

Thesis title: Role Performance of Mothers of Children
with Disability: An Explorative Study



By:

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Statement of authorship

Except where it 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 seminar. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree 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, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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Dedication

Dedicated to my honorable and beloved
grandfather.

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List of Abbreviations

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

BHPI: Bangladesh Health Professions Institute

BTRF: Bangladesh Therapy & Rehabilitation Foundation

CRP: Centre for the Rehabilitation of the Paralysed

CWD: Children with Disability

EI: Educational_Level

OT: Occupational Therapy

QCA: Qualitative Content Analysis

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WHO: World Health Organization

Abstract

Background: Role performance is an important part of a human being. When mothers have children with any disability, their works, roles, and responsibilities being more. During playing their roles they face many challenges, barriers. They do a lot of works to manage and balance their family.

Objective: The aim of this research is to explore mothers of CWD different types of role performance. And find out how the mothers balance their everyday occupational roles.

Methodology: This study was conducted by using qualitative content analysis approach. Purposive sampling was used for selecting participants. Data was collected by using face to face interview with a self-developed interview question.

Result: The study shows that mothers of CWD can engage only in fundamental self-care activities that must be required to do. They can engage in paid productive activities which assists them in taking extra care and help to give more times of their children, and can also engage in almost all of unpaid activities. They can only engage in those leisure activities that can do with their children. And by using some strategies mothers are balancing their occupational roles and they can reduce the difficulties.

Conclusion: Mothers have a lot of roles and responsibilities in their family. But when mothers have CWD, their responsibility being more than the typical mothers. This study is conducted to explore these mothers' everyday occupation as well as their occupational role balance. OTs can give advice mothers as well as education on how to keep a healthy work-life balance.

Key word: CWD, Mothers' everyday occupation, Role performance.

CHAPTER I: Introduction

1.1 Background

Occupational role performance is an important part of a human being. A mother has a lot of roles and responsibilities in her family. But when a mother has a child with any disability, her responsibility is being more than the typical mother. There is sufficient evidence that mothers of children with disability have poorer health, well-being, and quality of life than mothers of typically developing children (Sim et al. 2021).

Persons with disabilities are people who have long-term physical, mental, intellectual, or sensory impairments that prevent them from actively participating in society. (UNCRPD, 2006). About One billion people (15% of the world population) are experiencing some forms of disability (“Disability inclusion,” 2021). There is an estimated 16 million people with disabilities in Bangladesh which is around 10% of the country's population (“About disability,” n.d.).

Mothers are the central persons of the family. They do a lot of works to manage and balance their family. During playing their roles, they face many challenges, barriers. The religious and cultural context have also obstructed the occupations for mothers of children with disabilities. Caregiving is a natural and important part of motherhood, but if the children has any disability, the mothers may need to assist the children with basic tasks such as feeding, hygiene, dressing, transportation, communication, body mobilization, play, and communication for more hours per day (Ranehov & Hakansson, 2018).

Traditionally, mothers have been the primary caregivers of their children with disability. In addition to, taking care of children, mothers need to manage their self-care, leisure, and regular job, the situations become hard. In many cases, mothers leave their paid productive works to focus on the children care, and this has a major impact on their daily life, requiring a greater investment of time and resources. This circumstance can increase mental stress and health problems in these mothers as well as the impact on their physical health and the impact on occupational performance (Cantero-Garlito et al., 2020).

The majority of mothers' daily activities consist of their caregiving roles and responsibilities, which include caring for children while supporting their skill development, doing chores, and working. Mothers have to devote time to self-care, social activities, and recreational activities. Even though their children rely on them for many daily activities, and this dependence can last much longer than it does for typical children, Mothers of children with disability have additional challenges due to their occupations. (Crowe & Michael, 2010). This extended period of prioritised care responsibilities may reduce the amount of time available for mothers to engage in self-care, social and leisure activities, and productive activities, potentially affecting their health and well-being (Bourke- Taylor et al., 2010,p.).

Occupation includes all the activities or tasks that an individual performs each day. For example, getting dressed, playing a sport, taking a class, cooking a meal, getting together with friends, and working at a job are considered occupations. It refers to everyday activities and roles that bring meaning and purpose into people's life, including things they need to, want to and are expected to do in their environment (World Federation of Occupational Therapy, 2019). In areas like self-care, leisure, and work, a popular theoretical model of human occupation identifies person and

environment related factors to explain how people choose, organize, and orchestrate their daily occupations (Bourke-Taylor, 2017).

So far, no research has been done on the occupations of mothers of children with disabilities in Bangladesh. In all the research reviews researcher has done in different countries, the everyday occupations of mothers of CWD have been explained. Further explained workloads, burdens, social challenges and barriers that cause physical and mental stress (depression, stress, family conflict) to mothers of CWD in various ways. But there was a knowledge gap—no research on how to balance the daily occupational role of mothers of CWD in any research or how to do their work in a stress-free way. Researcher wanted to find out the everyday occupation of mothers of CWD and what occupations are important for them. So, researcher thought about the workload of mothers of CWD and also thought about how, in what way they can do their daily activities in a well-organized and stress-free way. Through this study demonstrated how mothers of CWD can achieve a healthy work-life balance .I am interested in doing this research, thinking about the mothers of CWD from that point of view.

1.2 Justification of the Study

The researcher has broadly explained the occupation of mothers of children with disabilities through this study. Mothers of CWD face a variety of social challenges and barriers that make it very difficult for them to perform everyday occupations and responsibilities. This study shows how mothers can achieve a healthy work-life balance. Occupational therapists and other health care providers who work with CWD. But it's unclear how those mothers manage their professional and personal lives. However, the study showed the balance of mothers' occupational roles and also

showed how much time mothers of CWD spend on their activities and which activities are more important to them.

In Bangladesh, there is not enough research regarding occupation of mothers of children with disabilities. This study will help to know about occupation of mothers of children with disabilities as well as their everyday occupational roles balance. Occupational therapists only work with clients, not mothers. But mothers of children with disability do a lot of works that are not seen. During performing daily occupational roles, mothers are facing different kinds of barriers, challenges that can lead those mothers to mental health illness (depression, stress, family conflict). Occupational therapists will develop knowledge about the occupation on those mothers, they will be able to work with those mothers, and they can apply the family-center approach, family education, family counseling, where they will be playing a vital role as rehabilitation program of rehabilitating their children. And OTs will play a great role for these mothers who cannot manage & balance their everyday occupation and I think that the occupational therapist will help improve the occupational performance of mothers of children with disability. This will add a new dimension to the work of occupational therapists. That's why I'm interested to conduct this study.

This study can also assist other professionals such as social workers, counselors and vocational trainers, psychologists, and psychiatrists on this topic.

Finally, from this research study for the mothers of children with disabilities will get appropriate education, counseling from an occupational therapist who has to enrich knowledge by the study and it will create the best rehabilitation program outcome

which indicates the best services to the children with disability as well as their mothers.

1.3 Operational Definition

Occupation: A person's usual or principal work or business, especially as a means of earning a living. “Occupations are everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economical thread of their communities (productivity)”. (CAOT,1997, pp.31 & 181).

Self-care activity: The activities we have to do every day for our self-care are known as self-care activities. For example- washing hands & mouth, brushing teeth, combing hair, dressing, shaving, taking meal, having shower etc. (“Self-care,” 21).

