

**COPING WITH THE PROBLEMS IN THE RELATIONSHIPS
AND SOCIAL LIFE OF MOTHERS OF CHILDREN
WITH CEREBRAL PALSY**

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This thesis is submitted in total fulfillment of the requirements for the subject
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Statement of authorship

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

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This thesis has not been submitted for the award of any other degree or diploma in any other tertiary institution.

The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, it will be duly acknowledged as undergraduate thesis.

I am only responsible for any imprecision or mistake on my research study.

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Dedication

Dedicated to my honorable and beloved parents.

Acknowledgement

With the grace of Almighty Allah I have completed the research project so at first I would like to pay my gratitude to the almighty Allah whose blessings enable me to complete this study within the time. I would like to express my gratitude to my parents who always inspired and helped me to carry out this study. Then I want to offer my convenient gratefulness to my honorable supervisor Md. Monjurul Habib for his proficient guidance and help throughout the study. I would also like to gratefully acknowledge my previous course coordinator Mohammad Mosayed Ullah for his guidance in my study. To the In-charge of Pediatric unit, I thank you for giving me permission for data collection to conduct the research. I am thankful to all the staff of library of BHPI for helping me using reference book and other supports. I want to acknowledge my honorable teacher Umme Aeyman and Nazmun Nahar for their instruction to data analysis during my study. I would like to give my special thanks to the persons who help me to translate the interview from Bangla to English. I would also like to thanks Ashley for her help with my written. Finally I remember all my friends with the feelings of gratitude for their inspiration and moral support in different critical situation of the study.

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List of abbreviations

BHPI-Bangladesh Health Professions Institute

B.Sc. - Bachelor of Science

CP-Cerebral palsy

CRP-Centre for the Rehabilitation of the Paralysed

OT-Occupational Therapy

WHO-World Health Organization

Abstract

Cerebral palsy is a common condition in Bangladesh which causes childhood disability. In most cases the mother is the primary caregiver for her child with cerebral palsy. Mothers face many problems when caring her child and cope as best as they can.

Aim of the study: To identify the coping strategy of mothers of children with cerebral palsy with the problems in the relationships and social life

Objectives of the study: The objectives of the study are to find out the problems of mothers in their relationships with other persons and in their social life and how they cope with those problems.

Methodology: Qualitative methodology was used to conduct this study. Participants for this study were the mother of children with cerebral palsy who are taking treatment in CRP for their child. For data collection 6 mothers were purposively selected and an in-depth interview was conducted with a semi-structured open-ended questionnaire. Then the data was analyzed using qualitative content analysis.

Result: The mothers interviewed reported problems with their relationship with their in-laws and financial difficulties due to the extra cost associated with having a child with CP. They also face problems in their social life due to negative talking within society about their child. To cope with these problems the mothers report to Allah for support and to accept their fate. They also utilize alternative technique such as expressing feelings, trying to solve problems, seeking cure and staying away from the person who makes the problems.

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1.1. Introduction

The birth of a child with disabilities is an event that affects all family members and in the relationships between them (1, 2). According to World Health Organization (WHO), “disability is any restriction or lack (resulting from any impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (3). Childhood disability often imposes a social and emotional burden for children and their families (4, 5). According to World report on disability, “about 15% of the world’s population were estimated to be living with disability and the Global Burden of Disease estimates the number of children aged 0–14 years experiencing moderate or severe disability at 93 million (5.1%), with 13 million (0.7%) children experiencing severe difficulties” (6). There are many reasons that cause childhood disability, one of the most common causes of childhood disability is cerebral palsy (7).

In United States it is estimated that there are 764,000 children and adults living with cerebral palsy. There are 2.3 to 3.6 (studies vary) of every 1,000 individuals have cerebral palsy and this prevalence can be compared with prevalence statistics in other countries (8). In Bangladesh childhood disability is not uncommon and cerebral palsy is a common condition. In one study it was found that the prevalence of cerebral palsy in Bangladesh is 6/1000 children (7). Prevalence rate for cerebral palsy vary somewhat in different countries and regions largely reflecting economic and nutritional factor and access to good obstetric care (7).

Many problems arise in a family when a child is born with CP including caring problems of child, cost and time associated with treatment and equipment, problems in social interaction of the families of a child with disability. It is a common belief that the mother is responsible for the child having a disability and family members are not interested to take care of the child. The mother is then left to take all responsibility of her child. So mother faces many kinds of problems like physical problems, emotional problems, social problems etc. All these problems have a great impact on

mother's life. Different studies show that for having a child with CP there was a great impact on mother's relationship with other person and mother's social life (2, 9). Many mothers have a poor relationship with other family member and are often confined to the home and restricted in social and community activities. The impact of these, result in emotional stress among the mothers which is likely to affect mother's caregiving capacity (10). So Mothers try to cope with these problems. Mothers use different coping strategies for example some mothers try to solve the problems and some blame their fate and avoid negative feelings.

1.2. Background

For having a child with disability many difficult situation may be created in a family and most families are unprepared to cope with its occurrence (2). The practical day to day needs of the child creates challenges for the mother of the child (11). A number of studies have examined the daily challenges and problems faced by mothers who have a child with CP (9, 11-13). There are also many studies about coping strategies used by mothers of a child with a disability (2, 13-15). In these studies it was found that mothers face physical, emotional, social, and economical problems as well as many kinds of problems for their child like they face problems for taking care of their child, doing all household works with child, seeking care for child treatment and going outside of home with child. All these problems have a great impact on mother's life. In a study by Reeta Peshawaria, he found the following areas of impact for mothers of a child with a disability- physical care, health, career, support, financial, social, relationship, embarrassment, sibling effect. (16). Different studies show that mothers cope with their problems in these areas following some coping strategies (13, 14). Coping strategies used by mothers were different due to the following factors poverty, mother's educational background, external and internal resources (2, 13, 14). But using a right coping strategy is very important for mother. If mother can't cope with their problem then it will cause more stress and it will affect the mother's health as well as her child's health. So it is very important to use appropriate coping strategies in an appropriate situation to help the mother with her problems.

In Bangladesh there are also many studies about mothers of child with CP such as problems and difficulties faced by mothers of children with CP, their stress level, their reasons for stress etc (17-19) . But in Bangladesh there is no significant study about how the mothers of child with CP cope with their problems. This paper explores the coping strategies of mothers of children with CP.

1.3. Significance of the study

The mother of a child with cerebral palsy is like a co-therapist for their child and plays an important role in getting a better prognosis for their child. But Mothers face many problems in their life for their child with CP which may cause stress among the mothers. So coping with the problems is very important for the mothers because if mother cannot cope with problems then they cannot take proper care of their child and child will not get the proper chance to improve their condition. Mothers try to cope with their problems in their own way. But different mother use different coping strategy in their situation. So for improving quality of life of mother and their children it is important to know how mother cope in their everyday life.

In occupational therapy, occupational therapists practice family centered intervention for the children. So Occupational therapists have an important role on mother's health. Many mothers may complain to therapist many kinds of problems they have face in their everyday life for their child and continuing their child treatment. So it is important to educate the mother about how can they overcome and cope with their problems. So if it was known that how mother cope with their problems then it helps the occupational therapist to learn about coping procedure of mothers and it helps therapist while treating other mother who have same problems. Therapist can also use other researches such as journal and books to learn helpful coping strategies and teach these to mothers.

By this study occupational therapist, children with cerebral palsy and their mothers will benefit. Mothers of children with CP will be able to improve their quality of life and will be encouraged to continue their child's treatment. And by educating mother about coping skill occupational therapist will also be able to provide better service for the children with cerebral palsy.

