortion is illegal, such as Ireland and the United Arab Emirates (UAE), prevalence is higher, varying from 17 to 31 per 10,000 live births. Conversely, the prevalence in France is quite low such as 7.5 Down syndrome per 10,000 births but this is probably due to a high percentage of Down syndrome pregnancy terminations. There are three types of Down syndrome: trisomy 21

(nondisjunction), translocation and mosaicism. About 95 percent of Down syndrome cases are caused by trisomy 21. Mosaicism accounts about one percent of all cases of Down syndrome and translocation accounts four percent of all cases of Down syndrome (National Down syndrome Society, 2012).

2.1.1. Symptom of Down syndrome

Bull (2011) mentioned that the symptoms of Down syndrome vary from person to person, and people with Down syndrome may have different problems at different times of their lives. Common physical symptoms of Down syndrome include:

- Decreased or poor muscle tone.
- Short neck with excess skin at the back of the neck.
- Flattened facial profile and nose.
- Small head, ears and mouth.
- Upward slanting eyes, often with a skin fold that comes out from the upper eyelid and covers the inner corner of the eye, white spot on the color part of the eye (called Brush field spots).
- Wide, short hands and short fingers.
- A single deep crease across the palm of the hand and a deep groove between the first and second toes.

Some common cognitive and behavior problems may include:

- Short attention span.
- Poor judgment.
- Impulsive behavior.
- Slow learning.
- Delayed language and speech development.

Physical development in children with Down syndrome is often slower than development of children without DS. For example, because of poor muscle tone, a child with DS may be slow learn to turn over, sit, stand, and walk. Because of these delays, they can't learn to participate in physical exercise activities like other children. It may take them longer than other children to reach developmental milestone. Cognitive impairment, problem with thinking and learning, is common in people with DS and usually ranges from mild to moderate. Only rarely is Down syndrome associated with sever cognitive impairment. Martin *et al.*(2009) said that most

children with Down syndrome develop the communication skills they need, although it might take longer for them to do so compare with other children.

2.1.2. Cause of Down syndrome

Down syndrome occurs in all countries and all socioeconomic groups. The cause of the extra full or partial chromosome is still unknown. Older mothers are more likely to have a baby affected by Down syndrome than younger mothers. In other words, the prevalence of Down syndrome increases as the mother's age increases. According to the National Down syndrome Society (2012) incidence of Down syndrome 1 in 2000 births when the mothers' age 20 years, 1 in 900 at the age of 30 years, 1 in 600 at the age of 33 years, 1 in 300 at the age of 36 years, 1 in 100 at the age of 40 years and 1 in 30 births at the age of 45 years of the mothers. However, due to higher birth rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age. Maternal age is the only factor that has been linked to an increased chance of having baby with Down syndrome resulting from trisomy 21 and mosaicism. However, maternal age is not linked to the chance of having a baby with translocation. Most of the cases of translocation have a hereditary component – one unaffected parent is a carrier of a trans located chromosome. For this reason, the chance of translocation occurring in a second pregnancy is higher than the chance of nondisjunction occurring in a second pregnancy.

2.2. Experiences of families with Down syndrome children

Families are usually unprepared for the birth of child with Down syndrome and for the impact of it will have on their lives. The responsibilities of the parents towards the children with special needs need a large amount of time to complete. These responsibilities can be physically challenging for parents, can disrupt family and social relationships, and can affect caregiver employment. These additional impacts, family caregivers of children with DS can be at increased risk to experience depression, physical health problems, and decreased quality of life. Shelley, Vivian and Nadia, (2009) mentioned that parents of a DS child experience more stress and a diminished psychological well being compared with parents of a typically developing child. Although having a DS child might not be as distressing as once thought, these parents experience more stress and may be at greater risk of developing a depressive disorder. However, those parents also experience stress when the child grows older

and encounters difficult transitional periods like learning to speak or finding an appropriate school. Parenting is challenging and many families of young children find parenting stressful if one child has DS. It has been shown (Roach, Orsmond, and Barratt, 1999) that parents of DS children perceived more care giving difficulties, child-related stress such as: demanding, unacceptability, and parent-related stress such as: incompetence, depression, health problems, role-restriction than the parents of typically developing children. Brain & Susan (2006) mentioned that the brothers and sisters of the children with DS also experienced difficult moments. They often begin to realize that not everyone in society shows positive views toward their siblings with DS. They feel confused such as why people stare at their siblings at the public place and what should they do when people make fun of their siblings. They feel too much pressure, sometime self imposed, particularly in the situation such as school where the parents is unavailable. The families are more likely to be struggling to cope and experiencing depression or health problems and the relationships become stressed and family life affected. Heiman (2002) indicated that parents of children with special needs experience greater stress and a larger number of care giving challenges, such as more health problems, greater feelings of restriction, and higher levels of parental depression than parents of non-disabled children. Some families experience difficulties in financial assistance or claimed on inadequate and insufficient support. Families with children with Down syndrome face both the normal pressures and tensions of family life. Such families usually require assistance in order to reorganize their lives toward positive adaptation.

2.3. Mothers' daily life with Down syndrome children

A daily life is a person's daily activities, experiences, feelings which depend on individual's living environment, work pattern, social environment and surrounded all things. Bookman *et al.* (2007) mention that daily life includes a persons' daily self care activities (feeding, bathing, dressing, and grooming), productive works (within an individual's place of residence, in outdoor environments, or both) and leisure. Daily life also contains a person's social environments. Activities of daily livings (ADLs) of an individual contain self care, productive works and leisure. Mothers are the main career of their children. Aaron *et al.* (2010) mothers of a child with special needs experience difficulty with their children's care. The care of a child with

disabilities is a responsibility on the families, mainly the mothers who are affected by this situation. The parents do not always have the same views of their families and the issues which cause stress. The needs of fathers have received much less attention than the needs of mothers for the caring of the children with DS. According to Ramisch *et al.* (2005) having a child with developmental disability has a negative effect on parent functionality and the daily life of the mother more than the father. In this study, the daily life of the mothers contains their ADLs, social participation, acceptance from their families and communities and their financial situation due to have the DS children.

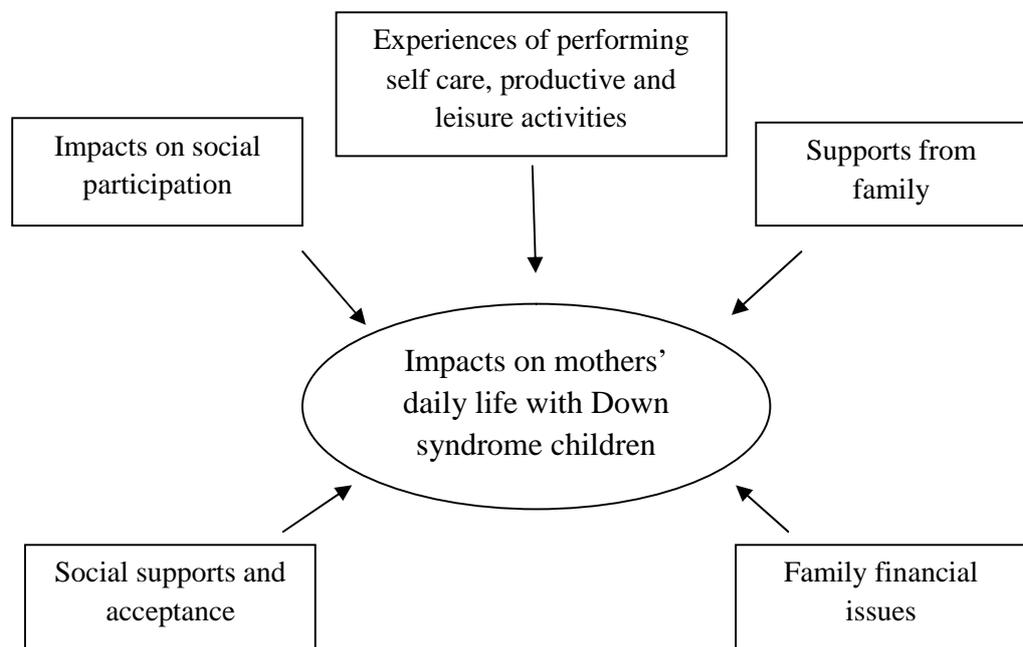


Figure-1: impacts of Down syndrome children in mothers' daily life.

