Exploring Parenting Practice and Challenges of Parents of Children with Cerebral Palsy

By

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A thesis submitted to Brac Institute of Educational Development in partial fulfillment of the requirements for the degree of
Master of Science in Early Childhood Development

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Declaration

It is hereby declared that

1. The thesis submitted is my own original work while completing degree at BRAC University.

2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.

3. The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.

4. I have acknowledged all main sources of help.

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Approval

The thesis/project titled “Exploring Parenting Practice and Challenges of Parents of Children with Cerebral Palsy” submitted by

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Ethics Statement

Title of Thesis Topic: Exploring Parenting Practice and Challenges of Parents of Children with Cerebral Palsy.

Student name: Mahmuda Binta Yeakub

1. Source of population

Parents of 3-8 years old CP children in Saidpur, Nilphamari

2. Does the study involve (yes, or no)

a) Physical risk to the subjects
b) Social risk
c) Psychological risk to subjects
d) discomfort to subjects
e) Invasion of privacy

3. Will subjects be clearly informed about (yes or no)

a) Nature and purpose of the study
b) Procedures to be followed
c) Physical risk
d) Sensitive questions
e) Benefits to be derived
f) Right to refuse to participate or to withdraw from the study
g) Confidential handling of data
h) Compensation and/or treatment where there are risks or privacy is involved

4. Will Signed verbal consent for be required (yes or no)

a) from study participants
b) from parents or guardian
c) Will precautions be taken to protect anonymity of subjects?

5. Check documents being submitted herewith to Committee:

a) Proposal
b) Consent Form
c) Questionnaire or interview schedule

Ethical Review Committee:

Authorized by:
(chair/co-chair/other)

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Abstract

This study attempts to explore and learn about the knowledge and perceptions of parents in Bangladesh who have children with cerebral palsy (CP), their mental health, the caregiving burden they encounter, and the coping strategies that they use. A qualitative approach was followed to conduct the study. In-depth interviews and focus group discussions were conducted with ten parents (five mothers and five fathers) to gain insight into the personal experiences of these participants. The result shows that all the parents at the beginning of their child's CP diagnosis did not have any information on the condition, thus they faced emotional difficulties, stress, and anxiety after the diagnosis. Through the years, parents discussed their child's condition with the healthcare providers and slowly gathered more knowledge about the disorder and its management. Despite this progress, parents continued to struggle with several issues such as financial constraints, availability of a specialized service, and stigmatization. Parents have reacted to the situation with feelings of depression, anxiety, and loneliness and this is damaging their mental health. However, family support, social networks, and professional support turned into valuable assets in coping with these problems. The results emphasize the necessity for increased awareness, improved healthcare services, and comprehensive support for families of children with CP in Bangladesh.

Keywords: Cerebral Palsy, Movement Disorder, Children with Disabilities, Mental Health

Dedication

This thesis is dedicated to my Beloved Mother, Father, My Mother-in-law & Father-in-law.

Acknowledgement

At first, I would like to thank the Almighty Allah, who provided me with the opportunity to complete my Masters in Science at BRAC Institute of Educational Development, BRAC University. Then, I would like to express my deepest gratitude and profound respect to my mentor Sakila Yesmin, Senior Lecturer & Research Lead, BRAC Institution of Educational Development, BRAC University for her valuable time, suggestions, motivations, and guidance in every step throughout this journey. It would not be possible to complete this thesis work without her suggestions, feedbacks, and continuous support. I have learned many things from her throughout this learning process. I want to convey my gratitude to the course coordinators, and all the faculty members, from whom I learned and gathered immense knowledge about early childhood development. They are always there for us whenever we need their help. I am very grateful to the fathers and mothers who gave their valuable time for the interviews and the group discussions and shared their thoughts and opinions. I am also grateful to my family and friends for motivating me. Last but not the list, I am thankful to my husband and my sister from the core of my heart. Without their continuous support and sacrifice, it would not be possible

