

Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood



By

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Statement of Authorship

Except where it is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or seminar. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree in any other tertiary institution. The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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Dedication

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List of Abbreviations

ADLs	Activities of Daily Living
BHPI	Bangladesh Health Professions Institute
CP	Cerebral Palsy
IADLs	Instrumental Activities of Daily Living
IRB	Institutional Review Board
MOHO	Model of Human Occupation
OT	Occupational Therapy/ Occupational Therapist
UK	United Kingdom
US	United States
WHO	World Health Organization

Abstract

Background: The transition to adulthood is a critical developmental stage. Adolescents with cerebral palsy (CP) in Bangladesh face unique challenges influenced by stigma, mobility limitations and limited access to therapy and rehabilitation services. Although many gradually gain independence in self-care and education, their experiences are shaped by cultural expectations, social attitudes and environmental barriers. Research in this area remains limited in low-resource settings like Bangladesh. Understanding their lived experiences is essential for strengthening support systems and promoting inclusion.

Aim: This study aims to explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process.

Methods: A qualitative phenomenological design was used. Purposive sampling selected adolescents diagnosed with CP. Data were collected through face-to-face, in-depth, semi-structured interviews guided by the Model of Human Occupation (MOHO). Thematic analysis was conducted following Braun and Clarke's six-step approach.

Results: Findings revealed both progress and ongoing challenges. Participants reported increased confidence and independence in academic and daily living activities. However, they experienced pain, stigma, mobility restrictions and limited therapy access. Family support, especially from mothers, played a vital role in promoting emotional resilience and independence. Despite barriers, adolescents expressed determination and hope for the future.

Conclusion: The transition to adulthood for adolescents with CP in Bangladesh is shaped by interconnected physical, social, emotional and cultural factors. Strengthening family support, inclusive education and access to rehabilitation services is essential to enhance independence and quality of life.

Keywords: Cerebral palsy, Adolescents, Transition to adulthood, Lived experiences.

CHAPTER I: INTRODUCTION

1.1 Background

Cerebral palsy (CP) is a collection of chronic, non-progressive, lifelong motor impairments. Presently, 80% of people with CP live to be over 30 and over 90% of them live past the age of 18 (Bagatell et al., 2017). The global incidence is generally reported to be between 2 and 3 per 1000 births (Paneth, 2021). This statistic probably understates the actual prevalence in LMICs (Paneth, 2021). The estimated number of children in Bangladesh who have cerebral palsy (CP) is 233 514 (95% CI: 219 778–254 118), while the observed prevalence is 3.4 per 1000 (95% CI: 3.2–3.7). Among them, spastic cerebral palsy affected 79.6%. Overall, 79.6% of the children with cerebral palsy had at least one associated handicap (67.6% had speech, 39.0% had intellectual, 23.7% had epilepsy, 10.2% had visual and 10.2% had hearing) (Khandaker et al., 2019). Being one of the largest groups of people with disabilities and the most prevalent major debilitating disorder in childhood that affects people for the rest of their lives, it is crucial to comprehend what life is like for those who have cerebral palsy (Carroll, 2015).

The process of gradually embracing new roles and adjusting current ones is known as transition (Bagatell et al., 2017). As adolescents and young adults transition from child-centered to adult-oriented healthcare systems, transition is defined as "the intentionally planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults (Ryan et al., 2023). For young people with physical disabilities like cerebral palsy and special health care needs, the transition to adulthood can be difficult (Bagatell et al., 2017).

The transition to adulthood for young people with cerebral palsy will be examined in this study with a focus on a number of important issues including Physical and health-related issues such as limited mobility, chronic pain, functional decline and the risk of additional health conditions with social isolation, communication difficulties and difficulty accessing higher education and employment because of societal biases and inadequate support systems (Jahnsen et al., 2020). Though the focus has been scattered with some research addressing education, others focusing on employment, and others on mental health, the emotional, social, and physical difficulties that people with cerebral palsy face throughout transition are becoming better understood (Dalgaard et al., 2021). Existing research will gain qualitative depth by integrating the viewpoints of adolescents with cerebral palsy (Ryan et al., 2023).

1.2 Justification of the study

Adolescence is a critical phase in human development marked by increasing autonomy, identity formation and social role changes. For adolescents with cerebral palsy (CP), this transition is often disrupted due to physical limitations, systemic barriers and lack of transitional planning (Bagatell et al., 2017). The lived experiences of adolescents with CP in South Asian settings like Bangladesh where cultural, economic, and gender norms significantly affect development remain underexplored (Boyle et al., 2022).

This age group represents the early-to-mid adolescent phase when life goals, roles and self-concept begin to emerge. These years are foundational for determining future occupational paths and social participation (Keller et al., 2007). Bangladeshi adolescents with CP face layered challenges including stigma, gender inequality, overprotective family roles and inaccessible public services all of which influence their journey to adulthood (Normann et al., 2022). Existing literature highlights that many

Bangladeshi adolescents with CP experience poor health-related quality of life and lack opportunities to build life skills or plan for adult roles (Winkens et al., 2023).

In collectivist societies like Bangladesh, family is central in decision-making. Adolescents are often not included in their own transition planning, making their direct voices essential for designing inclusive interventions (Magill-Evans et al., 2005). Research shows that most adolescents with CP receive little to no training in daily living, decision-making, or work readiness. OTs can bridge this gap through structured intervention programs (Ryan et al., 2023). In resource-limited countries, therapists often function as advocates and coordinators, helping clients and families navigate fragmented services and advocate for inclusive policies (Dimitrova et al., 2023; Bagatell et al., 2017). This study will help OTs develop culturally relevant, family-inclusive transition frameworks and contribute to holistic, client-centered rehabilitation in Bangladesh and similar contexts (Aviram et al., 2022).

1.3 Operational Definition

The operational definitions relevant to the study are given below:

1.3.1 Lived Experiences

A person's first-person description of their conscious experience, as subjectively interpreted and given meaning through reflection is referred to as lived experience. It focuses on how people interpret key life events, especially those that have emotional or developmental significance (J. A. Smith et al., 2010).

1.3.2 Cerebral palsy

Cerebral palsy (CP) is a brain disorder that appears in infancy or early childhood and permanently affects body movement and muscle coordination. Cerebral palsy is caused by changes in the developing brain that disrupt its ability to control movement and

maintain posture and balance. The term cerebral refers to the brain. Palsy refers to problems with movement (Paneth, 2021).

1.3.3 Adolescents

Adolescents are people who are 12 to 18 years old and going through biological, cognitive, emotional and social changes (WHO, 2014).

1.3.4 Journey to Adulthood

The term journey to adulthood involves a complex set of developmental, psychological and social processes where adolescents begin assuming adult roles, responsibilities and identities (Keller et al., 2007).

1.3.5 Social and Cultural Perspective

A theory known as the sociocultural perspective is applied in domains like psychology and education to raise awareness of the situations that surround people and the ways in which their unique behaviours are influenced by social and cultural elements. This refers to the combined influence of social structures, cultural beliefs and norms (Lopes et al., 2021).

1.4 Aim of the study

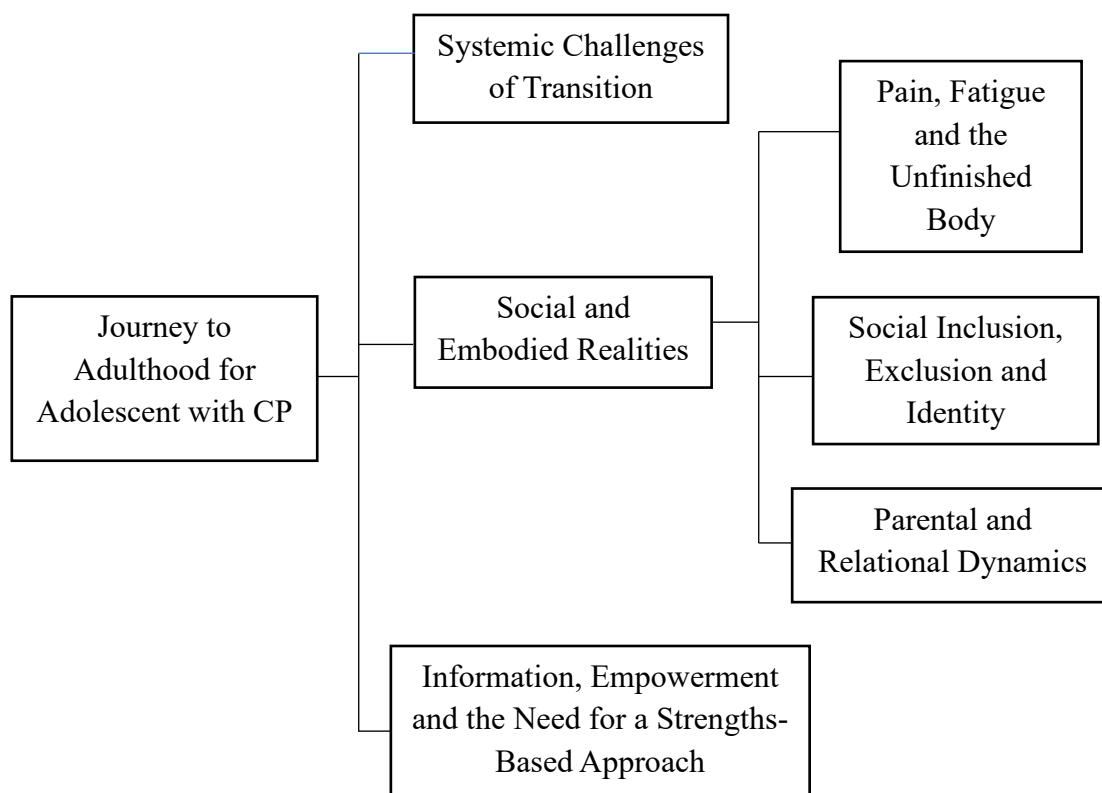
To explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process.

CHAPTER II: LITERATURE REVIEW

This chapter provides an overview of articles exploring the transition from adolescence to adulthood in adolescents with cerebral palsy (CP). Transitioning to adulthood requires taking on new roles, developing self-management skills and striving for independence, which can be especially challenging due to complex healthcare, education and social systems that often create stressful experiences. This literature review synthesizes research from the past twenty years to explore their experiences, the challenges they face and the support that helps them cope with this transition. Key gaps in the evidence are also identified and presented at the end of the chapter. Articles were retrieved through searches in Google Scholar and PubMed published over the last ten years.

Figure 2.1

Overview of Literature Review findings



2.1 Systemic Challenges of Transition

A growing body of qualitative research indicates that adolescents with cerebral palsy (CP) often experience difficulties when moving from child- to adult-oriented services. This transition is often described as fragmented, poorly planned and hard to manage. For example, qualitative interview studies from Ireland and Canada by Boyle et al. and Larivière-Bastien et al. reported that young people experience the transition as discontinuous and confusing. Similarly, Bagatell et al. (2017) using focus group interviews with young adults with CP in the United States, found that many felt unprepared for adult life, making this period stressful and overwhelming. In a Canadian qualitative interview study involving youth and adults with physical disabilities, further highlighted that the transition process often lacks continuity, coordination and cooperation between pediatric and adult healthcare providers (Young et al., 2009). This lack of coordination increases the challenges faced by adolescents. In contrast, some studies suggest that transition is not gradual but rather sudden. Adolescents are often “thrust into adulthood” with an abrupt reduction in services once they enter the adult system. Mwinbam et al. (2023), using a phenomenological interview approach with caregivers in Ghana, described how families experience a sudden withdrawal of services when children age out of child-focused care.

A cross-sectional study from Ireland involving 75 adolescents with CP showed that only a small number received essential transition supports such as having a named transition worker or meeting adult care teams before transfer (Ryan et al., 2023). Carroll, through semi-structured interviews with young adults with CP in the United States found that adult healthcare providers often have limited knowledge of CP. As a result adolescents are required to explain their condition and care needs themselves. In contrast, a Danish qualitative interview study suggested the use of care coordinators or

system “navigators” to help adolescents access adult services and reduce stress during transition (Normann et al., 2022).

2.2 Social and Embodied Realities

Research shows that growing up with CP is both a physical and social experience. Adolescents’ lives are shaped by their bodies, their environments and their relationships with others. Qualitative interviews with adolescents and families in Canada found that everyday experiences are closely linked to bodily changes and emotional responses during adolescence (Lariviere-Bastien et al.). Similarly, a phenomenological study from the UK described how young people experience daily life through their bodies, which affects their sense of time, space and participation (Finlay, 2014). A Swedish qualitative interview study also showed that relationships with family and peers strongly influence identity development and emotional well-being (Bjorquist et al., 2015). Together, these studies suggest that CP is not only a physical condition but also a social and relational experience that shapes how adolescents see themselves and interact with the world (Boyle et al., 2022; Aviram et al., 2022).

2.2.1 Pain, Fatigue and the Unfinished Body

Adolescents and young adults with CP frequently experience persistent physical discomfort including chronic pain and fatigue which significantly impacts daily life. Many qualitative studies report that adolescents and young adults with CP experience long-term pain and fatigue which significantly affect their daily activities. Interviews with adolescents with disabilities in Canada showed that ongoing pain reduces energy levels and limits participation in school, leisure and social activities (Lindsay, 2016). Caregiver interviews in Ghana revealed that pain is often linked to muscle tightness during growth and may sometimes require surgical intervention (Mwinbam et al., 2023). Studies from the UK further described how bodily functioning can be

unpredictable, with adolescents experiencing both good and bad days. This uncertainty often creates feelings of vulnerability and frustration (Magill-Evans et al., 2005). Other research highlighted that bodily challenges are closely connected to identity development with some adolescents viewing their bodies as barriers to normal life (S. E. Smith et al., 2021). This is consistent with McLaughlin & Coleman-Fountain also drawing from UK-based adolescent interviews, suggesting that societal and medical perspectives sometimes frame the body as unfinished further complicating self-perception and daily experiences.

2.2.2 Social Inclusion, Exclusion and Identity

Young people with CP often highlight the importance of social inclusion and accessible environments in their daily lives. Lindsay (2016), through Canadian qualitative interviews with adolescents found that they value leisure and recreation sometimes even more than functional goals emphasized by caregivers and clinicians. However, Stewart et al. in a qualitative Canadian study involving interviews with adolescents with disabilities, reported experiences of social exclusion and bullying in school, deeply affecting their sense of belonging. Despite these challenges, many adolescents actively work to build positive identities. Phenomenological interview studies showed that success is often defined by happiness, self-confidence and feeling accepted, rather than physical ability alone (Freeman et al., 2018b). Other qualitative findings also highlight adolescents' resilience and creative problem-solving skills as they adapt to environmental and social barriers (Kerklaan et al., 2020).