2.3.1. Activities of daily living

Mothers of the children with Down syndrome face challenges to perform their ADLs such as their own self care activities, productive works, and leisure due to spend a lot of time to look after their children. Due to the physical and cognitive developmental delay the children with DS can't perform their self activities and they are totally depended on their mothers. Wayne and Krishnagiri, (2005) mentioned that raising a child with special needs is challenging for the mothers in maintaining a balance among work, leisure and daily living activities.

- **Self care**

According to Elwood and Longley (2010) self-care includes eating, bathing, dressing and grooming and all health decisions people make for themselves to get and stay physically and mentally fit. Self care includes exercising to maintain physical fitness and good mental health as well as eating well, practicing good hygiene and avoiding health hazards. These mothers can't maintain time schedule for their own self care mainly the time for their eating and bathing. Cunningham (1996) also reported the mothers of DS children have difficulties to maintain their stamina or energy for manage their own self care properly due to spend more time to look after their children.

- **Productive works**

The mothers of the children of DS face difficulties to maintain their productive works such as house hold activities and employments. They spend their most of the time due to caring their children. It stated that (Wayne and Krishnagiri, 2005) a mother of a child with DS have to spend her most of the time to look after the child and less time to productive work. It has been shown (Barnett and Boyce, 1995) that those mothers have less time for paid employment or service. For mothers of DS children, employment outside the home is a positive and protective factor. Working mothers feel less stress and more life satisfaction even with the extra demands of work, child care and family. Working outside the home provides social communication and friends, a different role, a change of daily needs and an increase in income. However, fewer mothers of children with DS can continue to work.

- **Leisure**

Goodinet *al.*(2005) stated that leisure or free time is time spent away from business, work, domestic chores and education. It also excludes time spent on necessary activities such as sleeping. Another concept of leisure is social leisure, which involves leisure activities in social settings, such as additional activities. Leisure is very important for a person and specially the mothers of the children with DS because they feel more stress than the mothers of the typically developed children. After spending a lot of time to look after the children with DS and other activities the mothers can't get time for their own leisure. According to Hsich and Puymbroeck, (2013) these mothers have continuous worry about their children so that they spend their most of the time with their children with DS and don't get time for leisure. There is also another reason

that they experienced prejudice, social barriers, and poor service during their leisure participation. Some caregivers internalized the negative attitudes of others about their children and in some case they felt ashamed of being seen in public. The feeling of a perceived stigma became a barrier that prevented them from leisure participation and increased their social isolation.

2.3.2. Social participation

Social participation means carrying out one's life habits in one's environment such as school, work place, and neighborhood. Carrying out these life habits depends especially on the age of the person, expectations of the living environment and cultural aspects. It has mentioned (Piskuret *al.* 2014) that social participation is an individual's involvement in activities that provide interaction with others in society or the community such as different social contact with community people, attending in different social function, social relationship and involve in social activities. The mothers who have the children with Down syndrome can't participate in different social functions properly due to spend a lot of time to look after their children and other works. It has been mentioned (Barnett and Boyce, 1995) that the mothers of the special needs children give up their roles in the society, attain less to social activities and have less social life due to their increased responsibilities for child care. The mother of a child with DS dedicates more time to care and spend less time in social activities. Abbeduto *et al.*(2004) conducted a study and it has been showed that the mothers of the children with DS have more closeness in relationship with their children and spend much time with their children than the mothers of children with autism and fragile X syndrome. After spending a large time to look after their children, households' activities, and other works these mothers can't take appropriate preparation to go for attaining any functions some time. Moreover, the stigmatizing attitudes of the people in the society are also a cause to prevent the full social participation of the mothers who have the children with DS. It has showed (Hsich and Puymbroeck, 2013) that the mothers of the DS children experience different social stigma and negative attitudes from the community which make then isolated from the social participation. When the people stare their children with a negative view the mothers become embarrass in that situation which cause less social participation for them.

2.3.3. Supports from family

The mothers of the children with special needs such as Down syndrome need enough supports from their family members. These mothers experience various kinds of stress, depression, and anxiety about their children's future. They also worry about their children's ability and their safety. Bourke *et al.* (2008) mentioned that mothers of children with Down syndrome appear to experience poorer mental health. They need greater supports from their family both mentally and physically to ensure a better management of their child and their own psychological well-being. A study conducted in United States (Urbano and Hodapp, 2007) and reported that parents of children with DS had divorced, separated or were showing particularly more poor marital relationship than the parents of the typically developed children. It also showed that the divorce is higher among the parents who have less income and less educated. However, in contrast, it also reported that the incidence of divorce of the parents who have children with DS were lower than the parents of the children with other birth defects. According to Hsich and Puymbroeck (2013) the support from the husband is the most important factor in decrease anxiety. In a family the supports from one's spouse is the most important source of emotional support for caregivers of children with special needs. When the fathers provide emotional and caring supports, the mothers' experience of the caretaking and other burden become less. Usually the husbands help their wives in completing tasks and caring the children (Cuskelly, Hausar-Cram and Riper, 2009). A study conducted in Singapore (Joosa and Berthelsen, 2006) and reported that many mothers of the children with Down syndrome explained their family relationship as similar to all families. Their husbands provide enough support in take care of family. Reeja and Sujatha (2013) mentioned that husband is most supportive person in caring children with Down syndrome and also the siblings of the children with DS accepting them and caring them. Siblings are very protective of a child with a developmental delay and would take on care responsibilities. It has found (Cuskelly, Hausar-Cram and Riper, 2009) that grandparents are the vital supporting members in the families of the children with DS. Dissimilarly it also found (Ergun and Ertem, 2012) that the mothers were blamed by their in-laws for the disability in their respective children. In most of the case at the beginning the parents-in-laws are not supportive and they don't even want to look the DS child but gradually they start to accept the condition of the children with Down syndrome (Joosa and Berthelsen, 2006). Moreover family Support is essential for the

mothers of children with disabilities. Coping with the stress, emotions and difficult decisions is often overwhelming and upsetting for families.

