Navigating cultural context barrier faced by children with cerebral palsy: parent's perspective

By

Anika Tahsin Fima

February 2025

This thesis is submitted in total fulfilment of the requirements for the subject RESEARCH 2 & 3 and partial fulfilment of the requirements for the degree of

Bachelor of Science in Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Faculty of Medicine

University of Dhaka

Thesis completed by:

Anika Tahsin Fima
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

Supervisor's Name, Designation, and Signature

Sk. Moniruzzaman
Associate Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

Name of the Co-supervisor

Amena Rahman
Lecturer
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

Head of the Department's Name, Designation, and Signature

Sk. Moniruzzaman
Associate Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

+

Board of Examiners

Prof. Sk. Moniruzzaman

Professor and Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

.....
Signature

Dr. Md. Shakhaoat Hossain, PhD

Chairman & Associate Professor
Department of Public Health and Informatics
Jahangirnagar University
Savar, Dhaka-1342, Bangladesh.

.....
Signature

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.

Anika Tahsin Fima
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Peralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

Acknowledgement

At First, I thank the Almighty Allah for giving me the strength, patience, and perseverance to complete this thesis. My heartfelt gratitude goes to my parents and family members, whose unwavering support and constant encouragement have been a source of inspiration throughout my academic journey. I would like to express my deepest and sincere gratitude to a number of individuals who provided me with guidance, encouragement and motivation in different phases of this study. I am deeply grateful to my supervisor, Prof. Sk. Moniruzzaman, Professor and Head, Department of Occupational Therapy, BHPI, and my co-supervisor, Amena Rahman, Lecturer, for their invaluable guidance, time, effort, and constructive feedback. Their constant support and insightful suggestions were instrumental in the completion of this thesis.

I would like to express my gratitude to my friends especially Aritri Biswas and Nishat Tasfia and Israt Jahan Ela for their encouragement and support throughout my studies. Their support made the process more manageable for me. Last but not the least I am profoundly grateful to all the participants who took the time to share their personal insights and experiences. This study would not have been possible without their openness and willingness to contribute.

I sincerely apologize if I have unintentionally omitted anyone deserving of acknowledgement.

Dedication

I dedicate this work to all the caregivers and families of children with cerebral palsy, whose courage, resilience, and daily struggles inspired this research. This study would not have been possible without their openness and willingness to share their experiences.

Lastly, I dedicate this thesis to myself**,** for staying strong, focused, and committed throughout this journey. This is a testament to my hard work and perseverance.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ADL	Activities of Daily Living
BHPI	Bangladesh Health Professions Institute
CBR	Community-Based Rehabilitation
CP	Cerebral Palsy
CRP	Centre for the Rehabilitation of the Paralysed
FGDs	Focus Group Discussions
ICF	International Classification of Functioning, Disability and Health
IRB	Institutional Review Board
OT	Occupational Therapy
QoL	Quality of Life
WHO	World Health Organization

Abstract

Background: Although cerebral palsy (CP) is medically well defined, the lived experiences of affected children and their families in low and middle-income countries such as Bangladesh are strongly influenced by cultural beliefs, stigma, and limited resources. CP is frequently attributed to fate, divine punishment, or past sins, contributing to blame, shame, and social exclusion. These misconceptions often delay professional care and restrict access to rehabilitation services, while financial hardship and low awareness further limit long-term support.

Aim: To explore cultural beliefs and contextual barriers faced by families of children with CP in Bangladesh and to examine how these factors influence caregiving practices and access to treatment and rehabilitation.

Methods: A qualitative phenomenological design was adopted. Nineteen primary caregivers of children diagnosed with CP were recruited through purposive sampling. Data were collected via three focus group discussions conducted at the Centre for the Rehabilitation of the Paralysed (CRP), Savar, Bangladesh. Discussions lasted 30–35 minutes and were analyzed using Braun and Clarke's thematic analysis framework.

Results: Four major themes emerged: (1) misconceptions and knowledge gaps regarding CP; (2) cultural and religious influences on healthcare decision-making; (3) family and social dynamics shaping caregiving practices; and (4) structural and functional barriers to care and participation. Key subthemes included misunderstandings about CP causes and prognosis, reliance on spiritual or traditional treatments, influence of elders in decision-making, gendered caregiving

responsibilities, social stigma, financial constraints, environmental inaccessibility, and limitations in daily participation.

Conclusion: Cultural beliefs, stigma, family pressure, and socioeconomic barriers significantly affect access to care and participation for children with CP in Bangladesh, increasing caregiver burden particularly for mothers. Culturally responsive rehabilitation strategies, caregiver education, and community awareness initiatives are essential to reduce misconceptions, promote early intervention, and strengthen family-centered care. Further research across diverse regions is recommended to inform inclusive service development.

Keywords: Cerebral palsy; cultural beliefs; healthcare barriers; stigma; caregivers; Bangladesh; rehabilitation; social inclusion.

CHAPTER I: INTRODUCTION

1.1 Background

Cultural beliefs frequently frame cerebral palsy as a result of divine punishment, fate, past sins, or supernatural forces, which contributes to stigma and social exclusion (Patel et al., 2017a). Families may experience blame, shame, and fear of judgment from the community, leading them to hide their children or delay seeking professional care (Mweshi et al.,2001). Such cultural barriers limit access to early diagnosis, rehabilitation services, and social participation, ultimately affecting children's developmental outcomes.

Cerebral palsy is medically well defined, its impact extends beyond physical impairment. The experiences of children with cerebral palsy and their families are strongly shaped by cultural context, social norms, and belief systems (Mweshi et al.,2001). In many low and middle-income countries, including Bangladesh, disability is often understood through cultural, religious, and traditional explanations rather than biomedical perspectives (Patel et al., 2017a).

Social stigma remains a major cultural barrier for children with cerebral palsy. Negative community attitudes often result in discrimination, isolation, and reduced opportunities for education and inclusion (Jia Qi et al., 2023). These beliefs not only affect children but also place significant emotional and social burdens on parents and caregivers. In many contexts, children with cerebral palsy are perceived as incapable of learning or contributing to society, leading to exclusion from schools and community activities (Jia Qi et al., 2023).

Low awareness and limited understanding of cerebral palsy further reinforce cultural barriers. Families with limited access to information may rely on traditional healers or spiritual interventions before seeking medical or rehabilitation services (Patel et al., 2017a). Financial constraints, combined with cultural misconceptions, discourage many families from continuing long-term rehabilitation, especially in resource-limited settings (Mweshi et al.,2001). Exploring cultural barriers and contextual influences is critical for informing inclusive policies, improving service delivery, and strengthening rehabilitation systems. By focusing on cultural context, this study seeks to understand how beliefs, stigma, and social norms shape the experiences of children with cerebral palsy and their families. Such insights are necessary to promote awareness, reduce stigma, improve access to care, and enhance social participation for children with cerebral palsy in Bangladesh.

1.2 Justification of the study

Cerebral palsy is a lifelong neurological condition that affects movement, posture, and daily functioning. However, its impact goes beyond medical problems. The lives of children with cerebral palsy (CP) are strongly influenced by the cultural, social, and environmental contexts in which they live. In many societies, disability is misunderstood, and cerebral palsy is often seen as a curse, divine punishment, or the result of supernatural causes. These beliefs lead to stigma, discrimination, and social exclusion, creating barriers to healthcare, rehabilitation, education, and social participation for children and their families.

These issues show that cerebral palsy should not be viewed only as a medical condition but also as a social and cultural issue. Although the social model of disability highlights social barriers and discrimination, it does not fully consider how physical

impairment affects everyday life. Children with cerebral palsy face both physical challenges and cultural or social barriers. Understanding how these factors interact is important for developing family-centered and culturally appropriate services and interventions. There is a clear lack of research that focuses on cultural barriers faced by children with cerebral palsy, especially in low- and middle-income countries. In Bangladesh, very few studies explore how cultural beliefs, social stigma, and community attitudes affect children with cerebral palsy and their families. Most existing research focuses mainly on medical treatment and physical limitations, with little attention to social and cultural experiences. In addition, many studies are quantitative and do not capture the real-life experiences of families. This gap highlights the need for qualitative, context-specific research.

In Bangladesh, cultural beliefs, social stigma, and low awareness strongly influence how cerebral palsy is understood and managed. Families may experience isolation and may hide their children due to fear of judgment and discrimination. By exploring cultural contexts and barriers, this study aims to provide useful knowledge to support culturally sensitive healthcare, encourage early intervention, and promote inclusive policies. The findings may help reduce stigma, improve service use, and support better policies to improve the lives of children with cerebral palsy and their families.

1.3 Operational Definition

1.3.1 Cultural Context

Cultural context refers to the shared beliefs, values, traditions, religious interpretations, and social norms within a community that influence how cerebral palsy is understood, perceived, and managed by families and society (Mohamed Madi et al., 2019a).

1.3.2 Cultural Barriers

Cultural barriers refer to culturally rooted beliefs, misconceptions, attitudes, and practices such as beliefs in supernatural causation, stigma, shame, and discrimination that restrict access to healthcare, rehabilitation, education, and social participation for children with cerebral palsy (Patel et al., 2017b).

1.3.3 Stigma

Stigma refers to negative attitudes, labeling, discrimination, and social exclusion experienced by children with cerebral palsy and their families as a result of culturally influenced beliefs about disability (Lanfer et al., 2025).

1.3.4 Social Inclusion

Social inclusion refers to the participation of children with cerebral palsy in family life, education, community activities, and social interactions without discrimination or exclusion (Muderedzi et al., 2017).

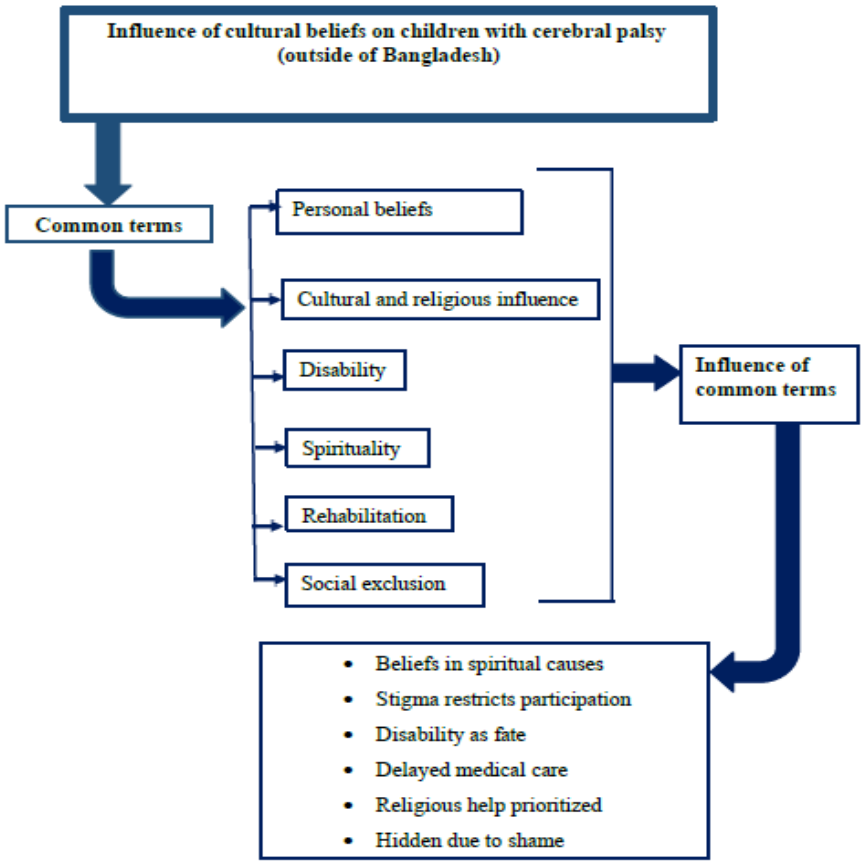
1.4 Aim of the study

This study aims to understand how cultural beliefs shape the decisions of families, influence access to therapy, and affect the overall well-being of the children. It seeks to explore how these beliefs impact the care and rehabilitation of children with cerebral palsy.