1.4. Aim of the study

To identify the coping strategies of mothers of children with cerebral palsy with problems in relationships and social life

1.5. Objectives of the study

1. To find out the problems with mothers of children with CP in the relationship with their family members and other persons
2. To find out the problems with mothers of children with CP in their social life
3. To know how mothers cope with the problems in their relationships
4. To know how mothers cope with the problems in their social lives

1.6. Literature review

1.6.1. Cerebral palsy:

Cerebral palsy (CP) is one of the most common congenital (existing before birth or at birth) disorders of childhood. It is a disorder that affects muscle tone, movement, and motor skills (the ability to move in a coordinated and purposeful way). This disorder can also lead to other health issues, including vision, hearing, and speech problems, and learning disabilities (20).

CP is usually caused by brain damage that occurs before or during a child's birth, or during the first 3 to 5 years of a child's life. There is no cure for CP, but treatment, therapy, special equipment, and, in some cases, surgery can help a child who is living with the condition (20). The injury and damage to the brain is permanent in cerebral palsy. The brain does not "heal" as other parts of the body might. Because of this, the cerebral palsy itself will not change for better or worse during a person's lifetime. On the other hand, associative conditions may improve or worsen over time. The effects of cerebral palsy are long-term, not temporary. An individual diagnosed with cerebral palsy will have the condition for their entire life (21).

Cerebral palsy affects muscle control and coordination, so even simple movements like standing still are difficult. Other vital functions that also involve motor skills and muscles such as breathing, bladder and bowel control, eating and learning may also be affected when a child has CP (20). So children with cerebral palsy need extra care and support from their family. But behavior of child and burden of everyday caregiving of child create many problems of mother in their daily living activities (17).

1.6.2. Problems of mother for having child with Cerebral Palsy:

When a child has functional impairment and needs long term support or is dependent on parents then the parents face more challenges when providing care for their child (10). Mothers have the greater responsibility for daily care of their children so face more challenges and face with more child care related stress than fathers (2). Having a child with cerebral palsy mother experiences physical, emotional and social suffering (12, 13, 22).

The burden of everyday caregiving and the increased care demands of the child creates physical pressure on mother(13). Family members of some mothers are unwilling to be involved in providing care for the child with a disability. Some fathers also believed that caring is not their primary role and their wife is solely responsible for caring for their child and all caregiving responsibilities alone. The increased physical care needs of her child as well as having to complete all domestic responsibilities result in physical strain of mothers (12, 13).

Mothers face problems emotionally when they don't get proper health and education service for their child. A lack of information and services are contributing factor to the emotional stress experienced by mothers. (10). Mother felt frustrated and powerless when they tried to integrate therapy into their daily life at home but didn't see any progress in their child due to not being able to implement therapy on their child properly. Their children would cry and display a lack of motivation to actively engage in treatment programs so stress was increase among the mother (12). Children with disability like cerebral palsy, need extra care and extra services like food, clothing, hospital charges, transport, schooling, and assistive devices such as wheelchairs etc. Lack of fund for these services or poverty is a contributing factor for mothers stress (13).

In many cases when a child has cerebral palsy the family members or relatives of mother and community people view mothers negatively. They were blamed for their child disability and many people regarded it as a punishment of mothers. Mother also faces problems when admitting her child at school. Mothers felt powerless and frustrated when their child was the victim of personal prejudice, and when their child faces difficulty with their peer group (12).

All these problems and experiences impact on the mother's life. When caring for a child with cerebral palsy, mothers do not get enough time to fulfill other roles in the family. It also creates extra pressure on the mothers' physical health and creates poor relationships with family members. Caring for their child also restricts spontaneity of mother which limits everyday activities of mother and in many ways disconnects mothers from their community (9-11). This information shows that child with a disability has a great impact on mother.

1.6.3. Impact of having a cerebral palsy child on the relationship of mothers:

The term 'relationship' is rooted from the word 'relation' and is defined as a mutual affiliation or connection between individuals or groups of people or entities (23). A relationship is a connection between two or more people or entities by affinity or kinship who share common connections, ideas, interest, feelings, beliefs and the like (24). Relationships are highly special and valuable and are necessary as human are social beings and do not live in isolation or vacuums and are interdependent on one another for many things (24). Relationships are associated with life and living, man/woman is inherently a social animal and relationships are most important to him/her and he/she cannot live normally outside of a web of relationships. No one can exist without at least one relationship (25). Relationships can be family relationships between husband and wife, brother and sister etc. (26).

A significant issue for the mothers of children with cerebral palsy is poor relationships with parent-in-law and husband because many of them thought that giving birth to a child with CP can bring social stigma and shame (12). Mothers felt hurt, helpless and powerless when their children were marginalized because of their disability, there was great distress when parents-in-law believed that the child caused them to lose face and placed a burden on the entire family. In most cases mother was only responsible for caring their child so mother was left to bear all caregiving responsibilities alone (13). Maintaining a balance between different roles created tensions of mother and balancing the role as caregiver for providing home therapy and the role as a parent created damage on family relationship (12). In some cases the mother was blamed for their child's disability and it was regarded as women's punishment from their relatives. Negative attitudes of relatives and members of the community towards the mother also create poor relationship between mother and their relatives (10).

1.6.4. Impact of having a cerebral palsy child on the social life of mothers:

A social life is the time people spend outside their own life, inside other peoples. People mostly have a social life during weekend when they have finished their routine jobs. Social life is also what people celebrate, what they eat, what kind of music they

listen to, etc. (27). It combines various components: activities, people, and places. While all of those components are required to define a social life, the nature of each component is different for every person, and can change for each person, as affected by a variety of external influences (28).

The term social refers to a characteristic of living organisms. It always refers to the interaction of organisms with other organisms and to their collective co-existence. So social life is not something planned. It could be considered to be anytime we have interacting with other people in our lives. That can be at work, on the bus, buying sandwiches for lunch, at any events we go as well as social events (28).

Mothers of children with a disability have additional caregiving responsibilities but receive little additional support from their husband or from extended members of the family (10). So caring for child restrict spontaneity of mother and this lack of spontaneity limits everyday activities of mother and in many ways disconnects mothers from their community. In many instances mothers have intentionally restricted their social interactions in order to meet caregiving demands (15). Mothers also recognized the wider community often identify them negatively and were stigmatized and blamed for having a child with a disability (10). Some members of the community still believe that children with disabilities are shameful or embarrassing to the family and should be hidden from other people. In some cases children are abused by peers. These attitudes result in children being isolated from others (13). When mothers go outside the home with their child the attitude of others harm their dignity so mothers withdraw from social engagements (12).

1.6.5. Coping of mothers with the problems for their cerebral palsy child:

Coping with the problems that arise from having a child with disabilities is a highly individual process and there is evidence to suggest that some families and mothers may never adjust fully to this event (29). Coping has been defined as problem solving efforts made by an individual when the demand of a given situation taxes adaptive resources (2). Coping includes the cognitive and behavioral effort to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the individual (2). To cope, families or mothers use their existing resources and strategies (14).

Coping strategies are defined as the active process and behaviors that someone actually tries to employ to help them to manage, adapt to or deal with a stressful situation (14). Coping strategies can be divided into two main kinds: problem-focused coping strategies and emotion-focused coping strategies (30). Problem-focused coping strategies are used to tackle the problem directly. They involve managing the source of stress by confronting the problems, generating strategies and remobilizing resources. So they also regarded as positive coping in a general sense (15). Emotion-focused coping strategies are used to handle feelings of distress, rather than the actual problem. Emotion-focused coping aims to change a person's negative emotional state. This usually involves ventilation, displacement, rejection, indifference and so on. Since it does not target the problem itself, emotion-focused coping is also known as avoidance coping and negative coping (15).