2.3.4. Social supports and acceptance

Social supports are extremely important for the mothers who have DS children. For living in the community a mother of the children with DS needs enough supports from society. It has found out (Hsich and Puymbroeck, 2013) that the enough supports from the society prevent the mothers from different depression and anxiety to have the children with DS. Joosa and Berthelsen, (2006) mentioned that social supports are very important. The friends are usually the main supporter. On the other hand, the parents with children with DS also make their own supportive group to contact with the other parents of children with DS. These mothers also face different stigmatizing attitudes from the society. According to Cuskelly, Hausar-Cram, and Riper (2009) general community holds fairly negative views about parenting a child with DS. The view of the community towards the children with special needs as a burden. The community views for the family of the children with DS only as a tragedy. The social supports and acceptance vary from culture to culture. A study conducted in Taiwan (Hsich and Puymbroeck, 2013) and reported that families of children with disabilities in Western countries and Asian countries usually share similar care giving experiences and outcomes. However, the Asian societies consist some traditional beliefs which are not appears usually in Western cultures. Most of the Asian society beliefs that everything happens for a reason. They belief that good works bring rewards in the future and bad works result in punishment. These traditional beliefs create a social stigma against people with disabilities and their family members because it invokes the idea that a disability represents punishment resulting from evil conduct in a previous life. With this traditional belief, providing care to the child with a disability is often considered a way to form the sin; therefore, parents may be unwilling to accept help from extended family and friends. However, the negative views and such kind of social stigma towards the children with DS are decreasing day by day.

2.3.5. Financial impact on family

The impacts on the families to have the children with Down syndrome also influence the financial condition of the family. According to Hira *et al.*(1993) the financial condition of the family is all income and expenses of the family. The source of

income may include wages, investments savings accounts and trusts. On the other hand, expenses include bills, education, health, taxes, and clothing. The changes of financial states of a family depend on the income and expenses at the certain time. The mothers of the children with DS experience various type of difficulties. Financial states also influence the perceptions of a family who have child with DS. It has been shown (Abbeduto *et al.*2004) that the mothers of the children with DS tend to be more depressed if there is lower family income. The children with DS have higher risk to have other health problems. Children with DS are at increased risk for certain health problems. While there is an increased risk for certain medical conditions compared to the children with other disabilities and the typically developing children. Congenital heart defects, increased vulnerability to infection, respiratory and hearing problems, obstructed digestive tracts, sleep apnea and child-hood leukemia occur with greater frequency in children with DS. Adults with DS are also at increased risk for Alzheimer's disease, thyroid conditions and sleep apnea. Shelley, Vivian and Nadia, (2009) mentioned that Children with DS have a higher risk of several physical complications like heart disease and hearing loss. In another study has been also shown (McGrath *et al.*2011) that children with Down syndrome were more likely to have intellectual disability, heart problems, muscular dystrophy, arthritis, epilepsy, asthma, migraines, and allergies than other children with disabilities. The medical care expenses are more in the family who have the child with DS than the family of the child with other disabilities. According to McGrath *et al.* (2011) the families of the children with DS faced more financial challenges. The families of the children with DS more time reported financial problems caused by the child's health conditions. Those families of the children with DS described that they provided more time for child caring and family members had reduce or stop working because of the child's health. They had to pay more for child's medical care and they need additional income to cover child's medical expenses. However, they reported their children's health needs caused financial problems for their family. The families of children with Down syndrome lead the lower financial well- being and career opportunities for parents than the families of the typically developed children.

The mothers of the DS children give up other roles in society, attend less to social activities and have less social life due to their increased responsibilities for childcare and it also make difficulties to maintain mothers' own self-care, productive works and

recreational activities. In this study it has found out that the impact on mother's daily life such as mothers' performance in ADLs, social participation, how much they get supports from their family and community and their financial situations to have the children with Down syndrome.

CHAPTER 3 METHODOLOGY

The study aim is to identify the impact on mothers' daily life of having children with Down syndrome. In order to explore this impact the researcher used the Ethnographic method under Qualitative research design. The researcher has chosen two study areas, the William and Marie Taylor School (CRP) and the Beautiful Mind School (Dhaka) and has selected the sample through the convenience sampling procedure. Data was collected by face to face interviews with semi-structured open ended questionnaires.

3.1. Study design

The study design used here was the qualitative research design, and the Ethnography study method. According to Bailey (1997) the Ethnography study method can be defined as

“The researcher will study how individuals create and understand their daily lives; how people see, explain, and describe the world in which they live.”

Hoey (2013) mentioned that the term “ethnography” has come to be equated with practically any qualitative research project where the aim is to provide a detailed, in-depth description of everyday life and practice. Ethnography may be defined as a qualitative research process whose aim is cultural analysis. The researcher find out the understanding of culture through the image of what we call perspective, or what might be described as the individual's point of view. Interviews provide for data collection by asking specific but open-ended questions. However, this study design can identify the life ways and or patterns or experience of the people in their living environment and also can find out the beliefs, values, attitudes and experience of a group of people. This method has used to identify the impact on the daily life of mothers' with DS children, by finding out their beliefs, values, thoughts and experiences.

3.2. Study settings

The William and Marie Taylor Inclusive School

The William and Marie Taylor (WMT) Inclusive School is a school located within The Centre for the Rehabilitation of the Paralyzed. Since 1993 CRP has operated a special needs school. Recognizing the short comings of the segregated educational system, CRP began construction of an inclusive school building in 2003. This new

school combines CRP's mainstream school which accommodates children of staff members and local children, with the special needs school. By mixing and interacting with disabled children at an early age, many of the barriers and superstitions surrounding disability will be broken down, leading to a more tolerant and understanding society. An inclusive educational environment also enables children with special needs to access a level of education suitable for their capabilities and to have the same access to sporting, recreational and extra-curricular activities as those attending mainstream schools. In an interview (Appendix-6) it has been known that the total students of the school are 298 and 107 of them special needs students. Among them five students are Down syndrome children. There is inclusive classes included class play-class five. There are five special need classes and one vocational training class.

The Beautiful Mind School

The Beautiful Mind (BM) is a private organization registered under the Ministry of Social Welfare, Bangladesh. This organization was established in 2004 by the founder chairperson Dr. Shamim Matin Chowdhury – a Bangladeshi child and Adolescence Psychiatrist and an Autism Specialist. This co-educational school is situated at Dolipra North of Uttara Model Town, Dhaka. The school building is a custom-built house. Academically this school follows the National Curriculum and the Foundation stage. In an interview (Appendix-7) it reported that the aim of the organization is to meet the needs of the students with Autism and mental Retardation by providing appropriate education and treatment. The Classes are formed on the basis of the children's age and special needs. There are 150 special needs students. Among these there are 13 students are children with Down syndrome. This school does not list children according to their disability.

3.3. Study population

The mothers of children with Down syndrome are population of this study and they have been selected from two study areas including the William and Marie Taylor School CRP-Savar, Dhaka, and the Beautiful Mind School, Uttara, Dhaka.

3.3.1. Study sample

There is no set sample size for qualitative studies. Sample for qualitative studies are generally much smaller than those used in quantitative studies. Morse, (2000)

mentioned that sample size depends on some factors such as; the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the number of interviews per participant, and the qualitative method and study design used. It has been shown (Mason, 2010) that 20 to 60 participants are usually suitable sample size in an ethnography study method and at least 10 participants are needed to reliably establish a consent in a qualitative study.

The researcher selected 10 mothers of children with Down syndrome as participants through convenience sampling procedure. This sample size ensures the information which needed in this study. Therefore, this sample technique has used.