CHAPTER II: LITERATURE REVIEW

The student researcher conducted a comprehensive search of scholarly databases, including Google Scholar and PubMed, to identify relevant literature for this study. The search terms used were: “cultural beliefs OR cultural perceptions OR social beliefs OR parental beliefs” and “barriers faced by children with cerebral palsy” and “caregivers or parents or family experiences or parental views”. The initial search focused on studies conducted in South Asia and other low- and middle-income countries. However, due to the limited number of studies specifically addressing cultural beliefs and cerebral palsy, the search was later expanded to include global literature. Only peer reviewed articles published in English were included, with no restriction on year of publication.

Figure: 2.1 overview of Literature



2.1 Cultural and Traditional Beliefs About the Causes of Cerebral Palsy

Cultural and traditional belief systems play a significant role in shaping how cerebral palsy is understood and interpreted by families and communities, particularly in low- and middle-income countries (Mweshi et al.,2001). These beliefs influence not only the perceived causes of the condition but also families responses, coping strategies, and decisions regarding healthcare and rehabilitation (Mohamed Madi et al., 2019b). In many cultural contexts, cerebral palsy is not primarily viewed through a biomedical lens; instead, it is often explained using spiritual, religious, or supernatural frameworks (Mukushi et al., 2019).

Research conducted in South Africa revealed that parents and caregivers held diverse and sometimes conflicting beliefs about the causes of cerebral palsy, including prolonged or difficult labor, neonatal jaundice, curses, witchcraft, and divine punishment (Mukushi et al., 2019). Although some caregivers acknowledged medical explanations, limited awareness and understanding of neurological causes were evident, particularly among families from marginalized communities. These misconceptions often resulted in feelings of guilt, blame, and confusion, which further complicated the caregiving experience (Mweshi et al.,2001).

Similar patterns have been observed in Middle Eastern contexts. In Saudi Arabia, mothers of children with cerebral palsy frequently perceived the condition as a test from God or as part of divine will, reflecting the strong influence of religious beliefs on disability perceptions (Mohamed Madi et al., 2019c).While faith provided emotional comfort and acceptance for some mothers, it also shaped health-seeking behaviors, sometimes leading to delayed engagement with rehabilitation services (Mohamed Madi et al., 2019c). Religious and cultural norms therefore acted as both coping mechanisms and potential barriers to early intervention (Mohamed Madi et al., 2019c).

Studies from Zimbabwe further illustrate the complexity of cultural interpretations of cerebral palsy. Disability was commonly attributed to witchcraft, avenging spirits, or punishment from God, leading to harmful cultural and religious practices such as faith healing, isolation, or restriction of children within the home (Mukushi et al., 2019).These beliefs often resulted in abuse, neglect, and violation of children's rights (Mukushi et al., 2019). However, contrasting evidence from the Tonga community in Binga, Zimbabwe, demonstrated that cerebral palsy was sometimes viewed as a natural life occurrence, with children generally accepted as part of the community (Muderedzi et al., 2017). This contrast highlights that cultural beliefs are not homogenous and vary significantly even within the same country (Muderedzi et al., 2017).

Overall, the literature demonstrates that cultural and traditional beliefs strongly shape how cerebral palsy is perceived, understood, and managed across different contexts (Mweshi et al.,2001);(Mohamed Madi et al., 2019a);(Mukushi et al., 2019). These beliefs influence parental attitudes, treatment choices, and access to rehabilitation, emphasizing the need for culturally sensitive approaches in disability services (Muderedzi et al., 2017).

2.2 Caregiver Perceptions, Emotional Responses and Burden of Care

Caring for a child with cerebral palsy places substantial emotional, physical, social, and financial demands on caregivers, particularly in resource-limited settings (McNally & Mannan, 2013). The long-term nature of the condition, combined with limited support systems, often leads to caregiver stress, fatigue, and emotional distress (Menlah et al., 2020). Caregiver's perceptions of disability and its causes further shape their emotional responses and coping mechanisms (McNally & Mannan, 2013).

In Tanzania, caregivers described profound emotional strain related to continuous caregiving responsibilities, uncertainty about their child's future, and social

isolation within their communities (McNally & Mannan, 2013). Financial hardship was a recurring concern, as many families struggled to afford transportation, medical care, and rehabilitation services (McNally & Mannan, 2013).Limited availability of services and lack of professional support exacerbated caregiver burden and negatively affected their overall wellbeing (McNally & Mannan, 2013).

Similarly, in Ghana, caregivers of children with cerebral palsy reported extensive caregiving burdens affecting multiple aspects of their lives (Menlah et al., 2020). These included physical exhaustion, emotional stress due to stigma, marital strain, and loss of income (Menlah et al., 2020). Caregivers also expressed loneliness and helplessness due to limited social and governmental support (Menlah et al., 2020). The literature indicates that caregiving responsibilities extend beyond managing physical impairments and are deeply embedded within social and cultural contexts (McNally & Mannan, 2013; Menlah et al., 2020). Cultural gender roles often place the primary caregiving burden on mothers, increasing emotional stress and limiting self-care opportunities (Menlah et al., 2020).

2.3 Stigma, Discrimination, and Social Exclusion

Stigma associated with cerebral palsy remains a major barrier to social inclusion and healthcare access across cultural settings (Patel et al., 2017b). Negative societal attitudes and misconceptions often result in discrimination and reduced community participation (Lanfer et al., 2025).

In Botswana, stigma significantly influenced caregiver's daily lives and care-seeking behaviors (Patel et al., 2017b). Many avoided public transportation and community spaces due to fear of ridicule and judgment (Patel et al., 2017b). Stigma also affected decisions related to education and rehabilitation services. (Patel et al., 2017b)

Similarly, caregivers in Sierra Leone experienced verbal abuse, social rejection, and family exclusion rooted in cultural and spiritual beliefs (Lanfer et al., 2025). These experiences often led families to hide children or withdraw socially (Lanfer et al., 2025).

2.4 Awareness, Health-Seeking Behavior, and Utilization of Rehabilitation Services

Awareness and knowledge about cerebral palsy are critical determinants of health-seeking behavior (Sharma & Sinha, 2014). In many low-resource settings, misconceptions significantly hinder timely diagnosis and rehabilitation (Sharma & Sinha, 2014).

In India, families demonstrated low awareness of cerebral palsy, disability legislation, and rehabilitation services (Sharma & Sinha, 2014). Negative beliefs were significantly associated with socioeconomic status (Sharma & Sinha, 2014). Utilization of occupational therapy services was particularly poor (Sharma & Sinha, 2014).

2.5 Cultural Context and Parental Expectations of Rehabilitation

Parental expectations of rehabilitation are shaped by cultural values, socioeconomic conditions, and healthcare systems (Jindal et al., 2018). Understanding these factors is essential for family-centered rehabilitation planning (Jindal et al., 2018).

Indian parents emphasized physical function and mobility, while Canadian parents prioritized participation and environmental support (Jindal et al., 2018). These differences highlight the importance of culturally responsive rehabilitation services (Jindal et al., 2018).

2.6 Key Gaps in the Evidence

2.6.1 Geographical Gaps

Most existing studies on cerebral palsy have been conducted in African, Middle

Eastern, and South Asian countries outside Bangladesh, including South Africa, Zimbabwe, Saudi Arabia, Ghana, Tanzania, Botswana, India, and Sierra Leone. (McNally & Mannan, 2013; Menlah et al., 2020 ; Mohamed Madi et al., 2019a).While these studies provide valuable insights into cultural beliefs, stigma, and caregiver burden, evidence specific to Bangladesh remains limited. Furthermore, most available Bangladeshi data focuses on medical or epidemiological aspects, with minimal exploration of caregiver's psychosocial experiences and cultural influences on rehabilitation decisions.

2.6.2 Methodological Considerations

The majority of existing research relies on descriptive or cross-sectional designs, which limits understanding of caregiver's lived experiences and long-term adaptation processes. (McNally & Mannan, 2013; Menlah et al., 2020). Although qualitative studies exist, few have applied a phenomenological approach to deeply explore caregiver's perceptions of cultural beliefs, religious interpretations, and family dynamics. There is also limited integration of cultural, emotional, and functional dimensions within a single study, highlighting a need for context-sensitive qualitative research in low-resource settings.

2.6.3 Disability Coverage Gaps

Current literature mainly emphasizes physical impairments and caregiving burden, while giving less attention to children's participation, communication difficulties, and social inclusion (Jindal et al., 2018).Functional limitations affecting daily activities and peer interaction are underexplored, particularly from caregiver's perspectives. Moreover, limited evidence exists on how environmental barriers and rehabilitation access jointly affect family wellbeing in low-income contexts

2.6.4 Focus Gaps

Although caregiver stress and stigma are widely documented (Patel et al., 2017b). Fewer studies examine how cultural norms, religious beliefs, and extended family influence healthcare-seeking behavior and caregiving roles simultaneously. Additionally, little attention has been given to caregiver's resilience, coping strategies, and balancing faith with medical rehabilitation (Mohamed Madi et al., 2019c).The role of collective family decision-making and its impact on early intervention remains insufficiently explored.

CHAPTER III: METHODS AND MATERIALS

This chapter aims to present the study question, aim, and objectives, along with the methods used, including the rationale for the research design, study setting, study participants, ethical considerations, data collection process, data management and analysis, and trustworthiness.

3.1 Study Question, Aim and Objective

3.1.1 Study Question

In which ways do cultural beliefs influence the way children with cerebral palsy are cared for, treated, and included in society?

3.1.2 Aim

This study aims to understand how cultural beliefs shape the decisions of families, influence access to therapy, and affect the overall well-being of the children. It seeks to explore how these beliefs impact the care and rehabilitation of children with cerebral palsy.

3.1.3 Objective

- To identify social and cultural perspectives regarding children with cerebral palsy.
- To explore the influence of cultural factors on decision-making of parents about child.
- To explore the Barriers to participation and support system.

3.2 Study Design

3.2.1 Study method

This study adopted a qualitative research design to explore how cultural beliefs and social contexts shaped the lived experiences of children with cerebral palsy and their caregivers in Bangladesh. Qualitative research enables an in-depth understanding of human experiences by exploring perceptions, meanings, motivations, and behaviors within natural settings. The strength of qualitative research lies in its ability to capture rich, detailed narratives that reflect personal realities, cultural beliefs, social norms, and caregiving practices. This approach allowed caregivers to express their experiences in their own words, providing valuable insights into how cultural barriers influence participation and care for children with cerebral palsy (Muhammad et al., 2023).

Focus Group Discussions (FGDs) were used as the primary method of data collection. FGDs encouraged interaction among participants, allowing them to share, compare, and reflect on their caregiving experiences collectively. This method supported deeper exploration of shared cultural meanings and community influences while allowing flexibility in responses (Permanent, 1995). Through group discussion, participants were able to articulate challenges, beliefs, and coping strategies related to raising children with cerebral palsy within their cultural environment. To understand the essence of caregivers lived experiences, elements of a phenomenological approach were integrated into data collection and analysis. This supported the identification of meaningful patterns and themes grounded in parent’s real-life perspectives. The qualitative design therefore provided an appropriate framework to explore cultural barriers and caregiving experiences in depth.

3.2.1 Study Approach

A phenomenological approach was adopted to explore caregiver's lived experiences of raising children with cerebral palsy within their cultural context. Phenomenology focuses on understanding how individuals perceive and make meaning of their everyday experiences. This approach emphasizes participant's voices and allows researchers to gain insight into the subjective realities of their lives. It is particularly suitable for examining complex social phenomena because it focuses on participant's subjective experiences and interpretations rather than numerical measurement (Phenomenology In Qualitative, n.d.).

For this study, the phenomenological approach was considered most appropriate, as it supported an in-depth exploration of parental perspectives and highlighted the meanings caregivers assigned to their experiences of raising children with cerebral palsy in Bangladesh.