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List of Acronyms

CP	Cerebral palsy
FGD	Focus group discussion
IID	In-depth interview
BRAC IED	BRAC Institute of Educational Development
NGO	Non-governmental organization
SSC	Secondary School Certificate
UNICEF	United Nations International Children's Emergency Fund

Chapter I: Introduction & Background

1.1 Introduction

Cerebral palsy (CP) is a severe neurological disorder characterized by limited mobility and motor dysfunction, often damaging the developing brain. It is the most common physical disability in childhood, with a worldwide prevalence of about 2 to 3 per 1,000 live births (Oskoui, 2013). Although the condition varies widely in severity and symptoms, children with CP can experience difficulties with mobility, communication and activities of daily living, requiring lifelong support and they are looked after.

The journey of nurturing of a child with cerebral palsy is multifaceted, often presenting unique challenges for families. Parents and caregivers play a critical role in navigating the challenges of their child’s condition, nursing management, accessing support services, and advocating for the child’s needs but while parents play a critical role in caring for children with CP differ in their experiences, perspectives and needs.

In Bangladesh, the stories of parents elevating children with CP are deeply stimulated through the cultural, social, and monetary context of the country. Despite progress in healthcare and incapacity rights, families stricken by CP often stumble upon several demanding situations in accessing support offerings, navigating societal attitudes, and securing sources for his or her infant's care. Understanding the specific experiences and perspectives of nurturing youngsters with CP is critical for growing culturally touchy interventions and support structures tailored to the wishes of this population. This studies pursuits to explore the journey of parents for children with CP, shedding light on their experiences, coping strategies, and guide needs inside the context of

Bangladesh's socio-cultural landscape. By amplifying the voices of those mother and father, this take a look at seeks to tell coverage and exercise initiatives aimed toward enhancing the nicely-being and high-quality of existence of households stricken by cerebral palsy (Raina, 2004).

This study seeks to address the parents' experience regarding nurturing a child with cerebral palsy. By gaining insights into the reviews, challenges, and coping techniques of parents, this study aims to shed light on the diverse and often underrepresented voices inside the CP network. Understanding the intricacies of parental studies can inform the development of focused interventions, support services, and guidelines to higher meet the wishes of families stricken by CP.

In the subsequent sections, this thesis concept outlines the specific targets, methodology, and significance of the look at, as well as the expected contributions to current literature and implications for exercise and policy. By delving into the nuanced reviews of parents, we endeavor to foster extra inclusive and supportive surroundings for families suffering from cerebral palsy.

1.2 Statement of the Problem

Nurturing of a child with CP is not just a medical journey but a deeply personal and transformative experience for parents and caregivers. But in the midst of medical challenges and medical interventions, the minor realities of nurturing a child with CP often still overshadow the emotional development, daily triumphs, suffering, and impact of its profound effect on family development is greatly enhanced in educational discourse and social issues.

Parents nurturing children with CP in Bangladesh face a myriad of complex challenges stemming from a variety of socioeconomic, health, and cultural factors

Cerebral palsy, a lifelong neurological disorder in cognitive impairment due to brain damage during early aging has an important consequence for the physical, emotional, and financial burden on affected families (Rosenbaum, 2007). Despite global efforts to increase disability rights and promote inclusive practices, Bangladeshi families affected by CP often struggle with access to essential services such as treatment, medical services, and educational support a they don't get it right about (Ahmed, 2013).

Socioeconomic disparities exacerbate these challenges, as many families lack the funds for essential medical and supportive services The situation is particularly dire in rural areas due to limited health care facilities and lack of specialized medical personnel (Halder, 2007) .These financial constraints often force parents to choose between caring for a child with CP and meeting their other basic household needs, resulting in chronic poverty and inadequate care.