2.2.3 Parental and Relational Dynamics

Family relationships play a major role in how young people with CP experience the move toward adulthood. As Kim et al. in a U.S. qualitative study involving parents of

youth with disabilities, described the intensive emotional and practical responsibilities families face. Magill-Evans et al. using a qualitative multiple-case study with six Canadian families also found that parents often take on persistent advocacy roles. A study in Ireland using qualitative synthesis, suggested that many parents feel they must constantly fight with health, education, and social care systems taking on an ever-present combative responsibility (Boyle et al., 2023). Similarly, based on Swedish adolescent and parent interviews showed that young people rely heavily on their families to manage both daily challenges and major decisions (Bjorquist et al., 2015). On the contrast, Interviews with Canadian parents and adolescents suggested that autonomy is shaped not only by the young person's abilities but also by practical barriers such as limited accessible transport and by how much parents and professionals trust the young person's decision-making. As adolescents grow older this intense involvement can start to feel uncomfortable and may lead to tensions around independence and decision-making (Jahnsen et al., 2020; Ryan et al., 2023). Similarly, Freeman et al. through qualitative interviews in the UK and Canada, showed that parents' beliefs about their child's readiness for independence strongly influence the opportunities the young person has to make their own choices. This highlights the importance of professionals supporting both parents and young people, acknowledging that the young person's needs, interests and goals may not always match those of their parents.

2.3 Information, Empowerment and the Need for a Strengths-Based Approach

Across many qualitative studies, adolescents with CP report limited access to clear and timely information about adult life. This includes information on employment, education, relationships, sexuality, and independent living. Interviews from the UK,

Canada and Denmark consistently identified information gaps during the transition process (Freeman et al., 2018b; Normann et al., 2022). A meta-ethnography that combined international qualitative findings showed that adolescents want to feel informed, empowered, and involved in decisions about their lives. However, they often feel ignored due to power imbalances with parents and professionals (Boyle et al., 2022). Other studies emphasize the importance of self-advocacy skills, real-life practice and flexible individualized information to support readiness for adulthood ((Keller et al., 2007; Gaskin et al., 2021). On the contrast, opportunities to practice skills in real-life contexts can strengthen confidence and readiness for adulthood (Freeman et al., 2018b). These ongoing challenges point to the need for strengths-based services grounded in partnership, participation and respect for young people's rights (Boyle et al., 2023).

2.4 Key gaps of the study

- Most studies were published between 2010–2023 focus on the transition to adulthood for adolescents with CP, showing a narrow time frame.
- Most research on adolescents with CP comes from high-income countries and there is no study from Bangladesh, where health, social care and school systems work very differently.
- Adolescents with severe disabilities such as permanent wheelchair users are rarely included in studies.
- No research has looked at how factors like location, severity of disability and personal life experiences together shape the support available for adolescents with CP in Bangladesh.
- Most studies rely on small, interview-based designs with very few longitudinal or mixed-methods approaches to capture changes over time.

- The transition age group “teenagers moving into adulthood” is often underrepresented, with studies focusing mostly on children or adults.

This chapter highlights these gaps, providing an overview of what is known, the challenges in existing research and the need for studies that focus on the specific context and experiences of adolescents with CP in Bangladesh.

CHAPTER III: METHODS AND MATERIALS

This chapter includes the aim, ethical considerations, the study setting, the approach to sampling and recruitment, data collection procedures and data management and analysis.

3.1 Study Question, Aim, Objectives

3.1.1 Research Question

How do adolescents with cerebral palsy in Bangladesh experience their journey to adulthood and what social and cultural factors influence their journey?

3.1.2 Aim

To explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process.

3.1.3 Objectives

- To explore the perception about transitioning process of adolescents with cerebral palsy.
- To explore the social and cultural challenges faced by adolescents with cerebral palsy.
- To understand how family members' roles influence the transition to adulthood for adolescents with cerebral palsy within the cultural and social context.

3.2 Study Design

3.2.1 Study Method

This study adopts qualitative research is the most appropriate as it allows in-depth explanation of personal perspectives, feelings a qualitative research method, which is suitable for exploring the lived experiences of young people with cerebral palsy (CP) during their transition to adulthood. In this context, qualitative research is most appropriate because it attempts to fetch information on lived experiences of young people with cerebral palsy (CP) while making a transition to adulthood (Mackiewicz, 2018). Qualitative research is essential for understanding the experiences and challenges faced by individuals in ways that cannot be captured quantitatively. Since CP affects people differently, qualitative research will help capture the diversity in experiences including social, emotional and health care transitions. This allows the participants to voice their opinions and feelings to provide the researchers with detailed insights into the barriers and facilitators they face (Bjorquist et al., 2015).

3.2.2 Study Approach

A phenomenological approach has been used to capture participants' real-life experiences and their meaning-making processes (Mackiewicz, 2018). This study employed a phenomenological approach, as it intends to investigate the lived experience of young persons with cerebral palsy (CP) throughout their transition into adulthood. Since CP influences physical impairment, social interaction and emotional well-being, experience-centered narratives were vital to map subjective realities of young adults going through this transition (Bjorquist et al., 2015). This approach allowed the participants to reveal their own particular battles, hopes and coping mechanisms-awesome, first-person commentary that quantitative research might fail to perceive (Mackiewicz, 2018).

3.3 Study Setting and Period

3.3.1 Study Setting

The data for this study were collected from the William and Marie Taylor Inclusive School at CRP, Savar. The school provides a welcoming and inclusive environment where children with and without disabilities learn side by side. It offers accessible classrooms, trained teachers and ongoing support from CRP rehabilitation professionals, helping students build their academic, social and daily living skills in a supportive setting. Three of the participants were also staying at the Marigold Hostel at CRP. The hostel offers a safe and caring living environment for students with disabilities who stay on campus while attending school. Because the hostel and school are closely connected, students receive consistent care, supervision and easy access to therapy services throughout their daily routines.

3.3.2. Study Period

The study was conducted from 15 June 2025 to 15 December 2025. The data collection period was from 2 August 2025 to 15 September 2025.

3.4 Study Participant

3.4.1. Study Population

The participants in this study were adolescents aged 12–20 years with a confirmed diagnosis of Cerebral Palsy (CP).

3.4.2. Sampling Technique

The sample was collected among participants using a purposive sampling technique. Purposive sampling is used in research studies to select a specific group of individuals for analysis. This method is appropriate when the researcher has a clear idea of the characteristics and they are interested in studying, want to select a sample representative

of those characteristics. This technique will help to select adolescents with CP who are currently experiencing the journey to adulthood, making them the most informative candidates for the research (Mackiewicz, 2018). Participants were selected through purposive sampling because they met the inclusion criteria being within the required age range, having a diagnosis of CP and attending the William and Marie Taylor Inclusive School or staying in the Marigold Hostel. The criteria used to choose the participants are described below.

3.4.3. Inclusion and Exclusion Criteria

i. Inclusion Criteria:

- The adolescents who are clinically diagnosed with any form of cerebral palsy.
- Adolescents aged 12 to 20 years diagnosed with any form of cerebral palsy.
- Ability to communicate verbally.

ii. Exclusion Criteria:

- Individuals with severe cognitive impairments preventing meaningful participation. As severe cognitive impairments limit the individual's ability to understand questions, reflect on experiences and provide meaningful responses, they would be unable to participate reliably in a phenomenological interview process, which relies on reflective and communicative abilities (Uhre et al., 2024).

3.4.4 Study Sample

A total of 8 adolescents with CP took part in this study. They were selected because they had real, first-hand experiences with the transition to adulthood. The number of

participants was finalized when the interviews no longer brought new information, meaning the key ideas had already been clearly heard.

3.4.5. Participant Overview

An overview of the identified participants is presented in Table 3.1 in the next page

Table 3.1

Participants Overview

Pseudonym	Age (Years)	Sex	Type of CP	Mobility Status	Education Level
Rahim	14	M	Spastic Diplegic	Wheelchair user	Primary
Rashed	13	M	Spastic Diplegic	Wheelchair user	Primary
Jamila	15	F	Spastic Diplegic	Wheelchair user	Primary Special
Arif	20	M	Spastic Diplegic	Wheelchair user	Primary Special
Razzak	20	M	Spastic Hemiplegic	Walks independently	Vocational
Zakir	15	M	Spastic Diplegic	Wheelchair user	Primary Special
Rasheda	12	F	Spastic Diplegic	Wheelchair user	Primary
Sonali	13	F	Spastic Diplegic	Wheelchair & walking frame user	Primary

3.5 Ethical Considerations

As a statement of ethical principles for medical research, the World Medical Association (WMA) created the Declaration of Helsinki (World Medical Association, 2022). This ensures that the research adheres to ethical guidelines set by international and national research standards (Holstila et al., 2016).

3.5.1 Ethical Clearance

Ethical clearance has been obtained from the Institutional Review Board (IRB) of the Bangladesh Health Professions Institute (BHPI) by explaining the study purpose

through the Department of Occupational Therapy and the IRB clearance number is CRP-BHPI/IRB/07/2025/1102. All the participants have been informed that their information has been used in the research but their names and addresses will be confidential.

3.5.2 Informed Consent

Participants were asked to give both verbal and written consent before taking part in the face-to-face interviews. The researcher explained the purpose of the study in simple terms, and once the participants agreed to take part, their data was collected.

Information sheet:

Each participant was given an information sheet that clearly explained what the study was about, what they would be asked to do and the overall purpose of the research.

This helped them understand the study before deciding to join.

Consent form:

After being explained the purpose of the study, the participant was asked to voluntarily participate in the study. The consent was obtained through a written consent form.

3.5.3 Right of Refusal

Participants had the right to withdraw from participating in the study voluntarily. They were informed that they could withdraw their consent within 2 weeks from the data collection without providing any reason by informing the student. The student researcher provided the Bangla Translated Withdrawal Form to the participants. No participants withdrew their data, so all the data was included in the research.

3.5.4. Unequal Relationship

The researcher maintained an equitable relationship with the participants, devoid of any power dynamics or roles that could create imbalances in the relationship.

3.5.5. Risk and Beneficence

The student researcher ensured that participants faced no risks or adverse consequences as a result of their involvement in this study. Participants did not receive any financial or other incentives for participating in the study.

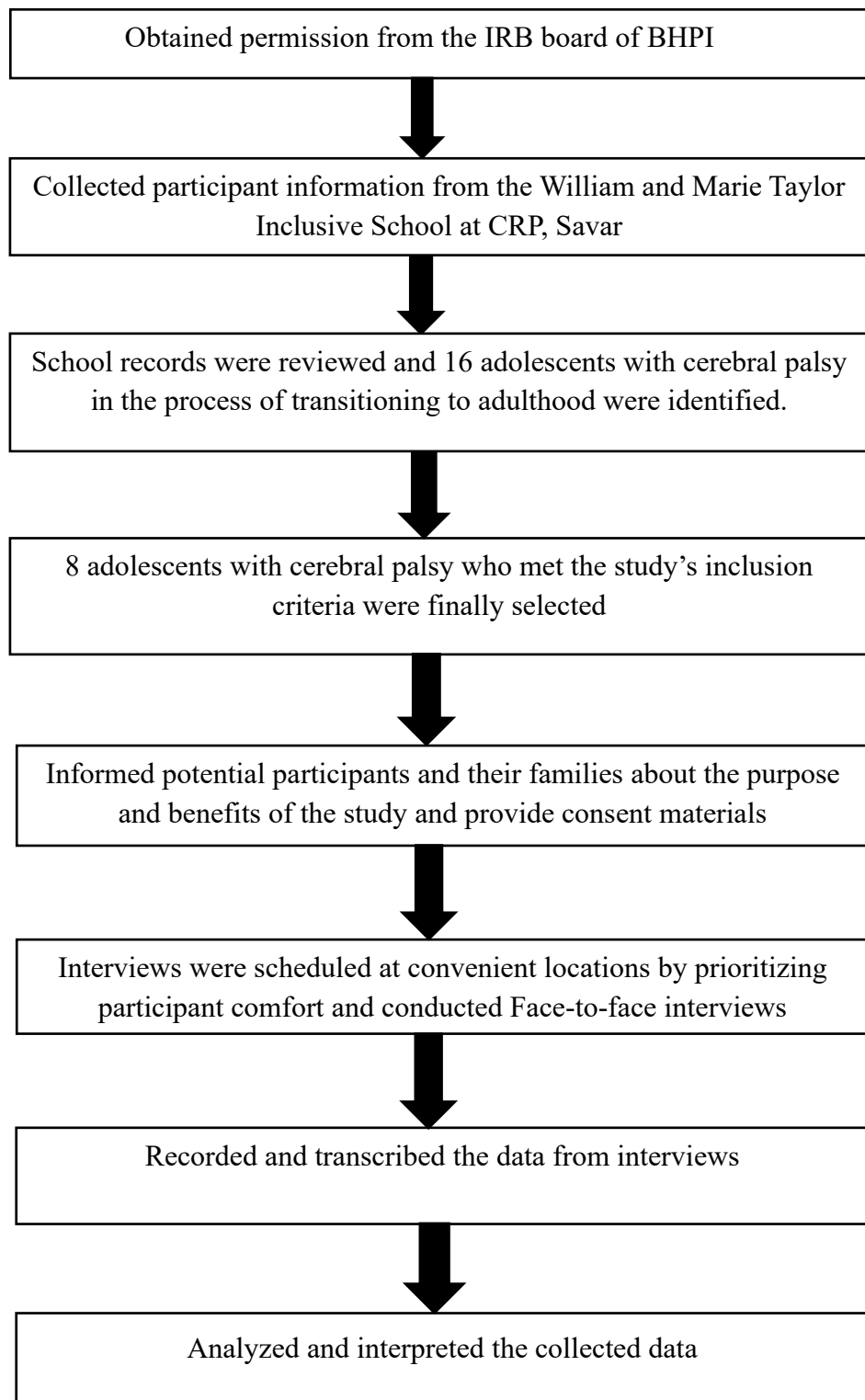
3.5.6. Confidentiality

Participants' information was kept strictly confidential. Their names and identities were not shared with anyone except the supervisor, as outlined in the information sheet. Additionally, the student researcher secured the signatures of volunteers on a transcription contract form, ensuring they agreed not to disclose any information. Participants were assured that their identities would remain confidential in all future uses, including reports, publications, conferences and any other written or verbal discussions.

3.6 Data Collection Process

3.6.1. Participant Recruitment Process

Recruitment in qualitative research is a crucial methodological aspect (Negrin et al., 2022). It also impacts the trustworthiness of qualitative research (Jessiman, 2013). The participants were recruited from diverse backgrounds. The participation recruitment diagram is given in Figure 3.1.