3.3 Study Settings and Period

3.3.1 Study Settings

Data for this study were collected from parents and primary caregivers of children with cerebral palsy. The participants were selected specifically from the Pediatrics Unit of the Centre for the Rehabilitation of the Paralysed (CRP), Savar.

3.3.2 Study Period

The study was conducted from 15 June 2025 to 15 December and data were collected from 2 August to 15 September 2025.

3.4 Study Participant

3.4.1 Study Population

Parents or primary caregivers of children (aged 2-12) diagnosed with cerebral palsy.

3.4.2 Sampling Techniques

A purposive sampling method was adopted for this study to select participants who could give meaningful insights into how cultural beliefs influenced the general quality of life of children with cerebral palsy.

3.4.3 Inclusion and Exclusion Criteria

(i) Inclusion Criteria

- Parents or caregivers of children with cerebral palsy (age 2-12) who are actively involved in their care and decision-making.
- Individuals willing to discuss their beliefs, experiences, and challenges related to raising a child with cerebral palsy.

(ii) Exclusion Criteria

- Caregivers who are unable to speak or communicate verbally will be excluded from the study.
- Caregivers with severe mental health conditions will also be excluded.

3.4.4 Sample Size

A total of 19 participants were included in this study. All participants were primary caregivers of children with cerebral palsy who met the inclusion criteria and were receiving services at the selected study setting in Bangladesh. Data were collected through three focus group discussions (FGDs). Two FGDs consisted of 6 caregivers each, and the third FGD consisted of 7 caregivers, giving a total of 19 participants (6 + 6 + 7= 19).

Table 3.1

Overview of focus group discussions

Number of focus group	Date	Location	Participants per group
FGD 1	3 August 2025	Centre for the Rehabilitation of the Paralysed (CRP), Paediatric Department, Inpatient Unit, Bangladesh	6
FGD 2	5 August 2025	Centre for the Rehabilitation of the Paralysed (CRP), Paediatric Department, Inpatient Unit, Bangladesh	6
FGD 3	17 August 2025	Centre for the Rehabilitation of the Paralysed (CRP), Paediatric Department, Inpatient Unit, Bangladesh	7

3.4.5 Participant Overview

A total of 19 participants participated in this study, and all were either parents or primary caregivers of children diagnosed with cerebral palsy. All had been actively involved with the daily care of their children, including physical support, therapy adherence, and educational supervision.

Data collection was carried out through three FGDs conducted at the Pediatrics Unit of the Centre for the Rehabilitation of the Paralysed (CRP), Savar. The participants were chosen with varied socio-economic and cultural backgrounds, representing both rural and semi-urban areas. For confidentiality purposes, pseudonyms were used to mask participant's identities. The participants and their characteristics are summarized in the following table:

Table 3.2

Overview of participants

Child name (pseudonym)	Age of child (years)	Sex	Relation with caregiver	Residence (rural /urban)
Kushum	2 years	Female	Mother	Rural
Arifa	2 years 5 months	Female	Mother	Rural
Mahin	3 years	Male	Mother	Urban
Reza	4 years	Male	Mother	Urban
Sayem	7 years 1 months	Male	Mother	Rural
Mohin	3 years 8 months	Male	Mother	Rural
Hamid	7 years 2 months	Male	Mother	Rural
Lamia	3 years 3 months	Female	Mother	Rural
Nadia	3 years	Female	Mother	Rural
Mahbub	4 years 8 months	Male	Mother	Rural
Sadaf	3 years	Male	Mother	Rural
Saima	2 years 28 days	Female	Mother	Rural
Soumik	7 years	Male	Mother	Urban
Naim	2 years	Male	Mother	Rural
Jannat	3 years	Female	Mother	Rural
Hasan	3 years	Male	Mother	Rural
Mahim	3 years	Male	Mother	Rural
Afia	2 years	Female	Mother	Rural
Sudip	5 years	Male	Mother	Urban

3.5 Ethical Considerations

This study followed the Helsinki Declaration guidelines. Ethical approval was obtained from the BHPI Institutional Review Board (IRB) through the Department of Occupational Therapy. The reference number is CRP-BHPI/IRB/07/2025/1093.

3.5.1 Informed Consent

All participants received an information sheet explaining the purpose of the study, procedures, expected duration, and potential risks. Written informed consent was taken before each interview. Participants were allowed to withdraw at any point without penalty.

3.5.2 Unequal Power Relationship

The researcher acknowledged the unequal relationship between interviewer and participant. Respectful interaction, non-judgmental listening, and clear explanation were maintained to reduce any pressure or influence.

3.5.3. Risk and Beneficence

The study involved no physical risk. Some emotional discomfort was possible while sharing personal experiences. Participants were assured of support if needed. The benefits included contributing to research that may improve services for children with CP.

3.5.4 Confidentiality

All collected data were kept confidential. Participant's names were replaced with codes, and recordings were stored securely. Only the researcher and supervisor had access to the data.

3.5.5 Power Relationship

Participants were reminded that their decision to participate or withdraw would not affect the therapy or services their child receives at CRP

3.6 Data Collection Process

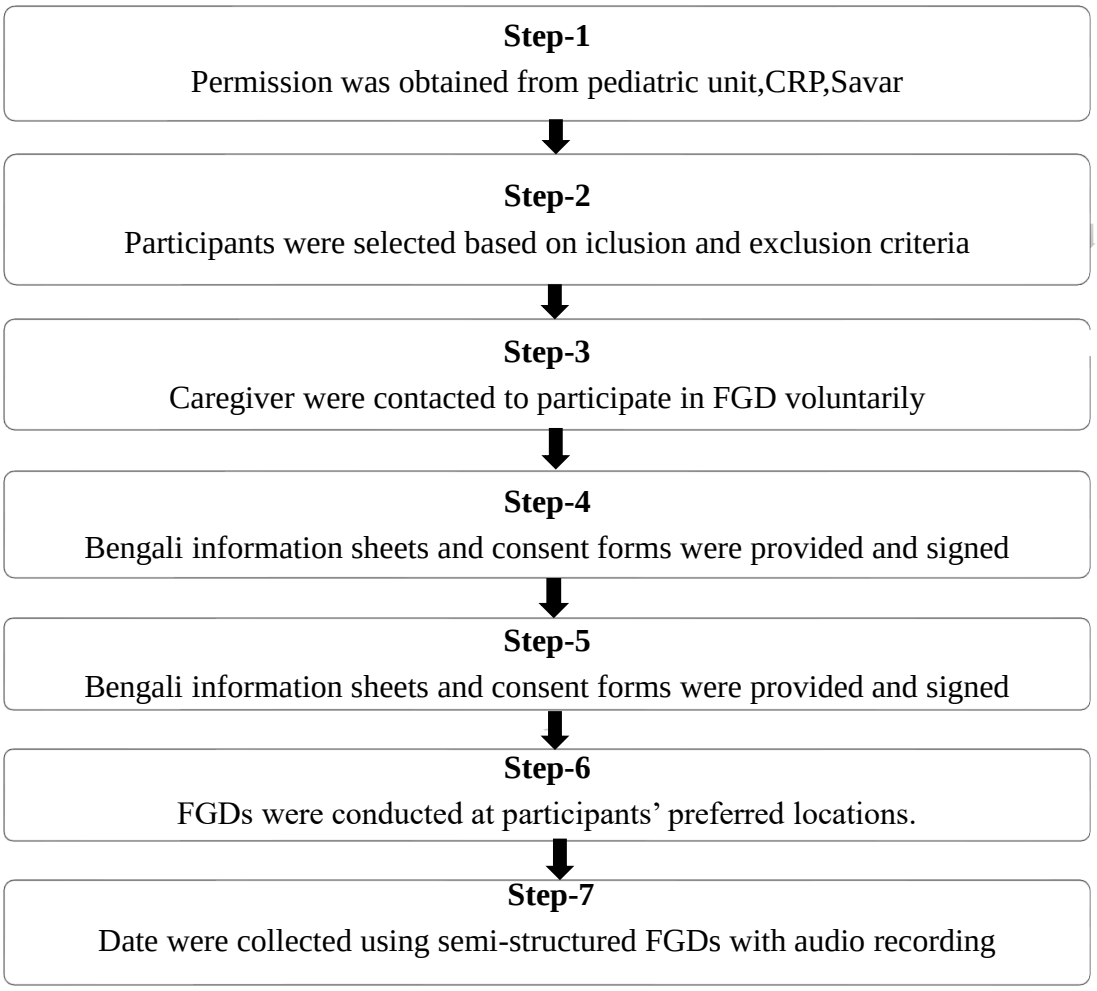
3.6.1 Participant Recruitment

The Centre for the Rehabilitation of the Paralysed (CRP), Savar, Pediatric unit was the source of the participants for the focus group discussion. The researcher contacted

parents who fit the inclusion criteria after obtaining departmental approval. Parents who were interested were invited to participate in the focus group after the study's purpose was explained. The information sheet and consent form were given to those who agreed to participate after the study's purpose was thoroughly explained. Until enough people were included and data saturation was reached, recruitment went on.

Figure 3.1

Overview of the participant recruitment process



3.6.2 Data Collection Method

Data for this study were collected through focus group discussions (FGDs) with caregivers of children with cerebral palsy. Focus group discussion is widely used in

qualitative research to gather rich narrative data and shared meanings through group conversation (Permanent, 1995).

The focus group discussion (FDGs) was used to gather data, allowing parents to discuss their experiences with one another. To ensure comfort and confidentiality, the FGD was held in a quiet, private room within CRP and was conducted in Bangla. The conversation lasted between sixty and ninety minutes. By directing the conversation, posing questions from the interview guide, and urging participants to speak freely, the researcher served as a moderator. With permission, an audio recording of the conversation was made. The group environment encouraged parents to freely share their opinions and react to one another's experiences, which deepened the data. This approach aligns with qualitative principles, which emphasize interactive and contextual exploration of lived experiences.

3.6.3 Field note

Field notes were taken and the two individual interviews. Before each session, the researcher noted the environment, the participant's initial expressions, and any factors that might influence their comfort level. After personal interviews, additional notes were written to record observations such as participant's non-verbal cues, emotional reactions, hesitations or important moments that were not captured in the audio recording. These field notes helped the researcher understand the context more clearly and supported the interpretation of the data. The notes added depth to the findings by providing insight into the participant's emotions, comfort, and overall interaction with the researcher. Conducting a pilot interview helps researchers refine questions, improve interviewing techniques, and receive feedback on the content and structure of the guide (Griffee, 2005).