Leisure activity: Activities which are done by the people for their personal interest and to spent their spare time in their everyday life are known as play or leisure. Example- Painting in leisure period to spent the spare time, play football in the leisure, gardening etc. (“Leisure activity,” n.d.).

Productive activity: The activities we need to do every day to accomplish our job and house holding activities are known as work and productive activities. Example- Meal preparations, shopping, take care of others, cleaning, job performance etc. (Reid & Riddick Grisham, 2015).

Occupational roles: The different positions in society we have. These are pattern of occupational behaviour composed of configuration of self-maintenance, productivity, leisure and rest occupations.

Occupational performance: The ability to perceive, desire, recall, plan, and carry out roles, routines, tasks, and sub-tasks in response to internal and/or external demands for self-maintenance, productivity, leisure, and rest.

Activity: Activities are considered small units of goal directed behaviors that make up tasks (cited in Radomski and Latham 2014, 7th ed., p19).

Activities of daily living (ADL's): Activities of daily living (ADLs), often termed physical ADLs or basic ADLs, include the fundamental skills typically needed to manage basic physical needs, comprised the following areas: grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating.

Instrumental activities of daily living (IADL's): Instrumental Activities of Daily Living are similar to ADLs. These actions are important to being able to live independently, but are not necessarily required on a daily basis. Activities to support daily life within the home and community that often require more complex interactions than those used in ADLs.

CHAPTER II: Literature Review

This section has represented in the relevant information of this study. In this literature review section, the student researcher has explained the key terms of this study. Relevant literature has been included a review of the daily occupations for special children's mothers. For this study, the student researcher has searched the mothers' everyday occupations who has children with different types of disabilities such as- Cerebral palsy, Autism, Down syndrome, Intellectual disability, ADHD, etc. Most of the literature showed that mothers' professional and personal life so burden & challengeable. They don't get enough time or scope to maintain their everyday occupation & work properly (Crowe & Michael, 2011).

2.1 Mothers occupational goals

A qualitative study was conducted to know the "Occupational Goals of Mothers of Children with Disabilities". For that study thirty-eight (38) mothers were included and their children aged 3 to 13 years. The authors identified that the mothers' occupational goals are such as- taking care of their own health and well-being, wanted to expanding their social life, improving their children's quality of life, well household management, wanted to balance their work, home, and community responsibilities and wanted to sharing the workload (Donovan et al., 2015).

2.2 Mothers extensive care responsibilities

A qualitative study was conducted in Rural Areas of a Spanish Region on "Mothers Who Take Care of Children with Disabilities". The data was collected by in-depth interviews and the authors found that the mother plays extensive care responsibilities

which impact on their well-being and daily life. Eventually, for providing the excessive care they couldn't maintain their daily life (Cantero-Garlito et al., 2020).

2.3 Mothers challenging caregiving experiences

The challenging caregiving experiences of Taiwanese mothers of children with cerebral palsy (CP) were studied using a phenomenological research approach. The study included 15 mothers who were the primary caregivers for children with cerebral palsy aged 0–18 years. The authors identified that mothers caregiving experiences were very challenging such as- Experiencing burden as a sole primary caregiver: Poor relationships with their parents-in-law or husbands were a significant issue for the mothers, because giving birth children with CP can bring social stigma, shame and disgrace to a traditional Chinese family. Managing the challenges of balancing demands. Being marginalised by others: When school staff failed to provide their children with basic personal care and adequate physical support, mothers were disappointed and frustrated. And encountering limited or no professional support: Some mothers lost all trust in doctors and in their own ability to make health-care decisions (Huang et al., 2011).

2.4 Mothers as hidden worker

An in-depth interview was conducted to know 'working but not employed: Mothers of adults with intellectual disability as hidden workers' with 18 mothers in Taiwan, both working and unemployed, who had adult children with an intellectual disability (ID). The authors found that the mothers were - moving from the formal to the informal labor market: 38.9% mothers left the labor force when their children with intellectual disability (ID) had intensive and long-term care needs. After leaving the formal labor market, the majority of mothers (83.3 %) found work in the informal employment. Employment patterns: when mothers were married, pregnant, giving birth to their first

child, or giving birth to a child with ID, they left the formal labor market or worked outside of it. Helping family's business without payment: Some mothers helped their husband, son, mother-in-law, or husband's family (e.g., by painting walls, cleaning, selling vegetables at markets, or cooking for workers). Hidden paid work: The mothers in that study switched from the formal to the informal labor market and worked a variety of jobs to meet their financial obligations, such as rent payments, diaper and milk purchases, and day-care fees for their children with ID. The mothers did not identify themselves as employed or as one of the family earners, despite having paid work at home (e.g., as a child-minder or outsourced home worker) or unpaid family work (e.g., self-employed work) (Chou et al., 2014).

2.5 Mothers managing family routine

An interpretive phenomenological approach was used to know “the experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing”. Purposive sampling methods were used to recruit twenty mothers of children with ASD, aged between 28 and 56 years who lived in Western Australia (WA). The authors identified that the mothers' perceptions towards health and wellbeing when managing family routines emerged- keeping on track keeping healthy; my life is busy because I do everything for everyone else; keeping on track all the time is tiring or frustrating; looking after my family by looking after myself; and I am not perfect and it is OK. By changing their perspectives and supporting their own health and wellbeing, mothers may be able to cope with everyday demands in managing family routines. Family routines reflect mothers' values and needs; thus, a thorough understanding of family routines may be a key to supporting mothers' occupational engagement (McAuliffe et al., 2018).

2.6 Mothers' everyday occupations

Sim et al. (2021) performed a systematic review aimed to identify the everyday occupations for the East Asian mothers who have children with disabilities. In that study, they reviewed 32 articles (taken from- Taiwan, Japan, China, Hong Kong & Korea). That reviewed represented 415 mothers' everyday occupations. That systematic review study showed that- most of mothers couldn't maintain self-care (insufficient sleep, fatigued, stressed and had no time for themselves), leisure (they were socially isolated and housebound) and productive occupations properly (Jobs were commonly part-time, home-based, or their own businesses). And had to caring their children more times (child's self-caring, engaging in therapy, playing and various activities) , faced different types of social & environmental barriers (discrimination from their own families, the community, husbands' distancing from themselves, and feeling blamed for bearing a child with disability) and sometimes they couldn't manage & balance their work routines. (Huang et al., 2012, p193).

2.6.1 Activities of daily living

Since mothers spend so much time for caring of their children with disability that they face challenges performing their ADLs such as self-care, productive work, and leisure. Children with disabilities are unable to perform self-activities due to physical and cognitive developmental delays, and they are wholly dependent on their mothers. According to Sim et al. (2021), raising a child with special needs requires mothers to find a balance between work, leisure, and day-to-day activities.

- **Self-care:** Elwood and Longley (2010) describe self-care as "all health decisions people make for themselves to get and stay physically and mentally fit." Self-care involves staying physically fit and mentally healthy, as well as eating well, keeping a clean environment, and avoiding health risks. These

mothers are unable to keep track of their own self-care, particularly when it comes to eating and bathing.