Figure 3.1*Overview of Participant Recruitment Process*

3.6.2. Data Collection Method

The student researcher collected data for this study through face-to-face, in-depth, semi-structured interviews. The face-to-face method allowed the student researcher to ensure that the participant was responsive and provided an opportunity to build rapport. It also enabled the researcher to observe additional emotional and behavioral cues while the participant answered the questions. The semi-structured interview format provided flexibility, with broad, open-ended questions designed to elicit detailed responses (Liamputtong & Rice, 2020). The interviews were recorded using a mobile phone, which was kept in flight mode to prevent interruptions from calls or messages during the session. The duration of each interview ranged from 20 to 35 minutes.

3.6.3. Data Collection Instrument

A self- developed semi-structured interview guide was developed as the main tool for data collection in this study. Semi-structured interviews allow the researcher to ask guiding questions while also giving participants the freedom to share their experiences in their own way (Creswell, 2018). The guide was created using the Model of Human Occupation (MOHO) as a framework to ensure that key areas of volition, habituation, performance and environment were explored (Kielhofner, 2008). The questions were aligned with the study objectives and covered the following areas:

- Adolescents' thoughts and feelings about growing up.
- Daily routines and changes experienced over time.
- Social and cultural challenges they face in their community.
- Family support and communication during the transition process.

All questions were written in simple and friendly language so that adolescents could understand them easily and feel comfortable responding (Patton, 2015).

3.6.4 Field Test

A field test of the interview guide was conducted with one participant to assess its clarity, relevance and effectiveness in capturing meaningful data about the transition experiences of adolescents with CP. Based on feedback from that initial field test, a few additional questions were added to explore participants' experiences with independence, coping strategies and navigating challenges in daily life. A second field test was then conducted to ensure that the updated guide effectively captured these aspects.

3.7. Data Management and Analysis

In this study, thematic analysis was used to make sense of the interview data. This approach helps identify patterns and key themes, allowing a deeper understanding of the participants' experiences and perspectives. The student researcher chose thematic analysis because it provides clear steps for organizing and interpreting qualitative data (Braun & Clarke, 2006). The analysis was carried out following six steps outlined by Braun and Clarke, which are described below. Six steps were followed according to Braun & Clarke, which are described below.

Step 1: Making yourself familiar with the data

In the first step, the student researcher familiarized with the data by conducting interviews and transcribing the data verbatim in Bangla, followed by translating it into English. Two of the transcriptions was translated by a volunteer. The student researcher then rechecked and retranslated the translation. The supervisor reviewed all transcriptions and translations. Afterwards, the student researcher thoroughly read the transcriptions from beginning to end to understand the meaning and patterns in the data, marking the important points.

Step 2: Generating the initial codes

In this step, the student researcher identified important points from the data and highlighted the relevant sentences. The researcher then generated initial codes based on the marked points and named them accordingly. The supervisor reviewed these initial codes.

Step 3: Searching for tentative themes

The student researcher wrote down the codes from each interview on individual pieces of paper, in sequential order. After reading the translations and discussing them with the supervisor, the researcher highlighted similar codes. Subsequently, the student researcher organised these codes into potential themes and subthemes.

Step 4: Reviewing themes

The student researcher created an initial thematic map and discussed it with the supervisor.

Step 5: Defining and naming themes

The student researcher refined and revised the themes and sub-themes, finalizing them for the results. Clear names and definitions for the themes and sub-themes were generated to ensure that the readers could easily understand them. The respected supervisor reviewed all the themes and sub-themes.

Step 6: Producing the report

According to the themes, the student researcher produced the report for the dissertation by writing the results chapter, incorporating verbatim quotes from participants. Thematic analysis aimed to explore participants' perspectives, opinions, knowledge, and experiences regarding the subject (Braun & Clarke, 2013). Since the student

researcher was investigating the experience of self-advocacy among individuals with SCI, thematic analysis was the appropriate method for analyzing the data.

3.8 Trustworthiness and Rigor

Trustworthiness was maintained by methodological and interpretive rigor.

3.8.1 Methodological Rigor

Congruence: A phenomenological approach was chosen for this qualitative study, as it aligns well with the research aim and objectives (see section 3.2: Study Design).

Responsiveness to Social Context: Face-to-face interviews were conducted in a comfortable and convenient setting for the participants, allowing the student researcher to understand their context through direct interaction (see section 3.3.1: Study Setting).

Appropriateness and Adequacy: Participants were selected using purposive sampling based on specific inclusion and exclusion criteria. A total of eight adolescents with CP were included, and data were collected through face-to-face interviews (see sections 3.4.2 and 3.6.1: Sampling Techniques and Participant Recruitment Process).

Transparency: The student researcher was responsible for collecting and analyzing the data. To minimize bias, the supervisor provided guidance and multiple perspectives throughout the data analysis process (see section 3.6 and 3.7: Data Collection Process and Data Management and Analysis).

3.8.2 Interpretive Rigor

Authenticity: The findings were presented accurately, supported by verbatim quotations from participants to reflect their true experiences (see Chapter IV: Results).

Coherence: The data were carefully aligned with the study's aim and objectives. The student researcher transcribed all interviews verbatim in Bengali, the participants' first

language, and then translated them into English. Each transcription was checked by the supervisor before data analysis began (see section 3.7: Data Management and Analysis).

Reciprocity: The student researcher ensured that translations stayed true to the participants' original words, without changes or interpretations. The data analysis was conducted independently and was not discussed with participants (see section 3.7: Data Management and Analysis).

Typicality: To help readers understand how the findings may apply in other contexts, the researcher provided a detailed description of the study setting and participants (see sections 3.4.5 and 3.7: Participant Overview and Data Management and Analysis).

Permeability of the Researcher's Influence: Ethical guidelines were strictly followed to minimize bias. Personal values, assumptions, or preconceptions were monitored, and all research steps were reviewed with the supervisor to ensure objectivity (see section 3.7: Data Management and Analysis).

CHAPTER IV: RESULTS

This chapter explores the lived experiences of adolescents with cerebral palsy as they move toward adulthood. The findings highlight their developing self-awareness, growing independence, family support, social interactions, daily challenges and future aspirations.

Table 4.1

Overview of Results

Themes	Subthemes
Theme 1: Emerging Self-Awareness and Identity	Awareness of Physical and Pubertal Changes Emotional Maturity and Inner Growth Changing Interests, Responsibilities and Emerging Identity
Theme 2: Journey Toward Functional and Academic Independence	Learning to Manage Self-Care and Daily Activities Academic and Organizational Independence Mobility and Functional Skill Development
Theme 3: Family as an Emotional and Practical Support System	Emotional Support and Encouragement Caregiving and Teaching Functional Skills Parental Expectations, Concerns and Cultural Responsibility
Theme 4: Social Experiences of Inclusion and Stigma	Experiences of Friendship and Belonging Encounters with Stigma, Avoidance and Public Curiosity
Theme 5: Negotiating Barriers Within Personal and Structural Contexts	Mobility Limitations and Environmental Restrictions Academic Difficulties and Performance Anxiety Limited Therapy Access Hindering Skill Development

	Emotional Strain and Psychological Burdens
Theme 6: Hopes and Aspirations for the Future	Career Ambitions and Desire for Independence Hope, Altruism and Imagining Meaningful Adulthood

4.1 Theme One: Emerging Self-Awareness and Identity

This theme captures the adolescents' increasing awareness of their changing bodies, emotions and emerging identities. Participants described "growing up" not only as a biological process but as a shift in self-understanding, maturity and responsibility. Their reflections reveal how bodily change, emotional growth and evolving roles shape their perception of adulthood.

4.1.1 Subtheme one: Awareness of Physical and Pubertal Changes

Participants frequently described physical growth like height, weight, strength and puberty as the first markers of adulthood. For many, these bodily changes were deeply meaningful because they affirmed their development despite ongoing disability. Rahim shared,

"Yes, As I grow up, of course I get taller that is a normal change and my weight also increased, because I sit and lie down most of the time at home and don't play so my weight has increased even more after growing up."

It reflecting a sense of pride in physical growth. Another participant Rashed reflected the same trend, saying that "my body has become much stronger than before I didn't have this much strength earlier." The statement linking physical changes with increased capability. Puberty was also recognized explicitly. Arif mentioned the growth of facial hair, stating, "I feel like I have become a bit taller than before and umm... I have grown beard on my face."

These descriptions show clear awareness of sexual maturity and bodily transition. Some adolescents also commented on changes in body shape. Such as Razzak commented, I have grown taller and thinner than before. The statement highlighting how disability intersects with developmental change. These accounts demonstrate that bodily transformation serves as a fundamental entry point into the experience of becoming an adult.

4.1.2 Subtheme Two: Emotional Maturity and Inner Growth

Several participants expressed reduced fears, greater confidence and the ability to process emotions more effectively. As Rahim reflected, “A lot of my fear has decreased compared to before.” While another Participant Sonali affirmed, “Earlier, I was very afraid of the dark and being alone but now I am not afraid anymore.” These statements illustrate increased emotional security and resilience.

Participants also described deeper emotional understanding. A girl Jamila who had previously experienced emotional hurt said, “Now that I’m here, I understand everything. Things like liking someone are different. There are many different kinds of feelings. I have learned these after coming here.” This statement indicating a shift toward emotional reflection and maturity. Other participants described resilience emerging from everyday experiences of hardship. It referring to comments that earlier caused distress.

4.1.3 Subtheme three: Changing Interests, Responsibilities and Emerging Identity

Participants described shifting interests and responsibilities as integral to becoming older. A boy Rashed explained,

“For me, growing up means learning to do everything on my own, understanding things by myself and learning to take my own responsibility and

being able to do my own work. For example, my little brother still doesn't understand much and can't talk properly that's why he is still small. So, for me growing up means learning to take my own responsibility and being able to do my own work. It also means having a job and being able to meet my own needs."

It revealing a perception of adulthood tied to competence and understanding and reflecting a growing sense of personal accountability. Several described changing hobbies and preferences as Arif said "I used to watch cartoons all the time but now I don't like cartoons at all, mostly I watch anime." However, increased responsibility also brought anxiety. One boy Rahim expressed fear about academics, stating, "My math and English are weak and I need to improve them. To become an occupational therapist, this is necessary and it sometimes makes me feel a bit scared." It showing that identity development can be both exciting and overwhelming.

4.2 Theme Two: Journey toward Functional and Academic Independence

Independence emerged as a central marker of adulthood for the adolescents. Participants interpreted growing up as the ability to carry out daily living tasks, manage academics and move independently. These achievements brought not only practical improvement but emotional pride, confidence and a sense of adult identity.

4.2.1 Subtheme One: Learning to Manage Self-Care and Daily Activities

Participants repeatedly described increasing independence in self-care as a core part of growing up. Many recalled earlier dependence and felt proud about their progress. One adolescent Rahim said proudly, "Earlier I couldn't eat, dress, toilet alone but now I can do all those things." Another participant Arif shared, "Later, after therapy my fingers got better and now I can write and I don't have any problems. Now I'm trying to wash my clothes by myself." The statement is emphasizing the role of practice and therapy.

Self-care independence provides emotional empowerment and showing how functional achievements translated into psychological growth. As Rasheda described specific tasks independency and said, “I can now manage brushing, bathing and folding clothes” and Other participant Sonali mentioned “Earlier, my mom had to feed me because I couldn’t eat by myself but now I can eat by myself using my hands.” These experiences reveal independence not as a purely physical accomplishment but as a meaningful part of becoming an adult.

4.2.2 Subtheme Two: Academic and Organizational Independence

Participants described studying independently, organizing their materials and managing their routines. Just like One of them Zakir said, “I study by myself.” Similarly another participant Jamila shared, “I Can arrange my school bag and study table.” These achievements reflecting a positive outlook on academic success which support the development of organizational independence.

Some participants described needing strategies to maintain focus. Rashed explained, “I have to keep studying continuously. Sometimes I take a two minutes break, otherwise my brain doesn’t work properly.” It showing awareness of learning strategies to gain independence. Another participant Sonali mentioned, “Even if my mom doesn’t wake me up, I can get up on my own because I have a small alarm clock.” The given statement demonstrates the role of using tools to support independence such as an alarm to wake herself.

4.2.3 Subtheme Three: Mobility and Functional Skill Development

Several participants spoke about learning wheelchair transfers, improving walking and standing ability and strengthening their hands. One participant Jamila said, “Here I learned how to get onto a wheelchair. Before this, I couldn’t get onto a wheelchair.

while another participant Zakir said, “I can, um... move my wheelchair by myself, get on and off it alone.” These statements reflecting as mobility improvements were described as major milestones toward independence.

Others described gradual improvement in movement and motor skills. Like Rasheda stated, “I haven’t learned anything extremely advanced but I have learned few things as like Earlier, I couldn’t stand at all. Now, with a little support, I can stand for a long time.” Again Arif said, “Then my fingers before I couldn’t open them, they used to stay tightly folded. Now I can open them fully.” However, persistent mobility limitations hinder functional independence. As Rahim explained, “Outside means I go to school and sometimes I suddenly visit my friends’ houses. But because of my leg problem, I don’t go out much.” It revealing how disability continues to shape daily experience.

4.3 Theme Three: Family as an Emotional and Practical Support System

In the Bangladeshi sociocultural context family networks are central to identity, decision-making and caregiving. Participants described their families as emotional anchors, teachers, motivators, and protectors. Their narratives revealed that family support was not only functional but deeply relational, shaping their sense of safety, self-worth and future possibilities. This theme captures the multidimensional role families play in emotional stability, skill development and shaping expectations for adulthood.

4.3.1 Subtheme One: Emotional Support and Encouragement

Adolescents repeatedly described their families especially mothers as their primary sources of emotional comfort and stability. When faced with frustration, fear or social rejection, they turned to family for reassurance. One boy Rahim expressed,

“My mother helps me a lot and I never feel afraid or uncomfortable asking for help from her. When I get frustrated about myself and feel like, Will I be able to do this task? then my mother finds videos of people who are in worse condition than me but are still doing many things. She shows me those videos and says, You have to do it. You have to do even better. You have to grow up more.”

It capturing the emotional security embedded in family relationships and described how his mother supported him through moments of discouragement. For some adolescents, family encouragement directly influenced confidence and resilience. One participant Zakir explained that after being excluded by peers Parents comforted him saying, “Dear, don’t be sad. You can’t walk, that’s why they act that way.” This statement helping him regain emotional strength. Another participant Razzak shared mother’s encouragement in study that she said, “You want to be an occupational therapist, so you must study science, improve your math and English.” It demonstrating how emotional and academic motivation are associated within the family environment. This emotional support created a stable foundation from which adolescents felt capable of navigating social and academic challenges.

4.3.2 Subtheme Two: Caregiving and Teaching Functional Skills

Participants reported that Mothers were heavily involved in teaching daily living skills and assisting with tasks that adolescents could not perform alone. One boy Razzak described, “My mother helps me picking out fish bones to eat, serves food, sometimes helps me take a bath, washes my clothes and folds them.” Similarly another Participant Rasheda shared,

“My mom helps me with everything. I cannot eat properly, so she feeds me. She helps me get dressed, because I can’t do it alone. She picks out my school clothes, ties my hair, makes my bed and helps me when I ask.”