The aim of familial coping is to maintain the balance between the demand and resources (31). Families can do this by reducing the number of demands such as a mother can leave her job to be able to take care of her child or by acquiring additional resources such as by gathering new information on the child's disability (14). Hartley quoted Porter and Mckenzie's words in his research (13), "the way families respond to and cope with disability depends on four issues, internal and external resources, support, their own goals for their children and the local culture". Internal resources include personality characteristics, energy and self-determination. External resources include support from the extended family and community and government programs (32).

In different research it was found that mothers use different types of coping strategies in their everyday life with their child (2, 13, 14). Burr & Klein studied and classified a large number of coping strategies and some researcher (13, 14) showed that classification in their study. In different study about coping, researchers compare their result with this classification or use it as a preliminary framework for their study (13, 14). Burr & Klein's classification or conceptual framework of coping strategies is given bellow:

Table-1: The conceptual framework of coping strategies by Burr & Klein

Highly abstract strategies	Moderately abstract article
Cognitive	<ul style="list-style-type: none">○ Be accepting the situation and others.○ Gain useful knowledge.○ Change how the situation is viewed or defined (reframe the situation).
Emotional	<ul style="list-style-type: none">○ Express feelings and affection.○ Avoid or resolve negative feelings disabling expressions of emotions.○ Be sensitive to other's emotional needs.
Relationship	<ul style="list-style-type: none">○ Increase cohesion (togetherness).○ Increase adaptability.○ Develop increased trust.○ Increase co-operation.○ Increase tolerance of each other.
Communication	<ul style="list-style-type: none">○ Be open and honest.○ Listen to each other.○ Be sensitive to non-verbal communication.
Community	<ul style="list-style-type: none">○ Seek help and support from others.○ Fulfill expectations in organizations.
Spiritual	<ul style="list-style-type: none">○ Be more involved in religious activities.○ Increase faith or seek help from god.
Individual development	<ul style="list-style-type: none">○ Develop autonomy, independence and self-sufficiency.○ Keep active in hobbies.

Coping strategies used by mother are differ from one another. The ability of mothers to cope is influenced by several factors such as child behavior, caregiving demand and family functioning (10). Many parents felt that a realistic outlook of the child's disability and acceptance of the situation had helped them to cope. Gaining useful knowledge and adequate information are important determinants of parental coping. Some mothers gain enough knowledge about her child's diagnosis which is a positive coping strategy for them (14). This is also an example of problem focused coping

strategy which are associated with the educational background and age of the mothers (2).

The most frequently used coping strategies by the parents or mother are: information and acceptance, good family co-operation and social support (14). Adequate information about the child's condition is also very important for coping of mother. A realistic outlook of the child's condition, acceptance of the situation and involving the child in domestic cores and family activities help the parents to cope with their children (13, 14). In most cases it was found that mother can cope with their problems for good family co-operation and support. For physical challenges mothers seek help from alternative care providers such as family members, friends or neighbor to maintain a balance of her everyday activities and reduce pressure. So being together, doing things together and family cohesion increase the ability of coping of mothers (14, 33). Support is also a key factor for coping of mothers which may be social support and physical or material support. Mothers exchanging their experience with other parents who have a child with a similar disability, take adaptive training courses from different hospitals, make assistive device such as parallel bars, special seats etc find it very rewarding (13, 14). Emotional activities such as getting rest and relaxation from the everyday duties or open expression of feelings are also helpful in the coping process (14). For mothers who work out of the home, use different strategies such as select their hours of work so that her family members can look after her child or beg for private care. Mothers who works full time hours, they relied heavily on praying for extra help privately but it was possible when they have large financial support (33).

Coping strategies used by parents differ for different reasons such as parents' initial experiences, parents' attitudes and personal characteristics, parent's participation in their child's care and housework and parents' experiences of social support (14). For example, Taanila quoted Willoughby word in his research (14) that if the family members are supportive or spouse relationship is good, the spouse can help each other by giving love, support and understanding to each other. But if it is poor, a child disability created more difficulties in the family and inhibits coping of mothers.

2.1. Study design

The study aim was to find out the problems of mothers with children with cerebral palsy and the coping strategies they use in their social life and relationships. Qualitative methodology was selected for this study because it is exploratory in nature by which the researcher can gain insights into another person's views, opinion, feelings, and beliefs within their own natural setting (34). Qualitative research aims to describe the experience of people in particular settings and to understand their perspectives (35). Qualitative research methods and designs are also helpful to health professionals to gain a holistic overview of the context being researched (36). So researcher used this method and researcher used qualitative content analysis under the qualitative methodology. Qualitative content analysis is a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes (37).

How individual create and understand their daily lives, how people see and describe the world in which they live was the focus of this study and researcher wants to explore the problems mothers experience in their life and want to identify how they cope with their problems so qualitative content analysis was used as study design of this study.

2.2. Study setting

The study area for this study was paediatric unit of the Centre for the Rehabilitation of the Paralyzed (CRP). This setting was chosen for study area because many children with cerebral palsy go there with their mothers to receive treatment. As participants were gotten in that setting who fulfilled the aims of the study so paediatric unit of CRP was selected for the study site.

2.3. Study Participant

The participants were the mothers (6 mothers) of children who have cerebral palsy and who are taking treatment from the pediatric unit of CRP at Savar.

2.3.1. Inclusion criteria

1. Mothers of children with CP
2. Mothers who's child's Age rang is between 2-7 years
3. Mothers who's Child need full time assistance/care
4. Mothers who are the primary caregiver of her child
5. Mothers who are willing to share information with resaercher

2.3.2. Participant selection procedure

Purposive sampling procedure was used for participant selection. Qualitative research most often uses purposive sampling rather than random sampling strategies (38). Purposive sampling involves identifying participants who are most likely to provide relevant information that addresses the objectives of the study (22). For qualitative methodology a small number of participants are appropriate. This small number of participants provides a representative picture of the study (39). So a small number of target participants were selected and 6 mothers purposively selected as the participants of the study according to the above mentioned criteria.

2.4. Field Test

Before starting data collection a field test was conducted with two participants. A field test was necessary to help to refine the data collection plan. The field test's function is to ensure that the research instruments are workable and acceptable to the participants and manageable (40). From the field test the researcher became aware about which parts the participants found difficult to understand. Participant's interviewed data was not analyzed because time was limited. The situation of the interview, participants' responses were only generalized, and considered whether the data collection was going in the right way. The answers that came out from these selected questions helped to modify the questions where necessary. This also helped to structure the questionnaire.

2.5. Ethical consideration

To conduct the research some ethical consideration were maintained to avoid ethical problems. During the study period following issues was considered:

- Permission was taken from Bangladesh Health Professions Institute (BHPI) an academic institute of Centre for the Rehabilitation of the Paralyzed (CRP) to conduct the research.
- Permission was taken from the in-charge of pediatric unit of CRP to collect data from that unit.
- All participants were informed about aim, objective and significant of the study.
- Consent from all participants was taken by signing in a written consent form.
- All participants were informed that their information will be kept strictly confidentially and will not expose their identity.
- It was clearly explained to the participants that the interview was recorded by audio tape recorder and information was written on the form.
- Participants had full right to withdraw themselves from the study at any time without hesitation.
- The researcher was available to answer any study related questions or inquiries from the participants.
- All sources used in the study were cited and acknowledged appropriately.