- **Productive works:** CWD mothers struggle to keep up with household work and employments. Because of their children, they spend the majority of their time caring for them. According to the study, a mother with CWD must dedicate the majority of her time to caring for her child and only a small portion of her time to productive work. Those mothers have less time to work or serve in the community (Crowe & Michael, 2011). Even with the added demands of work, child care, and family, working mothers report less stress and greater life satisfaction. Working outside the home provides social interaction and friendships, as well as a new role, a shift in daily needs, and a raise in pay. Mothers with CWD, on the other hand, are less likely to be able to continue working.
- **Leisure:** Time spent away from business, work, household chores, and education is referred to as leisure or free time. It also doesn't include time spent on essential activities like sleeping. Another type of leisure is social leisure, which involves leisure activities that take place in a social setting, such as hobbies. Leisure is very important for a person, particularly for mothers of CWD children, who feel more stress than mothers of typically developed children (Ranehrov & Hakansson, 2018). After spending so much time caring for disabled children and participating in other activities, mothers don't have time for themselves. These mothers are constantly concerned about their children, so they spend the majority of their time caring for their disabled children and have little time for themselves.

2.7 Mothers' Occupational Balance and Participation

A mixed-methods study was conducted to know “The Impact of Autism Services on Mothers' Occupational Balance and Participation” and Participants were mothers of children, adolescent, or young adult with autism living in Alberta, Canada.

2.7.1 Impact of professional supports and services on mothers' workforce participation: Quantitative Results: 78% of survey respondents reported that the professional supports and services for their children impacted their employment and mothers' employment were impacted by their children's services. Almost one third of the mothers decreased work hours and/or stopped working because of their children's service needs. Qualitative Results: from 19 interviewed mothers- six mothers worked full time, nine worked part time, four mothers did not work in paid employment, one of whom clarified that she would have chosen to stay home with her children regardless of the additional demands of her child's service needs (Hodgetts et al., 2013).

2.7.2 Impact of Professional Supports and Services on Mothers' Leisure

Participation:

Quantitative Results: The professional supports and services decreased mothers' time to participate in leisure occupations. Almost half of the survey (48%) respondents reported disrupted leisure, 62% of the mothers reported that they participated in both family and individual (adult-oriented) leisure activities, 23% indicated that they did not participate in any individual or adult-oriented leisure occupations and 15% of our sample indicated they had no participation in leisure occupations, with two mothers responding, “*Is this a joke?*” to the question. Qualitative Results: Mothers identified the leisure occupations in which they and their family participated, but they did not ask about their frequency of participation or specifically how professional services

disrupted leisure participation. For example, one mother's written answer said that she participated in downhill skiing, but when asked in the interview "*How [she] found time for this activity?*," she stated that she had "*only gone once since she was diagnosed 3 years ago! Now I don't even have time to go to [the local ski hill].*" (Hodgetts et al., 2013)

2.8 Mothers' burdens

A descriptive and analytical longitudinal study was used for Zimbabwean mothers who Caring for a child with Cerebral Palsy. Mothers of 46 children were included. That study showed that they faced some burden such as - physical burden, economical burden, and psychosocial burden. That's why they couldn't balance their everyday occupation (Dambi et al., 2015).

2.9 Key Gap of the Evidence

- Among the published literatures found, three articles worked on everyday occupations of mothers of CWD, four articles worked on extensive care responsibilities of mothers of CWD and an article worked on mothers' burden. However, it is not clearly mentioned about how mothers of CWD are managing their occupational roles balance.
- The time of publication shows that the studies regarding role performance of mothers of CWD conducted between 2005 to 2021.
- Five studies were qualitative study, one study was longitudinal study, two studies were scoping review, and one was mixed method study. However, the samples size of these studies were small.
- Eight studies were conducted regarding role performance of mothers of CWD in Taiwan, Spanish region, Western Australia, East Asia, Canada and Zimbabwean. But no study on this topic have been conducted in south Asia and /or Bangladesh.

But there was a knowledge gap—no research on how to balance the daily occupational role performance of mothers of CWD in any research or how to do their work in a stress-free way. Therefore, it is important to find out way of occupational role balance of mothers of CWD.

CHAPTER III: Methodology

3.1 Research question, aim and objectives

Research question

What are the role performance of the mothers of children with disability?

Aim of the study

The aim of this research is to explore the different types of role performance of mothers of children with disability.

Objectives of this study

- To find out every day self-care activities of the mothers of children with disability.
- To find out productive activities of the mothers of children with disability.
- To find out every day leisure activities of the mothers of children with disability.
- To find out how the mothers balance their occupational roles.

3.2 Study design

Researcher used phenomenological qualitative research design to know about the occupations for the mothers of children with disability. This approach can be used to knowing everyday occupational role performance and living experienced of the participants. As qualitative research can address the experience of particular event and how the life circumstances are influenced through the event of the people so the researcher used qualitative research design. This was examined in Bailey, (Hissong et al., 2014) “Qualitative research tries to verify or generate descriptive theory that is grounded in the data gleaned from the investigation”. Phenomenological perspective can be implemented to any study where the investigator concerns with peoples’ view on their own life or situation. This phenomenological qualitative research design can

be used to knowing living experienced of the participants. According to Hick's (2000), when the researcher willing to find out the research questions in search of experience, feelings and performance of the participants a qualitative research design is appropriate for this study. As has been argued (Hennink et al., 2010), with the purpose of writing the oral histories of participants there is need to qualitative research design by a qualitative approach and it is suitable for gaining insights, judgment, experience and perception of the participants. This research aim is to explore the experience of everyday occupation for the mothers of children with disability and it has represented the participants own experience of view about their occupation. So, the researcher used phenomenological approach of qualitative research design.

3.3 Study setting and period

The study was conducted at Bangladesh Therapy and Rehabilitation Foundation (BTRF)-special needs school in Dhaka where mothers of children with disability are available. The time duration of this study was April 2021 to February 2022.

3.4 Study participant

Study population

The mothers whose children has disability (different types of disability like- Cerebral palsy, Autism, Down syndrome, ADHD, etc.) & fulfill the inclusion and exclusion criteria of this study.

Sampling procedure

The student researcher was used purposive sampling for this qualitative study who would be met the inclusion criteria. Purposive sampling was used because the researcher would use judgment for selecting participants (French, Reynolds and

Swain, 2001). Sample was collected from a wide range of population. Purposive sampling method is used in qualitative studies to study live experienced, life engagement of a specific population by using specific selection criteria.

Sample size

Sample sizes were very small and there is not necessarily representative of the vast population in qualitative research study (Patton and Cochran, 2002). For the reason, the sample size of this study would be small size which number was within 08-12.

Inclusion criteria

- Mothers who were the primary caregiver of the children with disability.
- Age: 20-45 years.

Exclusion criteria

- Mother has any physical illness or physical disability were excluded.
- Mothers with diagnosed cognitive problem or mental illness.

Participant recruitment process

The student researcher went to special needs school and took permission from the Director and Head of the school to collect data and selected the participants who fulfilled the inclusion criteria. After selecting participants researcher took consent from the participants and collected data.

3.5 Ethical consideration

Ethical considerations implemented to avoid ethical problem. The student researcher granted permission from the Institutional Ethical Review Board through the department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of CRP to conduct the study by maintaining the mentioned guidelines of Helsinki Act 1964-2013 and Nuremberg Code 1947.

Informed consent

The researcher was developed a consent form in Bangla and English for taking consent from participants. During interview, the student researcher took permission from each participant who was interested to participate with signature on a written consent form and the student researcher took signature of the witness. The student researcher was clearly explained the role of the participants in this study and informed them that they were not harmed by this study. The student researcher was also discussed the benefit of this study. Participants was informed that the given information would not share with others except the research supervisor. And the student researcher was clarified the rights of the participants.