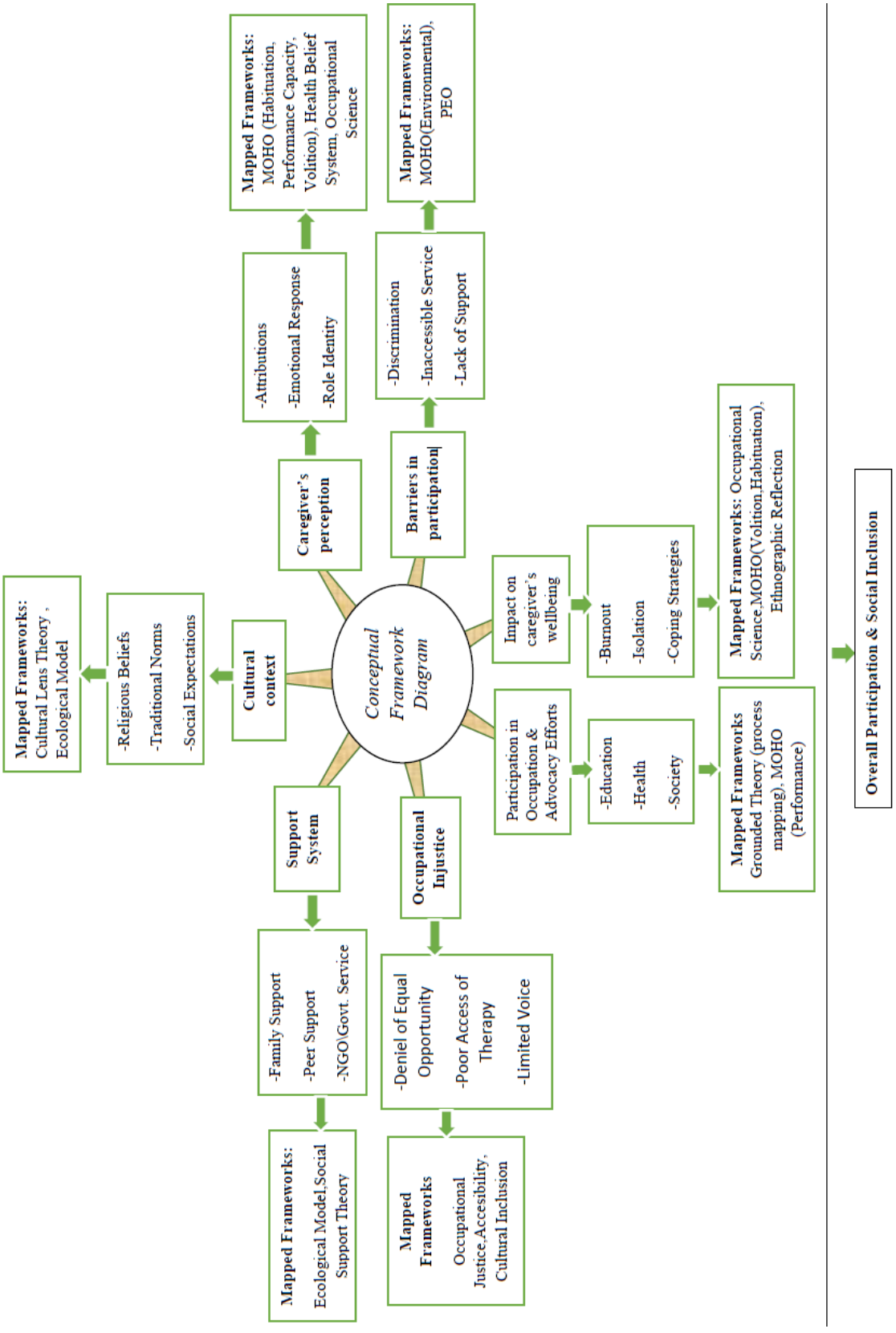
3.6.4 Data Collection Instrument

A semi-structured focus group discussion guide was used as the primary instrument for data collection. Semi-structured guides are commonly used in qualitative research because they combine the structure of a prepared questionnaire with the flexibility to explore emerging insights (Iii, 2010).This balance allows researchers to cover key topics while adapting to participants' spontaneous concerns.

The guide consisted of open-ended questions focusing on cultural beliefs, family and social influences, healthcare decision-making, financial priorities, and participation barriers experienced by caregivers of children with cerebral palsy. The semi-structured format enabled caregivers to share in-depth descriptions of their lived experiences while giving room for probing and clarification by the moderator. The guide was initially prepared in English and then translated into Bangla to ensure clarity and cultural relevance. Translation helped maintain participant's comfort and allowed them to express complex feelings and cultural narratives more naturally. The use of a semi-structured guide follows best practices in qualitative inquiry, which recommend open-ended questions to capture participant's worldviews and contextual interpretations.

Figure 3.2

Figure of conceptual framework



3.6.5 Reflective Diary

Throughout the focus group process, the student researcher maintained a reflective diary. The diary included personal reflections on the discussion, challenges faced during moderation, reactions to sensitive moments, and thoughts about emerging ideas. This helped the researcher remain aware of potential biases and maintain an objective approach. The reflective diary contributed to enhancing the trustworthiness and transparency of the study.

3.6.6 Non-Participant Role

The student researcher took the role of a non-participant moderator during the focus group. This means the researcher did not share personal opinions or take part in the conversation as a participant. The role was only to guide the discussion, listen attentively, and create a comfortable environment where parents felt free to speak. The researcher avoided influencing the responses and maintained professional boundaries throughout the session.

3.6.7 Data Management and Analysis

Data analysis in this study followed the six steps of thematic analysis by Braun and Clarke (2013). Thematic analysis is a method that helps researchers identify patterns and themes in data, especially when exploring complex issues like caregiving experiences. By using this method, the researcher was able to uncover deep and sometimes contradictory views that reflect real-life experiences.

The six steps followed in the analysis are described below:

Step 1: Familiarization with the data

The first step involved the researcher becoming familiar with the data. This was done by conducting interviews, transcribing them verbatim in Bangla, and translating them into English. A volunteer initially translated one of the transcripts, but the researcher

rechecked and retranslated it to ensure accuracy. All translations and transcriptions were further reviewed by the supervisor. Afterward, the researcher thoroughly read the transcripts and noted initial ideas and thoughts.

Step 2: Generating initial codes

In this step, the student researcher identified key points from the data by highlighting relevant sections. The researcher used a systematic approach to assign codes to interesting features across the entire dataset. The initial codes were reviewed and refined with the help of the supervisor.

Step 3: Generating themes

In the third phase, the student researcher wrote down all the codes on separate sheets of paper, organizing them by meaning. Similar codes were grouped together, and the researcher worked closely with the supervisor to review and refine the codes. These were then organized into potential themes and written on sticky notes. These sticky notes were placed on the wall to help visualize the relationships between concepts and identify emerging themes.

Step 4: Reviewing potential themes

The student researcher then reviewed the codes and potential themes again, checking if the identified relationships made sense. A thematic map was created to show how themes and sub-themes were related. The findings were discussed with the supervisor to refine the themes. By the end of this phase, twelve potential themes and sub-themes emerged.

Step 5: Defining and naming themes

The student researcher revisited the themes and sub-themes, refining and merging them as necessary. After careful review, nine final themes were identified. Each theme and sub theme was then given a specific name and clear definition to ensure they were easy

to understand. The supervisor helped in the final review of these themes to ensure accuracy and consistency.

Step 6: Producing the report

In the final step, the student researcher wrote the results section for the thesis. This included detailed descriptions of each theme, supported by verbatim quotes from the participants to clearly present the findings. These quotes were used to ensure the themes truly reflected the participant's experiences.

3.7 Trustworthiness and Rigor

The trustworthiness of this study was maintained by following methodological and interpretive rigor (Fossey et al., 2002).

3.7.1 Methodological Rigor

3.7.1.1 Congruence

The research design was carefully chosen to match the philosophical approach of the study. A phenomenological approach was selected because it closely aligned with the research aim, which was to explore the lived experiences of caregivers. (see Section 3.6.7:Data Management and Analysis).

3.7.1.2 Responsiveness to Social Context

Investigating the real-life issue, which is referred to as responsive to social context, was utilized in an emergent research design (Fossey et al., 2002).

The study was designed to be responsive to real-life issues. Data were collected through face-to-face interviews in a setting convenient for the participants, helping the researcher gain a better understanding of the context in which caregiving happens.

3.7.1.3 Appropriateness and Adequacy: The sample, data collection methods, and analysis procedures were all well-suited to the research goals. Convenience sampling was used to select participants, and data were collected through face-to-face interviews

to ensure rich, detailed information was gathered.

3.7.1.4 Typicality: This refers to how well the results can be applied to different contexts (Fossey et al., 2002). The student researcher provided a detailed description of the study's context to ensure a clear understanding for the readers (see Sections 3.2 and 3.6.7:Participant Overview and Data Management and Analysis).

3.7.1.5 Transparency: The student researcher was responsible for all data collection and analysis steps. The supervisor was actively involved in reviewing and providing feedback at each stage, ensuring there was no bias in the process.

CHAPTER IV: RESULTS

This chapter discusses the influence of cultural belief faced by children with cerebral palsy. There are four themes, and multiple sub-themes for each theme were developed from focus group discussion. An overview of the themes and sub-themes are included in Table 4.1

Table 4.1
Overview of result

Theme	Sub theme
Theme One: Misconceptions and Knowledge Gaps Surrounding Cerebral Palsy	Knowledge Gaps Regarding the Causes and Progression of Cerebral Palsy
	Lack of Awareness and Advocacy Related to Rehabilitation Services
	Cultural Myths and False Explanations Surrounding Disability
Theme Two: Cultural and Religious Determinants of Healthcare Decision-Making	Cultural Beliefs Influencing Healthcare-Seeking Behavior
	Spiritual and Religious Interpretations Directing Treatment Decisions
	Cultural Norms Shaping Perceptions of Responsibility and Care
Theme Three: Family and Social Dynamics in Decision-Making for Children with CP	Influence of Elders and Extended Family on Parental Decisions
	Impact of Social Criticism and Stigma on Parental Decision-Making
	Negotiating Parental Authority within Collective Family Structures
Theme Four: Structural and Functional Barrier to Participate and Care	Financial Strain and Occupational Disruption Influencing Core Priorities
	Environmental and Structural Barrier to Participation
	Functional Limitations Offering Daily Activities and Inclusion

4.1 Theme one: Misconceptions and Knowledge Gaps Surrounding Cerebral Palsy

This theme explores how caregivers experienced widespread misunderstandings

and inaccurate beliefs about cerebral palsy in their communities. Parents explained that most people around them, including relatives and neighbors, had very limited understanding of the condition. Many assumed it was a temporary problem that would improve on its own or compared it to ordinary childhood weakness. Such misconceptions caused emotional distress, confusion, and feelings of guilt among parents, who often had to explain and defend their child's situation.

4.1.1 Knowledge Gaps Regarding the Causes and Progression of Cerebral Palsy

Caregivers demonstrated insufficient knowledge regarding the causes, neurological basis, and long-term progression of cerebral palsy, often leading to confusion about prognosis and expectations. Caregivers described that people often misunderstood the causes and nature of cerebral palsy. Many believed that CP was a temporary illness or a simple developmental delay that could resolve with basic care. Some parents shared that people compared their child's condition to fever or general weakness, which made them feel their concerns were ignored. One mother said,

"People kept telling me that it is nothing serious, just a phase like other childhood illness. They said if I feed him properly and let him rest, he will get better, but nothing worked. I felt helpless and alone" (Participant-1, FGD-1).

These experiences highlight the confusion and emotional pain caused by knowledge gaps about CP. Another caregiver shared, "Even relatives said I did something wrong during pregnancy and that's why my child is like this. It hurt me deeply because I took care of everything during pregnancy" (Participant-2, FGD-2).These experiences highlight the confusion and emotional pain caused by knowledge gaps about CP.

4.1.2 Inadequate Awareness of Rehabilitation and Advocacy Resources

There was a significant lack of awareness about available rehabilitation services, early intervention programs, and advocacy mechanisms, limiting timely and informed healthcare engagement. Parents reported that awareness about rehabilitation services was very low. Many caregivers did not know about rehabilitation service. Some families felt lost because they had no guidance and were often laughed at when they tried to explain therapy benefits. One mother explained,"I tried telling neighbors that therapy can help, but they just laughed and said it won't work. I felt very lonely. If someone had explained these services earlier, my child could have started therapy sooner." (Participant-3, FGD-1)

The absence of advocacy programs made parents feel that they had to educate the community themselves, which added stress and frustration.

4.1.3 Cultural Myths and False Explanations Surrounding Disability

Cultural narratives and misinformation contributed to false explanations of disability, including supernatural or moral interpretations, shaping attitudes toward care and intervention. Cultural myths about the causes of cerebral palsy were common. Some people believed that the child's condition was a curse, punishment for sins, or caused by maternal actions during pregnancy. One mother said,

"Some elders told me that my child's condition is because of a curse and suggested rituals to fix it. I tried some because I didn't know better. Later I realized these were all myths, but the stress was very high" (Participant-4, FGD-2).

Another caregiver stated," People said my child is like this because of my past sins. I cried many nights feeling guilty and hopeless. I had no idea what to do, and it made everything harder" (Participant-5, FGD-1).