2.6. Data collection tools/materials

The data was collected using in-depth interviews with a semi-structure questionnaire. For this a questionnaire was developed based on the study objectives. Questionnaire utilized open ended questions based on the ‘relationship’ and ‘social’ settings of the NIMH Disability Impact scale. The NIMH Disability Impact Scale is made of 11 section, each section has questions that are recorded on a scale to explore the impact of disability on children with mental illness (16). In a study of Kishore (15) it was found that this was a relevant scale to use for children with CP also. Although the NIMH Scale was not used in it’s pure form for this study, due to it’s use with children with CP and its focus on impact of disability, it was considered a relevant source to

base interview questions for this study. For collecting data some other materials were also used. Tools or materials that was used for data collection are-

- ❖ Semi-structure open ended questionnaire
- ❖ Mobile tap-recorder
- ❖ Paper
- ❖ Pen
- ❖ Clip board
- ❖ Consent form

2.7. Data collection procedure

To collect the data, permission was taken from the incharge of the pediatric unit of CRP. Then data was collected from mothers at the inpatient pediatric unit of CRP. Researcher used the room where the mothers stayed for collecting data. Semi-structure face to face interview was conducted to collect information from mothers. Face to face interview was helpful to build rapport with participants and help participants to feel more freedom to explain their feelings more easily. Open-ended question with semi-structure interview was also used. Open-ended questionnaire are most useful in dealing with complicated information when slight differences of opinions are important to know (36).

Before collecting data consent form was provided to the participants. The aim and objectives of the research was also explained to the participants. Rapport was build with the participants to promote their trust so that they feel comfortable to speak in detail without hiding the truth. It was very important as the participants may feel uneasy to share some sensitive issues and express their feelings and views or may hide the truth. Without building trust and freedom participants would not express their personal matters (36). During the interview session, the researcher also ensured that environment was quiet and participants felt comfortable. The interviews were conducted in Bengali so that participants could understand easily. All the interviews and discussions were recorded on a mobile tape-recorder as it is too difficult to write all questions in detail at the interview time. The researcher also used diary and pen to document the expressions of participants.

2.8. Data analysis

Qualitative content analysis was used to analyze the data. In this type of analysis coding, categories are derived from the text data (37). Qualitative content analysis facilitates contextual meaning in text through the development of emergent themes derived from textual data. (41). According to Stemler (42), content analysis has been defined as a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding. The first step of coding involve reading the text several times (43). Coding began through line by line analysis where phrases, sentences or whole sections are posted into particular analytic categories. Categories are established to support the generation of ideas and a similar piece of code or idea fell into a particular category (41). Then third level of analysis establishes core themes within each main category (43).

In the first step of analysis the whole interviews were transcribed in Bangla from mobile tape-recorder. Then the Bengali transcript was translated into English. Two copies of data was completed where one set is translated by own and another set of data translated by the volunteer group. The accuracy of two data sets was verified by matching both English and Bangla transcription. After that it was read several times to find out what the participants actually want to say. Then the data was organized according to each interview question. Then each participant's answer was analyzed to find out some coding. From these coding some major categories were made. The codes were organized in table and were indicated according to participant's response. The category was developed in relation to the objectives of the study. Following this process five categories from twelve questions were found out. Finally the major and minor codes were detected from the table of categories according to each participant's response. After that the most important codes were identified that come out from the maximum number of participant's response and these were the themes which reflect the findings of the study.

The result and discussion are presented together in this study. Literature also supported in this regards. The result and discussion were presented together in this section because this is common practice in reporting on qualitative studies (44). This chapter represents the findings of the study in combination with participants' perspective and interpretations with the literature support. So, all interviews and transcripts are studied several times to find out the codes and categories to discover the themes. Researcher determined some categories from completed data analysis.

3.1. Themes of the study

Theme-1: For having a disable child most of the mother faces problems in their relationship with their in-laws which is mostly due to spending extra money in childcare.

Theme-2: Mothers face problems to maintain social and community participation mostly due to negative talking by the society people about their child condition.

Theme-3: Mothers of children with cerebral palsy choose praying to Allah to cope with their relationship problems and also use other techniques as coping strategies such as expressing feelings, trying to solve problems, seeking cure and staying away from problems.

Theme-4: Most of the cases mothers of children with cerebral palsy choose the acceptance of their luck as coping strategy for the problems of their social life.

Table-2: Overview of data analysis and result

Objectives	Questions	Themes	Categories
Objective-1: To find out the problems with mothers of cerebral palsy children in the relationship with their family members and other persons	1, 3, 5, 7	Theme-1: For having a disable child most of the mother faces problems in their relationship with their in-laws which is mostly due to spending extra money in childcare.	Category-1: Problems with mothers of child with cerebral palsy with familial and social relationships Category-2: Reason for problems in the relationship of mothers
Objective-2: To find out the problems with mothers of cerebral palsy children in their social life	9,11	Theme-2: Mothers face problems to maintain social and community participation mostly due to negative talking by the society people about their child condition.	Category-3: Problems of mother with her social life
Objective-3: To know how mother cope with the problems in their relationships	2,4,6,8	Theme-3: Mothers of children with cerebral palsy choose praying to Allah to cope with their relationship problems and also use other techniques as coping strategies such as expressing feelings, trying to solve problems, seeking cure and staying away from problems.	Category-4: Coping strategy by the mother for the problems with her relationships
Objective-4: To know how mothers cope with the problems in social life	10,12	Theme-4: Most of the cases mothers of children with cerebral palsy choose the acceptance of their luck as coping strategy for the problems of their social life.	Category-5: Coping strategy by the mother for the problems with her social life

3.2. Discussion

At each table interview findings were described with coding. Under the different categories mothers' different opinion is different codes. The tick was given only for those columns where the mothers spoke about those issues. Here 'P' was used for participant and 1, 2, 3.... indicate participant's number.

3.2.1. Category-1: Problems with mothers of child with cerebral palsy with familial and social relationships

Disability in a child affects not only child's life but also the family life. A mother of a child with disability faces many kinds of problems that affect a mother's relationship with family members and other persons. In this study most mothers came from a joint family (see appendix-6) and said that they face problem for their child in their relationship with their in-laws (see table-3) including father-in-law, mother-in-law, sister-in-law etc.

Table-3: Problems with mothers of child with cerebral palsy

Coding	P-1	P-2	P-3	P-4	P-5	P-6
Problems with In-laws	√	√	√	√	√	√
Problems with Relatives	√	√		√	√	
Problems with Husband		√		√	√	
Problems with Neighbor		√		√		√

Most of the mothers said-

"I have many kinds of problems with my in-law. My father-in-law, sister-in-law, everybody think me as a bad woman. They think that as I am bad so my child was disabled. Their thinking is my child will remain in this condition forever, she never could walk. They talked with me in bad language and saw me as a bad person."

In a study it was found that mother felt hurt and powerless when their parents-in-laws believed that the disable child caused them to go down face and placed a burden on

the entire family. So there has a poor relationship with mothers and their parents-in-laws (12).

Some mothers told about their husband (table-3). One of the mothers said that-

“I have problem with my husband. He was not interested to take child but I took so after having a disable child he tortured to me.”

Literature showed that giving birth to a child with cerebral palsy brings social stigma, same and disgrace to a family. For this reason there created a poor relationship with mother of cerebral palsy child with their husband (12).

Some mothers also told about the problems with their relatives and neighbor. They mentioned that for having a child with CP they had poor impact on the relationship with their neighbor.