Unequal relationship

There is no power or unequal relationship in this study.

Risk and beneficence

Researcher ensured that there is no physical, emotional and economical risk or hazard for the participants of this study. And researcher also be compelled about the benefit of this study.

3.6 Data Collection**Field test**

Before starting data collection, the investigator completed a field test with two participants. It is important to carry out a field test before collecting the final data as it helps the researcher to refine the data collection plan (DePoy & Gitlin, 2016). And it was necessary to conduct a field test to help the researcher for purifying the data collection plan. During the interview, researcher informed the participants about the aim and objectives of the study. From the field test the researcher was aware about

which part of the question participant found difficulty or they did not understand properly. Researcher observed the situation of the interview, participant's response thus help to modify the question where necessary. Finally, the researcher has modified his approach of questioning. So that the questions are easy to understand by the participants.

Data collection method

All data was collected through face-to-face in-depth interview by using a self-developed interview question (B2B International, 2020). In this study, the student researcher was explored the experience of mothers' occupational role performance. In-depth interview was conducted in this study to collect data thoroughly from the participants. With in-depth interview participants were given freedom to explain occupations in their own words. The interview question was written in Bengali and English so it was easily understood for all participants. The student researcher started from the initial stage of the data collection procedure. At first, the student researcher verbally present the details of the study such as, aim, objectives and purpose of the study then explain the rights, roles, benefits and importance of the written consent form in a descriptive way and arranged the interview in a suitable place. Before starting the interview, the student researcher asked the participants about the place of interview. When the participants were agreed with the researcher and they would be felt comfort with the place, then the student researcher was started to interview. The student researcher was collected data from each participant within 20-30 minutes.

Data collection instrument

- **Interview Question:** A self-developed question was used for collecting data from participant. In interview question include demographic question such as

name, age, occupations (self-care, productivity, leisure and occupational roles), education, and marital status.

- Smart phone (Redmi note 8) has been used for recording the interview which has voice recorder software.
- Consent form
- Information sheet
- Withdrawal form
- General information form

3.7 Data analysis

It was suggested in the qualitative research that such collected data be analyzed in order to organize the information into different codes, categories, and themes (Bowling, 1997). Data analysis allowed the student researcher to establish the study aims according to collected information from participants. The appropriate analysis of data would give an accurate result for the study. The researcher selected Qualitative Content Analysis (QCA) method for analyzing data. QCA follows the three steps (coding, categorizing and generating theme) to present the result of the study. The analysis of data began from transcribe of interviews. At first, the student researcher would organize the interviews and transcribe the entire interview in Bengali from the mobile voice recorder. Each of the transcripts were translated from Bengali to English by 3 different individuals, one was the researcher and another two were such person who did not know about the aim or objectives of the research question. Then the researcher would verify all of the transcriptions and read it several times to find out what the participants wanted to say. Following that, the researcher confirmed the data and found the actual themes of the study. When the researcher would notice some similarities between the data, the researcher would organize the data according to

some major categories and under those categories some codes would be established. The codes came out from the research question and each code was separated from each other. After that the codes and themes would be made under each category by analyzing participants answer and information. After finishing the coding; the researcher can detect some important codes that would be reflected the theme of the study findings.

3.8 Rigor of the study

This study was conducted through rigorous manner. The entire study was conducted in a systematic way by following research steps under the supervision of an experienced supervisor. At the time of data collection and data analysis, the researcher never tried to influence the result by her own value or perspectives. The researcher accepted answers of the participants what they delivered. The researcher prepared transcript from the field notes and audio recording. Soon after the interview it was written. Translation has been completed by three people to avoid biasness then researcher completed the same translation and record to reduce mistake and compared it with the Bangla transcript. The researcher has checked translated data for several times so that no information get missed. All of notes kept safe to maintain confidentiality. In the result chapter, the researcher not influence the result by personal view.

CHAPTER IV: Results and Discussion

In result and discussion chapter, it has presented the result of the research study and presented the findings by using different literature. In qualitative studies, it is common practice to present result and discussion together in one section (Bailey, 1997). The result section of this study has been clearly described so that the study's findings can be properly evaluated. This section also has been used to discuss the research findings. This section explains the different types of descriptions, as well as the similarities and differences among them, as experienced by the participants. The occupational role performance of the participants were divided into different codes and themes were discovered using these categories. The aim of this research is to explore the different types of role performance of mothers of children with disability. There were four objectives of this study. Five themes emerged from the four categories.

4.1 Findings of the study

1. Mothers of CWD are engaged in fundamental self-care activities that must be required to do. Without fundamental self-care activities, they are unable to care for themselves.
2. Mothers of CWD can engage those paid productive activities such as online business, crafting, or a part-time job. Which assists them in taking extra care as well as helping to give more time of their children.
3. Mothers of CWD do almost all of the household chores in addition to raising their children. Which are very important for them.

4. Mothers of CWD can only engage in those leisure activities that they must do with their children in their leisure times. They have no option to engage in leisure time on their own, except for the child.

5. Mothers of CWD do not take any professional guidelines for balancing their occupational roles, but they have developed some strategies of their own, through which they can reduce their difficulties and challenges.

4.2 Participants overview

The study participants were mothers of the children with disability who were the primary caregiver of their children. The age range of the participants were 20 to 45 years. All of the participants were educated. Some of them were doing paid work and some of them were housewife.

P*	Age	EL	Profession	Child's age	Child's condition	Child's sex	Total child no
01	42 years	Masters	Job and business	5 years 3 months	ASD	Male	1
02	29 years	B.Sc.	Housewife	9 years	Learning disability	Male	2
03	37 years	Degree	Teacher	9 years	ASD	Male	2
04	31 years	B.A	Online business	7 years	Down syndrome	Male	2
05	41 years	BDS	Dentist	5 years 6 months	ADHD	Female	1
06	28 years	H.S.C	Housewife	8 years	ASD	Female	2
07	31 years	L.L.B	Housewife	3 years	ADHD	Female	2
08	34 years	Masters	Housewife	6 years	ASD	Male	3

*P= Participants number, EL=Educational_Level

Table 4.1 Socio-demographic information of the participants

4.3 Summary table of this study

Categories:	Themes:	Findings:
1. Mothers' participation in self-care activities	Self-care activities of mothers	Mothers of CWD are engaged in fundamental self-care activities that must be required to do. Without fundamental self-care activities, they are unable to care for themselves.
2. Mothers' participation in their paid and non-paid productive activities	Paid work	Mothers of CWD can engage those paid productive activities such as online business, crafting, or a part-time job. Which assists them in taking extra care as well as helping to give more time of their children.
	Non-paid work	Mothers of CWD do almost all of the household chores in addition to raising their children. Which are very important for them.
3. Mothers' participation in leisure activities	Leisure activities of mothers	Mothers of CWD can only engage in those leisure activities that they must do with their children in their leisure times. They have no option to engage in leisure time on their own, except for the child.
4. Way of maintaining the mothers' occupational role balance	Occupational role balance of mothers	Mothers of CWD do not take any professional guidelines for balancing their occupational roles, but they have developed some strategies of their own, through which they can reduce their difficulties and challenges.