Cultural attitudes towards disability in Bangladesh also play an important role in shaping the experiences of these families. Stigma and discrimination against individuals with disabilities are common, leading to social discrimination and reducing opportunities for children with CP (Miles, 2002). Such social attitudes can be detrimental to the child and the parent's self-esteem, making the care process more challenging. Widespread stigma often discourages families from seeking outside help or advocating for their rights, thus limiting their access to available resources.

The education system in Bangladesh poses additional challenges for children with CP. Inclusive teaching is underutilized, and teachers are often inadequately prepared to meet the needs of students with disabilities (Ahsan, 2012). As a result, many children with CP are excluded from mainstream education or do not receive the individualized attention they need to make academic progress. This lack of educational support further hinders their progress and chances for a better life.

Furthermore, the lack of support services and services specifically designed for families affected by CP further compounds the challenges faced by these parents Without appropriate guidance and resources, parents often experience increased levels of stress and burnout, as it can negatively affect their mental health and overall well-being (Gray, 2016). This highlights the urgent need for comprehensive, context-specific interventions that address the unique needs of Bangladeshi families nurturing children with CP.

This study seeks to explore the unique challenges and support needs of Bangladeshi parents nurturing children with CP, and shed light on the determinants of their experiences and well-being in the Bangladeshi context. By identifying the key issues these families face, this study aims to identify targeted interventions and programs that address the specific needs of children with CP and improve their families and, ultimately their lives and social inclusion in Bangladesh.

1.3 Purpose of the Study

The main purpose of the study is to explore the parenting practice including daily lives, mental health issues and experiences of parents who are nurturing children with CP. Another purpose is to explore the challenges faced by the parents in raising children with CP.

1.4 Significance and Justification of the Study

The significance of this study is that it focuses on the often-overlooked experiences of parents nurturing children with CP in Bangladesh These parents face unique challenges due to socioeconomic differences, health due to inaccessible programming and cultural norms. The research aims to explore and amplify the voices of these parents and to value and acknowledge their lived experiences, in order to enhance their resilience and unwavering commitment to their children. In a society where the experiences of individuals with disabilities and their families are highly stigmatized, this research seeks to highlight the dignity and relevance of those affected by CP, and seeks to foster and own inclusive communities encourage greater empathy.

Insights from this study will provide valuable guidance for the development of targeted interventions and support services tailored to the unique needs of families affected by CP. By identifying specific parental stressors, coping strategies, and support needs, research aims to inform policy makers, health care providers, and service organizations of practical and flexible programs that can improve the lives of these families directly improve (Davis & Gavidia-Payne, 2009).

In addition to individual support, this research seeks to influence broader policy changes that support the rights, dignity, and inclusion of individuals with CP and their families through policy reform, social services enhancement, and advocating for changes in social consciousness, research aims to challenge existing stigmas and break down barriers to inclusion was authored. Collaborating with advocacy groups, policymakers, and community leaders, the research seeks to foster policy change, fostering a more just and compassionate society (Jamie C. Brehaut, et al., 2004).

This study will provide valuable guidance for the development of targeted interventions and support services tailored to the specific needs of families affected by CP. By identifying specific parental stressors, coping strategies, and support needs, the study aims to inform policymakers, health care providers, and service organizations of useful vulnerable policies and it can directly improve the lives of these families. These benefits are essential for practical and effective interventions, addressing the day-to-day challenges of caregivers (UNICEF, 2014).

Finally, the study seeks to enhance understanding of the complexity of factors influencing parenting experiences such as race, ethnicity, socioeconomic status, and gender Through that identity upon examination of these intersecting types, research aims to highlight the unique challenges faced by marginalized communities within the CP population. This nuanced approach ensures that recommended interventions address these needs comprehensively and comprehensively (Shields, 2006).

1.5 Research Questions

a) What are the parenting practices of parents of children with cerebral palsy (CP)?

b) What mental health issues do parents of children with CP face?

c) What challenges do parents of children with cerebral palsy face in raising their children and how can those challenges be mitigated?