3.2.2. Category-2: Reason for problems in the relationship of mothers

Problems of mothers in the relationship arise in many ways. When a child was disabled, a lot of money was spent behind the child and it created many kinds of problems among mothers. As most mothers live in a joint family and their family monthly income are 6000-12000TK (see appendix-6), economical conditions play an important role which creates problems among the family. Most of the mothers (see table-4) said that for spending extra money due to childcare and child treatment there created many problems in their family. One mother said that-

“My mother-in-law said that the amounts which were spend for this child, we can eat easily by that amount of money. As there was spend so much money for my child treatment so they also told me many things. Every time they told that they have problem to manage the cost of family.”

In a study of Hartley it was found (13) that lot of money is spent by many families in seeking a cure for their child disability. For a child with disability they need extra money. They need money for basic necessity of child such as food and clothing and they need money for hospital charge, assistive device etc. So it was an extra burden for a family and for this reason there created negative relationship among the family members.

Table-4: Reason for problems in the relationship of mothers

Coding	P-1	P-2	P-3	P-4	P-5	P-6
Spending extra money for childcare	√	√	√	√	√	
Blaming mother as a reason for child with disability	√	√	√			√
Not getting support with household works as well as child caregiving	√					√
Bad behavior by in-laws			√	√		
Force by husband or in-laws to leave husband's house for the child	√				√	
Negative talking indicating mother for having disable child by neighbor		√			√	
Husband leaving because child has a disability				√		
Bad behavior by relatives due to child toileting		√				

Some mothers mentioned about blaming themselves. One mother said that-

“She blamed me because she thinks I was responsible for everything of my child. My daughter was born in my parent's house. For this reason she blamed that as the child was born in our house so she was like us.”

Huang showed in his research (12) that in some families mother was blamed for their child disability by their family members. Family members or husband of mother also thought that mother was responsible for their child's disability. Another study also showed that mother frequently expressed that they were blamed for their child disability and it was regarded as women's punishment from their relatives (10).

Two mothers mentioned about getting no support from family members (table-4). One mother said that-

“They didn't help me by giving any kind of support or didn't assist me in my child caregiving like bathing, feeding or by taking the child for a while. However if my

mother-in-law help me and understand my problems then it will be better. But she can't accept this anyway for the child."

It was also supported by the literature that some father believed that caring was not their primary role and their wife was only responsible for caring their child (13). In the research of Huang also found (12) that family members of some mothers didn't help mothers by assisting her in child care for the child with a disability. So mothers have to work all tasks alone including child care and other family tasks. But in another study it was found that grandparents gave support to parents caring for disabled child and this presented a basis for developing a close relationship (45). Another study of Glasscock also found (46) that caregiving help from their husband allowed them to have more time and energy to provide care for their child. So assisting by family members and relationship with mothers are vary in family to family.

Two mothers also mentioned about bad behavior by their in-laws for having a child with disability. One mother said that-

"When I stayed in my father-in-law house, everybody including my sister-in-law behave with me very bad. They didn't like me for my child. They told me many kinds of negative words."

As in some family parents-in-laws and other members believed that the disable child caused them to lose face and placed a burden on the entire family so they don't behave well with the child's mother (12). They don't provide any support to the mother and they torture mother in many ways by talking negative thing or by bad behavior.

Some mothers mentioned that for having disabled their parents-in-law and their husband don't want that she stayed at their house and forces the mother to leave the house (table-4). One mother said-

"I have to do extra works for my child like washing my child clothes so I cannot work other works of family in timely. So everybody was angry with me. They said to me to go away from their family."

Another two mothers also mentioned about another two problems in their interview. In few cases it was found that husbands go away leaving the mother for having disabled child and some relatives of mothers also feel boring when mothers go to their house with their child as the child can't express their needs and do toilet anywhere.

3.2.3. Category-3: Problems of mother with her social life

Mothers of children with cerebral palsy have to face some social suffering. Some mothers expressed negative attitude of society people toward them (see table-5). One of the mothers said-

“If I went any function with my child, I have problems to adjust with society people. Everybody told me that my child is disabled. Everybody told me bad. Then I felt bad in my mind.”

It was also supported by literature that the community people often identified mothers negatively and mothers were stigmatized and blamed for having a child with disability (10). When mothers go outside of their house, such kind of negative attitude and negative talking hurt the mothers. So mothers try to avoid that place and these persons. By this way mothers' social interactions were decreased and they are left behind from social activities.

Table-5: Problems of mother with her social life

Coding	P-1	P-2	P-3	P-4	P-5	P-6
Negative talking by society people about child with disability		√		√		√
Getting no permission by father-in-law and mother-in-law to go social functions for child with disability		√			√	
Not getting enough time for interaction in social works due to hard working			√		√	
Difficulties in child caretaking at different social functions			√	√		

Two mothers mentioned that they don't get permission to go any function by their family members for her disabled child. One of the mothers said-

"My father-in-law and mother-in-law also didn't give me permission for going anywhere."

Literature showed that some family members like parents-in-law of mothers of cerebral palsy child think that a disabled child can bring social stigma and shame to their family. So they want to hide their children from society (12). They don't want that the disabled child is familiar with other peoples and their mother go outside with her child.

Two mothers mentioned about time management (table-5). One mother said that-

"I have to work all tasks with my child so I didn't get time for mine." Another mother said that- Many times I felt restriction for different recreational activities. Whole day I have to pass time to her. I have many tensions for her. I don't get any time to rest myself. Every time I was in tension and hard working. I have to spend whole time behind her.

In the literature it was found that mothers get little additional support from their husband and from extended number of the family for the care of child with disabilities and household activities. For this many mother were often confined to the home and restricted in social and community activities (10, 13).

Two mothers mentioned that if they went in different social functions then they have problems and their child's has also problems as mother don't get proper opportunity to take care of her child in those settings. One of the mothers said-

"If I went with my child then she had problems. I had also problems. Different people said different comments by seeing my child. So I felt hurt. As my child cannot walk, sit and speak so I don't go anywhere with my child."

Literature showed that the poor design of public facilities affected the disabled child's involvement outside of home. Mothers also felt powerless and frustrated when their disabled child was the victim of personal prejudice and had difficulty to relate with their peers. For these entire reasons mother withdraw themselves from further social engagement (12).

3.2.4. Category-4: Coping strategy by the mother for the problems with her relationships

Mothers of children with cerebral palsy cope with their problems in many ways. The coping strategies used by mothers differ for some factors. Some studies showed that level of education and age are significant factors in parental coping (47, 48). Problem solving coping strategies are associated with age and educational background.

Table-6: Coping strategy by the mother for the problems in the relationships

Coding	P-1	P-2	P-3	P-4	P-5	P-6
Prayed to Allah by crying			√		√	√
Expressing feelings to husband		√	√			
Try to solve problems by trying others to understand				√	√	
Seeking for help from mother-in-law					√	√
Avoid the person who talk negatively		√		√		
Try for treatment to improve child condition	√					√
Take economical support from parents					√	
Taking support from neighbor					√	
Consoling own self thinking as a bad luck	√					
Stayed separately with husband for the problems with other persons	√					
Stayed at father's house for problem with husband				√		
To be independent by self working				√		

In this study mothers educational level is up to S.S.C and most of cases their age is 21-24 years (see appendix-6). As the mother's educational level was not so high so most of the cases mothers of children with CP don't search information to gain knowledge about their child condition and keep beliefs in their mind that God can do everything. So they choose praying to Allah to cope with their problems in their relationship. Most of the mother said that-

“I have cried. I have prayed to Allah by crying.”