3.3.2. Participant selection procedure

The Convenience sampling procedure has used in this study. The convenience sampling method has used because it is easy and not time consuming. According to Latham (2007) convenience sampling includes participants who are readily available and agree to participate in a study. This is a relatively easy choice for the researcher when a group of people can't be found available. By using this procedure the researcher selected the participants who were conveniently available and also included the following inclusion criteria:

3.3.3. Inclusion criteria

- Mothers who have the children with Down syndrome.
- The mothers have been selected whose DS children' age are between 6-14 years. A study in the Pakistan showed that mothers of mentally disabled children of this age range experienced more difficulty to cope with their living condition (Ergun and Ertem , 2012).

3.3.4. Field test

According to Twing (2012) a field test is a test to check on the quality and appropriateness of test questions and procedures. It is important in a study to make sure that the questions can measure what it is planned to measure. Field tests collect original data through face to face interviews, surveys or direct observation. A field test was conducted with a mother of a child with Down syndrome, to check out the validity and reliability of the questions which were to be used for data collection in the study. It helped to make a plan that how the data collection procedure can be carried out, sorting out the difficulties during questioning, making a basic plan of

questioning and if there is needed any modification of the questions and re-set the semi-structured open ended questions for data collection in the study.

3.4. Data collection

Data has collected from the participant through face to face interviews. Bailey (1997) stated that in ethnographic research, interviews are always conducted face to face. Interviews conducted face-to-face are close and the researcher can contact directly and develop rapport with the participant. The researcher used open ended questionnaire in semi-structured interviews for data collection in this study.

3.4.1. Data collection procedure

According to Moriarty (2011) Interviews are most common data collection method in qualitative research and flexible way to asking people about their opinion and experiences. Qualitative interviews are generally described as either being semi-structured or in-depth. The semi-structured interview conducted on the basis of this study's aim which is to identify the impact on people's life through their perception and experience. Semi-structure interview is similar to unstructured interview which makes an interview more like a normal conversation. With semi-structured questionnaire participant have more freedom to explain their feeling and experience in their own word. For this reason the researcher used this procedure for data collection in this study. At first the researcher took permission from those organization which was choose as study settings. Then researcher took consent from the participants through inform consent paper and fix appointment with the participant for interview. The semi-structured open ended questions has used (Appendix-4) in the interview. The researcher started the interview first as a normal conversation then gradually started the questions for data gathering. Because it is important to build a rapport with the participant thus the participant feel easy to answer and not make the tendency to hide. Then researcher recorded the interview with recorder.

3.4.2. Ethical consideration

Crossman (2014) mentioned that the ethical considerations are self- regulatory guidelines for making decisions and defining professions. By establishing ethical codes, the professionals maintain the reliability of the profession. The researcher was granted permission from the study supervisor and Head of the department from the

department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP) to conduct the study. The researcher maintained some ethical consideration like: After getting the permission of doing this study from the academic institute the researcher started to do it. The researcher has informed participants before to invite participation in the study and ensure that all participants were informed about their rights and reserves and about the aim and objectives of the study. Before starting the interview the researcher has used a written consent to take the permission of each participants of the study. It has been also ensured that all kinds of confidentiality highly maintained. The researcher ensured not to leak out any type of confidentialities and the participant had the rights to leave the study when she wants. There are all rights of the participant reserved and researcher was accountable to the participant to answer any type of study related question. The researcher also ensured that the organization is not hampered by this study.

3.4.3. Data collection tools

- Consent form- was used to take permission from the participant to collect data in the study.
- Semi-structured open ended questionnaire- used to conduct the interview (attached in Appendix-4).
- Tape recorder- used to record all answer from the participants according to the questionnaire. According to the Morgan and Guevara (2008) the most obvious value of audio recording is that it offers an accurate summary of what was said, and this is especially important for in-depth interviews.
- Pen and paper- used to take observation notes from participants.

3.4.4. Data analysis

The researcher used qualitative content analysis to analyze the data. Content analysis is a systemic method of reduction and analysis. Qualitative content analysis focuses on the informal content of a text. It is about remove meaning that can't be read when only focusing on the formal aspects.

Bailey (1997) mentioned

“Qualitative data analysis was a complex process. Content analysis was used to discover themes as it was a common data analysis procedure most often used in qualitative data and based on searching for repeated words, phrases or concepts.”

According to Hsieh and Shannon (2005) Content analysis process is a widely used qualitative research technique. In content analysis coding categories are derived directly from the text data. QCA is one of numerous research method used to analyze text data. It has used in this study not as being a single method. It has been used for data analysis with ethnographic study method in this study. At first data has transcribed in Bangla which collected from the interview through the recorder. After transcription each of the transcript were translated into English by three individuals people who were not present in the study settings and don't know about the aim or objectives of the research question. After completing the transcription, researcher confirmed those to check the correctness of the data. As the researcher found some answer categories according to the question categories (from Appendix-4), question no. 1, 2, 3 were for identifying how the mothers maintain self-care, productive and leisure activities and question no. 4 explored how the mothers maintain social participation, question no. 5, 6 found out how much they get supports from their family and society and question no. 7 identified the change of financial condition which they faced. These questions of the interviews were categorized into different meaning units. Under each of those categories, the interviewed data were coded in meaning. Coding means naming segments of data with a label that at the same time categorizes summarizes and accounts for each piece of data. By this progression and reduction process those data was forming the themes.

3.5. Rigor of the study

Koshar (2014) mentioned that the rigor in qualitative research has to do with our ability to determine if the conclusions are trustworthy. That makes them equal to validity and reliability in research. There was no biasness to select the participants and the researcher never influenced the participants by the researcher's own perceptions during the data collection. Data was recorded carefully and there was no biasness impression towards the participant's answers. A trustful relationship with participants was always maintained and the document was kept confidential. The data transcription and translation was checked in several time and data analysis was in

systemic and scientific way. The researcher did not influence the outcome of the study.

SUMMARY OF DATA ANALYSIS AND RESULT

Objectives	Questions	Categories	Themes
<p>1. To explore the mothers' experiences of maintaining their self care activities, productive activities, leisure and social participation, at the same time as caring for the children with Down syndrome.</p>	<p>Question Number: 1, 2, 3, 4.</p>	<p>1. Mothers' experience about maintain self care activities. 2. Mothers' experience about maintain productive activities. 3. Mothers' experience about maintain leisure. 4. Mothers' perception about their social participation</p>	<p>1. Most of the mothers can't maintain properly their self care, productive and leisure activities. However, they face more difficulties in maintaining productive and leisure activities than self care activities.</p>
			<p>2. Most of the mothers can maintain their social participation. They expressed that can participate in different social functions.</p>
<p>2. To identify the mothers' experiences in case of supports from family and society as well as if they have any changes in financial conditions due to have a DS child.</p>	<p>Question Number: 5, 6, 7.</p>	<p>5. Mothers' experience about to get physically, mentally & financial supports from family. 6. Mothers' experience about to get positive supports from neighbors or community. 7. Mothers' thought about the change of financial condition in their life.</p>	<p>3. Most of the mothers mentioned positive supports from family but didn't get social support enough because of neighbors' negative view towards disability (DS). 4. Many of the mothers experienced that their financial conditions turn out to be worse due to the child's medical care, education and other expenses.</p>

CHAPTER 4

RESULT AND DISCUSSION

In this study, the findings have been reported with the discussions in the same section. This section explains the categories of description and the commonalities and variations within those categories as experienced by the participants. Through these categories the participants' experiences have divided in various codes and find out the themes.