These acts of caregiving were not perceived as dependence but as expressions of love and security. Parents also taught practical skills to prepare adolescents for adulthood. One participant Rahim explained, “I used to have trouble getting ready for school especially wearing shirts, then mother teaches me buttoning now I am trying to learn.” It showing how mothers acted as informal occupational therapists. Fathers also contributed to skill development and future orientation; one of them Arif shared,

“My father talks to me a lot. He says I am growing up. He says that since I will have a job, I need to learn computers properly, understand everything, recognize money and learn to count money. He says I must learn to do all tasks properly.”

These instances demonstrate how adolescents rely on their families while also learning to participate more actively in their own care.

4.3.3 Subtheme Three: Parental Expectations, Concerns and Cultural Responsibility

Parents carried strong hopes and deep worries about their children’s future. Several adolescents internalized these concerns, showing awareness of parental anxiety. One girl Jamila shared,

“My mother worries a lot about me. She always says, “When we die, how will you live? Now we are educating you. If you study well and get a job, it will be good for you. You will earn your own money.”

The statement demonstrating the emotional weight of familial expectations. Another participant Zakir expressed the cultural reality of long-term caregiving. As he said, “To me, growing up means being able to achieve something in life to work to do something on my own. Parents don’t stay with us forever.” It showing the adolescents’ awareness of parental fear about who will care for them in adulthood. Many adolescents

described explicit academic and career expectations. One girl Rasheda shared, “My dad always say to do my studies, become a doctor and always remember this You will have to teach your younger sisters.” This reflects Bangladeshi cultural norms where education and professional success symbolize family pride and future security. Families also engaged in future planning as one participant Zakir explained, “My parents said that before they die, they will arrange something for me so that I can work and earn in my life”, revealing how cultural responsibility and disability intersect in long-term planning. Family expectations, while sometimes heavy, provided direction and structure as adolescents imagined their adult lives.

4.4 Theme Four: Social Experiences of Inclusion and Stigma

Adolescents with cerebral palsy frequently encounter complex social interactions that influence their sense of belonging. While some participants described positive friendships and acceptance, many also shared experiences of exclusion, public curiosity and hurtful judgments. This theme captures how adolescents negotiate social worlds shaped by cultural beliefs, stigma and community attitudes.

4.4.1 Subtheme One: Experiences of Friendship and Belonging

Many participants described joyful and supportive peer relationships. These positive experiences contributed to a stronger sense of confidence and social identity. One adolescent Rahim shared,

“In class, my classmates and friends help me a lot. The whole class helps me. If I cannot finish copying the whole lesson, they write the rest for me. Before exams, my mother often collects notes from them they never refuse. They never say no because this is how they have grown up with us.”

While another Participant Rashed affirmed, “My friends are very good and they never treat me differently.” Such interactions made them feel valued and recognized within social spaces. Social participation grew stronger as communication skills improved. A girl Sonali expressed, “I understand and can speak fluently now. I can write and express myself.” This increased fluency allowed her to participate more actively among peers. Others described enjoying outings, games, and meeting new people. Arif said, “I like meeting new people. I like new friends. If a new student comes to my class, I talk to them and make friends. I feel very happy doing this.” The description showing growing social comfort.

4.4.2 Subtheme Two: Encounters with Stigma, Avoidance and Public Curiosity

Despite positive interactions, many adolescents also faced exclusion or insensitive behavior. Several described hurtful comments from childhood. Rahim shared, “When I was small, I couldn’t do anything my mother said we used to hear a lot of comments. Like my grandfather said, he will have to beg for a living and my uncle said, he will never be able to talk.” These early experiences left emotional scars and shaped their ongoing sense of vulnerability.

Social exclusion remained present in adolescence. As Jamila shared, “In school some people avoid me, refuse to sit beside me and tease me Then I feel very hurt. I don’t say anything. I just stay quiet.” While Zakir recalled, “There are some healthy kids who play outside I used to want to play with them, but they wouldn’t include me. They said we won’t take you in the game. Hearing that made me sad and I used to cry quietly.” These experiences reflect how disability stigma remains embedded in daily interactions. Public curiosity was another recurring theme. Adolescents described strangers staring and asking insensitive questions. As Rashed explained,

“Sometimes when I go outside, strangers stare at me and ask How did this happen to you, What happened to your legs etc.... Outside people look at me differently, like they doubt I can do things. They keep asking the same questions again and again it annoys me a lot. But if someone asks once and then behaves normally, then I feel fine.”

These encounters created discomfort and irritation, also highlighted how societal perceptions shape their lived experience. Despite this, some participants developed emotional resilience over time by showing growth in coping ability.

4.5 Theme Five: Negotiating Barriers Within Personal and Structural Contexts

While adolescents described moments of growth, confidence and progress their narratives also revealed the structural and personal barriers that complicate the transition to adulthood. These barriers were not simply physical; they were connected with academic struggles, environmental restrictions, emotional burdens and limited access to rehabilitation services. These adolescents’ stories show how disability interacts with societal limitations, shaping daily experiences and influencing how they envision their future.

4.5.1 Subtheme One: Mobility Limitations and Environmental Restrictions

Mobility challenges were the most commonly described barrier. Many adolescents expressed difficulty participating in outdoor activities or moving comfortably in daily environments. As Rahim shared, “Outside means I go to school and sometimes I suddenly visit my friends’ houses. But because of my leg problem, I don’t go out much.” Similarly, Sonali expressed, “Since I need a wheelchair, sometimes it’s hard to go outside.” These barriers restricted their participation in social life and reinforced dependence on others.

Environmental limitations also played a role. Some described difficulty accessing therapy spaces, uneven outdoor paths and needing support with transfers. One participant Jamila explained, “At home, my mother helps me. Here, the caregivers help for example, when the bathroom floor is slippery because of water, they hold me and help me go and come back,” showing that physical barriers extended beyond personal ability and into structural accessibility issues. These mobility obstacles affected autonomy, social participation and emotional wellbeing.

4.5.2 Subtheme Two: Academic Difficulties and Performance Anxiety

Several adolescents highlighted academic pressure as a significant barrier. Academic struggles created anxiety and insecurity, particularly in subjects like mathematics and English. One adolescent Rahim admitted, “I have some weaknesses in math and English, so I need to fix those”. While Rasheda shared, “To get a job and to grow up, you need to study a lot and learn many things. When I think about all this studying, I feel a little scared.” These struggles often influenced how they perceived adulthood seeing education as both essential and challenging.

Academic environments were also stressful due to teaching inconsistencies or cognitive overload. A participant Rashed explained, “I enjoy studying, but sometimes it becomes difficult because one teacher leaves and another teacher comes immediately..... Sometimes I take a two minutes break, otherwise my brain doesn’t work properly,” reflecting the emotional strain caused by inconsistent teaching arrangements and mental exhaustion. These academic barriers influenced confidence and self-perception, shaping how adolescents imagined their future roles in society.

4.5.3 Subtheme Three: Limited Therapy Access Hindering Skill Development

Access to rehabilitation while central to their progress was often inconsistent. One boy Rahim expressed concern and said, “When I am in class at school, during therapy time

they call me from class and take me for therapy. But outside I don't get much therapy, I can't take it regularly. At CRP it also takes time to get a serial." Highlighting how limited access could slow physical development and learning. Others noticed plateaus in progress, such as one participant Rasheed discussed,

"For the last few days I haven't learned any new tasks, like even yesterday I didn't learn anything new because today I had an exam, so yesterday I studied only for my exam. Other than that, I haven't learned anything new recently."

These statements reveal the psychological impact of inconsistent therapy frustration, reduced motivation, and fear of regression. The adolescents' awareness of these plateaus demonstrated their growing maturity and self-reflection.

4.5.4 Subtheme Four: Emotional Strain and Psychological Burdens

In addition to physical and academic barriers, adolescents described emotional challenges that shaped their lived experiences. Some expressed fear linked to disability or past experiences. One participant Rasheda shared,

"I enjoy giving therapy but sometimes I get very scared when suddenly made to stand during therapy. I feel like I might fall and then I get really scared. If I tell my mom, she doesn't listen to me; she says I have to stand."

While another Razzak reported that "Before, I used to be scared of ghosts and dark places and I didn't like talking much." Their emotional narratives illustrated how fear often related to their physical limitations. Feelings of frustration and sadness were also evident, especially when peers excluded them and when skills were difficult to learn. One boy Zakir described crying alone and shared "There are some kids who play outside I used to want to play with them but they wouldn't include me. They said, "We won't take you in the game." Hearing that made me sad and I used to cry quietly." These

responses highlight the internal emotional labor adolescents carry as they negotiate the realities of disability and societal expectations.

4.6 Theme Six: Hopes and Aspirations for the Future

Despite the challenges they described, adolescents with cerebral palsy expressed strong future aspirations, demonstrating an internal drive to achieve meaningful roles, independence and contribution. Their narratives were infused with hope for education, employment, family support, mobility improvement and the ability to help others. This theme captures how adolescents dream of adulthood not as a burden but as an anticipated stage of possibility, dignity and personal achievement.

4.6.1 Subtheme One: Career Ambitions and Desire for Independence

Many adolescents articulated clear and passionate career aspirations often aligned with helping professions and creative pursuits. Several expressed dreams of becoming a doctor. Others envisioned futures as occupational therapists, teachers, artists and shop owners. One participant Rahim shared proudly, “I learned through therapy and from then on I felt that if I become an occupational therapist”, showing a desire not only for employment but also for giving back. Financial independence was a recurring theme. A boy Razzak stated simply,

“I will get a job at CRP and earn money. With the money I earn, I will bring many nice things home chicken, goat, kebabs, pilau, I will eat all these. I will buy many expensive clothes and wear new clothes. Then I will buy a big car. After that, I will travel abroad. I will take my mother with me when I travel abroad.”

These aspirations reflected maturity and awareness of adult responsibilities. Some adolescents described dreams of travel and exposure beyond Bangladesh. Their

ambitions showed a desire to transcend limitations imposed by disability and societal expectations.

4.6.2 Subtheme Two: Hope, Altruism and Imagining Meaningful Adulthood

Beyond personal ambitions, many adolescents expressed desires to help others and contribute meaningfully to society. One participant Rahim reflected, “I learned through therapy and from then on I felt that if I become an occupational therapist, I can also teach these skills to someone else. That gives me a lot of motivation.” This altruistic orientation shows a maturing sense of responsibility and empathy.

Many participants imagined adulthood not only as a personal achievement but also as an opportunity to uplift their families. One boy Zakir talked affectionately about his mother, said, “I will get a job at CRP and earn money..... I will travel abroad and I will take my mother with me.” Others spoke of becoming someone their parents could be proud of, demonstrating strong cultural values of family-centered aspirations.

CHAPTER V: DISCUSSION

The present study aimed to explore and understand the lived experiences of adolescents with cerebral palsy (CP) in Bangladesh as they transition into adulthood, focusing particularly on the social and cultural challenges they face during this process. This chapter discusses the findings in light of the existing literature, highlighting the similarities and differences between the current results and previous research.

The findings of this study reveal that adolescents with cerebral palsy in Bangladesh experience the transition to adulthood as a complex and multidimensional process involving physical, emotional, social and cultural dimensions. Participants in this study described becoming aware of their bodily and emotional changes as the first step toward self-recognition and maturity. They associated physical growth and pubertal development with pride and a sense of normalcy, indicating that these changes reaffirmed their identity as growing adolescents despite living with disability. This is consistent with earlier research which suggests that adolescents with disabilities often interpret physical and biological changes as markers of inclusion in typical developmental paths (Schmidt et al., 2020). Emotional growth was also a recurring feature as participants expressed a greater ability to manage fear, regulate emotions, and reflect on personal experiences as an indicator of developing emotional maturity described in studies on psychological adjustment among youth with physical disabilities (Lindsay, 2016). The findings further show that independence emerged as a central marker of adulthood. Participants described increasing self-reliance in daily self-care, academic activities and mobility as significant milestones. This previous studies that highlight independence and self-determination as key elements of successful transition among individuals with cerebral palsy (Liljenquist et al., 2018).

Participants expressed pride in being able to eat, dress or bathe independently tasks that symbolized not only physical improvement but also self-worth and dignity. Similar studies have shown that mastery of daily living skills enhances confidence and promotes a sense of adulthood (Lopes et al., 2021). In addition, academic independence was highly valued. Adolescents described learning to study alone, manage their routines and use strategies to remain organized. These findings align with evidence that academic self-management supports self-efficacy and future aspirations in young people with disabilities (Kim et al., 2011). Mobility and functional skill development were particularly meaningful as participants viewed improvements in walking, transfers or wheelchair use as symbols of liberation and adult identity. Yet, the persistence of physical and environmental barriers reflects the broader challenges of accessibility in low- and middle-income countries as described by (Magill-Evans et al., 2005).

The role of family emerged as deeply influential in shaping adolescents' emotional security, independence and future orientation. Families particularly mothers were described as the central support system, providing emotional encouragement, practical assistance and guidance. This finding is consistent with studies showing that family involvement is a crucial factor in promoting resilience and adjustment among children with disabilities, particularly in collectivist societies (Ryan et al., 2023). Mothers often acted as both caregivers and teachers and helping adolescents develop functional skills and confidence. Fathers, on the other hand, were often associated with future planning, career guidance and the inculcation of social responsibility. These observations reflect the interdependent family model characteristic of South Asian contexts, where caregiving is perceived as an act of love and duty rather than dependence (Aviram et al., 2022). Participants also expressed awareness of their parents' expectations and concerns, particularly regarding future independence and

security. Many adolescents internalized their parents' worries, understanding that education and employment were vital to sustaining themselves in adulthood. This aligns with existing research showing that parental expectations strongly influence adolescents' aspirations and perceived self-competence (Boyle et al., 2023). While family support was largely positive, the findings suggest that strong parental involvement can sometimes delay autonomy as family members may overprotect adolescents due to societal stigma and fear of future uncertainty. This tension between care and independence has been highlighted in earlier disability transition studies (Lindsay, 2016).