Table 4.2 Summary table of this study

4.4 Categories of description and discussion

This study is divided into four categories. According to the different opinions of the participants, each category has reflected the participants' occupations through the different codes. The participants were given a tick in the columns where they describe themselves. 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.

Category 1: Mothers' participation in self-care activities.

Under this category one theme was emerged as follows-

Theme one: Self-care activities of mothers

Coding	P1	P2	P3	P4	P5	P6	P7	P8
Brushing	✓	✓	✓	✓	✓	✓	✓	✓
Eating	✓	✓	✓	✓	✓	✓	✓	✓
Bathing	✓	✓	✓	✓	✓	✓	✓	✓
Dressing	✓	✓	✓	✓	✓	✓	✓	✓
Sleeping	✓	✓	✓	✓	✓	✓	✓	✓
Combing hair	✓	✓	✓	✓	✓	✓	✓	✓
Skin care		✓		✓		✓	✓	
Consult with doctor		✓	✓	✓		✓	✓	

Table 4.3 Mothers' participation in self-care activities.

From this table, it has seen that most of the participants reported that they give importance some self-care activities (brushing, eating, bathing, dressing, combing hair and sleeping). Because they informed these are very important for their self-caring.

One of the mothers said that,

“Due to caring of my child I do not get enough time. But as much as I have time, I eat, bathe and sleep. I do these things for my own care. Because I think these are important for taking care of my family. And if I’m fine, then my family will be fine. When I do these in the right way, then I’m satisfied”.

One of the mothers mentioned that, “To take care of myself, I understand sleeping, bathing, eating, etc., and these are the things I do. But I can't do these things satisfactorily because I don't have enough time”. One of the mothers added that, “I can hardly take care of my hair, skin etc. Even sometimes I do not have time to go to doctor for my sickness”.

The mothers are the primary caregivers for their children. More attention is required for disabled children. That is why mothers dedicate the majority of their time to caring for their disabled children. They are unable to maintain proper self-care after spending so much time caring for their child and other responsibilities(Bourke- Taylor et al., 2010,p.).Most of the mothers spend 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 participation and maintaining self-care activities few mothers mentioned, “I can’t maintain properly and any how I have to manage my self-care activities”. Some mothers stated, “I can maintain with satisfaction and I don’t face any difficulties to maintain”.

Most of the mothers’ opinion was that they have less time to maintain their self-care activities properly due to spend much time to look after their children, household activities and other activities. They also described that they can do their important self-care activities. And when they do their self-care activities properly, they would satisfy.

Category 2: Mothers' participation in their paid and non- paid productive activities.

Under this category two themes were emerged as follows-

Theme one: Paid work

Paid productive activities								
Coding	P1	P2	P3	P4	P5	P6	P7	P8
Teacher			✓					
Part-time job						✓		
Online business	✓				✓			
Crafting	✓							
Farming			✓					

Table 4.4 Paid productive activities.

From this table, it has seen that few of the participants reported that they are engaged in paid productive work, and another participants are not able to engage in paid productive work, because of their caring workload.

The mothers of children with disability have less time to manage productive work properly due to spend more time for look after their child.

One of the mothers mentioned that,

“For properly take care of my baby, I left my job. I was an assistant professor. Besides, I had a chamber. I would practice there. I stopped practicing temporarily and I sacrificed 60% of my career. At present, I’m doing a part time job as a dental surgeon”.

One of the mothers stated that,

“I’m a working mother. I’m a craft in charge. Besides, I’m the owner of a business and also doing a research. No task is less important to me. I look after my child and I’m working hard to run my business effectively & efficiently”.

One of the mother added that,

“I’m a teacher of special school and also doing tuition as special educator to provide home service. Besides, I earn money by farming birds. I have to manage time although it hard to me.

The majority of mothers have found it difficult to maintain their productive work because they spend so much time caring for their children. Their professional and personal lives are both burdened and difficult. They don't have enough time or scope to properly maintain their work (Crowe & Michael, 2011).

Another half of the participants stated that they are housewife. That’s why they are not able to engage in paid productive work due to spend more time for look after child and house hold works.

One of the participants mentioned that, “I was a lawyer, actually I have no scope to continue my profession. Because I have two children and one is special child. I’m a housewife & I’m not assimilated with earning”.

One of the participants stated that,

“I wish I had a job of my own or if I could do something for myself. That would have been the most satisfying for me. I mean, I had my own identification”.

Most of the mothers’ opinion was that they have less time, blocked time to engage in paid productive work due to time shortage for their children caring and household activities. Despite their education, they are unable to apply what they have learned and do not have the opportunity to practice or carry out other implementations.

Theme two: Non-paid work

Non-paid productive activates								
Coding	P1	P2	P3	P4	P5	P6	P7	P8
Caring of child	✓	✓	✓	✓	✓	✓	✓	✓
Caring of others		✓	✓		✓			✓
Shopping	✓			✓	✓	✓	✓	✓
Cleaning		✓	✓	✓		✓	✓	✓
Meal preparation		✓	✓	✓	✓	✓	✓	✓
Taking the child to school	✓	✓			✓			✓
Taking the child to therapy session	✓	✓	✓	✓	✓	✓	✓	✓
Volunteer work					✓			

Table 4.5 Non-paid productive activates.

From this table, it has seen that most of the participants reported that they are engaged in non-paid productive activities. And the mothers who do not related with paid work are explained that they can get enough time for caring of their child and household works. And most of mothers are satisfied to manage their non-paid work.

One of the mothers mentioned that, “I work at home all day long. There is no paid income in it. I have no opportunity for income. My homework load is excessive & 24 hours non-paid for me”. One of the mothers said that, “Everything I have to do. I look after my children, marketing, cooking and doing everything at home. Because I do those things, I don't have a job”. Some mothers stated that, “Actually, I’m a housewife. So my all the works are non-paid and there is no problem”.

Most of the mothers’ opinion was that they are housewife and have more time to engage in non-paid productive work and they can maintain with satisfaction to look after their children and household activities.

One of the mothers said that,

“I do not get enough time at all. My mother abide with me. She assists me a lot. In fact, I do not have to do all the household works. After office I usually take care of my child and organizing my documents that’s it.”

One of the mothers added that,

“I look after my family. Taking care of my baby and my father are very important to me. My father who is 71 years old man, due to covid-19 pandemic he can’t go outside. I have to help him in doing his activities. Besides, I do others house works.

Some of mothers’ opinion that they are working mothers. They have time limit to do household works. They face difficulties to maintain properly. These children, according to Crowe & Michael (2011), require more care and supervision than children without disabilities. These mothers dedicate the majority of their time to their children and devote less time to other activities.

Category 3: Mothers’ participation in leisure activities

Under this category one theme was emerged as follows-

Theme one: Leisure activities of mothers

Coding	P1	P2	P3	P4	P5	P6	P7	P8
Gardening					✓		✓	
Visiting outside	✓			✓			✓	
Rearing pet			✓					
Watching TV		✓		✓		✓	✓	✓
Listening music			✓			✓		
Reading book/ newspaper		✓			✓			
Praying					✓			

Using social media	✓
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Table 4.6 Mothers' participation in their leisure activities

From this table, it has seen that most of the participants reported that they are engaged in leisure activities. They are participated a variety of leisure activities like – gardening, visiting outsides, watching TV, reading book etc. They feel satisfied when they can take the time to do their important leisure activities. But in most cases, because they do not have enough time, they are not able to do their leisure activities satisfactorily. Mothers who have children with disability are spending their extra time to look after their child, involve in house hold works and other works. Most of the mother said that they can't spend time for leisure activities.