4.1. Theme of the study

Theme 1: Most of the mothers can't maintain properly their self care, productive and leisure activities. However, they face more difficulties in maintaining productive and leisure activities than self care activities.

Theme 2: Most of the mothers can maintain their social participation. They expressed that can participate in different social functions.

Theme 3: Most of the mothers mentioned positive supports from family but didn't get social support enough because of neighbors' negative view towards disability (DS).

Theme 4: Many of the mothers experienced that their financial conditions turn out to be worse due to the child's medical care, education and other expenses.

4.2. Categories of description and discussion

There are seven categories in this study. Each category has reflected the experiences of the participants through the different codes according to the different opinions of the participants. The tick was given in those columns where the participants provide their description. In the category table 'P1' was used for participant 1, 'P2' for participant 2, 'P3' for participant 3, 'P4' for participant 4, 'P5' for participant 5, 'P6' for participant 6, 'P7' for participant 7, 'P8' for participant 8, 'P9' for participant 9, 'P10' for participant 10.

Category -1: Mothers' experience about maintain self care activities.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Can't maintain properly	✓		✓						✓	
Difficult to maintain properly		✓					✓	✓		✓
Can maintain somehow							✓			✓
No difficulties to maintain.				✓	✓	✓		✓		

Table 1: Mothers' experience about maintain self care activities.

A mother is the main caregiver of a child. Children with Down syndrome needs more care because a DS child can't maintain his/her own activities as a child without DS. This is why mothers give their most of the time to look after their children with Down syndrome. After spending a lot of time to look after their child and other works they can't maintain their self care properly. In interviews most of the mother said that they have to spend much time to look after their child so they face difficulties to maintain their eating and bathing time. Among of them a mother said,

“I have three child and I have to give (spend) much time for caring this child then I forget if I take my bath or lunch properly. Sometime it seems that I can't take my lunch because I go to the school to pick up my child from the school.”

Caring a child with Down syndrome is difficult for a mother because she need to spend more time to care her child and less time to complete her daily living activities. Mother is the main career of a child. The children with down syndrome need more care than the children without down syndrome due to their behavioral conditions, cognitive impairment and developmental delays. It has been mentioned (Cuskelly, Hausar-Cram and Riper, 2009) that mothers take the primary child caring role to the children with Down syndrome. They spend more time with their children for care thus they get less time for their self care activities. Wayne and Krishnagiri, (2005) mentioned ,

“Raising a child with special needs is one factor that challenges parents in achieving a

balance among work, leisure and activities of daily living”.

Most of the mother spends their maximum time towards the child caring, house hold activities, and other jobs or works. It makes sometime challenge to them to maintain all works properly. About the experience of maintaining self- care few mothers mentioned,

“I can’t maintain properly and any how I have to manage”.

During interviews few mothers mentioned that though they can’t maintain properly their self care, somehow they have to manage because they are the main career of their child and they have to do this. It has been shown (Joosa, and Berthelsen, 2006) that mothers consider the change in their lives that the event or the child with Down syndrome has brought. Some mothers stated,

“I can maintain and I don’t face any difficulties to maintain”.

On the basis of the behavioral condition of a child with Down syndrome; a mother of a child with DS faces less difficult to maintain their self care than the mother of the children with other disabilities. Cuskelly, Hausar-Cram and Riper (2009) parents of a child of Down syndrome experience fewer negative effects and more positive effects than the parents of children with other disabilities like a child with autism. However, mothers of DS children have higher levels of well-being than the mothers of children with other conditions.

Most of the mothers’ opinion was that they have less time to maintain their self-care activities due to spend much time to look after their children, household activities and other activities.

Category -2: Mothers' experience about maintain productive activities.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Can't complete properly.	✓							✓	✓	✓
Difficult to complete properly.		✓	✓				✓	✓		
Need others help to complete.							✓	✓		
Can complete properly.				✓	✓	✓				

Table 2: Mothers' experience about maintain productive activities

A mother with a special need child faces many challenges to make a proper balance in productive works like house hold activities and employment. According to the Barnett and Boyce (1995) those mothers have less time to paid employment. Most of the mother mentioned that they have difficulties to complete house-hold activities due to spend more time to look after their children. A mother said,

"I have to spend much time to look after my child. I have other children also and I have to look after them too their school, studies... but big time (much time) of mine in a day, I spend to care (look after) this child so I feel challenges to manage all things."

It stated that (Wayne and Krishnagiri, 2005) a mother of a child with Down syndrome have to spend her most of the time to look after the child and less time to productive work. They face difficulties to achieve a balance to maintain all works. During the interviews a very few mothers mentioned that they need others help to complete the house hold activities. One mother said,

"I have to take care of my child and spend much time with my child but due to have a house maid I can manage it somehow."

The mothers of children with Down syndrome have less time to maintain productive work due to spend extra time for look after their child. Some mothers stated,

"I can complete my house hold activities and there is no problem."

Cuskelly, Hausar-Cram and Riper (2009) mentioned that the Down syndrome advantage is that families whose children with Down syndrome are functioning more poorly than the average or those who have severe behavior problems such as autism.

In many cases, the behavior of the children with Down syndrome makes fewer problems than the children with other disabilities like autism. Most of the mothers' experience was that they face challenges to maintain their productive work due to spend much time to look after their children. According to Cunningham (1996) these children need more care and high level of supervision than the children without disabilities. These mothers spend their most of the time along with their children and less time to other activities.

Category -3: Mothers' experience about maintain leisure.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Don't get time for leisure at all due to spend much time only with the child.				✓						
Don't get time for leisure at all due to spend more time for look after child, house hold works and other works.			✓						✓	✓
Get very less time for leisure.	✓	✓					✓	✓		
Get enough time for leisure.					✓	✓				

Table 3: Mothers' experience about maintain leisure

Mothers who have children with Down syndrome can't spend leisure time due to spend much time to look after their child, involve in house hold works and other works. The leisure activities for example: chat with others, take some rest or do any creative works such as gardening, and visit to neighbor's house or outside is difficult to maintain for the mothers. Most of the mother said that they can't spend time for leisure activities. Many mother mentioned,

“I don’t have enough time for leisure.”

These mothers face difficulties to maintain their leisure activities. Others have shown (Hsich, and Puymbroeck, 2013) that mothers experienced various barriers that potentially kept them from participating in leisure activities as normally as they wished. The main barrier of leisure activities is time restriction. The need of physical and verbal assistance in the activities of daily life can be time consuming for the mothers of children with disability. These mothers don’t have time for themselves. They have limited their leisure participation due to a feeling of restriction in time. One mother said,

“No, I don’t get much time for spend as leisure (leisure activities). I do house hold work till evening and then I engage my children to complete their home-work; my whole day passes this way with them.”

Mothers who have the children with Down syndrome face challenges to maintain time for their leisure activities. According to the Wayne and Krishnagiri, (2005) these mothers feel difficulties to gain a balance among their leisure, work like house hold work, child care and daily living activities. During interview another mother mentioned,

“I have to busy with my son all time. Moreover, I have to do other works too like, house-hold activities, cooking, cleaning all things... I don’t get any time to go somewhere from home. I can’t even take rest because I always worried about my child.”