In a study by Heaman it was found (2) that praying is a frequently used coping strategy by parents of children with disabilities. The largest number of mothers uses prayer as a positive reappraisal approach which is an emotion-focused form of coping.

Two mothers mentioned about feeling expression to their husband (table-6). One mother said that-

“I told everything to my husband. My husband told me ‘be patient, everybody will tell you but you should manage it’.”

It was also supported by the literature that open expression of feelings and affections was considered helpful in the coping process (14). By sharing the problems and feelings mothers get a bit of relax from everyday stress. Literature also found that if the marital relationship is good then spouse can help each other by giving support and understanding to each other (14). So mother chooses their husband to express their feeling and problems and it was helpful to reduce their stress.

Two mothers mentioned that they try to solve their problems by trying others to understand. They also seek help from their family members (table-6) to finish their task so that there will not be created any problems with them about the tasks. One mother said that-

“I tried my mother-in-law to understand her by saying that God give me such kind of child, if you treat her then she will be well.”

Another mother said that-

“When my father-in-law was not present at home, my mother-in-law helped me in my task..... Then my mother-in-law has supported me and she tries to be understandable to my father-in-law.”

Taanila showed in his research (14) that good family co-operation is an important coping strategy for mother of children with disabilities. Being together, doing things together is very important for mothers coping. So mother tries to improve the cohesion and togetherness among the family members. For this mother try to

understands the family members to realize their wrong thinking about the child and try to improve family co-operation.

Some mothers stay away from their neighbor and relatives who behave badly with mothers for their child. They mentioned that they avoid the person and place where they feel uncomfortable. One mother said that-

“I had no interest to go to my relative house. I stayed in my home. I didn’t go anywhere.”

One mother mentioned about taking support from parents and neighbor (table-6). Mother said that-

“My mother gives me money and I come here with that money. They gave money for treatment because I had quarreled with my father-in-law for money.”

In the study it was showed that support is a common key factor in carer’s coping strategy. The mothers of disabled child seek help and support from their relatives, friends or neighbor (13, 14). Support may be physical, material or economical support and it was regarded as essential for managing in everyday life of mothers. By this mothers can be able to cope with the experiences and challenges that are arises for a child with a disability.

One mother told about her bad luck and chooses staying separately with her husband for the problems with her in-laws members. Mother said that- *“I have bad luck so there are no benefits by talking anything. Then it was seen that I can’t stay at home so now I stay separately with my husband in another house.”*

Then another mother mentioned about staying at father’s house and working to be independent. Mother said that *“my father took me in my father house.”* She also said that- *“I kept my child to my mother and then I came to Dhaka and worked at a garment.”*

From mother’s interview it was seen that if the husband-wife relationship is good then mothers can get support from their husband for the problems in their in-laws house but if it was not good then they faces more problems and seek helps from their parents house.

3.2.5. Category-5: Coping strategy by the mothers for the problems with her social life

To cope with problems which are arisen in the social life of mothers of disabled child, mothers use almost the same coping strategy that they use for the problems of their relationship. But most of the mothers make a mind that as she has a disable child so problems may be arise in their life and they accept their luck (see table-7). One of the mothers said that-

“Every place where I go, I go with her. Though I had problems, I took her.”

In the literature it was found that a realistic outlook of the child’s disability and acceptance of the situation had helped the parents to cope them in their life. Parents keep a positive attitude toward their child future which made it easier to help them to accept the situation (14). So mother of children with disability kept in their mind that their child will be better in future and as now she is disabled so problems may be appeared. They thought it as their luck. So they tried to involve their child in different activities and they are mentally prepared to accept all situation.

Table-7: Coping strategy by the mothers for the problems in the social life

Coding	P-1	P-2	P-3	P-4	P-5	P-6
Acceptance of the luck		√	√	√	√	
Trying for treatment to improve child condition			√	√		√
Discussing with husband to solve the situation			√			
Seek out alternative way to finish household tasks					√	
Pray to Allah				√		
Taking support for household work by family members				√		

Three mothers mentioned about child’s treatment. They try for treatment of their child to improve child condition and to reduce their problems. One of the mothers said that-

“I have taken my son to this medical. I will continue my child treatment. My hope is my son can walk and sit and can speak by calling me mother.”

Literature showed that seeking a cure is one kind of coping strategy for the parents. Families of the disabled child try for treatment and seeking a cure from their child condition. Many parents developed the behavior of moving from one hospital or healer to another (13). So mother of a disable child try to treat their child for getting well thinking that if their child will get well then their problems will be minimize.

One mother mentioned that she discussed with her husband (table-7) and was inspired for child treatment by her husband and neighbor’s support. Mother said that-

“I discussed with my husband. I discussed about the treatment of my child with my husband. My neighbor also told me for not to be worried. They gave me support. My husband and neighbor inspired me to treat my child and not to be worried.”

In some cases mothers of disable child rearrange their daily routine and find out the alternative way to finish their household tasks. One mother said that-

“I know when my child sleeps so I try to finish my works in that time.”

The literature showed that mothers of disable child gradually learn to take care of her child and finds her to be able to cope. By this way mothers also get time for themselves and their hobbies (14). So mothers gradually understand the situation and they find out the way of working so that they can get time for themselves.

3.3. Limitations

As an undergraduate student, the researcher has faced several barriers during the study period. These barriers are written as the study limitation. At the beginning of the first research in life, researcher felt some limitation due to not utilize the times. To conduct the qualitative study it is needed to find out in-depth information. In this case the researcher requires high skills for conducting an interview and collecting valuable field notes. But it is the first time for the researcher to conduct this study as a part of 4th year course curriculum in occupational therapy department. So researcher's skill to conduct interview may influence to get in-depth information. But the researcher offered maximum effort to collect information and tried to collect information from participants without bias and analyzed that in a systematic way. Then another limitation is, the researcher conducted the interview in Bengali and then it was translated into English. Therefore there might be chance to alteration of the actual meaning of information given by the participants.

Therefore a limited study is conducted about mothers' coping strategy for their problems on Bangladeshi perspective, so there was limited information from books, Google search and journal about Bangladeshi mothers coping strategy with their problems. But researcher found several study on coping strategies of mothers on other countries of the world. So researcher uses their findings in her research.

4.1. Recommendation

After completing the research the researcher found some recommendation. The researcher took small number of participants for the study and find out some coping strategies of mother. Then researcher felt that if she took large numbers of participants, she can get more information and can generalize the data. So further studied should be conducted with large number of participants including with different age and different educational level of mothers. Further studies are also needed to find out how coping strategies are different from mother to mother in Bangladesh. From the study finding researcher found that mothers have many problems in their life for their child so mother came to receive treatment to improve their child condition and take it as a way to minimize their problems so therapist should take it in their mind and they should provide suggestion to the mother about their problems during intervention session.

4.2. Conclusion

The study has been conducted to find out the coping strategy of mother with the problems in their life. From the result of the study it was found that mother faces problems in their relationship with their parents-in-law and other in-laws members. They face problems in many ways, mainly for spending extra money for the child and for their child care-taking. It was also found that mother face problems socially for their child because society people see mother negatively and talk negatively. On the other hand mothers also don't get time to spend outside of their home for their child. So mothers face so many problems for their child. But as there were problems, there was also solution. So mother tries to manage their problems. Different mother manage their problems in different way. To cope with the problems mothers use different techniques or coping strategies in their situation. From the study it was found that for the problems in the relationship mother chooses praying to Allah for coping and try to

solve problems by increasing cohesiveness among the family members. On the other hand for the problems in the social life most of the mother accept their luck and try for treatment of their child so that their child will be well because if their child will well then their problems for their child will be reduced.