4.2 Theme Two: Cultural and Religious Determinants of Healthcare Decision-Making

This theme explains how cultural beliefs and religious understanding strongly shaped how caregivers interpreted cerebral palsy and how they made decisions about treatment. For many families, medical knowledge was not the first source of understanding. Instead, community advice, cultural traditions, and spiritual explanations guided early responses to the child's condition. Parents often described confusion during the initial stage, where they struggled to understand whether their child's condition required medical care or spiritual healing. These beliefs influenced when therapy started, what type of treatment was chosen, and how consistently rehabilitation services were followed.

4.2.1 Cultural Beliefs Influencing Healthcare-Seeking Behavior

Traditional health beliefs and community norms influenced pathways to care, including reliance on informal or non-medical sources before accessing rehabilitation services. Cultural beliefs played a significant role in shaping healthcare-seeking behavior among caregivers. Many parents reported that when they first noticed developmental delays, they did not immediately seek professional help. Instead, they listened to family elders, neighbors, and community members who reassured them that the child would improve naturally. Cerebral palsy was frequently misunderstood as temporary weakness or delayed growth rather than a permanent neurological condition.

Several caregivers explained that advice from others encouraged them to try home remedies, traditional healing, or spiritual practices before consulting doctors. This created long delays in diagnosis and rehabilitation. Parents described feeling pressured to follow community suggestions even when they personally felt

something was wrong. Cultural expectations of respecting elders often prevented mothers from questioning such advice. One mother explained how people constantly minimized her concerns that-

"Everyone around me kept telling me that my child is just slow and will be fine with time. They said not to waste money on doctors and therapy. I listened to them because I trusted their experience. Months passed, and nothing improved. Only then did I realize that listening to people instead of professionals cost us precious time." (Participant-1;FGD-2)

Another caregiver shared how fear-based messages affected her emotionally:"My child had severe jaundice, so I took him for phototherapy at the hospital. People say I allowed to harm the baby by giving phototherapy treatment."(Participant-2;FGD-2)

Cultural beliefs also created guilt and self-blame. Parents often questioned their own actions during pregnancy or childbirth due to community pressure. These experiences left caregivers emotionally exhausted and uncertain about the right path for treatment. Even after starting therapy, many families continued to struggle with mixed messages from society, which affected their confidence in rehabilitation.

4.2.2 Spiritual and Religious Interpretations Directing Treatment Decisions

Religious frameworks played a central role in meaning-making, influencing acceptance of disability and decisions regarding medical versus spiritual interventions. Spirituality played a complex and deeply emotional role in caregiver's experiences. For many parents, faith served as a coping mechanism, offering hope during difficult times. Prayer was described as a source of strength, helping caregivers manage stress, exhaustion, and uncertainty. Several parents expressed belief that healing

ultimately depends on Allah, and they regularly prayed for their child's recovery. In fact, religious interpretations also influenced treatment decisions in ways that sometimes delayed rehabilitation. Some caregivers described being advised to rely solely on prayer, holy water, or spiritual rituals. These suggestions often came from respected religious figures or elders, making it difficult for parents to refuse. One mother explained, "she felt torn between her responsibility to seek medical care and her belief in divine healing. "Feelings of guilt were commonly reported. Parents shared that community members suggested their child's condition resulted from past sins. Such comments deeply affected emotional wellbeing, leading to self-blame and sadness. One mother shared her struggle:

"People told me that maybe Allah is testing me or punishing me for something I did before. I started blaming myself. I cried at night asking Allah what mistake I made. I prayed constantly, but deep inside I also knew that prayer alone is not enough. Still, it took time for me to accept therapy."(Participant-4;FGD-2)

Despite this, many caregivers eventually adopted a balanced approach, combining faith with medical treatment. They emphasized that while prayer provides emotional comfort, therapy and rehabilitation are essential for physical improvement. One mother explained that she prays regularly but also ensures her child attends therapy, believing both are important.

This sub-theme shows that religion functioned both as emotional support and as a potential barrier to consistent healthcare engagement. While faith strengthened resilience, misinterpretations contributed to delays in treatment. These findings highlight the importance of integrating religious understanding into health education, helping families see medical care as compatible with spiritual belief rather than separate from it.

4.2.3 Cultural Norms Shaping Perceptions of Responsibility and Care

Sociocultural expectations defined caregiving responsibilities, often assigning primary caregiving roles to mothers within patriarchal or collectivist family systems. This sub-theme describes how cultural expectations and traditional gender roles shaped caregiver's understanding of responsibility and daily care for children with cerebral palsy. Mothers reported that caregiving was widely viewed as their primary duty, while fathers were often expected to focus on financial responsibilities. These norms placed a heavy emotional and physical burden on mothers, who became the main providers of daily care, therapy routines, feeding, hygiene, and emotional support.

Many mothers explained that society automatically blamed them when their child showed developmental difficulties. They felt judged for not doing enough even when they were already overwhelmed. Caregivers described how relatives and neighbors frequently questioned their parenting, reinforcing the belief that child disability was linked to maternal failure. This created deep feelings of guilt, exhaustion, and self-doubt. Some mothers also shared that household duties continued alongside caregiving, leaving little time for rest. They struggled to balance therapy appointments, home exercises, cooking, cleaning, and caring for other children. Despite this workload, emotional support for mothers was limited, as cultural norms discouraged expressing distress openly. One caregiver shared that-

"Everyone expects me to handle everything because I am the mother. From morning to night only I feed him, clean him, take him to special school, and still manage housework. If something goes wrong, people blame me first." (Participant-8; FGD-2)

In contrast, father's involvement was often viewed as optional or exceptional. When fathers participated in caregiving, mothers expressed gratitude rather than seeing it as shared responsibility. This reflects how deeply gendered expectations shaped family roles. Another mother explained, "My husband is very kind. He helps sometimes…he supports us financially." (Participant-3;FGD-3)

4.3 Theme Three: Family and Social Dynamics in Decision-Making for Children with CP

This theme explains how family structure, extended relatives, and social surroundings strongly influenced parents' decisions regarding care and treatment for children with cerebral palsy. Caregivers described that raising a child with CP was not an individual responsibility but deeply shaped by collective family systems and community expectations. Mothers especially reported limited autonomy in making healthcare decisions, as elders and relatives often held authority. Emotional wellbeing was also affected by constant social observation, judgment, and unsolicited advice.

Parents shared that they had to balance their own understanding with family pressure. While some families provided encouragement and support, others unintentionally delayed treatment by minimizing the child's condition or offering traditional advice. Social stigma further increased parental stress, influencing decisions related to schooling, therapy attendance, and community participation. Many mothers expressed emotional exhaustion from managing caregiving alongside family expectations.

4.3.1 Influence of Elders and Extended Family on Parental Decisions

Decision-making processes were frequently shaped by senior family members, reflecting hierarchical and collective family structures. Elders and extended family

members played a central role in shaping decisions about treatment and care. Parents described that grandparents, uncles, aunts, and neighbors often gave strong opinions about their child's condition. In many cases, caregivers followed this advice due to cultural respect for elders, even when they felt uncertain. This often resulted in delayed medical consultation and rehabilitation. Several parents explained that elders advised waiting, believing the child would develop normally over time. Others discouraged therapy, viewing it as unnecessary. Mothers shared that living in joint families made it difficult to oppose this opinion. One caregiver explained that-

"People told us that this is not something that needs a doctor. Everyone said to wait to see what happened next. Because elders said it, we listened. I wanted to go earlier, but they said the child will improve naturally. Later we understood that we should have taken medical help much earlier." (Participant-4;FGD-3)

However, positive family involvement also existed. Some fathers actively participated in caregiving, which reduced emotional burden on mothers. Supportive partners helped with feeding, bathing, and transport to therapy sessions. One mother stated: "My husband takes full responsibility when I am not there. He feeds him, cleans him, and carries him. He never complains. That support gives me strength. Without him, managing everything would be impossible."(Participant-6;FGD-2).These contrasting experiences highlight how family influence could either delay care or strengthen caregiving capacity.

4.3.2 Impact of Social Criticism and Stigma on Parental Decision-Making

Experiences of stigma and social judgment influenced parental confidence, healthcare choices, and social participation. Social criticism and stigma deeply shaped parental decisions and emotional wellbeing. Parents described facing judgmental

comments, staring, and negative labeling from neighbors and community members. These experiences led many caregivers to withdraw socially and limit their child's exposure to public spaces. Mothers reported that people often compared their child with typically developing children, creating feelings of shame and inadequacy. Some avoided enrolling their children in school due to fear of rejection or ridicule. Social pressure also reduced participation in community activities, leaving families isolated. One mother said, "My child cannot walk or talk, so I did not admit him to school. I just assumed no school would accept him. I was afraid of people's judgement." (Participant-5,FGD-2).Another caregiver described emotional distress caused by social reactions like this-

"When people talk badly about my child, it feels like he is not even seen as human. I hear their comments and feel empty inside. Sometimes I go to another room and cry quietly. These words hurt more than the physical work of caring for him."

These experiences demonstrate how stigma limited children's opportunities while increasing caregiver's emotional burden. Parents constantly navigated between protecting their child from harm and wanting them to participate in education and social life.

4.3.3 Functional limitations offering daily activities and inclusion

This sub theme describes how children's physical and communication limitations directly affected their ability to participate in daily activities and social inclusion. Caregivers explained that motor impairments, poor balance and dependence on others made even simple daily tasks difficult. These limitations reduced children's independence and placed a continuous physical and emotional burden on caregivers, particularly mothers, who became responsible for almost all aspects of

daily care.

Parents shared that their children could not walk independently, had difficulty sitting, feeding themselves, or communicating basic needs. Because of this, caregivers had to assist with every activity, including bathing, dressing, feeding, and mobility. Mothers described carrying their children from one place to another throughout the day, which caused physical exhaustion and body pain. Despite their fatigue, caregivers continued these tasks without rest, as there was often no alternative support. One mother explained these feelings by saying-

"He cannot walk on his own, so I carry him everywhere. From one room to another, when I go outside, when I cook, he is always with me. There is no one else to help most of the time. It becomes very tiring, but as a mother I cannot stop." (participant-1;FGD-2)

Functional limitations also affected children's ability to engage in play and social interaction. Parents reported that other children often avoided playing with their child due to communication difficulties or slow movements. Some children were unable to understand social cues such as smiling or gestures, which further reduced peer interaction. This lack of engagement created emotional distress for caregivers, who felt heartbroken seeing their child excluded. Parents further explained that public spaces were not designed for children with disabilities. Uneven roads, lack of ramps, and crowded transport made taking children outside extremely challenging. Because of these barriers, many families preferred to stay at home, which further isolated both the child and caregiver.

Overall, functional limitations significantly restricted children's daily participation and increased caregiver burden. Mothers described feeling physically exhausted and emotionally overwhelmed, yet continued providing constant care.

These challenges highlight how disability affects not only the child but the entire family system, influencing routine activities, social inclusion, and caregivers' wellbeing.

4.4 Theme Four: Structural and Functional Barrier to Participate and Care

This theme describes how financial hardship, environmental limitations, and children's functional difficulties created major barriers to participation and caregiving. Parents reported that even when they wanted to provide proper education, therapy, and social exposure for their children, structural challenges made these goals difficult to achieve. Limited access to disability-friendly schools, lack of transportation, financial pressure, and absence of inclusive community spaces restricted children's involvement in everyday activities.

Caregivers explained that their lives became centered around managing treatment, household responsibilities, and constant supervision of their child. Many mothers reported social isolation, as they avoided gatherings due to fear of negative comments. Physical exhaustion was common, especially among mothers who carried their children everywhere and managed care alone.

4.4.1 Financial Strain and Occupational Disruption Influencing Core Priorities

Financial pressure strongly influenced caregiving decisions. Parents described spending large amounts on medical visits, therapy, transport, and sometimes traditional healers. Some caregivers had to reduce work hours or stop working completely to provide full-time care, which further increased economic stress.