Social experiences played a significant role in shaping adolescents' sense of identity and belonging. Participants described both supportive friendships and painful encounters with stigma. Positive social relationships, particularly within inclusive educational settings, enhanced confidence and self-expression. This supports research suggesting that inclusive school environments promote belonging, peer acceptance, and social participation among children with disabilities (Schmidt et al., 2020). However, many participants also encountered social exclusion, teasing and public curiosity, experiences that mirror broader societal attitudes toward disability in Bangladesh and other low- and middle-income countries (Datta et al., 2024). These findings echo global disability studies emphasizing that attitudinal barriers are more significant than physical ones in shaping participation and well-being (Shakespeare, 2014). Another important finding was the interplay between personal and structural barriers. Participants identified mobility limitations, inaccessible environments, inconsistent academic support and irregular therapy services as significant obstacles. These barriers reflect broader systemic challenges such as limited rehabilitation infrastructure, insufficient assistive technologies and lack of inclusive public spaces. Studies in similar contexts

have shown that environmental inaccessibility and fragmented healthcare systems remain major constraints to achieving functional independence among people with cerebral palsy (Freeman et al., 2018a). Academic difficulties and performance anxiety were also evident, suggesting that adolescents face considerable pressure to excel academically despite structural and cognitive barriers. These struggles often resulted in stress and self-doubt, consistent with findings that educational participation without adequate support can increase anxiety and reduce self-efficacy (Shafran et al., 2020). Emotional strain including fear of failure, sadness from social exclusion and frustration over slow progress was a common experience, highlighting the psychological dimension of living with disability during adolescence.

Despite these challenges, adolescents in this study expressed remarkable hope, ambition and altruism when imagining their futures. They articulated clear career goals, often aspiring to become doctors, occupational therapists, teachers and professions associated with helping others. These aspirations reflect an internalization of positive role models and a desire to contribute meaningfully to society. Similar findings have been reported in research highlighting how youth with disabilities derive purpose from helping others and envisioning themselves as agents of change (Winkens et al., 2023). Financial independence and the ability to support their families were recurring motivations, reflecting both cultural expectations and personal pride. Hope was a sustaining emotional force, allowing participants to view adulthood not as a burden but as a phase of possibility. This optimism underscores the resilience and adaptive capacity observed among youth with disabilities in resource-limited settings (Gaskin et al., 2021).

Overall, the findings show that the transition to adulthood for adolescents with cerebral palsy in Bangladesh is shaped by self-development, family dynamics, societal

attitudes and structural barriers. Their experiences align with global literature but offer distinct insights into how cultural values, family interdependence and limited rehabilitation resources influence this transition. This study also helps address the lack of research on disability and adolescence in low- and middle-income countries, where social and cultural contexts strongly shape life opportunities. The results suggest that promoting independence for adolescents with cerebral palsy requires functional training, family education, inclusive schooling, and community awareness. Occupational therapists can support self-advocacy, emotional coping and social participation, helping them transition more smoothly to adulthood in Bangladesh.

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Study Strength

- This study explored the lived experiences of adolescents with CP in Bangladesh as they transition into adulthood a topic rarely examined in the Bangladeshi context.
- The use of a qualitative phenomenological approach allowed an in-depth understanding of personal, social and cultural factors that shape the transition process.
- Data were collected through face-to-face interviews which provide rich and detailed narratives that captured participant's emotions, challenges and aspirations.
- Multiple aspects of transition were explored including self-awareness, independence, family support, social inclusion and future aspirations, creating a holistic view of the participants' lived realities.
- The findings address a significant gap in existing literature, offering valuable insights for professionals, educators and policymakers working with young people with CP in Bangladesh.

6.1.2 Study Limitation

- The study involved only eight participants; therefore, the findings may not be applicable to all adolescents with CP in Bangladesh.

- Most participants were from an urban institutional setting (CRP), so their experiences may differ from those living in rural areas with fewer resources.
- During some interviews, caregivers were present to support communication. Although this helped participants feel safe, it may have made some adolescents hesitant to express their true feelings.
- As data were based on self-reported experiences, responses may have been influenced by social desirability or recall bias.
- As this was the researcher's first independent qualitative study, some interpretive limitations may have occurred.

6.2 Practice Implication (Recommendation for Future Practice and Research)

6.2.1 Recommendation for Future Practice

- Family-centered approaches should be strengthened to support adolescents with CP during the transition to adulthood.
- Schools and rehabilitation centers should provide life-skills and independence training that encourages confidence and decision-making.
- Awareness programs should be developed to reduce stigma and promote inclusion in schools, communities, and workplaces.
- Policies should be designed to ensure accessible education, employment opportunities and continued therapy for adolescents with CP.

6.2.2 Recommendation for Future Research

- Future studies could include caregivers, teachers and health professionals to gain a more comprehensive understanding of the transition process.

- Research comparing urban and rural settings would help identify gaps in access to services and community support.
- Larger studies including adolescents with different levels of disability could provide a broader view of their challenges and strengths.

6.3 Conclusion

This study explored the experiences of adolescents with cerebral palsy in Bangladesh as they move toward adulthood. The findings show that these young people face both progress and challenges as they grow. They take pride in becoming more independent in self-care and study but still struggle with barriers such as stigma, mobility difficulties, and limited therapy access. Family support especially from mothers was found to be central in building confidence and teaching life skills. Despite their daily challenges, the adolescents showed great hope and determination for the future.

Overall, the transition to adulthood for adolescents with CP is shaped not only by physical growth but also by emotional, social and cultural factors. Strengthening family support, creating inclusive schools and improving access to therapy and community programs can help these young people build more independent and fulfilling lives in Bangladesh.

CHAPTER VII: REFERENCE

- Aviram, R., Khvorostianov, N., Harries, N., & Bar-Haim, S. (2022). Perceived barriers and facilitators for increasing the physical activity of adolescents and young adults with cerebral palsy: a focus group study. *Disability and Rehabilitation*, 44(22), 6649–6659.
<https://doi.org/10.1080/09638288.2021.1970252>
- Bagatell, N., Chan, D., Rauch, K. K., & Thorpe, D. (2017). “Thrust into adulthood”: Transition experiences of young adults with cerebral palsy. *Disability and Health Journal*, 10(1), 80–86. <https://doi.org/10.1016/j.dhjo.2016.09.008>
- Björquist, E., Nordmark, E., & Hallström, I. (2015). Living in transition - experiences of health and well-being and the needs of adolescents with cerebral palsy. *Child: Care, Health and Development*, 41(2), 258–265.
<https://doi.org/10.1111/cch.12151>
- Boyle, P., Galvin, K. T., Vuoskoski, P., & Stew, G. (2023). The Experience of Living through the Transition from Adolescence to Adulthood for Young People with Cerebral Palsy. *Occupational Therapy in Health Care*, 39(1), 72–91.
<https://doi.org/10.1080/07380577.2023.2211669>
- Boyle, P., Vuoskoski, P., Stew, G., & Galvin, K. T. (2022). Transitioning from adolescence to adulthood for young people living with cerebral palsy: a meta-ethnography. *Disability and Society*, 37(2), 231–253.
<https://doi.org/10.1080/09687599.2020.1822785>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
<https://doi.org/10.1191/1478088706qp063oa>
- Carroll, E. M. L. (2015). Health Care Transition Experiences of Young Adults With Cerebral Palsy. *Journal of Pediatric Nursing*, 30(5), e157–e164.
<https://doi.org/10.1016/j.pedn.2015.05.018>
- Dalgaard, N. T., Bondebjerg, A., Viinholt, B. C. A., & Filges, T. (2021). PROTOCOL: The effects of inclusion on academic achievement, socioemotional

- development and wellbeing of children with special educational needs. *Campbell Systematic Reviews*, 17(2). <https://doi.org/10.1002/cl2.1170>
- Datta, D., Chiu, H., Alazem, H., McCormick, A., Sun, G., & Tu, A. (2024). Can we do better supporting young adults with cerebral palsy as they navigate adulthood? A review of current and future transitional practices. *Neurosurgical Focus*, 57(2), 1–7. <https://doi.org/10.3171/2024.5.FOCUS24215>
- Dimitrova, M., Kammeyer-Mueller, J., Shaffer, M. A., & Gruber, M. (2023). Escaping the rut: Bridging research on expatriate and organizational newcomer adjustment. *Journal of World Business*, 58(6), 101486. <https://doi.org/10.1016/j.jwb.2023.101486>
- Freeman, M., Stewart, D., Cunningham, C. E., & Gorter, J. W. (2018a). “If I had been given that information back then”: An interpretive description exploring the information needs of adults with cerebral palsy looking back on their transition to adulthood. *Child: Care, Health and Development*, 44(5), 689–696. <https://doi.org/10.1111/cch.12579>
- Freeman, M., Stewart, D., Cunningham, C. E., & Gorter, J. W. (2018b). Information needs of young people with cerebral palsy and their families during the transition to adulthood: a scoping review. *Journal of Transition Medicine*, 1(1). <https://doi.org/10.1515/jtm-2018-0003>
- Gaskin, C. J., Imms, C., R. Dagley, G., Msall, M. E., & Reddihough, D. (2021). Successfully Negotiating Life Challenges: Learnings From Adults With Cerebral Palsy. *Qualitative Health Research*, 31(12), 2176–2193. <https://doi.org/10.1177/10497323211023449>
- Holstila, E., Vallittu, A., Ranto, S., Lahti, T., & Manninen, A. (2016). Helsinki. Cities as Engines of Sustainable Competitiveness: European Urban Policy in Practice, 175–189. <https://doi.org/10.4324/9781315572093-15>
- Jahnsen, R., Ramstad, K., Myklebust, G., Elkjaer, S., Pripp, A. H., & Klevberg, G. L. (2020). Independence of young people with cerebral palsy during transition to adulthood: a population-based 3 year follow-up study. *Journal of Transition Medicine*, 2(1). <https://doi.org/10.1515/jtm-2019-0002>

- Keller, T. E., Cusick, G. R., & Courtney, M. E. (2007). Approaching the transition to adulthood: Distinctive profiles of adolescents aging out of the child welfare system. *Social Service Review*, 81(3), 453–484. <https://doi.org/10.1086/519536>
- Kerklaan, J., Hannan, E., Hanson, C., Guha, C., Cho, Y., Christian, M., Hamiwka, L., Ryan, J., Sinha, A., Wong, G., Craig, J., Groothoff, J., & Tong, A. (2020). Perspectives on life participation by young adults with chronic kidney disease: An interview study. *BMJ Open*, 10(10), 1–12. <https://doi.org/10.1136/bmjopen-2020-037840>
- Khandaker, G., Muhit, M., Karim, T., Smithers-Sheedy, H., Novak, I., Jones, C., & Badawi, N. (2019). Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. *Developmental Medicine and Child Neurology*, 61(5), 601–609. <https://doi.org/10.1111/dmcn.14013>
- Kim, C. L., Hall, M. E. L., Anderson, T. L., & Willingham, M. M. (2011). Coping with discrimination in academia: Asian-American and Christian perspectives. *Asian American Journal of Psychology*, 2(4), 291–305. <https://doi.org/10.1037/a0025552>
- Liljenquist, K., Neil, M. E. O., & Bjornson, K. F. (2018). Young People With Cerebral Palsy : 98(9), 796–803.
- Lindsay, S. (2016). Child and youth experiences and perspectives of cerebral palsy: A qualitative systematic review. *Child: Care, Health and Development*, 42(2), 153–175. <https://doi.org/10.1111/cch.12309>
- Lopes, P. B., Shikako-Thomas, K., Cardoso, R., & Simões Matsukura, T. (2021). Social participation: the perspectives of adolescents with cerebral palsy and their mothers. *International Journal of Developmental Disabilities*, 67(4), 263–272. <https://doi.org/10.1080/20473869.2019.1623596>
- Mackiewicz, J. (2018). A Mixed-Method Approach. In *Writing Center Talk over Time*. <https://doi.org/10.4324/9780429469237-3>
- Magill-Evans, J., Wiart, L., Darrah, J., & Kratochvil, M. (2005). Physical & Occupational Therapy In Pediatrics Beginning the Transition to Adulthood Beginning the Transition to Adulthood: The Experiences of Six Families with

Youths with Cerebral Palsy. *Physical & Occupational Therapy in Pediatrics*, 25(3). <https://doi.org/10.1080/J006v25n03>

Mwinbam, M. M., Suglo, J. N., Agyeman, Y. N., & Kukeba, M. W. (2023). Family caregivers' experience of care with a child with cerebral palsy: The lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana. *BMJ Paediatrics Open*, 7(1), 1–10. <https://doi.org/10.1136/bmjpo-2022-001807>

Normann, G., Arntz Boisen, K., Uldall, P., & Brødsgaard, A. (2022). Navigating being a young adult with cerebral palsy: A qualitative study. *International Journal of Adolescent Medicine and Health*, 34(4), 187–195. <https://doi.org/10.1515/ijamh-2020-0039>

Paneth, N. (2021). Making cerebral palsy visible across the globe. *Developmental Medicine and Child Neurology*, 63(11), 1245. <https://doi.org/10.1111/dmcn.14950>

Ryan, J. M., Walsh, M., Owens, M., Byrne, M., Kroll, T., Hensey, O., Kerr, C., Norris, M., Walsh, A., Lavelle, G., & Fortune, J. (2023). Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study. *Developmental Medicine and Child Neurology*, 65(2), 285–293. <https://doi.org/10.1111/dmcn.15317>

Schmidt, A. K., van Gorp, M., van Wely, L., Ketelaar, M., Hilberink, S. R., Roebroek, M. E., Tan, S. S., van Meeteren, J., van der Slot, W., Stam, H., Dallmeijer, A. J., de Groot, V., Voorman, J. M., Smits, D. W., Wintels, S. C., Reinders-Messelink, H. A., Gorter, J. W., & Verheijden, J. (2020). Autonomy in participation in cerebral palsy from childhood to adulthood. *Developmental Medicine and Child Neurology*, 62(3), 363–371. <https://doi.org/10.1111/dmcn.14366>

Shafran, R., Bennett, S., Coughtrey, A., Welch, A., Walji, F., Cross, J. H., Heyman, I., Sibelli, A., Smith, J., Ross, J., Dalrymple, E., Varadkar, S., & Moss-Morris, R. (2020). Optimising Evidence-Based Psychological Treatment for the Mental Health Needs of Children with Epilepsy: Principles and Methods. *Clinical Child and Family Psychology Review*, 23(2), 284–295. <https://doi.org/10.1007/s10567->

019-00310-3

- Smith, J. A., Flowers, P., & Larkin, M. (2010). Interpretative Phenomenological Analysis: Theory, Method and Research. *QMIP Bulletin*, 1(10), 44–46. <https://doi.org/10.53841/bpsqmip.2010.1.10.44>
- Smith, S. E., Gannotti, M., Hurvitz, E. A., Jensen, F. E., Krach, L. E., Kruer, M. C., Msall, M. E., Noritz, G., Rajan, D. S., & Aravamuthan, B. R. (2021). Adults with Cerebral Palsy Require Ongoing Neurologic Care: A Systematic Review. *Annals of Neurology*, 89(5), 860–871. <https://doi.org/10.1002/ana.26040>
- Uhre, C. F., Caspersen, I. D., Lose, C., Rackauskaite, G., Robotham, R., & Hoei-, C. E. (2024). Cognitive functioning in children and adolescents with cerebral palsy : protocol for the Danish CPCog-Youth study.
- WHO. (2014). Health for The World’s Adolescents. World Health Organisation, 14. <https://apps.who.int/iris/handle/10665/112750>
- Winkens, K., Zijlstra, E., Post, W., van Os, C., & Smit, M. (2023). Unaccompanied, but not alone: A systematic review of the influence of social relationships on the transition of unaccompanied refugee adolescents to adulthood. *Children and Youth Services Review*, 155(October), 107190. <https://doi.org/10.1016/j.childyouth.2023.107190>
- Young, N. L., Barden, W. S., Mills, W. A., Burke, T. A., Law, M., & Boydell, K. (2009). Transition to adult-oriented health care: Perspectives of youth and adults with complex physical disabilities. *Physical and Occupational Therapy in Pediatrics*, 29(4), 345–361. <https://doi.org/10.3109/01942630903245994>

APPENDICES

Appendix A: Approval/Permission Letter

Approval Letter



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

Ref: CRP-BHPI/IRB/07/2025/1102

Date: 21.07.2025

To
 Nishat Tasfia
 4th Year, B.Sc. in Occupational Therapy
 Session: 2020-21, Student ID: 122200437
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal **Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood** by ethics committee.