Some mothers expressed their worried about their children through the interviews. Hsich and Puymbroeck (2013) stated that the feelings of constantly worry about the child prevent these mothers from participating in leisure activities. A very few mothers said,

“I can spend time for leisure.”

Few mothers experience was that they can maintain their leisure time. It depends on their environment, their support group. Moreover, the mothers of a DS child face less behavioral problem than the mothers of children with other disabilities. Some mothers said that they can’t spend their leisure time due to only look after their child and some

said that they don't get much time for leisure due to look after their child, house hold activities and many other works. However, the mothers of the DS children face difficulties to maintain time for their leisure activities.

Category -4: Mothers' perception about their social participation.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Can't participate at all.			✓						✓	
Can participate sometime.	✓									✓
Can participate now, than earlier.				✓			✓			
Can fully participate.		✓			✓	✓		✓		

Table 4: Mothers' perception about their social participation

Participate in different social function or activities are important as a social being. Social activities or function is not like daily activities. It arranges or occurs in a certain time that's why most of the mother can participate in social functions. Some mother mentioned that they can participate and there is no problem to participate in social function or activities. Many mother said,

"Yes, I can participate now but when my child was very young I can't participate."

The mothers of the children of DS experienced that they can participate in different social function. It is founded (Cuskelly, Hausar-Cram and Riper, 2009) that, parents of children with DS experience similar levels of well-being to those experienced by parents of normally developing children. In some cases, the mothers of DS children can participate in different social activities as the mothers of the children without disabilities. Many mothers of children with DS can participate in different social activities more than the mothers of the children with other disabilities or autism. Some mothers stated that they can't participate in social function due to lack of time and preparation. One mother said,

"I can't go for social functions...and there is always need a preparation to go somewhere but with my child I can't take any preparation."

Time restriction is the main cause to prevent the mothers of the children with Down syndrome from various social activities. It is mentioned (Barnett and Boyce, 1995) that a mother of a child with DS spend more time to care her child and less time in social activities. During the interviews most of the mothers of explained that they can participate in social activities and some mothers' experience was that they can't participate in social function due to time restriction and lack of preparation.

Category -5: Mothers' experience about to get physically, mentally & financial supports from family.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Can't get any physically supports.	✓		✓							
Live in a nuclear family & no other members to supports.	✓		✓							
Get enough physically, mentally & financial supports from family members.		✓		✓		✓	✓	✓	✓	✓
Family members are very supportive in extended family.		✓		✓		✓	✓			
Don't feel to need any support.					✓					

Table 5: Mothers' experience about to get supports from family

Most of the mothers said the get help from their family and their family members are very supportive. Many mothers said they get a lot of support from their husbands. Among these one mother said,

“My husband works outside. He takes care of the family too and he is really very supportive.”

In many families fathers are very supportive. They help in child care and basically they provide mental support to their wives to have the children with Down syndrome. Cuskelly, Hausar-Cram and Riper (2009) mentioned,

“Mothers perception of the caretaking burden was lighter when the fathers participate in tasks and provided emotional support.”

According to Joosa and Berthelsen (2006) many mothers of the DS children described their family relationship as similar to all families. Their husbands provide enough support in take care of family and they work together. It is also mentioned (Hsich and Puymbroeck, 2013) that the support from the husband is the most important factor in reduction anxiety. In a family the supports from one’s spouse is the most important source of emotional support for caregivers of children with special needs. Many mothers reported that they get physical support also from their family members. Some mothers mentioned through the interviews that the other members of the family like grandparents also support them. One mother said,

“My mother I mean my child’s grandmother helps me a lot. She helps me in household activities so I can take care of my child easily.”

It has been shown (Cuskelly, Hausar-Cram and Riper, 2009) that grandparents play a central supporting role for the families of the children with DS. Some mother said they live in a nuclear family where there is no other members to help or support them. One mother said,

“I live alone with my child (in a nuclear family) so there is no one to help me.”

There is also an advantage and disadvantage in both nuclear and extended family of the DS children. During interviews many mothers said that they get enough support from the family members in extended family. In other shown (Ergun and Ertem, 2012)to live with mentally disabled child are more challenging in nuclear family. The supports from family members and relatives are very important for the parents. Another mother said,

“No, I no need any help and I like to do myself all of my works.”

The children with DS who have less behavioral problems they need less supervision than the children with other disabilities. According to Cuskelly, Hausar-Cram, and

Riper (2009) mothers observed their child with DS as having some positive behavior that acted to maintain and develop connections between family members and with others. Most of the mothers get supports from the family members mainly from their husbands. They also get enough support from the other members of the family.

Category -6: Mothers' experience about to get positive supports from neighbors or community.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Can't get any positive support or help.	✓		✓	✓			✓	✓	✓	✓
Negative view from the community.	✓						✓		✓	✓
Don't get supports due to shift the family in a new place where there is contact with neighbors.			✓	✓				✓		
Neighbors become supportive than earlier.		✓								
Neighbors are always very supportive.					✓	✓				

Table 6: Mothers' experience about to get positive support from neighbors or society

Cuskelly, Hausar-Cram and Riper (2009) mentioned,

“Maternal well-being and mother's perceptions of family functioning were associated with their perceptions of the quality of the support they received.”

Mothers of the children with Down syndrome need social support as much as they need family supports. According to the Hsich and Puymbroeck (2013), level of the social supports is the most powerful predictors of depression and anxiety in mothers.

In this study, most of the mother said that they don't get support from society or neighbors. The neighbors have negative view and make hopeless word about the condition of the child. Some people in the society don't like that the DS children play with their normal child. Some mothers said,

“Some time when my child plays with their normal (typically developed) child then their parents move them away from my child. They don’t like that my child play with their child.”

There are some social stigmas still in our society. These negative views for the children with disabilities affect the mother’s quality of life by increasing their individual burden. For example: embarrassment, guilt, shame, anger, worry or other emotional upset. The mothers also experienced emotional turmoil due to the perception of negative attitudes toward their children (Hsich and Puymbroeck, 2013). In another study (Joosa and Berthelsen, 2006) in Singapore some mothers of the DS children described about the social exclusion about them and their child. The feeling of a perceived stigma became a barrier that prevented them from different social activities and increase their social isolation. Throughout the interviews, some mothers said they get social support and their neighbors are very supportive. One mother said,

“We three families are living in a flat. If my child stands on their bed they don’t make any negative word. They are very supportive. In that case, I think I am very lucky.”

The view of the society is becoming more positive day by day. The professionals’ studies about the special need child and the positive information are reached to the society through the social medias is also responsible to change the view of the society about the DS children. During interviews one mother said,

“I get support now more than before. This Eid-ul-fitar I went to home then I observed that everybody showed well behave and they are also supportive. But previous days all my neighbors neglected my child and said this child may not live any longer.”

According to Joosa and Berthelsen (2006) mothers mentioned that society now is accepting these DS children. Though they are still staring at the DS children when go outside, the negative view become less than before.

In this study, most of the mothers experienced that they don’t get enough social supports due to social barriers or negative view of the society towards the children with Down syndrome.

Category -7: Mothers’ thought about the change of financial condition in their life.