Several families explained that although disability cards and allowances existed, many were unaware of these services or received limited support. Mothers emphasized that financial help alone was not enough; they also needed emotional

and practical assistance. Another mother explained how caregiving affected employment-

"I do everything myself. His father has left, so managing both children becomes very difficult. I worry about money all the time. Therapy is expensive, and there is no fixed income. Sometimes I feel trapped between caring for my child and thinking how to survive." (Participant-3;FGD-1)

Families also described losing money on traditional healers before starting medical treatment, which increased financial burden.

4.4.2 Environmental and Structural Barrier to Participation

These environmental barriers reduced opportunities for learning, interaction, and emotional development. Environmental barriers significantly limited children's participation in education, play, and social activities. Parents reported absence of inclusive schools, lack of trained teachers, unsafe transport, and negative community attitudes. Many caregivers assumed schools would reject their child due to physical and communication difficulties. One mother explained: "My child cannot speak or walk, so I did not admit him to school. I just assumed no school would accept him. There are no children of the same age nearby. I avoid socializing because people say hurtful things."(Participant-3;FGD-3). Social stigma also prevented outdoor participation. Some parents avoided events to protect their children from gossip or judgment. Another caregiver described community reactions-

"I don't take my child out because people make shameful comments. Groups of people talk about him. Neighbors keep their children away, thinking it might spread. I tell people not to invite us anywhere. Anyone who talks badly about my child should not expect favors from us." (Participant-6;FGD-1)

4.4.3 Functional Limitations Offering Daily Activities and Inclusion

The child's motor and functional challenges, compounded by environmental barriers, limited engagement in education, play, and community participation. Functional limitations increased caregiver fatigue and emotional distress while reducing children's chances of social inclusion. Children's physical and communication difficulties further restricted independence and daily participation. Caregivers described constant lifting, feeding, cleaning, and supervising, leaving little time for rest. Mothers reported carrying their children everywhere, managing drooling, and handling mobility challenges alone. One caregiver shared, "He cannot walk or talk. When I go somewhere, I take him with me. There is no place to leave him."(Participant-2;FGD-2).Another mother explained: "My child cannot walk properly or move independently. Other children want to play but cannot match his pace. He does not understand smiles or play. That is why children cannot interact with him fully." (Participant-5;FGD-3). Functional limitations increased caregiver fatigue and emotional distress while reducing children's chances of social inclusion. In that fact one mother said, "He cannot interact with other children, and neighbors often avoid him for his drooling." (Participant-2; FGD)

CHAPTER V: DISCUSSION

This study aimed to understand the misconceptions and cultural beliefs about cerebral palsy (CP) and how these beliefs affect the care and decision-making process for children with CP. The findings revealed significant cultural barriers, including misunderstanding of CP and social stigma, which impact caregiving decisions and access to support. These results are in line with previous research, indicating that cultural perceptions strongly influence how families approach care and treatment.

A major theme that emerged from the study was the knowledge gap regarding CP. Many caregivers reported that community members frequently misinterpret the causes of CP, attributing it to common illnesses like fever or minor injuries during pregnancy. This finding mirrors earlier studies that highlight how cultural beliefs can lead to misconceptions about the condition (Mohamed Madi et al., 2019b). Some caregivers expressed frustration at the persistence of these misunderstandings despite their attempts to educate others. This misinformation often leads to delays in seeking appropriate medical care. As some caregivers reported, people around them insisted on traditional healing methods instead of modern medical treatments, resulting in further confusion and delayed intervention**.** These findings highlight the urgent need for public awareness campaigns that provide clear, fact based information about CP and its causes, as caregivers expressed a desire for simple, accurate explanations to help them advocate for their children more confidently.

In addition to the knowledge gap, lack of awareness and advocacy emerged as a significant barrier. Many caregivers reported the need for broader public education to correct misconceptions about CP and reduce the stigma attached to it. This supports findings from previous studies that show how stigma can discourage caregivers from

seeking care and lead to social isolation (Patel et al., 2017a).One mother highlighted the emotional toll of social judgment, saying, “Attitudes of people around cause the most stress to mothers. They judge our children as they raise their own.” This sentiment suggests that family education programs and community-based advocacy efforts are needed to create a more supportive environment for children with CP and their families.

The study also explored how cultural beliefs influence the decision-making process regarding healthcare. Many parents initially interpreted their child’s condition through a cultural lens, relying on superstitions and traditional beliefs rather than seeking immediate medical advice. This delay in seeking professional care was often due to cultural interpretations, such as the belief that the child’s disability was caused by spiritual interference or past sins. These beliefs led some parents to consult traditional healers first, delaying early diagnosis and biomedical treatment. These findings underscore the importance of integrating cultural understanding into healthcare settings. Healthcare providers need to engage with families in a way that respects cultural beliefs while promoting medical care. Understanding the cultural context of families can help reduce barriers to early diagnosis and ensure that caregivers are more likely to seek timely and appropriate treatment for their children. Many mothers reported receiving conflicting advice, with some relatives insisting that the child’s condition could be treated through traditional healing rather than medical care. Despite these pressures, most mothers in the study were determined to prioritize medical treatment for their children, even when faced with strong opposition from family members.

The study also found that physical and social barriers significantly hindered children with CP from fully participating in daily life and community activities. Caregivers reported that inaccessible infrastructure**,** lack of specialized schools, and

limited mobility aids restricted their children's ability to engage in education and social activities. These findings suggest that inclusive education and community participation programs should be developed to ensure that children with CP have the same opportunities as other children. Improving public infrastructure to be more accessible and providing support for mobility aids can significantly enhance the participation of children with CP in everyday life.

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Strengths

- Focus group discussions allowed open sharing and group interaction, which increased data depth and transparency of experiences.
- Audio recordings and field notes supported transparency and accuracy by capturing real voices, non-verbal expressions, and context.
- The qualitative design was suitable for meeting the study aims and exploring emotional and cultural issues.
- The qualitative approaches used in this study were the best fit for achieving the goal and objective.
- Future studies on this phenomenon will benefit from the findings of this study

6.1.2 Limitations

- The study included a small number of participants from only one rehabilitation center, limiting generalization.
- Some caregivers may not have fully shared sensitive experiences due to group discussion settings.
- As this is the first time a student researcher has conducted a study, any unintentional mistakes would affect the data's richness and quality.

6.2 Practice Implication (recommendation for future practice and research)

- The findings have important implications for rehabilitation, occupational therapy, and policymaking by highlighting cultural beliefs, caregiving burdens, and participation barriers faced by children with cerebral palsy.

- Occupational therapists can use these insights to design culturally sensitive interventions that address family beliefs, caregiving roles, and functional participation.
- Rehabilitation centers can develop caregiver education programs to reduce misconceptions about cerebral palsy and promote early intervention.
- Community-based awareness initiatives can be developed to reduce stigma and promote social inclusion of children with cerebral palsy.

6.2.1 Recommendation for Future Practice

- Future studies should include larger and more diverse samples across different geographical areas to improve generalizability.
- Comparative studies between urban and rural caregivers may help identify contextual differences in access to services and social support.
- Mixed-method research designs combining qualitative and quantitative approaches could measure functional outcomes, caregiver stress, and quality of life.
- Future research may include perspectives of healthcare professionals and educators to develop a more comprehensive understanding of care pathways for children with cerebral palsy.

CHAPTER VII: REFERENCE

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. The Australian and New Zealand Journal of Psychiatry, 36(6), 717–732. https://doi.org/10.1046/j.1440-1614.2002.01100.x

Griffee, D. T. (2005). *Research Tips: Interview Data Collection*. https://www.researchgate.net/publication/234757803_Research_Tips_Interview_Data_Collection

Iii, D. W. T. (2010). Qualitative Interview Design : A Practical Guide for Novice Investigators Qualitative Interview Design : A Practical Guide for Novice Investigators. 15(3), 754–760.

Jia Qi, L., Bee Mohd Hussain, R., & Giman Stephen, S. (2023). Cultural Beliefs towards Children with Disabilities: Perceptions of Parents in the Klang Valley, Malaysia. In The Malaysian Journal of Social Administration (Vol. 17).

Jindal, P., MacDermid, J. C., Rosenbaum, P., DiRezze, B., & Narayan, A. (2018). Perspectives on rehabilitation of children with cerebral palsy: exploring a cross-cultural view of parents from India and Canada using the international classification of functioning, disability and health. Disability and Rehabilitation, 40(23), 2745–2755. https://doi.org/10.1080/09638288.2017.1356383

Lanfer, H. L., Anderson, E., Bah, F., Krawiec, S., Rossmann, C., & Vines, A. (2025). Experiences of stigma among caregivers of children with disabilities in Freetown. 1–14.

McNally, A., & Mannan, H. (2013). Perceptions of caring for children with disabilities: Experiences from Moshi, Tanzania. African Journal of Disability, 2(1). https://doi.org/10.4102/ajod.v2i1.21

Menlah, A., Appiah Osei, E., Garti, I., Appiah, S., Frempomaa Agyare, D., Kwaku Agyen, J., Alorse Atakora, C., Amo Kwaning, D., & Ashriia Amoah, G. (2020). Perceptions and Experiences of Caregivers of Children with Cerebral Palsy in a Sub Urban District of Ghana. https://doi.org/10.21203/rs.3.rs-65343/v1

Mohamed Madi, S., Mandy, A., & Aranda, K. (2019a). The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia. Global Qualitative Nursing Research, 6. https://doi.org/10.1177/2333393619844096

Mohamed Madi, S., Mandy, A., & Aranda, K. (2019b). The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia. Global Qualitative Nursing Research, 6. https://doi.org/10.1177/2333393619844096

Mohamed Madi, S., Mandy, A., & Aranda, K. (2019c). The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia. Global Qualitative Nursing Research, 6. https://doi.org/10.1177/2333393619844096

Muderedzi, J., Eide, A. H., Braathen, S. H., & Stray-Pedersen, B. (2017). Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe. Cogent Social Sciences, 3(1). https://doi.org/10.1080/23311886.2017.1418144

Muhammad, D., Aslam, Z., Khan, K., Ashiq, A., Bibi, U., & Words, K. (2023). Phenomenology Qualitative Research Inquiry : A Review Paper. 9–13.

Mukushi, A. T., Makhubele, J. C., & Mabvurira, V. (2019). Cultural and Religious Beliefs and Practices Abusive to Children With Disabilities in Zimbabwe. Global Journal of Health Science, 11(7), 103. https://doi.org/10.5539/gjhs.v11n7p103

Patel, P., Baier, J., Baranov, E., Khurana, E., Gambrah-Sampaney, C., Johnson, A., Monokwane, B., & Bearden, D. R. (2017a). Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study. Child: Care, Health and Development, 43(6), 861–868. https://doi.org/10.1111/cch.12490

Patel, P., Baier, J., Baranov, E., Khurana, E., Gambrah-Sampaney, C., Johnson, A., Monokwane, B., & Bearden, D. R. (2017b). Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study. Child: Care, Health and Development, 43(6), 861–868. https://doi.org/10.1111/cch.12490

Permanent, G. D. (1995). Introducing focus groups ’ P. 311, 299–302.

Phenomenology In Qualitative. (n.d.). 1–15.

Sharma, R., & Sinha, A. G. K. (2014). A study on the awareness, beliefs, and service utilization among families of children with cerebral palsy in Jalandhar District of Punjab. CHRISMED Journal of Health and Research, 1(3), 170. https://doi.org/10.4103/2348-3334.138886

Unknown - Unknown - mweshi-mpofu-2001-the-perceptions-of-parents-and-caregivers-on-the-causes-of-disabilities-in-children-with-cerebral-annotated. (n.d.).

APPENDICES

Appendix A: Ethical Approval Form and Permission Letter
Ethical Approval Letter from IRB

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

Ref: CRP-BHPI/IRB/07/2025/1093 Date: 21.07.2025

To
Anika Tahsin Fima
4th Year B.Sc. in Occupational
Therapy Session: 2020-2021 Student
ID: 122200407

Subject: Approval of the thesis proposal **Navigating Cultural Context Barrier Faced by Children with Cerebral Palsy: Parent's Perspective** by ethics committee.