Dear Nishat Tasfia,
 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 Kaniz Fatema, Lecturer, 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 explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process. The study involves use of a Self-developed Interview Guide to explore how adolescents with cerebral palsy in Bangladesh experience their journey to adulthood and what social and cultural factors influence this journey, that may take 30 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 regards,

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

Permission Letter



বাংলাদেশ হেলথ 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 Principal,
William And Marie Taylor School (The Inclusive School of CRP),
CRP, Chapain, Savar, Dhaka-1343, Bangladesh.

Subject: Regarding permission for data collection for undergraduate research.

Sir,

With due respect I would like to draw your kind attention that I am a student of 4th Year B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI) which is an academic institute of Centre for the Rehabilitation of the Paralysed (CRP), affiliated to Faculty of Medicine, University of Dhaka. According to my course curriculum, I have to conduct research and my research title is **"Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood"** with myself & Kaniz Fatema as my thesis supervisor. The aim of my study is to explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process. In order to fulfill the objectives of this study, I would like to conduct interview of students with Cerebral Palsy at your school. I assure you that anything of my research project will not cause harm to the participants and collected information will be used solely for academic purpose. Your permission and support would be invaluable in facilitating the successful completion of my research.

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

Sincerely yours,

Nishat Tasfia

Nishat Tasfia

4th Year, B.Sc. in Occupational Therapy

Session: 2020-21, Student ID: 122200437

BHPI, CRP, Savar, Dhaka-1343

Recommendation from the Head of the Department:

Prof. Sk. Moniruzzaman

Prof. Sk. Moniruzzaman

Professor & Head

Department of Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

CRP, Savar, Dhaka-1343

Attachments: Copy of IRB Approval Letter

Permitted for Data
Collection from WMTs.

3-8-25
MD. ABDULLAH AL ZUBAYER
Principal
William and Marie Taylor School
CRP-Savar, Dhaka-1343

Appendix B: Information Sheet, Consent Form & Withdrawal Form

Information Sheet, Consent Form & Withdrawal Form (English Version)

Information Sheet/ Participant Explanatory Statement

Research title: Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood.

Name of the researcher:

Nishat Tasfia

4th year, B.Sc. in Occupational Therapy

Session: 2020-2021

Bangladesh Health Professions Institute (BHPI),

Centre for the Professionals of the Paralysed (CRP)

CRP-Chapain, Savar, Dhaka-1343.

Supervisor:

Kaniz Fatema

Lecturer

Department of Occupational Therapy

Bangladesh Health Professions Institute.

Call: 01855611776

Email: kanizot1993@gmail.com

Place of research: The study will be conducted in William and Marie Taylor Inclusive School at the Centre for the Rehabilitation of the Paralysed (CRP), Savar.

Introduction:

I am Nishat Tasfia 4th year student (Session: 2020-2021) of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of the Centre for the Rehabilitation of the Paralysed (CRP) which is under the Medicine

faculty of Dhaka University. As a part of course curriculum, I have to conduct a research project in this 4th year. This research project will be conducted under the supervision of, Kaniz Fatema, Lecturer, Department of Occupational Therapy (BHPI), Centre for the Professionals of the Paralysed (CRP). By this information sheet researcher will provide detailed information about the study purpose, data collection process, ethical issues. If you are willing to participate in this research then clear information about the study will be easier for you in decision making. Please take time to read the information given. If you face any problem understanding after reading, you can ask.

Background and aim of the research:

You are invited to participate in this research because Your participation is valued because firstly, you are attending in William and Marie Taylor Inclusive School and medically diagnosed with any type of Cerebral Palsy. The study focuses on understanding how adolescents with cerebral palsy in Bangladesh experience their transition to adulthood, identifying the social and cultural challenges they face, the barriers that might prevent them from transitioning smoothly and understanding how family members support or influence the transition to adulthood for adolescents with cerebral palsy. Your insights are essential in understanding the challenges, barriers and factors support during this process. Your involvement is entirely voluntary and greatly appreciated.

What does the research involve?

The research related information will be discussed with you throughout the information sheet before taking your signature on the consent form. After that, you will attend a face-to-face interview. After the participants participate, they will be accounted to answer all the questions. Student investigator will conduct interviews with you to explore your experiences as you transition into adulthood personal stories, challenges and what helps or hinders you in areas like education, employment, relationships, independence and societal participation. The interview will discuss your perspectives, analyze your responses to identify common themes and highlight key issues.

Why Were You Chosen for This Research?

You are invited to participate in this research because Your participation is valued because firstly, you are attending in William and Marie Taylor Inclusive School and

medically diagnosed with any type of Cerebral Palsy. Your insights are essential in understanding the challenges, barriers and factors support during this process. Your experiences is valuable as you transition into adulthood personal stories, challenges and what helps or hinders you in areas like education, employment, relationships, independence and societal participation. The interview will discuss your perspectives, analyze your responses to identify common themes.

Will you have to participate?

Your participation in this study is entirely voluntary. The research related information will be discussed with you throughout the information sheet before taking your signature on the consent form. After that, you will attend a face-to-face interview. After that, you will be accounted to answer all the questions. Participants will be given a consent withdrawal form to cancel their participation according to your wish within one week after conducting the interview. The recorded information will be kept confidential and your identity will not be revealed anywhere.

What are the possible risks and opportunities of participation?

There is no direct opportunity for this participation that means participants will not get any financial opportunity. Apart from this, there is no negative question in the scale. Therefore, there is no physical or mental risk to participants. Furthermore, your participation in this study will reveal your experience of transition to adulthood by identifying the social and cultural challenges you face, the barriers that might prevent you from transitioning smoothly and understand how family members support or influence the transition to adulthood for adolescents with cerebral palsy. That will help to highlight key areas that need attention to improve the transition for these individuals.

Will the participation be confidential?

The Researcher will strictly maintain the secrecy of the research. The participant's names will only be cited in the consent paper, while codes will be used in the question paper to maintain confidentiality. Only the related researcher and supervisor can know about it directly. The information paper will be locked in a drawer and the preservation of electronics will be in Occupational Therapy Department of BHPI and personal laptop of the researcher.

What will be the result of the research?

Through this study, we will gain an understanding of how adolescents with cerebral palsy experience the transition to adulthood. The findings will help explain how they perceive this transition, the social and cultural challenges they face, the barriers that prevent a smooth transition, and how family members support or influence this process. The results will highlight key areas that need attention to improve the overall transition experience for individuals with cerebral palsy.

Promotional Results

The results of this study may be shared through print or electronic media, academic publications, presentations, conferences, or other relevant platforms. Your identity will remain confidential in all forms of dissemination.

If you have any questions, you may contact us using the provided contact information.

Researcher:

Nishat Tasfia

4th year, B.Sc. in Occupational Therapy

Session: 2020-2021

Bangladesh Health Professions Institute (BHPI), CRP

CRP-Chapain, Savar, Dhaka-1343.

Call: 01763648250 Email: nishattasfia13@gmail.com

Supervisor:

Kaniz Fatema

Lecturer

Department of Occupational Therapy

Bangladesh Health Professions Institute, CRP

CRP-Chapain, Savar, Dhaka-1343.

Call: 01855611776 Email: kanizot1993@gmail.com

Consent Form

Assalamualikum. I am Nishat Tasfia, a 4th year student of the B.Sc. in Occupational Therapy program (Session: 2020–2021) at Bangladesh Health Professions Institute under the Faculty of Medicine, University of Dhaka. To fulfill my B.Sc. degree, I am required to conduct a research project, which is a part of my academic curriculum. The title of my research is “Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood”. The purpose of the study is to explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process. To complete my research project, I need to collect some information from you. Therefore, you may become an esteemed participant in this study. Information will be collected through face-to-face interviews, and the conversation will last approximately 30–40 minutes.

I would like to inform you that this is purely an academic study and will not be used for any other purpose. I assure you that all information will be kept confidential. Your participation is entirely voluntary. You have the right to withdraw your consent at any time within one week of data collection. However, withdrawal will not be possible after one week from the date of data collection. If you have any questions about this research, you may contact the researcher Nishat Tasfia or the supervisor Kaniz Fatema (Lecturer, Department of Occupational Therapy, BHPI, CRP, Savar, Dhaka).

Do you have any questions before we begin the interview?

Yes ☐ No ☐

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

Yes ☐ No ☐

Signature of the investigator and Date: _____

Signature of the participant and Date: _____

Signature of the witness and Date: _____

Withdrawal form

Research Title: Lived Experiences of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood.

Researcher's Name: Nishat Tasfia, 4th year, Occupational Therapy.

I,(Participant's Name) wish to withdraw from participating myself as a participant in this study.

Reason for withdrawing:

.....

Name of the participant:

Date:

Signature of the participant:

Date:

Name of the researcher:

Date:

Information Sheet, Consent Form & Withdrawal Form (Bangla Version)

গবেষণার তথ্যপত্র

গবেষণার শিরোনাম: সেরিব্রাল পালসিয়ুজ্জ কিশোর-কিশোরীদের জীবন অভিজ্ঞতা: প্রাপ্তবয়স্ক জীবনে উত্তরণের সামাজিক ও সাংস্কৃতিক দৃষ্টিভঙ্গি।

গবেষকের নাম: নিশাত তাসফিয়া

৪র্থ বর্ষ, বি.এসসি ইন অকুপেশনাল থেরাপি

সেশন: ২০২০-২০২১

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই),

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সুপারভাইজার:

কানিজ ফাতেমা

লেকচারার

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট

ফোন: ০১৮৫৫৬১১৭৭৬

ইমেইল: kanizot1993@gmail.com

গবেষণার স্থান: গবেষণাটি সেন্টার ফর দ্য রিহ্যাবিলিটেশন অব দ্য প্যারালাইজড (সিআরপি), সাভারের উইলিয়াম এবং মেরি টেইলর ইনক্লুসিভ স্কুলে পরিচালিত হবে।

ভূমিকা:

আমি নিশাত তাসফিয়া, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)-এর বি.এসসি ইন অকুপেশনাল থেরাপির ৪র্থ বর্ষের শিক্ষার্থী (সেশন: ২০২০-২০২১)। এটি সেন্টার ফর দ্য রিহ্যাবিলিটেশন অব দ্য প্যারালাইজড (সিআরপি) এর একাডেমিক ইনস্টিটিউট, যা ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন ফ্যাকাল্টির অধীনে। কোর্স কারিকুলামের অংশ হিসেবে আমাকে এই ৪র্থ বর্ষে একটি গবেষণা প্রকল্প পরিচালনা করতে হবে। এই গবেষণাটি অকুপেশনাল থেরাপি বিভাগের লেকচারার কানিজ ফাতেমার তত্ত্বাবধানে পরিচালিত হবে। এই তথ্যপত্রের মাধ্যমে গবেষণার উদ্দেশ্য, তথ্য সংগ্রহের প্রক্রিয়া এবং নৈতিক বিষয়গুলো সম্পর্কে বিস্তারিতভাবে জানানো হবে। আপনি যদি এই গবেষণায় অংশগ্রহণ করতে আগ্রহী হন, তবে এই তথ্যগুলো আপনাকে সিদ্ধান্ত নিতে সাহায্য করবে। দয়া করে তথ্যগুলো মনোযোগ দিয়ে পড়ুন। পড়ার পর কোনো অংশ বুঝতে অসুবিধা হলে আপনি প্রশ্ন করতে পারেন।

গবেষণার পটভূমি ও উদ্দেশ্য:

আপনাকে এই গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানানো হচ্ছে কারণ আপনি উইলিয়াম এবং মেরি টেইলর ইনক্লুসিভ স্কুলের শিক্ষার্থী এবং চিকিৎসাগতভাবে যেকোনো ধরনের সেরিব্রাল পালসিতে নির্ণীত। এই গবেষণার

উদ্দেশ্য হলো বাংলাদেশে সেরিব্রাল পালসি থাকা কিশোর-কিশোরীরা কীভাবে প্রাপ্তবয়স্ক জীবনে উত্তরণের অভিজ্ঞতা লাভ করে তা বোঝা, তারা কোন সামাজিক ও সাংস্কৃতিক চ্যালেঞ্জের মুখোমুখি হয় তা নির্ধারণ করা, কোন বাধাগুলো তাদের মসৃণভাবে উত্তরণের পথে প্রতিবন্ধকতা সৃষ্টি করে তা জানা এবং পরিবার কীভাবে তাদের এই উত্তরণে সহায়তা করে বা প্রভাব ফেলে তা বোঝা। আপনার অভিজ্ঞতা এই প্রক্রিয়া বোঝার জন্য অত্যন্ত গুরুত্বপূর্ণ।

গবেষণায় কী থাকবে?

গবেষণা সম্পর্কিত সমস্ত তথ্য এই তথ্যপত্রের মাধ্যমে আপনাকে জানানো হবে এবং এরপর আপনার সম্মতি ফর্মে স্বাক্ষর নেওয়া হবে। তারপর আপনার সাথে সামনাসামনি সাক্ষাৎকার নেওয়া হবে। সাক্ষাৎকারে আপনার ব্যক্তিগত অভিজ্ঞতা, চ্যালেঞ্জ এবং শিক্ষা, কর্মসংস্থান, সম্পর্ক, স্বাধীনতা এবং সমাজে অংশগ্রহণের মতো ক্ষেত্রে কী কী বিষয় আপনাকে সাহায্য করে বা বাধা সৃষ্টি করে, তা নিয়ে আলোচনা করা হবে। আপনার উত্তরগুলো বিশ্লেষণ করে মূল বিষয়গুলো চিহ্নিত করা হবে। সাক্ষাৎকারের পর অংশগ্রহণকারীদের একটি সম্মতি প্রত্যাহার ফর্ম দেওয়া হবে, যার মাধ্যমে আপনি সাক্ষাৎকার নেওয়ার এক সপ্তাহের মধ্যে ইচ্ছা করলে অংশগ্রহণ বাতিল করতে পারবেন। রেকর্ডকৃত তথ্য সম্পূর্ণ গোপন রাখা হবে এবং আপনার পরিচয় প্রকাশ করা হবে না।

আপনাকে কেন নির্বাচন করা হয়েছে?