Code	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
No change in financial condition.				✓	✓	✓				
Economical condition becomes worse.		✓	✓				✓	✓		✓
It creates extra costs		✓					✓	✓		
Economical condition becomes good.	✓								✓	

Table 7: Mothers’ thought about the change of financial condition in their life

Most of the mothers said that they have to sift their whole family one place to another for their child’s treatment and education which is expensive and it affects their financial conditions. A mother said,

“I have to move here for my child’s education and treatment... because there was no special school (special needs school) where I lived and here the cost of house, child’s education, treatment and others are very expensive. There is only one earning member in the family so I think it is financial changed.”

According to McGrath *et al.*(2011) the families of the DS children faced more financial impacts. The families of the DS children more time reported financial problems caused by the child’s conditions. Those families described that they provided more time for child caring and family members had reduce or stop working because of the child’s health. They had to pay more for child’s medical care and they need additional income to cover child’s medical expenses. However, they reported their children’s health needs caused financial problems for their family. It has been mentioned (Cuskelly, Hausar-Cram, and Riper, 2009) families of children with Down syndrome reported the lower quality of life, financial well- being and career opportunities for parents than the families of the children without disabilities. Some mothers said their economical conditions are not changed and it is same as before. Some mothers said,

“There is no change in financial condition.”

It is also depends on the previous financial conditions, the health condition of the children and the earning source. It is founded (Cuskelly, Hausar-Cram and Riper, 2009) that, parents of DS children experience similar levels of well-being to those experienced by parents of normally developing children. A very few mothers said,

“I think after birth of my child my financial condition become more progress and well. I think this child is lucky for our family.”

According to Cuskelly, Hausar-Cram and Riper (2009) usually disability is viewed as a burden. It was reported by the families of the DS children that the community view to have a child with a disability only as a tragedy. On the other hand some mothers also reported more positive perceptions of parenting and a more positive impact of the child with DS in their family.

In this study, most of the mothers of the children with Down syndrome reported the change in financial condition. Many of them explained it as financial problem and the condition is become worse due to increase their cost about medical care, educational and others expenses for the children with DS.

In this study, it has found that the mothers of children with Down syndrome face difficulties to maintain their time schedule for their own self care such as, eating and bathing. They face challenges to complete their house-hold activities due to spend more time to look after their children. They can't get leisure time due to this time restriction. They have to spend their maximum time to look after their children, house-hold activities and other works. In this study, the mothers get enough supports from their family. Family members are very supportive with them. The family members support them both of mentally and physically. The mothers don't get enough supports from community people. There are still some negative views in the communities towards the children with Down syndrome. The mothers also reported that their financial condition become worse due to have DS child. The families who have DS child need to pay extra cost because of the medical care, educational and other expenses. Therefore, it has a large impact on daily life of mothers to have DS children.

4.3. Limitation of the study

This study has conducted due to fulfillment of the course curriculum. There was a limitation in interviews sessions. The researcher has got very few times with the mothers at the school. Therefore, it becomes difficult to build rapport with them. However, the participants were very co-operative to share all of information. There was no study has been conducted related to the topic in Bangladesh. There have been found some information related to this study on global perspective from manual searching by books and journals from online database such as Google scholar, Google web page, pubmed, Hinari etc. Moreover, the study result would be more comprehensive if the participant had been taken from more than two study settings. Due to the time limitation the researcher selected only two study settings.

CHAPTER 5

CONCLUSION

Mother is the primary caregiver of a child. The child with Down syndrome can't maintain their self-care activities as a typically developed child due to their developmental delay. The children with DS are dependent on their mothers. The mothers have to provide more care to their DS children.

This study has been conducted to explore the impacts on the daily life of these mothers of the children with DS. Therefore, the findings of the study show that the mothers of the DS children face challenges to maintain time for their own self-care, productive works and leisure. They have to spend a lot of time to look after their children. The result has also showed that these mothers got enough supports from the family rather than the community. The mothers also expressed about their financial condition which is become worse due to increase the expenses for the medical care and educational care of their DS children.

This study is important for the Occupational therapist to work with mothers having children with Down syndrome. The Occupational therapist (OT) could provide recommendations and education to the mothers on many topics ranging from basic care requirements which will help the children's own self care. The OT could also promote the mothers' coping strategies in managing children with DS. The schools or the organization could also start different programs for the mothers such as educational programs, awareness programs and also the all mothers in the school can make self supports group. The Govt. should also take necessary steps to establish more special needs schools and ensure the arrangement of educational and awareness programs for mothers.

In future, further studies can be conducted in relation to this study such as the experience of care giving both parents of the children with DS compare with the parents of children with other intellectual disabilities. It will be better if it is possible to conduct the same study by using a large number of participants from different study settings.

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Appendix-1

Permission letter for conducting study

Date: 02-08-2019

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.

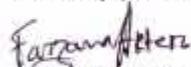
Madam,

I am Farzana Akhter, 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 the mothers' daily life to have a children with Down syndrome: mothers' perspective." and I will be tried to identify the impact on daily life of mothers with Down syndrome 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,

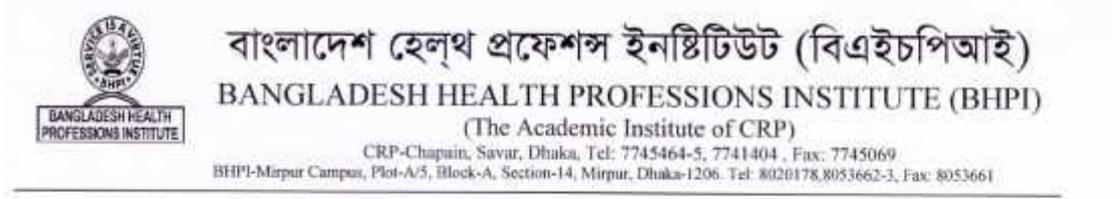


Farzana Akhter
4th year B. Sc in Occupational Therapy
Bangladesh Health professions Institute (BHPI)
Centre for the Rehabilitation of the Paralyzed (CRP).

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 recommendation of supervisor it may allow to conduct this study. 02/08/19
Supervisor Md. Yeasir Arafat Alve Lecturer in Occupational Therapy Department Bangladesh Health Professions Institute (BHPI) CRP, Savar, Dhaka-1343	Recommended to conduct the study according to proposal. 02/08/19

Appendix-2

Permission letter for data collection



তারিখ : ২৯.০৯.২০১৪

প্রতি
অধ্যক্ষ
উইলিয়াম এন্ড মেরি টেইলর স্কুল
সিআরপি, সাভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,
বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী ফারজানা আক্তারকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০১.১১.২০১৪ তারিখ থেকে ৩০.১১.২০১৪ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরণ করা হলো।

তাই তাকে সার্বিক সহযোগিতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে



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





বাংলাদেশ হেল্থ প্রফেশন 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 : ২৯.০৯.২০১৪

প্রতি

অধ্যক্ষ

বিউটিফুল মাইন্ড

উত্তরা ঢাকা।

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

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পঞ্চাশতন্ত্রদের 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 ফারজানা আকতার তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০১.১০.২০১৪ তারিখ থেকে ৩০.১১.২০১৪ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আশ্রয়ী।

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

ধন্যবাদান্তে

অধ্যাপক ডাঃ এম এ কাদের
অধ্যক্ষ
বিএইচপিআই।



Appendix-3

Consent form in English and Bangla

The researcher Farjana Akter, 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, “The impact on daily life of mothers with Down syndrome children: mother’s perception”.

In this study I am a participant 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.