To know the coping strategy of mother is very important. By recognizing the coping strategies used by the mother, professionals and service providers can find suitable ways to support the mothers. So the findings of the study will help the occupational therapist to provide an effective intervention to the child with cerebral palsy. Occupational therapist can suggest that strategies to mothers who need during the intervention session or therapist will find-out the better way of coping for the mother as mother has an important role in their child treatment.

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Appendix

Appendix-1 (Approval Letter)

Date: 23.10.2012

To

The Course Coordinator,
Department of Occupational Therapy
Bangladesh Health Professions Institute
CRP, Savar, Dhaka.

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

Sir,

I beg most respectfully to state that, I am a student of 4th year B.Sc. in Occupational Therapy of Bangladesh Health Professions Institute (BHPI). I am seeking permission to conduct the research project as a part of my 4th year course module. My research title is "Coping with mothers of cerebral palsy children with the problems in the relationship and social life". The aim of the study is to identify the coping strategy of mother of cerebral palsy children with the problems in the relationship and in their social life. Now I am looking for your kind approval to start my research project and I would like to assure that anything of my project will not be harmful for the participants.

I therefore pray and hope that you would be kind enough to give me the permission of conducting the research.

Yours obediently

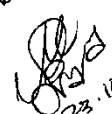
Sarmin Akter

Sarmin Akter

4th year, B.Sc. in Occupational Therapy,

Department of Occupational Therapy

BHPI, CRP, Savar, Dhaka.

Approved by	Signature & comments
Course Coordinator and Supervisor: Mohammad Mosayed Ullah Assistant Professor & Course Coordinator Dept. of Occupational Therapy Bangladesh Health Professions Institute CRP-Chapain, Savar, Dhaka- 1343.	<i>Good luck with the project All due permission needs to be taken. Respective authorities are requested to support her.</i>  23.10.2012

Appendix-2 (Permission Letter)

Date: 18.12.2012
To
The In-Charge
Paediatric Unit
Centre for the Rehabilitation of the Paralyzed (CRP)
Chapain, Savar, Dhaka-1343

Subject: Prayer for seeking permission to collect data from pediatric unit, CRP.

Madam,

I beg most respectfully to state that, I am a student of 4th year occupational therapy department of Bangladesh Health Professions Institute (BHPI). I am interested to conduct a qualitative study on paediatric unit. My research title is "Coping of mothers of cerebral palsy children with the problems in the relationships and social life." The aim of the study is to identify the coping strategy of mother of cerebral palsy children with the problems in the relationship and in their social life. Mothers of children with cerebral palsy who are admitted in pediatric unit of CRP are the participants of my research project. Now I am looking for your kind approval to start my data collection and I would like to assure that anything of my research period will not be harmful for the participants and also for the pediatric unit. Informed consent will be filled up by the mother for their ethical consideration.

So, I therefore, pray and hope that you would be kind enough to grant me the permission of collecting the data and will help me to conduct a successful study as a part of my course.

I remain madam,

Sarmin Akter

4th year, B. Sc. in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, Savar, Dhaka-1343

*She is permitted for
data collection. please
help her.*

Thanks
HOSNEARA ~~POORVEEN~~
Incharge Paediatric Unit
Chapain, Dhaka

18-12-12

Appendix-3A (Information Sheet)

I am Sarmin Akter, a final year student of the Occupational Therapy Department in Bangladesh Health Profession Institute (BHPI) the academic institute of CRP. I am continuing the B.Sc. course in Occupational Therapy. In 4th year of study it is mandatory to conduct a research under the research subject to pass the B.Sc. course. I would like to invite you to take part in the research study, titled “Coping with mothers of cerebral palsy children with the problems in the relationships and social life”. The aim of the study is to identify the coping strategy of mother of cerebral palsy children with the problems in the relationships and in their social life.

Your participation in this study is voluntary. You have full right to withdraw yourself from the study at any time without hesitation. Participation in this study might not benefit you and your child directly. It is mentioned that you will not be paid for your participation.

For the study purpose your answer will be tap recorded. It is important to inform you that confidentiality of all records will be highly maintained. Your name, your child name or any type of name identification indicator will not address in this research without your permission.

If you have any query now or later about the study, please feel free to ask the person stated below

Sarmin Akter
4th year student
B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute
CRP, Savar, Dhaka

Appendix-3B (Information Sheet-Translated)

তথ্য পত্র

আমি শারমিন আক্তার, পক্ষঘাতহস্তদের পুনর্বাসন কেন্দ্রের শিক্ষা-সংক্রান্ত প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট এর অকুপেশনাল থেরাপি বিভাগের ৪র্থ বর্ষের ছাত্রী। আমি অকুপেশনাল থেরাপিতে বি.এস.সি কোর্স করছি। বি.এস.সি কোর্সটিতে পাশ করার জন্য ৪র্থ বর্ষে একটি গবেষণা করতে হয়। আমি আপনাকে এই গবেষণায় অংশগ্রহন করার জন্য অনুরোধ করছি যার শিরোনাম “সামাজিক জীবন এবং অন্যান্য লোকজনের সাথে সম্পর্কের মাঝে সমস্যাগুলোর সাথে সেরেব্রাল পালসি বাচ্চার মায়েদের খাপ খাওয়ানো”। এই গবেষণার উদ্দেশ্য হচ্ছে সামাজিক জীবন এবং অন্যান্য লোকজনের সাথে সম্পর্কের মাঝে সমস্যাগুলোর সাথে সেরেব্রাল পালসি বাচ্চার মায়েদের খাপ খাওয়ানোর কৌশল খুঁজে বের করা।

এই গবেষণায় আপনার অংশগ্রহন স্বেচ্ছাকৃত। যেকোন সময় আপনার বিনা দ্বিধায় এই গবেষণা থেকে নিজেকে সরিয়ে নেওয়ার পূর্ণ অধিকার আছে। এই গবেষণায় অংশগ্রহন করে আপনি এবং আপনার বাচ্চা সরাসরি উপকৃত হবেন না। এখানে আরো উল্লেখ যে আপনার অংশগ্রহন এর জন্য আপনাকে কোন মূল্য পরিশোধ করা হবে না। গবেষণার উদ্দেশ্যে আপনার উত্তরটি রেকর্ড করা হবে। আপনাকে অবগত করা দরকার তথ্যগুলোর গোপনীয়তা সর্বোচ্চ সংরক্ষন করা হবে। আপনার নাম, আপনার বাচ্চার নাম অথবা কোন ধরনের নাম সনাক্তকরন নির্দেশক আপনার অনুমতি ছাড়া এই গবেষণায় ব্যবহার করা হবে না।

যদি এই গবেষণা সম্পর্কে আপনার আরো কিছু জানার থাকে তবে নিচে নাম দেয়া ব্যক্তির সাথে যোগাযোগ করুন।

শারমিন আক্তার

৪র্থ বর্ষের ছাত্রী,

অকুপেশনাল থেরাপি বিভাগ,

বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট,

সি.আর.পি, সাভার, ঢাকা

Appendix-4A (Consent Form)

To be completed by the:

a) Participant/witness (literate), if participant is illiterate

1. Have you read the information sheet? -----Yes/No
2. Have you had an opportunity to discuss this study and ask any question?
-----Yes/No
3. Have you had satisfactory answers to all your questions? -----Yes/No
4. Have you received enough information about the study? -----Yes/No
5. Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting present and future medical care of your children? -----Yes/No
6. Information from interview and questionnaire, those will be collected by the investigator might be examined by other person. However all personal details will be treated as highly confidential. Do you give your permission for these individuals to have access to your records? -----Yes/No
7. Do you agree to take part in this study? -----Yes/No

Participant's signature_____

Date_____

b) Investigator

I have explained the study to the above participant precisely and she has indicated her willingness to take part in the study.