আপনাকে এই গবেষণার জন্য আমন্ত্রণ জানানো হয়েছে কারণ আপনি উইলিয়াম এবং মেরি টেইলর ইনস্টিটিউট স্কুলে অধ্যয়নরত এবং আপনি চিকিৎসাগতভাবে সেরিব্রাল পালসিতে নির্ণীত। আপনার অভিজ্ঞতা এই গবেষণার উদ্দেশ্য পূরণে গুরুত্বপূর্ণ তথ্য প্রদান করবে, বিশেষ করে প্রাপ্তবয়স্ক জীবনের দিকে অগ্রসর হওয়ার সময় আপনার ব্যক্তিগত গল্প, চ্যালেঞ্জ, সহায়ক এবং বাধাস্বরূপ কারণগুলো সম্পর্কে।

আপনাকে কি অংশগ্রহণ করতে হবে?

আপনার অংশগ্রহণ সম্পূর্ণভাবে স্বেচ্ছামূলক। গবেষণা শুরু করার আগে আপনাকে এই তথ্যপত্রের মাধ্যমে সবকিছু জানানো হবে এবং তারপর সম্মতি ফর্মে স্বাক্ষর করতে হবে। এরপর আপনাকে সামনাসামনি সাক্ষাৎকারে অংশ নিতে হবে। সাক্ষাৎকারের পর আপনাকে সমস্ত প্রশ্নের উত্তর দিতে হবে। অংশগ্রহণকারীরা সাক্ষাৎকারের এক সপ্তাহের মধ্যে চাইলে সম্মতি প্রত্যাহার ফর্ম জমা দিয়ে যেকোনো সময় অংশগ্রহণ বাতিল করতে পারবেন। আপনার সকল তথ্য গোপন রাখা হবে এবং কোথাও আপনার পরিচয় প্রকাশ করা হবে না।

অংশগ্রহণের সম্ভাব্য ঝুঁকি ও সুযোগ:

এই গবেষণায় অংশগ্রহণের জন্য কোনো আর্থিক সুযোগ নেই। এছাড়াও প্রশ্নগুলোর মধ্যে কোনো নেতিবাচক বা ক্ষতিকর বিষয় নেই, সুতরাং এখানে কোনো শারীরিক বা মানসিক ঝুঁকি নেই। তবে আপনার অংশগ্রহণের মাধ্যমে জানা যাবে সেরিব্রাল পালসি থাকা কিশোর-কিশোরীরা কীভাবে প্রাপ্তবয়স্ক জীবনে উত্তরণ অভিজ্ঞতা করে, তারা কোন সামাজিক ও সাংস্কৃতিক চ্যালেঞ্জের মুখোমুখি হয় এবং পরিবার এই প্রক্রিয়ায় কী ভূমিকা রাখে। গবেষণার ফলাফল ভবিষ্যতে এসব ব্যক্তির উত্তরণ প্রক্রিয়া উন্নত করতে সহায়ক হবে।

গোপনীয়তা:

গবেষক এই গবেষণার তথ্য সম্পূর্ণ গোপনীয়ভাবে সংরক্ষণ করবেন। অংশগ্রহণকারীর নাম শুধুমাত্র সম্মতি ফর্মে থাকবে এবং প্রশ্নপত্রে কোড ব্যবহার করা হবে। তথ্যপত্রগুলো তালাবদ্ধ ড্রয়ারে সংরক্ষণ করা হবে এবং ইলেকট্রনিক তথ্য অকুপেশনাল থেরাপি বিভাগ ও গবেষকের ব্যক্তিগত ল্যাপটপে সংরক্ষণ করা হবে। শুধুমাত্র গবেষক এবং সুপারভাইজার এই তথ্যগুলোর অ্যাক্সেস পাবেন।

গবেষণার ফলাফল:

এই গবেষণার মাধ্যমে জানা যাবে সেরিব্রাল পালসি থাকা কিশোর-কিশোরীরা কীভাবে প্রাপ্তবয়স্ক হওয়ার অভিজ্ঞতা লাভ করে, তারা কোন সামাজিক ও সাংস্কৃতিক চ্যালেঞ্জের সম্মুখীন হয়, কোন বাধা তাদের পথে আসে এবং পরিবার কীভাবে এই উত্তরণ প্রক্রিয়ায় সহায়তা করে বা প্রভাব ফেলে। গবেষণার ফলাফল এসব ব্যক্তির উত্তরণ অভিজ্ঞতা আরও উন্নত করতে সহায়ক হবে।

ফলাফল প্রচার:

এই গবেষণার ফলাফল মুদ্রিত বা ইলেকট্রনিক মাধ্যম, একাডেমিক প্রকাশনা, উপস্থাপনা, সম্মেলন বা অন্যান্য প্রাসঙ্গিক মাধ্যমে প্রকাশ করা হতে পারে। তবে সব ক্ষেত্রেই অংশগ্রহণকারীর পরিচয় গোপন রাখা হবে।

যদি কোনো প্রশ্ন থাকে তবে আপনি প্রদত্ত ঠিকানায় যোগাযোগ করতে পারবেন:

গবেষক: নিশাত তাসফিয়া

৪র্থ বর্ষ, বি.এসসি ইন অকুপেশনাল থেরাপি

সেশন: ২০২০-২০২১

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি।

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩।

ফোন: ০১৭৬৩৬৪৮২৫০

ইমেইল: nishattasfia13@gmail.com

সুপারভাইজার: কানিজ ফাতেমা

লেকচারার

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি।

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩।

ফোন: ০১৮৫৫৬১১৭৭৬

ইমেইল: kanizot1993@gmail.com

সম্মতিপত্র

আসসালামু আলাইকুম। আমি নিশাত তাসফিয়া, ব্যাচেলর অব সায়েন্স ইন অকুপেশনাল থেরাপি প্রোগ্রামের ৪র্থ বর্ষের ছাত্রী (সেশন: ২০২০-২০২১), বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট, মেডিসিন অনুষদ, ঢাকা বিশ্ববিদ্যালয়। আমার বি.এসসি. ডিগ্রি সম্পন্ন করার জন্য একটি গবেষণা প্রকল্প পরিচালনা করা আবশ্যিক, যা আমার একাডেমিক শিক্ষাক্রমের অংশ। আমার গবেষণার শিরোনাম হলো -“সেরিব্রাল পালসি সম্পন্ন কিশোর-কিশোরীদের জীবন-অভিজ্ঞতা: প্রাপ্তবয়স্কতায় উত্তরণের সামাজিক ও সাংস্কৃতিক দৃষ্টিভঙ্গি।” এই গবেষণার উদ্দেশ্য হলো বাংলাদেশে সেরিব্রাল পালসি সম্পন্ন কিশোর-কিশোরীরা প্রাপ্তবয়স্কতায় রূপান্তরের সময় যে সামাজিক ও সাংস্কৃতিক চ্যালেঞ্জের মুখোমুখি হয়, সে সম্পর্কে তাদের জীবিত অভিজ্ঞতা অনুসন্ধান ও বোঝা।

গবেষণা প্রকল্পটি সম্পন্ন করার জন্য আমাকে আপনার কাছ থেকে কিছু তথ্য সংগ্রহ করতে হবে। সেই অনুযায়ী, আপনাকে এই গবেষণার একজন মূল্যবান অংশগ্রহণকারী হিসেবে অন্তর্ভুক্ত করা হতে পারে। তথ্য সংগ্রহ করা হবে সামান্যসামান্য সাক্ষাৎকারের মাধ্যমে, যার সময়কাল প্রায় ৩০-৪০ মিনিট হবে। আমি আপনাকে জানাতে চাই যে এটি সম্পূর্ণভাবে একটি একাডেমিক গবেষণা এবং কোনো অন্য উদ্দেশ্যে ব্যবহার করা হবে না। আপনার দেওয়া সকল তথ্য গোপন রাখা হবে। আপনার অংশগ্রহণ সম্পূর্ণ স্বৈচ্ছামূলক, এবং তথ্য সংগ্রহের তারিখ থেকে এক সপ্তাহের মধ্যে আপনি যেকোনো সময় অংশগ্রহণ প্রত্যাহার করতে পারবেন। তবে তথ্য সংগ্রহের এক সপ্তাহ পর আর প্রত্যাহার করা সম্ভব হবে না। যদি এই গবেষণা সম্পর্কে আপনার কোনো প্রশ্ন থাকে, আপনি গবেষক নিশাত তাসফিয়া অথবা সুপারভাইজার কানিজ ফাতেমা (লেকচারার, অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা) সাথে যোগাযোগ করতে পারেন।

সাক্ষাৎকার শুরু করার আগে আপনার কি কোনো প্রশ্ন আছে?

হ্যাঁ ☐ না ☐

তাহলে, সাক্ষাৎকারটি পরিচালনার জন্য কি আমি আপনার সম্মতি পেতে পারি?

হ্যাঁ ☐ না ☐

গবেষকের স্বাক্ষর ও তারিখ: _ _ _ _ _

অংশগ্রহণকারীর স্বাক্ষর ও তারিখ: _ _ _ _ _

সাক্ষীর স্বাক্ষর ও তারিখ: _ _ _ _ _

প্রত্যাহারপত্র

গবেষণার শিরোনাম: সেরিব্রাল পালসি সম্পন্ন কিশোর-কিশোরীদের জীবন-অভিজ্ঞতা: প্রাপ্তবয়স্কতায় উত্তরণের

সামাজিক ও সাংস্কৃতিক দৃষ্টিভঙ্গি

গবেষকের নাম: নিশাত তাসফিয়া, ৪র্থ বর্ষ, অকুপেশনাল থেরাপি

আমি,(অংশগ্রহণকারীর নাম), এই গবেষণায় অংশগ্রহণকারী

হিসেবে নিজেকে প্রত্যাহার করার ইচ্ছা প্রকাশ করছি।

প্রত্যাহারের কারণ:

অংশগ্রহণকারীর নাম:

তারিখ:

অংশগ্রহণকারীর স্বাক্ষর:

তারিখ:

গবেষকের নাম:

তারিখ:

Appendix C: Interview Guide

Questionnaire English Version

Sociodemographic questions

1. ID Number:

2. Participant's Name:

3. Age: _____ years

4. Gender:

☐ Male ☐ Female ☐ Other (specify): ____

5. Phone Number:

6. Current Education Level:

☐ Signature only

☐ Primary (Class 1–5)

☐ Secondary (Class 6–10)

☐ Higher Secondary

☐ Madrasa/Vocational

☐ Other (specify): ____

7. School Attendance Status:

☐ Regular ☐ Irregular ☐ Dropped out ☐ Never attended

8. Address:

9. Type of Cerebral Palsy (if known):

☐ Spastic ☐ Dyskinetic ☐ Ataxic ☐ Mixed ☐ Not sure

10. Mobility Status:

☐ Walks independently

☐ Walks with assistive device

☐ Wheelchair user

☐ Dependent on others

11. Communication Ability:

- ☐ Verbal
- ☐ Uses gestures/signs
- ☐ Uses communication aid
- ☐ Difficult to understand speech

12. Cognitive Functioning (as perceived by parent):

- ☐ Normal
- ☐ Mild intellectual disability
- ☐ Moderate intellectual disability
- ☐ Severe intellectual disability
- ☐ Not sure

13. Who do you live with?

- ☐ Both parents
- ☐ Mother only
- ☐ Father only
- ☐ Grandparents
- ☐ Siblings
- ☐ Other relatives
- ☐ Institutional care

Self-Developed Interview Guide (English Version)

The interview guide was created using the Model of Human Occupation (MOHO) as a framework to ensure that key areas of volition, habituation, performance and environment were explored.

Aim: To explore and understand the lived experiences of adolescents with cerebral palsy in Bangladesh as they transition into adulthood, with a particular focus on the social and cultural challenges they experience during this process.

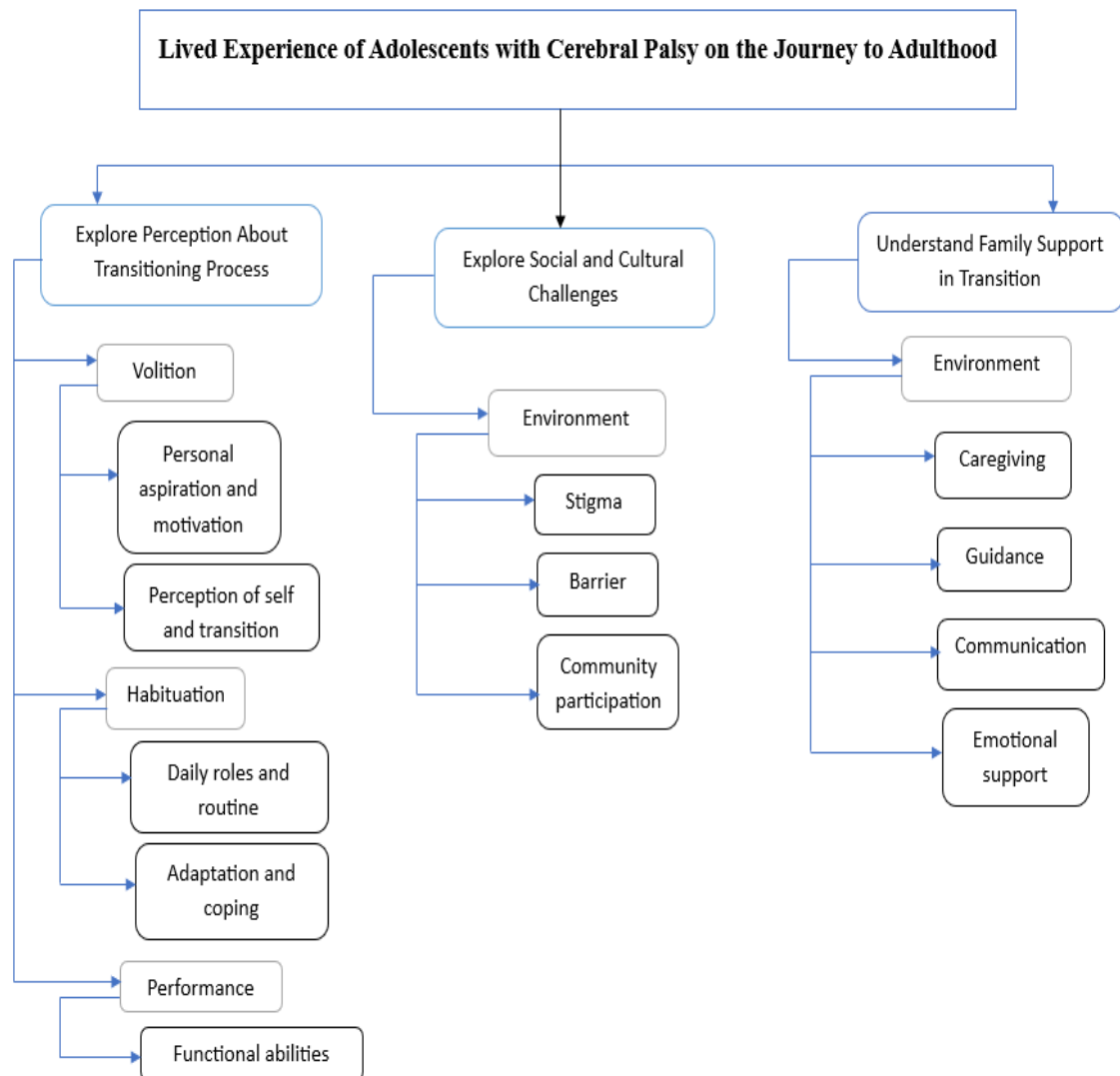
Self-Developed Interview Guide

Objective	Main Question	MOHO Component	Framework Domain
1.To explore the perception about transitioning process of adolescents with cerebral palsy	<p>When you think about becoming an adult what comes to your mind, Can you tell me your thoughts?</p> <p>Probe 1: What does being an adult mean to you?</p> <p>Probe 2: Can you tell me about some things you dream of doing in the future?</p> <p>Probe 3: Is there something you feel excited or worried about?</p>	Volition	Personal aspiration & motivation
	<p>Can you describe any changes you have noticed in yourself as you have gotten older?</p> <p>Probe 1: What physical changes have you noticed?</p> <p>Probe 2: Have you noticed changes in your feelings or thoughts?</p> <p>Probe 3: Can you tell me how these changes affected your daily life?</p>	Volition & Adaptation	Perception of self and transition