A very few mothers said, "I can spend time for leisure with my child". Few mothers can be participated in their leisure activities. It depends on their environment, their support group. The mothers who live in joint family or who have helping hands can engaged in leisure activities. Even they can maintain their leisure activities with satisfaction.

Many mother mentioned, "I don't have enough time for leisure". One of the mothers said that, "Leisure! I used to hear the name. I do not have leisure time. I do all my pending non-paid activities on the weekend".

One of the mothers added that, "I would do various activities in my leisure time. But after my baby was born, I try to do religious activities in the leisure time".

These mothers face difficulties to engage in their leisure activities. The main barrier of leisure activities is time restriction. These mothers don't have time for themselves.

They have

limited their leisure participation due to a feeling of restriction in time for their workload (Cantero-Garlito et al., 2020).

Category 4: Way of maintaining the mothers' occupational role balance.

Under this category one theme was emerged as follows-

Theme one: Occupational role balance of mothers

Coding	P1	P2	P3	P4	P5	P6	P7	P8
Get enough support from others	✓	✓	✓	✓	✓	✓	✓	✓
Make a priority list	✓	✓		✓	✓			✓
Following work routine	✓	✓		✓	✓			✓
Multitasking	✓						✓	✓
Exclude any tasks from list and do later	✓	✓	✓	✓	✓	✓		

Table 4.7 Way of maintaining mothers' occupational role balance.

From this table, it has seen that most of the participants reported that they are following different types of strategies to manage their occupational role balance. They can get enough support from others, make a priority list & work routine to balance their works etc. By following a variety of techniques they adjust their daily occupational roles.

Many mothers said that, "Yes, a maid helps me in my work". One of the mothers added that, "I live in the join family that is a big plus point for me. Everyone can work together". One of the mothers stated that, "I can adjust my daily routine".

Mothers who have supportive hands, they can maintain their works balance with satisfaction.

One of the mothers mentioned that, “Yes, I do two or more tasks simultaneously. My husband helps me a lot. As I can’t complete all activities every day, I face difficulties for this”. One of the mothers said that, “I can’t get time to eat timely due to workload, and sometimes I have to take meal once a day instead of three times”.

Most of the mothers of children with disability can’t maintain their works balance properly due to extensive care responsibilities to their family. And for the working mothers, it’s so difficult to maintain works balance (McAuliffe et al., 2018).

CHAPTER V: Conclusion

5.1 Strength of the study

The student researcher has been able to reach appropriate participants. The participants were very co-operative to share authentic information those are relevant to this study. And the student researcher was able to achieve the result according to the objectives though this study.

5.2 Limitation of the study

Limitations are a type of issue that can arise at any point during the study's conduct and construction. Every study has some limitations that are beyond the control of the researcher ("Research guides," 2021). During the time of conducting this study, there were some limitations present. By considering these limitations the researcher conducted this study.

- The student researcher has got enough time for data collection but he didn't get enough time for rapport build up with participants.
- The student researcher didn't reach enough article for literature support because there were very few research articles regarding this study.
- The student researcher was used only these online databases Google Scholar, Google Web page, PubMed, as others online databases weren't possible to access from this country.
- The study result would be more comprehensive if the participants had been taken from more than one study settings.

5.3 Practice Implication

Recommendations for Occupational Therapists in Bangladesh

Occupational therapists need to know the day to day activities of mothers of children with disabilities as many of them are having difficulties in balancing their occupational roles and it is also an important aspects of occupational therapy roles. They will encourage mothers to follow professional guidelines for balancing their occupational roles. The occupational therapist will go over various techniques and strategies which come out through this study for balancing mothers' occupational roles as well as give advice on how to do their job well. This will be highly beneficial to mothers in rehabilitation programs. The findings will be useful for further occupational therapy research and study.

Recommendations for further research

The researcher's recommendation is that OTs need to conduct research regarding this topic. This may involve:

Identify level of mental stress and burden among working mothers who have children with disabilities, Perception of society about mothers who have children with disability and Mothers of children with disability identify physical problems as a result of their excessive workload.

5.4 Conclusion

A child's primary caregiver is his or her mother in our social context. Due to developmental delay, the child with any disability is unable to maintain self-care activities as like as a typically developing child. Since children with disabilities are fully dependent on their mothers, they must dedicate more attention to their children (Ranehov & Hakansson, 2018).

This study has been conducted to explore the occupational role performance of mothers of children with disability. Therefore, the findings of the study showed that the mothers of children with disability can engage only in fundamental self-care activities that must be required to do, they can do those paid productive activities which assists them in taking extra care and help to give more times of their children. Almost they have to do all of the household chores which are very important for them. And they can do the leisure activities that they must do with their children in their leisure times. Furthermore, leisure is not an option. They 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. Mothers of children with disability follow a number of techniques & strategies for balancing occupational roles in addition to raising their children.

This study is important for the Occupational therapist to work with mothers having children with disability. Occupational therapy practitioners (OTs) can give educate mother regarding a healthy work-life balance. The OTs could also help mothers to develop coping strategies for managing occupational roles.

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APPENDICES

Appendix A:

Ethical Approval

Date: 08.11.2021.....

The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP-Savar, Dhaka-1343, Bangladesh

Subject: **Application for review and ethical approval.**

Sir,

With due respect I would like to draw your kind attention that I am a student of B.Sc. in Occupational Therapy, 4th year student at Bangladesh Health Professions Institute (BHPI), Centre for the Rehabilitation of the Paralysed (CRP). I would like to conduct a research titled, **“Occupation of mother of children with disability: An explorative study”** with myself, as the principal investigator Mohuya Akter, lecturer Department of Occupational Therapy, BHPI as my thesis supervisor. The purpose of the study is to explore the different types of occupation of mother of children with disability.

A self-developed interview question will be used in the study that will take about 20 to 30 minutes. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential.

Therefore, I look forward to having your approval for the thesis proposal and to start data collection. I also assure you that I will maintain all the requirements for study.

Sincerely yours,

Hafizur Rahman.

Md. Hafizur Rahman
4th Year B.Sc. in Occupational Therapy
Session: 2016-2017, Student ID: 122160239
Department of Occupational Therapy
BHPI, CRP/CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the thesis supervisor/concerned authority:

Mohuya Akter
08.11.2021

Mohuya Akter
Lecturer Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI),
CRP, Savar, Dhaka-1343, Bangladesh.



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
 (The Academic Institute of CRP)

Ref:

CRP/BHPI/IRB/11/2021/524

Date:

15/11/2021

To
 Md. Hafizur Rahman
 4th Year B.Sc. in Occupational Therapy
 Session: 2016-2017, Student's ID: 122160239
 BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Subject: Approval of the research project proposal “**Role Performance of Mothers of Children with Disability: An Explorative Study**” by ethics committee.

Dear Md. Hafizur Rahman,
 Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator and Mohuya Akter, Lecturer, Department of Occupational Therapy, BHPI as thesis supervisor. The following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Dissertation Proposal
2	Questionnaire (English and Bengali version)
3	Information sheet & consent form.