Dear Anika Tahsin Fima,
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 Prof Sk Moniruzzaman, Professor & Head, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP as thesis supervisor. The Following documents have been reviewed and approved:

SL No.	Name of the Documents
1	Research Proposal
2	Self-developed Interview Guide
3	Information sheet & consent form.

The purpose of the study is to understand how cultural beliefs shape caregiving and affect the overall participation of children with cerebral palsy. The study involves use of a self-developed interview guide to explore how cultural beliefs shape caregiving and affect the overall participation of children with cerebral palsy that may take 40 to 45 minutes to answer the Interview Guide and there is no likelihood of any harm to the participants. There is no benefit to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8:30 AM on 17 June, 2025 at BHPI (50th 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 regard,

Muhammad Millat Hossain
Associate Professor, Project and Course Coordinator, MRS
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭
CRP-Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd

Permission Letter for Data Collection

বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343 Tel: 02-7745464-5, 7741404, Fax: 02-7745069

Date: 02/08/2025

To
The head of the Pediatric Department
Centre for the Rehabilitation of the Paralysed (CRP)
CRP-Chapain, Savar, Dhaka-1343

Subject: Prayer for seeking permission to collect data for the research project

Sir,

With due respect to state that, I am a student of 4th year B. Sc. in Occupational Therapy department of Bangladesh Health Professions Institute (BHPI). In 4th year, I have to submit a research project to the University of Dhaka in partial fulfillment of requirements of the degree of Bachelor of Science in Occupational Therapy. My research title is **"Navigating Cultural Context Barrier Faced by Children with Cerebral Palsy: Parent's Perspective"** which is supervised by Prof. Sk. Moniruzzaman Professor & Head, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh. The purpose of the study is to understand how cultural beliefs shape caregiving and affect the overall participation of children with cerebral palsy.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.

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

Sincerely
Anika Tahsin Fima

Anika Tahsin Fima
4th year, B.Sc. in Occupational Therapy
Session: 2020-2021; Student ID: 122200407
Bangladesh Health Professions Institute
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

She will collect data from this Department please help her.
Thanks
7-08-25
Hosneara Perveen
Head of Department
Department of Paediatric
CRP, Savar, Dhaka

Recommendation from the Head of the Department:

Prof. Sk. Moniruzzaman
Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute
BHPI, CRP, Savar, Dhaka-1343, Bangladesh
Attachments: Copy of IRB Approval Letter.

Appendix B:Information Sheet and Consent Form **(English and Bangla Version)**

Participation Information Sheet (English Version)

Research Topic: Navigating cultural context barrier faced by children with cerebral Palsy

Researcher: Anika Tahsin Fima, B.Sc. in Occupational Therapy (4th Year), Session: (2020- 21), Bangladesh Health Professions Institute (BHPI), an academic institute of the Centre for the Rehabilitation of the Paralysed (CRP).

Supervisor: Prof Sk. Moniruzzaman ,Professor & Head,.Department of Occupational Therapy Bangladesh Health Professions Institute(BHPI)

Place of Research: The study will be conducted in Paediatric department,Inpatient unit, Centre for the Rehabilitation of the Paralysed (CRP)

Part 1: Information Sheet

Introduction

I am Anika Tahsin Fima, a 4th year B.Sc. student in Occupational Therapy at the Bangladesh Health Professions Institute (BHPI), affiliated with the Faculty of Medicine, University of Dhaka. As part of my academic requirements, I am conducting this research under the supervision of Prof Sk. Moniruzzaman ,Professor & Head,,Department of Occupational Therapy, BHPI.

The purpose of this study is to explore, through a cultural lens, how caregivers understand the barriers faced by children with cerebral palsy in their daily lives. Your experiences and insights will help reveal how cultural beliefs influence caregiving, access to therapy, and social participation. This understanding will support awareness-building and the development of better support systems. Participation involves a single interview lasting approximately 30–35 minutes. The study is completely safe, with no risks or harm to you, and there is no payment for participation.

Research Background and Objectives

You are invited to participate in this study because there is limited research in Bangladesh on how cultural beliefs affect the lives of children with cerebral palsy and their caregivers. This research seeks to Understand how cultural beliefs influence caregiving decisions, rehabilitation seeking behavior, and social attitudes toward cerebral palsy, Identify barriers and facilitators to accessing rehabilitation services due to cultural perceptions ,Explore the emotional and social impact of these beliefs on both the child and their family. Your participation will provide valuable insights that can

help improve awareness, support services, and disability inclusion policies in Bangladesh.Before signing the consent form, you will be provided with a detailed explanation of how the research will be conducted. If you agree to participate: You will be contacted by the researcher for a one-on-one interview at a time and place convenient for you.The semi-structure interview will take approximately 30-35 minutes and will focus on your beliefs, experiences, and perceptions about cerebral palsy.Your participation is entirely voluntary, and you can withdraw at any time without providing any explanation.

Benefits and Risks of Participation

There are no direct financial or material benefits for participating in this research. However, your insights will contribute to raising awareness and improving support systems for children with cerebral palsy and their families.There are no significant risks in participating, but discussing cultural beliefs and personal experiences may be emotionally sensitive for some participants. If you feel uncomfortable at any point, you may pause, skip a question, or withdraw from the study.

Confidentiality of Information

Your privacy and confidentiality will be strictly maintained.Your name and personal details will not be used in the final research report. Instead, pseudonyms will be assigned.Only the researcher and supervisor will have access to the raw data.Physical documents will be stored in a locked drawer, and electronic data will be securely stored on BHPI's computers and the researcher's personal laptop.The findings may be published in research journals, conferences, or academic discussions, but your identity will remain completely anonymous unless you provide explicit consent.

Information About Study Findings

The results of this study may be shared through academic publications, conferences, and social media to create awareness about cultural influences on disability care.

Participant Fees

There is no payment or financial incentive for participating in this research.

Source of Funding

This research is self-funded by the researcher and does not receive external funding.

Information about withdrawal from Participation

Even if you agree to participate, you have the right to withdraw at any time without giving any reason.

Complaints

If there is any complaint regarding the conduct of this research project, contact with the Association of Ethics. This proposal will be reviewed by Institutional Review Board (IBR), Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka-1343, Bangladesh, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka- 1343.

Bangladesh Health Professions Institute (BHPI)
Department of Occupational Therapy
CRP-Chapain, Savar, Dhaka-1343, Tel: 02-7745464-5, 7741404, Fax: 02-7745069

Consent Form
(Please read out to the participant)

Assalamu Alaikum,

I am Anika Tahsin Fima, a 4th year B.Sc. student in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), affiliated with the University of Dhaka. As part of my academic requirements, I am conducting a research project under the supervision of Prof Sk. Moniruzzaman, Professor & Head,,Department of Occupational Therapy, BHPI.

The title of my research is "Navigating Cultural Context Barriers Faced by Children with Cerebral Palsy:Parent's Perception".

The purpose of this study is to explore, through a cultural lens, how caregivers understand the barriers faced by children with cerebral palsy in their daily lives. Your experiences and insights will help reveal how cultural beliefs influence caregiving, access to the treatment & therapy, and social participation. This understanding will support awareness-building and the development of better support systems. Participation involves focus group discussion(FGD) lasting approximately 30–35 minutes. The study is completely safe, with no risks or harm to you, and there is no payment for participation.

All information shared by you will be kept strictly confidential. In any report or publication, your identity will remain anonymous unless you provide explicit permission. Participation is entirely voluntary, and you may withdraw at any time without any consequences. You also have the right to skip any question that you feel uncomfortable answering.

If you have any questions regarding the study, you may contact me Anika Tahsin Fima, or my supervisor Prof Sk. Moniruzzaman ,Professor & Head,Department of Occupational Therapy, BHPI

I consent to following:

Audio recording of interview

☐ YES

☐ NO

So, may I have your consent to proceed with the interview?

☐ YES

☐ NO

Signature & Date of Participant

……..

Participant’s Mobile no.:

……..

Signature & Date of Researcher

……..

BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
Department of Occupational Therapy
CRP-Chapain, Savar, Dhaka-1343
Tel: 02-7745464-5, 7741404 | Fax: 02-7745069

Withdrawal consent Form
(For voluntary withdrawal only)

Reason for Withdrawal:

……

……

……

……

……

……

……

Permission to use previous information:

☐ YES ☐ NO

Participant's Name: ……

Date: ……

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
অকুপেশনাল থেরাপি বিভাগ
সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩
ফোন: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ | ফ্যাক্স: ০২-৭৭৪৫০৬৯

তথ্যপত্র

ভূমিকা

আমি আনিকা তাহসিন ফিমা, ৪র্থ বর্ষের বি.এসসি. অকুপেশনাল থেরাপি শিক্ষার্থী, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের অধিভুক্ত। আমার শিক্ষাক্রমের অংশ হিসেবে আমি একটি গবেষণা পরিচালনা করছি। গবেষণাটি পরিচালনায় আমাকে তত্ত্বাবধান করছেন অধ্যাপক শেখ মনিরুজ্জামান, বিভাগীয় প্রধান, অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই।

গবেষণার উদ্দেশ্য হচ্ছে অভিভাবকদের অভিজ্ঞতা ও দৃষ্টিভঙ্গি থেকে জানা ,সাংস্কৃতিক ও সামাজিক প্রেক্ষাপট কীভাবে শিশুদের যত্ন, চিকিৎসা ও থেরাপি গ্রহণ এবং সামাজিক অংশগ্রহণে প্রভাব ফেলে তা অন্বেষণ করা। আপনার অভিজ্ঞতা ও মতামত আমাদেরকে বুঝতে সাহায্য করবে সাংস্কৃতিক বিশ্বাস কিভাবে চিকিৎসা ও থেরাপিতে প্রবেশাধিকার এবং সামাজিক অংশগ্রহণকে প্রভাবিত করে। এই গবেষণা সচেতনতা বৃদ্ধি এবং চিকিৎসা ব্যবস্থার উন্নয়নে সহায়ক হবে।অংশগ্রহণকারী ফোকাস গ্রুপের আলোচনায় অন্তর্ভুক্ত থাকবে, যা প্রায় ৩০–৩৫ মিনিট সময় নেবে। এই গবেষণায় সম্পূর্ণ নিরাপত্তা রয়েছে, আপনার কোনো ক্ষতি বা ঝুঁকি নেই, এবং অংশগ্রহণের জন্য কোনো অর্থ প্রদান নেই।

অংশগ্রহণের সুবিধা ও ঝুঁকি

গবেষণায় অংশগ্রহণের জন্য কোনো সরাসরি আর্থিক সুবিধা নেই। তবে, আপনার অভিজ্ঞতা শিশুদের এবং তাদের পরিবারের জন্য সচেতনতা বৃদ্ধি এবং সহায়ক ব্যবস্থা উন্নয়নে অবদান রাখবে। অংশগ্রহণের কোনো ঝুঁকি নেই, তবে সামাজিক বিশ্বাস আলোচনায় প্রকাশিত হতে পারে, তবে আপনার পরিচয় সম্পূর্ণ গোপন রাখা হবে, যদি না আপনি স্পষ্টভাবে সম্মতি দেন।

গবেষণার ফলাফল সম্পর্কিত তথ্য

এই গবেষণার ফলাফল একাডেমিক প্রকাশনা, কনফারেন্স এবং সামাজিক মাধ্যমে প্রচার করা হতে পারে, যাতে প্রতিবন্ধী যত্নে সাংস্কৃতিক ও সামাজিক প্রভাব সম্পর্কে সচেতনতা বৃদ্ধি পায়।

অংশগ্রহণের অর্থ

গবেষণায় অংশগ্রহণের জন্য কোনো অর্থ বা আর্থিক প্রণোদনা নেই।

অর্থায়নের উৎস

গবেষণাটি গবেষকের নিজস্ব তহবিল দ্বারা পরিচালিত এবং কোনো বহিরাগত অর্থায়ন নেই।

অংশগ্রহণ থেকে প্রত্যাহার

আপনি অংশগ্রহণে সম্মত হলেও, যেকোনো সময় কোনো কারণ ব্যাখ্যা না করেই গবেষণা থেকে সরে আসার অধিকার আপনার থাকবে।