	<p>Can you tell me about what you usually do every day from morning to night?</p> <p>Probe 1: Can you describe one activity in detail?</p> <p>Probe 2: How do you feel while doing it?</p> <p>Probe 3: Can you tell me why you do it this way?</p>	Habituation	Daily roles & routine
	<p>How has your day-to-day life changed as you grew older?</p> <p>Probe 1: Can you tell me about one change that was important to you?</p> <p>Probe 2: Can you give an example from yesterday or last week?</p> <p>Probe 3: How did you manage or adapt to this change?</p>	Adaptation & Coping	Adaptation & coping
	<p>Can you tell me about something you can do all by yourself?</p> <p>Probe 1: Can you describe a time you did it recently?</p> <p>Probe 2: How did you do it?</p> <p>Probe 3: How did it make you feel?</p>	Performance	Functional abilities
2. To explore the social and cultural challenges faced by adolescents with cerebral palsy	<p>Can you tell me about a time you faced difficulties in your community or society?</p> <p>Probe 1: What happened when you went to school, market, or a neighbor's house?</p> <p>Probe 2: How did people react when they met you?</p> <p>Probe 3: What did you do in that situation?</p>	Environment	Barrier

	<p>How do you feel when you meet people in different places you visit?</p> <p>Probe 1: Can you tell me about a place you like to go?</p> <p>Probe 2: Are there people or situations that make you feel different?</p> <p>Probe 3: What do you do when you feel that way?</p>	Environment	Stigma
3. To understand how family members support or influence the transition to adulthood for adolescents with cerebral palsy	<p>Can you tell me about someone who helps you at home?</p> <p>Probe 1: Can you tell me a story of when they helped you?</p> <p>Probe 2: Is it easy to ask for help?</p> <p>Probe 3: Has their help changed as you got older?</p>	Environment	Caregiving
	<p>Can you tell me about conversations you have had with your family about growing up?</p> <p>Probe 1: Who do you talk to when you have questions?</p> <p>Probe 2: What kind of advice do they give?</p> <p>Probe 3: How do you feel about these conversations?</p>	Environment	Communication

Fig: MOHO based Framework



Questionnaire Bangla Version

সামাজিক ও জনসংখ্যগত প্রশ্নাবলী

১। আইডি নম্বর:

২। অংশগ্রহণকারীর নাম:

৩। বয়স: _____ বছর

৪। লিঙ্গ:

☐ ছেলে ☐ মেয়ে ☐ অন্যান্য (উল্লেখ করুন): _____

৫। ফোন নম্বর:

৬। বর্তমান শিক্ষার স্তর:

- ☐ শুধু স্বাক্ষর করতে পারেন
- ☐ প্রাথমিক (শ্রেণি ১-৫)
- ☐ মাধ্যমিক (শ্রেণি ৬-১০)
- ☐ উচ্চ মাধ্যমিক
- ☐ মাদ্রাসা/কারিগরি শিক্ষা
- ☐ অন্যান্য (উল্লেখ করুন): _____

৭। বিদ্যালয়ে উপস্থিতির অবস্থা:

- ☐ নিয়মিত ☐ অনিয়মিত ☐ পড়াশোনা ছেড়েছেন ☐ কখনোই স্কুলে যাননি

৮। ঠিকানা: _____

৯। সেরিব্রাল পালসির ধরণ (যদি জানা থাকে):

- ☐ স্পাস্টিক ☐ ডিসকাইনেটিক ☐ এট্যাক্সিক ☐ মিশ্র ☐ জানি না

১০। চলাফেরার অবস্থা:

- ☐ নিজেই হাঁটতে পারেন
- ☐ সহায়ক যন্ত্র ব্যবহার করে হাঁটেন

☐ হুইলচেয়ার ব্যবহার করেন

☐ অন্যের উপর নির্ভরশীল

১১। যোগাযোগ করার ক্ষমতা:

☐ কথার মাধ্যমে বোঝাতে পারেন

☐ ইশারা/সাইন ব্যবহার করেন

☐ যোগাযোগের সহায়ক যন্ত্র ব্যবহার করেন

☐ কথা বোঝা কঠিন

১২। শেখার ক্ষমতা (অভিভাবকের ধারণা অনুযায়ী):

☐ স্বাভাবিক

☐ হালকা মানসিক প্রতিবন্ধকতা

☐ মাঝারি মানসিক প্রতিবন্ধকতা

☐ গুরুতর মানসিক প্রতিবন্ধকতা

☐ নিশ্চিত নই

১৩। আপনি কার সাথে থাকেন?

☐ মা-বাবা দুজনের সাথে

☐ শুধু মায়ের সাথে

☐ শুধু বাবার সাথে

☐ দাদা-দাদী/নানা-নানীর সাথে

☐ ভাই-বোনের সাথে

☐ অন্যান্য আত্মীয়দের সাথে

☐ প্রাতিষ্ঠানিক যত্নে

Self-Developed Interview Guide (Bangla Version)

নির্দিষ্ট লক্ষ্য	প্রধান প্রশ্ন
<p>১. বাংলাদেশে সেরিব্রাল পালসিযুক্ত কিশোর-কিশোরীরা বড় হওয়া বা প্রাপ্তবয়স্ক হওয়ার প্রক্রিয়া সম্পর্কে কীভাবে ধারণা করে, তা অনুসন্ধান করা।</p>	<p>১। আপনি যখন বড় হওয়ার কথা ভাবেন, তখন মনে কি ধরনের চিন্তা আসে?</p> <p>Probes:</p> <ul style="list-style-type: none"> • আপনার কাছে বড় হওয়া মানে কী? • আপনি বড় হলে কী হতে চান? • বড় হওয়ার কথা ভাবলে আপনার মন কেমন মনে হয়?
	<p>২। আপনি সকাল থেকে রাত পর্যন্ত কী কী করেন, সেটা বলুন।</p> <p>Probes:</p> <ul style="list-style-type: none"> • একটা কাজের গল্প বলুন, আপনি কীভাবে করেন। • সেই কাজ করতে আপনার মন কেমন লাগে? • আপনি ওই কাজটা কেন এইভাবে করেন, আমাকে শোনান।
	<p>৩। আপনি বড় হতে হতে আপনার প্রতিদিনের কাজে কী বদল এসেছে?</p> <p>Probes:</p> <ul style="list-style-type: none"> • আগে যা পারতেন না, এখন কী করতে পারেন? একটা উদাহরণ দিন। • গতকাল বা গত সপ্তাহে এমন কি কোনো ঘটনা ঘটেছে? বলুন। • তখন আপনি কীভাবে কাজ সামলিয়েছিলেন?
	<p>৪। আপনি বড় হতে হতে নিজের মধ্যে কী নতুন কিছু দেখছেন বা অনুভব করছেন?</p> <p>Probes:</p> <ul style="list-style-type: none"> • শরীরে কি কিছু বদল দেখেছেন? • মনে কোনো নতুন অনুভূতি এসেছে? • এই নতুন কিছু আপনার কেমন লাগে? ছোট্ট একটা গল্প বলুন।

	<p>৫। এমন কোনো কাজ আছে যা আপনি একা করতে পারেন?</p> <p>Probes:</p> <ul style="list-style-type: none"> • সাম্প্রতিক কোনো সময়ের গল্প বলুন, যখন আপনি একা কাজ করেছিলেন। • সেটা আপনি কিভাবে করেছিলেন, আমাকে শোনান। • কাজ করতে কেমন লাগলো?
<p>২. সেরিব্রাল পালসিযুক্ত কিশোর-কিশোরীরা প্রাপ্তবয়স্কতায় রূপান্তরের সময় কোন কোন সামাজিক ও সাংস্কৃতিক চ্যালেঞ্জের সম্মুখীন হয়, তা খুঁজে বের করা।</p>	<p>৬। আপনি বাইরে গেলে কোনো সমস্যার মুখোমুখি হয়েছেন কি?</p> <p>Probes:</p> <ul style="list-style-type: none"> • যেমন—স্কুলে, বাজারে বা প্রতিবেশীর বাড়িতে কখনও কিছু হয়েছিল, একটা গল্প বলুন। • মানুষ আপনার সাথে কীভাবে আচরণ করেছে? • তখন ওই পরিস্থিতিতে আপনি কি করেছিলেন?
	<p>৭। আপনি যখন বাইরে মানুষের সাথে দেখা করেন, তখন কেমন লাগে?</p> <p>Probes:</p> <ul style="list-style-type: none"> • এমন কোনো জায়গার গল্প বলুন, যেখানে গেলে আপনার ভালো লাগে। • কখনো কি কোথাও গিয়ে নিজেকে আলাদা বা ভিন্ন মনে হয়েছে? যদি হয়ে থাকে, একটা ঘটনা বলুন। • তখন আপনি কী করেছিলেন?
<p>৩. বাংলাদেশি সামাজিক ও সাংস্কৃতিক প্রেক্ষাপটে পরিবার কীভাবে সেরিব্রাল পালসিযুক্ত কিশোর-কিশোরীদের বড় হওয়া বা প্রাপ্তবয়স্ক হওয়ার প্রক্রিয়াকে সহায়তা করে বা প্রভাবিত করে, তা বোঝা।</p>	<p>৮। বাড়িতে আপনাকে কে সাহায্য করে?</p> <p>Probes:</p> <ul style="list-style-type: none"> • তারা কীভাবে সাহায্য করে? একটা গল্প বলুন। • সাহায্য চাইতে কেমন লাগে, বর্ণনা করুন। • বড় হওয়ার সাথে তাদের সাহায্যে কী বদল এসেছে? বিস্তারিত বলুন। <p>৯। বড় হওয়া নিয়ে পরিবারের কেউ আপনার সাথে কথা বলেছেন কি?</p> <p>Probes:</p> <ul style="list-style-type: none"> • আপনার কোনো প্রশ্ন থাকলে আপনি কার সাথে বলেন? একটা উদাহরণ দিন। • তারা কী বলেন—সহায়তার কথা বা কথা বলা। • এসব কথা শুনে আপনার মন কেমন হয়েছিল?

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

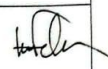
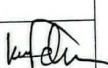
Title of thesis: Lived Experiences Of Adolescents with Cerebral Palsy: A Social and Cultural Perspective on the Journey to Adulthood

Name of student: Nishat Tasbia

Name and designation of thesis supervisor: Kaniz Fatema, Lecturer, Department of Occupational Therapy

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	25/05/25	BHPI Office	Discussion about research title	1hr	Titles discussed	Nishat Tasbia	Kaniz Fatema
2	28/05/25	BHPI Office	Title selection and guideline about finding relevant literature	1.5hr 30mins	Title selected and guideline discussed	Nishat Tasbia	Kaniz Fatema
3	29/05/25	BHPI Office	Discussion about aim and objectives	1hr	Aim and objectives discussed	Nishat Tasbia	Kaniz Fatema

4	31/05/25	BHPI Office	Interview guide planning	2hr 30mins	Planning done	Nishat Tasbia	Kaniz Fatema
5	01/06/25	BHPI Office	Preparing interview questions	2hr	Questions prepared	Nishat Tasbia	Kaniz Fatema
6	02/06/25	BHPI Office	Interview guide translation	3hr	Interview guide translation done	Nishat Tasbia	Kaniz Fatema
7	14/06/25	BHPI Office	Proposal writing guidance	1hr 30mins	Writing started	Nishat Tasbia	Kaniz Fatema
8	15/06/25	BHPI Office	Method discussion	3hr	Method discussed	Nishat Tasbia	Kaniz Fatema
9	15/06/25	BHPI Office	Proposal presentation checking	45mins	Checking completed	Nishat Tasbia	Kaniz Fatema
10	22/06/25	BHPI Office	IRB Proposal feedback discussion	2hr	Feedback received	Nishat Tasbia	Kaniz Fatema
11	25/06/25	BHPI Office	Title, aim and objective revision	2.5hr	Revision done	Nishat Tasbia	Kaniz Fatema
12	04/07/25	BHPI Office	Interview guide revision	2hr	Revision done	Nishat Tasbia	Kaniz Fatema
13	15/07/25	BHPI Office	Interview guide framework checking	3hr	Framework checked	Nishat Tasbia	Kaniz Fatema
14	20/07/25	BHPI Office	Method revision	50mins	Revision done	Nishat Tasbia	Kaniz Fatema

15	15/01/25	BHPI Office	Literature review writing discussion	2hr	writing style discussed	Nishat Tashia	
16	06/12/25	BHPI Office	Data analysis discussion	2hr 30mins	Discussion completed	Nishat Tashia	
17	09/12/25	BHPI Office	Result writing discussion	3hr	writing discussed	Nishat Tashia	
18	01/01/26	BHPI Office	First-draft checking and feedback	3hr 30mins	Feedback received	Nishat Tashia	
19	08/02/26	BHPI Office	Second draft improvement	1hr 30mins	Improvement checking done	Nishat Tashia	
20	10/02/26	BHPI Office	Second draft finalizing	2hr	Draft finalized	Nishat Tashia	

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.