The purpose of the study is to explore the different types of role performance of mothers of children with disability. The study involves use of a self-developed Interview Questions to explore different types of role performance of mothers of children with disability that may take 20-30 minutes to answer and there is no likelihood of any harm to the participants and/or participants may not have any direct benefit by participating in this study. The members of the Ethics Committee approved the study to be conducted in the presented form at the meeting held at 9:15 AM on 15th September, 2021 at BHPI 29th IRB Meeting.

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

Muhammad Millat Hossain
 Associate Professor, Dept. of Rehabilitation Science
 Member Secretary, Institutional Review Board (IRB)
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Permission letter for collecting data



Date: 14 December, 2021

To

The Director & Head

Bangladesh Therapy and Rehabilitation Foundation (BTRF).

House#03, Road#05, Block#B

PC Culture Housing Society, Shekhertek, Dhak-1207

Subject: Request for seeking permission to collect data from the mothers who have children with disability are taking rehabilitation services from BTRF.

Sir,

I beg most respectfully to state that, I am a 4th year B.Sc. in Occupational Therapy student of Bangladesh Health Professions Institute (BHPI), an academic institute of Center for The Rehabilitation of Paralyzed (CRP). I am interested to conduct a qualitative study on special child's mother. My research title is "Occupation of mothers of children with disability: An explorative study". The purpose of the study is to explore the different types of occupation of mothers of children with disability. The mothers who have children with disability are the participants of my research project. Now, I am looking for your kind approval to start my data collection from 14 December to 31 December, 2021. I would like to assure that your organization name and participant's information will remain confidential.

So, I therefore, pray and hope that you would be kind enough to grant me the permission for collecting the data and oblige thereby.

Sincerely yours,

Hafizur Rahman.

Md. Hafizur Rahman

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

Session: 2016-2017

Department of Occupational Therapy

*Forwarded for your kind consideration
and allow to collecting the data for
conduct his Research.*

Sk. Moniruzzaman
14/12/2021
Sk. Moniruzzaman
Associate Professor & Head
Dept. of Occupational Therapy
BHPI, CRP Savar, Dhaka-1343

Approved
15/12/2021
Fida Al - Shams
Founder & Managing Director
Bangladesh Therapy & Rehabilitation Foundation

Appendix B:

Information sheet and consent form (English Version)

Information sheet

I am Md. Hafizur Rahman, student of the Bangladesh Health Professions Institute (BHPI) is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. I am studying 4th year, B.Sc. in Occupational Therapy under the Occupational Therapy department of BHPI. In regards to the fulfillment of B.Sc. Degree, it is compulsory to conduct a research in 4th year of course curriculum. I would like to invite you to take part in my research study and the title is “**Role performance of mothers of children with disability: An explorative study**”. The aim of the study is to explore the different types of occupations of the mothers of children with disability.

Your participation will be voluntary. You may have the right to withdraw consent and discontinue participation from the study anytime within 1 week after the data collection but after 1 week of the data collection you can't withdraw from the study. This will not hamper to your personal and professional life. There is no incentive for participation in the study. There is no direct benefit & wages for participating in this study. But your experiences will be helped for services provider who are giving rehabilitation services.

An in-depth interview will be conducted with some questions regarding the study that will be recorded by mobile recorder. Confidentiality of all records will be highly maintained and all details will be kept on a confidential database that is only accessible to me and my supervisor. The identity of you not to be disclosed in any presentation or publication without your agreement. If you have any queries regarding this study please feel free to ask. I am accountable to answer all questions regarding this study.

Md. Hafizur Rahman

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

Department of Occupational Therapy

BHPI, CRP, Chapain, Savar, Dhaka-1343.

Consent Form

Assalamualaikum,

I am Md. Hafizur Rahman, 4th year B.Sc. in Occupational Therapy student at Bangladesh Health Professions Institute (BHPI) under the Faculty of Medicine, University of Dhaka. To obtain my Bachelor degree, I have to conduct a research project and it is a part of my course curriculum. My research title is “**Role performance of mothers of children with disability: An explorative study**”. To fulfill my research project, I need some information from you to collect data. So, you can be a respected participant of this research and the conversation time will be 20-30 minutes.

I would like to inform you that this is a purely academic study and will not to be used for any other purposes. I assure that all data will be kept confidential. Your participation will be voluntary. You may have the right to withdraw consent and discontinue participation from the study anytime within 1week after the data collection but after 1 week of the data collection you can't withdraw from the study.

If you have any query about the study, you may contact with researcher Md. Hafizur Rahman and/or supervisor, Mohuya Akter; Lecturer, Dept. of Occupational Therapy, BHPI, CPR, Savar, and Dhaka-1343.

Do you have any questions before start this session?

Yes

No

So, I can proceed with the interview.

Signature of the participant and Date:

Data collector's signature and date:

Researcher's signature and Date:

Information sheet and consent form (Bengali Version)

তথ্য পত্র

আমি মোঃ হাফিজুর রহমান, বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) এর ছাত্র, যা পক্ষাঘাতগ্রস্থদের পুনর্বাসন কেন্দ্র (সিআরপি) এর একটি শিক্ষা প্রতিষ্ঠান। আমি বি.এস.সি ইন অকুপেশনাল থেরাপি বিভাগের ৪র্থ বর্ষে অধ্যয়নরত আছি। এই কোর্সের অংশ হিসাবে চূড়ান্তবর্ষে আবশ্যিকভাবে একটি গবেষণা কর্ম সম্পন্ন করতে হয়। আমি আপনাকে এই গবেষণায় অংশগ্রহন করার জন্য আমন্ত্রন জানাচ্ছি। গবেষণার বিষয় হচ্ছে “বিশেষ চাহিদা সম্পন্ন শিশুদের মায়েদের পেশা: একটি অনুসন্ধানমূলক গবেষণা”। অধ্যয়নের লক্ষ্য হল শিশুদের মায়েদের বিভিন্ন ধরণের পেশা অন্বেষণ করা।

আপনার অংশগ্রহণ স্বেচ্ছায় হবে। ডেটা সংগ্রহের এক সপ্তাহের মধ্যে যে কোন সময় আপনার সম্মতি প্রত্যাহার করার অধিকার থাকতে পারে তবে ডেটা সংগ্রহের এক সপ্তাহের পরে প্রত্যাহার করতে পারবেন না। এটি আপনার ব্যক্তিগত ও পেশাগত জীবনে কোনরূপ ব্যাঘাত ঘটাবে না। এই গবেষণা হতে আপনি সরাসরি কোন উপহার বা পারিশ্রমিক পাবেন না। কিন্তু আপনার দেয়া তথ্য গুলো পুনর্বাসন সেবায় যারা নিয়োজিত আছেন তারা উপকৃত হবেন।

গবেষণার সাথে সম্পর্কিত কিছু প্রশ্ন নিয়ে আপনার একটি সাক্ষাৎকার নেয়া হবে যা মোবাইল অডিও দ্বারা সংরক্ষন করা হবে। আপনার কাছ থেকে প্রাপ্ত তথ্য গোপনীয়তার সাথে রাখা হবে। শুধুমাত্র গবেষক এবং তার তত্ত্বাবধায়ক তথ্য গুলো ব্যবহার করতে পারবেন। আপনার পরিচয় গবেষণার কোথাও প্রকাশ করা হবে না। গবেষণা সংক্রান্ত আপনার যদি কোনরূপ প্রশ্ন থাকে তাহলে আমাকে দ্বিধাহীনভাবে জিজ্ঞাসা করতে পারেন। গবেষণা বিষয়ক সকল প্রশ্নের উত্তর দেবার জন্য আমি সচেষ্ট থাকবো।