অভিযোগ

এই গবেষণার কার্যক্রম সম্পর্কে কোনো অভিযোগ থাকলে, তা বিএইচপিআই-এর ইনস্টিটিউশনাল রিভিউ বোর্ড (IRB)-এর কাছে জানানো যাবে। এই বোর্ডের দায়িত্ব হলো গবেষণায় অংশগ্রহণকারীদের সুরক্ষা নিশ্চিত করা।

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

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
অকুপেশনাল থেরাপি বিভাগ
সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩
ফোন: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ | ফ্যাক্স: ০২-৭৭৪৫০৬৯

সম্মতিপত্র

(অংশগ্রহণকারীর কপি)

আমি আনিকা তাহসিন ফিমা, ৪র্থ বর্ষের বি.এসসি. অকুপেশনাল থেরাপি শিক্ষার্থী, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের অধিভুক্ত। আমার শিক্ষাক্রমের অংশ হিসেবে আমি একটি গবেষণা পরিচালনা করছি। গবেষণাটি পরিচালনায় আমাকে তত্ত্বাবধান করছেন অধ্যাপক শেখ মনিরুজ্জামান, বিভাগীয় প্রধান, অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই।

গবেষণার শিরোনাম হচ্ছে "সাংস্কৃতিক প্রেক্ষাপটে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের সম্মুখীন হওয়া প্রতিবন্ধকতাসমূহ: অভিভাবকদের দৃষ্টিভঙ্গি অনুযায়ী"।

গবেষণার উদ্দেশ্য হচ্ছে অভিভাবকদের অভিজ্ঞতা ও দৃষ্টিভঙ্গি থেকে জানা ,সাংস্কৃতিক ও সামাজিক প্রেক্ষাপট কীভাবে শিশুদের যত্ন, চিকিৎসা ও থেরাপি গ্রহণ এবং সামাজিক অংশগ্রহণে প্রভাব ফেলে তা অন্বেষণ করা। আপনার অভিজ্ঞতা ও মতামত আমাদেরকে বুঝতে সাহায্য করবে সাংস্কৃতিক বিশ্বাস কিভাবে চিকিৎসা ও থেরাপিতে প্রবেশাধিকার এবং সামাজিক অংশগ্রহণকে প্রভাবিত করে। এই গবেষণা সচেতনতা বৃদ্ধি এবং চিকিৎসা ব্যবস্থার উন্নয়নে সহায়ক হবে।অংশগ্রহণকারী ফোকাস গ্রুপের আলোচনায় অন্তর্ভুক্ত থাকবে, যা প্রায় ৩০–৩৫ মিনিট সময় নেবে। এই গবেষণায় সম্পূর্ণ নিরাপত্তা রয়েছে, আপনার কোনো ক্ষতি বা ঝুঁকি নেই, এবং অংশগ্রহণের জন্য কোনো অর্থ প্রদান নেই।

আপনি যে কোনো তথ্য প্রদান করবেন তা সম্পূর্ণ গোপন রাখা হবে। কোনো প্রকাশনায় আপনার পরিচয় প্রকাশিত হবে না, যদি না আপনি স্পষ্টভাবে অনুমতি প্রদান করেন। অংশগ্রহণ সম্পূর্ণ স্বেচ্ছামূলক, এবং আপনি যেকোনো সময় কোনো প্রভাব ছাড়াই প্রত্যাহার করতে পারবেন। এছাড়াও, কোনো প্রশ্ন যদি আপনি উত্তর দিতে অস্বস্তিকর মনে করেন, তবে আপনার তা এড়ানোর অধিকার রয়েছে।

গবেষণা সম্পর্কিত কোনো প্রশ্ন থাকলে, আপনি আমাকে আনিকা তাহসিন ফিমা অথবা আমার তত্ত্বাবধায়ক প্রফেসর শেখ মনিরুজ্জামান, অধ্যাপক ও প্রধান,অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই এর সাথে যোগাযোগ করতে পারেন।

আমি নিম্নলিখিত বিষয়টি সম্মতি দিচ্ছি:

সাক্ষাৎকারটি অডিও রেকর্ড করা হবে

☐ হ্যাঁ

☐ না

তাহলে, আমি কি সাক্ষাৎকার গ্রহণের জন্য আপনার সম্মতি পেতে পারি?

☐ হ্যাঁ

☐ না

অংশগ্রহণকারীর স্বাক্ষর ও তারিখ:.....

অংশগ্রহণকারীর মোবাইল নম্বর:

গবেষণাকারীর স্বাক্ষর ও তারিখ:.....

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)
অকুপেশনাল থেরাপি বিভাগ
সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩
ফোন: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ | ফ্যাক্স: ০২-৭৭৪৫০৬৯

সম্মতি প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছামূলক প্রত্যাহারের জন্য)

প্রত্যাহারের কারণ:

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

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি:

☐ হ্যাঁ ☐ না

অংশগ্রহণকারীর নাম: .....

তারিখ: .....

Appendix C : Interview Guide (English and Bangla Version)

Socio-demographic information:

Child's Name:

ID Number:

Child's Age:

Birth Order:

Type of Cerebral Palsy:

Primary Caregiver of the Child:

Caregiver's Name:

Caregiver's Age:

Caregiver's Educational Qualification:

Religion:

Residence (Village/Urban):

Family Type:

Primary Decision Maker in the Family:

District:

Interview guide

1.Social and Cultural Perspectives

-How do you think people around you or society view your child’s disability?

2. Superstitions and Misconceptions

-Have you ever encountered any superstitions or misconceptions about your child’s disability? If so, please explain in detail.

3. Cultural Influence on Medical and Decision-Making

-In your opinion, how have family, social, or religious opinions influenced your decisions regarding your child’s medical treatment or therapy?

4. Barriers to Participation

-Due to cultural or social reasons, has your child ever faced difficulties in participating in school, play, or social events?

5. Support System

-In a social context, what kind of support or lack of support do you regularly feel from family, neighbors, friends, colleagues, or society?

6. Need for Positive Change

-In your view, what changes in society's outlook or in the cultural environment would make your child's life easier?

-What advice would you give to other parents who, like you, have children with disabilities?

Socio-demographic information(Bangla)

১. শিশুর নাম:

২. আইডি নাম্বার:

৩. শিশুর বয়স:

৪. কততম সন্তান:

৫. শিশুর সেরিব্রাল পালসির ধরন:

৬. শিশুর প্রধান অভিভাবক:

৭. অভিভাবকের নাম:

৮. অভিভাবকের বয়স:

৯. অভিভাবকের শিক্ষাগত যোগ্যতা:

১০. ধর্ম:

১১. বাসস্থান(গ্রাম/শহর):

১২. পরিবারের ধরন:

১৩. পরিবারের প্রধান সিদ্ধান্ত গ্রহণকারী:

১৪ জেলা:

Interview guide (Bangla)

১. সামাজিক ও সাংস্কৃতিক দৃষ্টিভঙ্গি

-আপনার সন্তানের প্রতিবন্ধিতা নিয়ে আশেপাশের মানুষ বা সমাজের দৃষ্টিভঙ্গি কেমন বলে আপনি মনে করেন?

২. কুসংস্কার ও ভুল ধারণা

-আপনার সন্তানের প্রতিবন্ধিতা সম্পর্কে কি কখনো কোনো কুসংস্কার বা ভুল ধারণার সম্মুখীন হয়েছেন? যদি হয়ে থাকেন, কিভাবে তা বিস্তারিত বলুন।

৩. চিকিৎসা ও সিদ্ধান্ত গ্রহণে সাংস্কৃতিক প্রভাব

-সন্তানের চিকিৎসা বা থেরাপি নেওয়ার সিদ্ধান্তে পারিবারিক, সামাজিক বা ধর্মীয় মতামত কীভাবে প্রভাব ফেলেছে বলে মনে হয়?৪. অংশগ্রহণে প্রতিবন্ধকতা

-সাংস্কৃতিক বা সামাজিক কারণে আপনার সন্তান স্কুল, খেলা বা সামাজিক অনুষ্ঠানে অংশ নিতে কোনো সমস্যার সম্মুখীন হয়েছে কি?

৫. সমর্থন ব্যবস্থা

-আপনি সামাজিক প্রেক্ষাপটে পরিবার, প্রতিবেশী, বন্ধু, সহকর্মী বা সমাজ থেকে প্রতিনিয়ত কী ধরনের সহায়তা বা অসহায়তা অনুভব করেন?

৬. ইতিবাচক পরিবর্তনের প্রয়োজনীয়তা অনুভব

-আপনার মতে, সমাজের দৃষ্টিভঙ্গি বা সাংস্কৃতিক পরিবেশে কি ধরনের পরিবর্তন হলে আপনার সন্তানের জীবন আরও সহজ হতে পারত?

-আপনার মত আরো যারা আছেন যাদের সন্তান প্রতিবন্ধী, তাদের জন্য কি কি পরামর্শ দিতে চান?

Appendix D: Supervision Contact Schedule

Bangladesh Health Professions Institute
Department of Occupational Therapy
4th Year B. Sc in Occupational Therapy
OT 401 Research Project

Thesis Supervisor- Student Contact; face to face or electronic and guidance record

Title of thesis: Navigating cultural context Barrier faced by child with cerebral Palsy.

Name of student: Arika Tahsin Fima

Name and designation of thesis supervisor: Prof. SK Monirruzzaman, Professor and Department of Occupational Therapy, BHPI

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	28-05-25	BHPI Building	Title discussion	30 minutes	Need more study about objective	Fima	
2	29-05-25	BHPI Building	Title and proposal Discussion	1.5 hrs	Got valuable Feedback about proposal making and presentation	Fima	
3	14-06-25	Office room	IRB Presentation Discussion	1.5hrs	Presentation finalized	Fima	
4	19-06-25	office room	Discussion about questioning model	30 minutes	Suggested revision to enhance clarity	Fima	
5	1-06-25	Office room	Discussion model and questioning model	1.5 hours	Model finalized	Fima	
6	24-06-25	Library	Interview guide discussion	1.5 hours	Useful Feedback fore better data collection	Fima	
7	31-06-25	Library	Feedback about Interview guide	1.5 hours	Overall Feedback was positive	Fima	
8	5-08-25	Office room	Discussion about Objective framework, literature review	30 minutes	Objective and framework approved.	Fima	
9	19-08-25	Library	Feild test analysis and interview guide reviews	1.5 hours	Necessary modifications suggested	Fima	
10	21-08-25	Library	Discussion about interview guide and focus group discussion	2.5hours	Discussion was productive	Fima	
11	24-09-25	Library	Discussion about data collection and FGD	3 hours	Good progress observed	Fima	
12	27-09-25	Library	give feedback on transcription, translation	3 hours	Minor correction suggested on traslation	Fima	
13	06-11-25	Library	Guidline about coding	3.5 hours	Discussion about coding was effective	Fima	
14	18-11-25	Library	Discussion about thematic analysis	2.5 hours	Theme refined	Fima	

15	20-11-25	[redacted] Office room	Feedback on coding, theme, subtheme	2 hr	Minor refinements suggested for clarity	Fima	Amene
16	02-12-25	Library	Guideline about result writting and discussion	3 hr	Helpful guidance got for result and discussion	Fima	Amene
17	10-12-25	Library	overcall feedback on writeup	3 hr	Got feedback on grammatical correction	Fima	Amene
18	31-12-25	Library	Feedback on first draft result	2.5hr	Suggestions was given to strengthen result.	Fima	Amene
19	01-02-26	Office room	Feedback on full first draft	1hr.	Got constructive feedback	Fima	[signature]
20	16-02-26	Library	Feedback on writeup	2.5hr	Final version reviewed. Approved with minor correction	Fima	Amene

Note:

1. Appointment number will cover at least a total of 40 hours; applicable only for face to face contact with the supervisors.
2. Students will require submitting this completed record during submission your final thesis.