Investigator's signature_____

Date_____

Appendix-4B (Consent Form-Translated)

সম্মতি পত্র

নিম্নের অংশটি পূরণ করবেন:

ক) অংশগ্রহণকারী / সাক্ষী (শিক্ষিত), যদি অংশগ্রহণকারী অশিক্ষিত হয়

১. আপনি কি তথ্য পত্রটি পড়েছেন? ----- হ্যা / না

২. আপনার কি এই গবেষণা নিয়ে আলোচনা করার সুযোগ আছে? -----হ্যা / না

৩. আপনার কাছে কি উক্ত প্রশ্নগুলোর সন্তোষজনক উত্তর আছে? -----হ্যা / না

৪. আপনি কি গবেষণাটি সম্পর্কে যথেষ্ট অবগত আছেন? -----হ্যা / না

৫. আপনি গবেষণা থেকে যে কোন সময় নিজেকে প্রত্যাহার করতে পারেন এবং এজন্য কারো কাছে জবাবদিহি করতে হবে না এবং এটা আপনার বাচ্চার বর্তমান ও ভবিষ্যত চিকিৎসার উপর কোন প্রভাব ফেলবে না। এ সম্পর্কে আপনি কি বুঝতে পেরেছেন? -----হ্যা / না

৬. প্রশমালা এবং সাক্ষাৎকার থেকে গবেষক কর্তৃক সংগৃহীত তথ্য অন্য লোক দ্বারা নিরীক্ষণ করা হতে পারে। যাহোক সমস্ত ব্যক্তিগত তথ্য অত্যধিক গোপনীয় থাকবে। আপনি কি তাকে আপনার তথ্য জানার অনুমতি প্রদান করছেন?

-----হ্যা / না

৭. আপনার কি এই গবেষণায় অংশগ্রহণে সম্মত আছেন? -----হ্যা / না

অংশগ্রহণকারীর সাক্ষর _____

তারিখ _____

খ) গবেষক

আমি গবেষণাটি উপরোক্ত অংশগ্রহণকারীর কাছে যথাযথভাবে ব্যাখ্যা করেছি এবং তিনি এই গবেষণায় অংশগ্রহণের সম্মতি প্রকাশ করেছেন।

গবেষকের সাক্ষর _____

তারিখ _____

Appendix-5A (Questionnaire)

Mother's code:

Age:

Educational level: Illiterate/Primary/S.S.C/H.S.C/B.A

Occupation: Housewife/Service women/Businessman/Teacher/Others

Type of family: Single family/Joint family

Total family income:

Ques-1: For having a disabled child did you feel that your relationship is negatively affected with your husband? If yes, please explain how it affects.

Ques-2: What did you do when you feel that problem?

Ques-3: For having a disabled child what kind of problems did you face with your in-laws? Please explain.

Ques-4: What did you do when you face that problem?

Ques-5: For having a disabled child what kind of problems did you face with your relatives? Please explain.

Ques-6: What did you do when you face that problem?

Ques-7: For having a disabled child did you face any negative effect in the relationship with your neighbors? If yes, please explain.

Ques-8: What did you do when you face that problem?

Ques-9: Did you feel restriction to attend in different social activities like marriage, birthday, milad etc for having a disabled child? If yes, why?

Ques-10: How did you face with that problem?

Ques-11: Did you feel restriction to pass your leisure or different recreational activities for having a disabled child?

Ques-12: If yes, what did you do when you feel that problem?

Appendix-5B (Questionnaire-Translated)

প্রশ্নাবলী

মায়ের কোড :

বয়স :

শিক্ষাগত যোগ্যতা : অশিক্ষিত/প্রাথমিক/এস.এস.সি/এইচ.এস.সি/বি.এ

পেশা : গৃহিনী/চাকুরীজীবী/ব্যবসায়ী/শিক্ষিকা/অন্যান্য

পরিবারের ধরণ : একক পরিবার/ যৌথ পরিবার

পরিবারের মোট আয় :

প্রশ্ন ১ঃ একজন প্রতিবন্ধী বাচ্চা হওয়ার কারণে আপনার স্বামীর সাথে আপনার সম্পর্কের মাঝে কি কোন নেতিবাচক প্রভাব পড়েছে? যদি হ্যাঁ হয় তাহলে কিভাবে, তা দয়া করে ব্যাখ্যা করুন।

প্রশ্ন ২ঃ আপনি যখন ঐ সমস্যার সম্মুখীন হয়েছেন তখন আপনি কি করেছেন ?

প্রশ্ন ৩ঃ একজন প্রতিবন্ধী বাচ্চা হওয়ার কারণে আপনার স্বামীর বাড়ির সদস্যদের সাথে আপনার সম্পর্কের মাঝে কি কি ধরণের সমস্যার সম্মুখীন হয়েছেন? দয়া করে ব্যাখ্যা করুন।

প্রশ্ন ৫ঃ প্রতিবন্ধী বাচ্চা হওয়ার কারণে আপনার আত্মীয় স্বজনদের সাথে আপনার সম্পর্কের মাঝে কি কি ধরণের সমস্যার সম্মুখীন হয়েছেন? দয়া করে ব্যাখ্যা করুন।

প্রশ্ন ৪ঃ আপনি যখন ঐ সমস্যার সম্মুখীন হয়েছেন তখন আপনি কি করেছেন?

প্রশ্ন ৬ঃ আপনি যখন ঐ সমস্যার সম্মুখীন হয়েছেন তখন আপনি কি করেছেন?

প্রশ্ন ৭ঃ প্রতিবন্ধী বাচ্চার কারণে আপনার প্রতিবেশীর সাথে আপনার সম্পর্কের মাঝে কি কোন খারাপ প্রভাব পড়েছে ? হ্যাঁ হলে, কিভাবে তা দয়া করে ব্যাখ্যা করুন।

প্রশ্ন ৮ঃ আপনি যখন ঐ সমস্যার সম্মুখীন হয়েছেন তখন আপনি কি করেছেন?

প্রশ্ন ৯ঃ প্রতিবন্ধী বাচ্চার কারণে আপনি কি বিভিন্ন সামাজিক অনুষ্ঠান যেমন বিয়ে, জন্মদিন, মিলাদ-মাহফিল ইত্যাদিতে অংশগ্রহণ করতে বাধা অনুভব করেছেন? হ্যাঁ হলে কেন ?

প্রশ্ন ১০ঃ আপনি কিভাবে ঐ সমস্যাগুলোর সাথে মোকাবেলা করেছেন?

প্রশ্ন ১১ঃ প্রতিবন্ধী বাচ্চার কারণে আপনি কি বিভিন্ন বিনোদনমূলক কর্মকাণ্ড বা আপনার অবসর সময় কাটাতে বাধা অনুভব করেছেন?

প্রশ্ন ১২ঃ হ্যাঁ হলে তখন আপনি কি করেছেন?

Appendix-6

Mother's characteristics at a glance

Characteristics	P-1	P-2	P-3	P-4	P-5	P-6
Age (in years)	23	21	24	22	21	32
Educational level	Class-9	Class-7	Class-6	S.S.C	Class-8	Class-5
Occupation	Housewife	Housewife	Housewife	Housewife	Housewife	Housewife
Types of family	Single	Joint	Joint	Joint	Joint	Joint
Total family income (in TK)	10,000	12,000	10,000	7,000	6,000	10,000