মোঃ হাফিজুর রহমান

৪র্থ বর্ষ, বি.এস.সি. ইন অকুপেশনাল থেরাপি,

বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

সিআরপি, চাপাইন, সাভার, ঢাকা-১৩৪৩

সম্মতিপত্র

আসসালামুয়ালাইকুম,

আমি মোঃ হাফিজুর রহমান, ৪র্থ বর্ষ, ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটে (বিএইচপিআই) বি.এসসি. ইন অকুপেশনাল থেরাপির একজন ছাত্র। আমার ব্যাচেলর ডিগ্রী পেতে, আমাকে একটি গবেষণা প্রকল্প পরিচালনা করতে হবে এবং এটি আমার অধ্যয়নের একটি অংশ। আমার গবেষণার শিরোনাম হল “বিশেষ চাহিদা সম্পন্ন শিশুদের মায়েদের পেশা: একটি অনুসন্ধানমূলক গবেষণা”। আমার গবেষণা প্রকল্পটি পূরণ করতে, ডেটা সংগ্রহ করার জন্য আমার আপনার কাছ থেকে কিছু তথ্য দরকার। সুতরাং, আপনি এই গবেষণার একজন সম্মানিত অংশগ্রহণকারী হতে পারেন এবং কথোপকথনের সময় হবে ২০-৩০ মিনিট।

আমি আপনাকে জানাতে চাই যে, এটি একটি সম্পূর্ণরূপে একাডেমিক অধ্যয়ন এবং অন্য কোন উদ্দেশ্যে ব্যবহার করা হবে না। আমি আশ্বাস দিচ্ছি যে সমস্ত তথ্য গোপন রাখা হবে। আপনার অংশগ্রহণ স্বৈচ্ছায় হবে। ডেটা সংগ্রহের এক সপ্তাহের মধ্যে যে কোন সময় আপনার সম্মতি প্রত্যাহার করার অধিকার থাকতে পারে, তবে ডেটা সংগ্রহের এক সপ্তাহের পরে প্রত্যাহার করতে পারবেন না।

এই গবেষণা সম্পর্কে আপনার কোন প্রশ্ন থাকলে, আপনি গবেষক মোঃ হাফিজুর রহমান, এবং/অথবা সুপারভাইজার, মল্লয়া আক্তার (অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই, সিপিআর, সাভার, ঢাকা-১৩৪৩) এর সাথে যোগাযোগ করতে পারেন।

তথ্য প্রদান শুরু করার আগে আপনার কোন প্রশ্ন আছে?

হ্যাঁ না

তাই, আমি ইন্টারভিউ নিয়ে এগিয়ে যেতে পারি।

অংশগ্রহণকারীর স্বাক্ষর এবং তারিখ:

তথ্য সংগ্রাহকের স্বাক্ষর এবং তারিখ:

গবেষকের স্বাক্ষর এবং তারিখ:

Appendix C:

Interview question (English)

1. What self-care activities do you do?
2. Do you get enough time for your self-care activities?
3. What self-care activities are more important to you?
4. What self-care activities do you do with satisfaction?
5. What paid productive activities (like- job, business, or other) do you do?
6. Do you get enough time to do paid productive activities?
7. What paid productive activities are more important to you?
8. What paid productive activities do you do with satisfaction?
9. What non-paid productive activities (like- activities with child, household management, shopping, cooking, and clean up) do you do?
10. Do you get enough time to do non- paid productive activities?
11. What non-paid productive activities are more important to you?
12. What non-paid productive activities do you do with satisfaction?
13. What leisure activities do you do?
14. Do you get enough time for your leisure activities?
15. What leisure activities are more important to you?
16. What leisure activities do you do with satisfaction?
17. How do you balance your occupational roles? Please explain.

Interview question (Bangla)

সাক্ষাৎকার প্রশ্ন

- ১। আপনি নিজের যত্ন নেয়ার জন্য কি কি কাজ করেন?
- ২। আপনি কি নিজের যত্নের জন্য পর্যাপ্ত সময় পান?
- ৩। আপনার নিজের যত্নের জন্য কোন কাজগুলি বেশি গুরুত্বপূর্ণ?
- ৪। আপনি নিজের যত্ন নেয়ার জন্য কোন কাজগুলি করে সন্তুষ্ট?
- ৫। আপনি উপার্জনের (যেমনঃ চাকরি, ব্যবসা বা অন্যান্য) জন্য কি কি কাজ করেন?
- ৬। আপনি কি উপার্জনক্ষম কাজের জন্য পর্যাপ্ত সময় পান?
- ৭। আপনার উপার্জনক্ষম কাজের মধ্যে কোন কাজগুলি বেশি গুরুত্বপূর্ণ?
- ৮। আপনি উপার্জনক্ষম কোন কাজগুলি করে সন্তুষ্ট?
- ৯। আপনি নন-পেইড (শিশু লালন-পালন করা, পরিবারের ব্যবস্থাপনা, কেনাকাটা, রান্না করা এবং পরিষ্কার করা) কি কি কাজ করেন?
- ১০। আপনি কি নন-পেইড কাজগুলি করতে পর্যাপ্ত সময় পান?
- ১১। আপনার নন-পেইড কাজের মধ্যে কোন কাজগুলি বেশি গুরুত্বপূর্ণ?
- ১২। আপনি নন-পেইড কোন কাজগুলি করে সন্তুষ্ট?
- ১৩। আপনি অবসর যাপনে কি কি কাজ করেন?
- ১৪। আপনি কি অবসরের কাজগুলি করতে পর্যাপ্ত সময় পান?
- ১৫। আপনার অবসর যাপনের জন্য কোন কাজগুলি বেশি গুরুত্বপূর্ণ?
- ১৬। আপনি অবসর যাপনে কোন কাজগুলি করে সন্তুষ্ট?
- ১৭। আপনি দৈনন্দিন কাজগুলিতে কিভাবে আপনার ভারসাম্য বজায় রাখেন?

General information

Date of interview:

Time:

Support period:

Participant Name:

Age:

Education:

Profession:

Address:

Phone number:

Total number of children:

Problems of the child:

Age of the child:

Gender:

সাধারণ তথ্যাবলি

সাক্ষাৎকারের তারিখঃ
স্থায়িত্বকালঃ

সময়ঃ

অংশগ্রহণকারীর নামঃ

বয়সঃ
পেশাঃ

শিক্ষাঃ

ঠিকানাঃ

ফোন নাম্বারঃ

মোট সন্তান সংখ্যাঃ

সন্তানের সমস্যাঃ

সন্তানের বয়সঃ

লিঙ্গঃ

Participant's Withdrawal From

(Applicable only for voluntary withdrawal)

Reason for withdrawal:

.....
.....
.....
.....
.....
.....

Whether permission to previous information is used?

Yes/No

Participant's Name:

Participant's Signature:

If you can't write, please give your finger print.

Date:



অংশগ্রহণকারীর প্রত্যাহার পত্র
(শুধুমাত্র স্বৈচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

প্রত্যাহার করার কারণ:

.....

.....

.....

.....

.....

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহণকারীর নাম:

অংশগ্রহণকারীর স্বাক্ষর:

.....

তারিখ:

যদি নিরক্ষর হয়*

অংশগ্রহণকারীর আঙ্গুলের ছাপ