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-

সম্মতিপত্র

গবেষক, ফারজানা আক্তার, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট এর ছাত্রী যা পক্ষাঘাতগ্রস্থদের পুনর্বাসন কেন্দ্র সি.আর.পি এর একটি শিক্ষা প্রতিষ্ঠান। তিনি অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষে অধ্যয়নরত আছেন। এই গবেষণাটি তার অধ্যয়নের একটি অংশ। গবেষণাটির শিরোনাম “ডাউনসিড্রোম শিশু জন্মের ফলে মায়েদের দৈনন্দিন জীবন ধারণের উপর প্রভাব”।

আমি ফারজানা আক্তার গবেষণাটির উদ্দেশ্য সম্পর্কে যথেষ্ট অবগত হয়েছি। আমি যে কোন সময় যে কোন মূহূর্তে গবেষণা থেকে অংশগ্রহণ বাতিল করতে পারব এবং এর জন্য কারও কাছে জবাবদিহি করতে বাধ্য থাকব না।

উক্ত গবেষণা অংশগ্রহণকারীদের উপকারে নাও আসতে 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 তাহলে নামহীনভাবে প্রকাশ করা হবে। আমার নাম, ঠিকানা এই গবেষণায় কোথাও প্রকাশ করা হবেনা।

স্বাক্ষর

অংশগ্রহণকারীর স্বাক্ষরঃ	তারিখঃ
স্বাক্ষীর স্বাক্ষরঃ	তারিখঃ
গবেষকের স্বাক্ষরঃ	তারিখঃ

Appendix-4

Questions in English and Bangla

Question set:

Name: Age: Occupation:

Child's age:

Number of family members:

Number of earning member in family:

1. Can you maintain your self-care activities every day besides caring your child?

- If you can't then why it is?
- How much time you can spend for you self-care activities every day?

2. House wife: can you complete your house hold activities besides caring your child?

- If you can't then why it is?

Service holder: can you maintain your work in your work place along with your child's caring?

- If you can't then why it is?

3. Can you spend your leisure time besides maintaining your child?

- If you can't then why it is?
- How much time you can spend as your leisure activities every day?

4. Can you participate different social function because of your child's caring?

- If you can't then which type of problem caused for this?

5. Do you get any type of help from your family members during the caring time of your child?

- If you get help then which type of these are?
- If you do not get then why it is and which type of problem these are?

6. Do you get any type of help from your neighbors during the caring time of your child?

- If you get help then which type of these are?
- If you do not get then why it is and which type of problem these are?

7. Do you identify any kind of financial change in your life because of your child's care giving?

- If so then which type of these change?

প্রশ্নাবলিঃ

নামঃ

বয়সঃ

পেশাঃ

বাচ্চার বয়সঃ

পরিবারের সদস্য সংখ্যাঃ

পরিবারের উপার্জনক্ষম ব্যক্তির সংখ্যাঃ

১. আপনি আপনার সন্তানের দেখাশোনার পাশাপাশি প্রতিদিনের নিজের পরিচর্যার কাজগুলো সঠিকভাবে করতে পারছেন কি?
 - যদি না পেরে থাকেন, তাহলে কেন?
 - আপনি কতটুকু সময় প্রতিদিন আপনার নিজের পরিচর্যার জন্য অতিবাহিত করেন?
২. গৃহিণীঃ আপনি আপনার সন্তানের দেখাশোনার পাশাপাশি ঘরের কাজগুলো সঠিকভাবে করতে পারছেন কি?
 - যদি না পেরে থাকেন তাহলে কেন?কর্মজীবীঃ আপনি আপনার সন্তানের দেখাশোনার পাশাপাশি আপনার কর্মস্থলের কাজগুলো করতে কোন ধরনের বাধাগ্রস্ত হচ্ছেন কি?
 - যদি হয়ে থাকেন তাহলে তা কি ধরনের প্রতিবন্ধকতা?
৩. আপনি আপনার সন্তানের দেখাশোনার পাশাপাশি অবসর সময় কাটাতে পারছেন কি ?
 - যদি না পেরে থাকেন তাহলে কেন ?
 - কতটুকু সময় আপনি অবসর সময় হিসেবে দৈনিক কাটাতে পারছেন?
৪. আপনি বিভিন্ন সামাজিক অনুষ্ঠানগুলোতে অংশগ্রহণ করতে পারেন কি ?
 - যদি না পেরে থাকেন- কি ধরনের প্রতিবন্ধকতার সম্মুখীন হচ্ছেন ?
৫. আপনি আপনার সন্তানের দেখাশোনার ক্ষেত্রে পরিবারের অন্যান্য সদস্য থেকে সহযোগিতা পান কি?
 - যদি পেয়ে থাকেন তাহলে সেগুলো কিধরনের ?
 - যদি না পেয়ে থাকেন তাহলে কেন এবং সেগুলো কি ধরনের সমস্যা ?
৬. আপনি আপনার সন্তানের লালন-পালনের ক্ষেত্রে প্রতিবেশীদের থেকে সহযোগিতা পান কি ?
 - যদি পেয়ে থাকেন সেগুলো কি ধরনের ?
 - যদি না পেয়ে থাকেন তাহলে কেন এবং সেগুলো কি ধরনের সমস্যা?
৭. আপনি আপনার সন্তানের লালনপালনের ক্ষেত্রে কোন বিশেষ ধরনের আর্থিক অবস্থার পরিবর্তন লক্ষ্য করেছেন কি ?
 - যদি করে থাকেন তাহলে সেগুলো কিধরনের ?

Appendix-5

Demographic information of the mothers

Participants	Age	Education	Occupation	Child's age	Number of family members
P1	35	S.S.C	Housewife	8 years	4
P2	40	H.S.C	Housewife	8 years	5
P3	40	Honors	Housewife	10 years	3
P4	32	B.A	Housewife	12 years	4
P5	30	Honors	Housewife	6 years	4
P6	34	Honors	Housewife	9 years	4
P7	32	Masters	Housewife	6 years 4 months	3
P8	42	Class- VIII	Housewife	14 years	5
P9	38	H.S.C	Housewife	9 years	4
P10	43	Honors	Housewife	11 years	6

Appendix-6

Personal communication documents with the Teacher of the William and Marie Taylor Inclusive School, CRP, Savar, Dhaka.

The William and Marie Taylor is an inclusive School. There are 298 students at present in the school. There are 107 special need students in this school and among them five students' condition is Down Syndrome. At present there are inclusive classes including class play to class five in this school. There are five special need classes and one vocational training class for the students.

Linda Bishwas. (2014). About The William and Marie Taylor Inclusive School. Farzana Akter [verbal communication] CRP, 3 July 2014.


3/7/2014

Appendix-7

Personal communication documents with the Occupational Therapist of Beautiful Mind, Uttara, Dhaka.

The Beautiful Mind: A special center for Autistic and Mentally challenged children is a private organization. The aim of the organization is to meet the needs of the students with Autism and Mental Retardation by providing appropriate education and treatment. The classes are formed on the basis of the children's age and special needs. There are 150 special needs students. Among them there are 13 students are Down syndrome children.

Palash Saha. (2014). About Beautiful Mind: A center for Autistic and Mentally challenged children.
Farjana Akter [face to face communication] CRP,
5 July 2014.


05.07.14
palash chandra saha
clinical occupational therapist

(According to Harvard referencing style 2013).