Chapter II: Literature Review

CP is a severe neurological disorder characterized by motor dysfunction resulting from damage to the developing brain. It is the most common anatomical disability in childhood, affecting approximately 2.1 per 1000 live births worldwide (Oskoui, 2013). Although considerable research focuses on the medical aspects of CP, there are significant gaps in understanding the lived experiences of families nurturing children with this condition This literature review aims to complement previous research together with parental perspectives on nurturing a child with cerebral palsy.

Family dynamics and relationships

Nurturing a child with CP significantly impacts family dynamics and relationships, affecting the emotional, social and practical aspects of family interactions Understanding these dynamics is important for families navigating the challenges posed by CP under all experience.

Furthermore, the presence of a child with CP can affect sibling relationships and dynamics within the family. Siblings may experience a range of emotions including jealousy, anger, guilt, or anxiety that guide their roles in the family system (Raina, 2004). The ideas and objects shown to a child with CP can make siblings feel neglected or shadowed, which can affect their sense of identity and self-worth but there are also examples of it as increased empathy, compassion and resilience in siblings as they adjust to life challenges in a CP-affected family.

Furthermore, CP can affect the functioning and coordination of the entire family. Families nurturing children with CP often make significant adjustments to meet the needs of the ill child, changing behaviors, roles, and responsibilities (Gray, 2012).

Financial pressures associated with medical bills, medical services, and primary care can significantly increase stress within the family system, affecting decision-making, lifestyle choices, and future planning.

Challenges in accessing essential support services

Despite the acknowledgment of the importance of support services, families nurturing children with CP often face barriers to accessing these resources. (K Davis, 2009). Limited availability of primary care, financial barriers, geographic differences in service delivery, and lack of knowledge of available resources These barriers exacerbate the stress experienced by families and emphasizes the urgent need to improve access and equity in support services.

Financial Strain and Socioeconomic Impact

Studies in Bangladesh have highlighted the significant economic impact of families nurturing children with CP. Parents often face out-of-pocket expenses for treatment and treatment covered by the public health system. This financial burden is a loss of income, as one or both parents may have to reduce their working hours or leave their jobs to care for their child full-time (Ahmed, 2013).

(Ahsan, 2012) found that families with CP and children with disabilities are more likely to be poor and socially excluded Research has shown that parents often take on more debt to pay for their child’s care, and leads to long-term -term financial instability. Furthermore, the lack of access to basic services and resources further compounds the financial and emotional burden on these families.

Stress and coping mechanism of parents with CP

Parents of children with CP often experience increased levels of stress compared to typically developing parents, as highlighted by (Gray, 2012). Long-term CP, as well as uncertainty about long-term prognosis and daily care demands, contribute to increased psychological distress in parents. (Davis, 2009) highlight the stressors these parents face, which includes maintaining a complex treatment regimen, complex health care navigation plans, advocating for their child’s needs overcoming social stigmas and stereotypes.

Support services for families

Support services are essential for families nurturing children with CP, including medical, educational, and social support programs; early and sustained treatment interventions, such as physical, occupational, and speech therapy, for significant physical and overall improvement; community support programs and counseling services help reduce stress and isolation; and improve parents’ mental health and coping skills. Inclusive policies and advocacy for adequate funding ensure access to needed resources and support, thus improving the quality of life for families affected by CP (Davis, 2009).

Chapter III: Methodology

3.1 Research Approach/ Design

A qualitative research approach was used to conduct the study. The study was explorative, obtaining detailed, in-depth information about the parenting practice of children with Cerebral Palsy and their challenges. In-depth interviews and focus group discussions were employed to collect the data from the participants.

3.2 Research Participants

The study involved parents of children aged 3–8 with cerebral palsy from middle-class backgrounds, who were willing to participate and provide information. The minimum education requirement of the participants was at least 8th grade. Ten parents were included in the study as participants.

3.3 Research Site

The study was conducted in Saidpur, Nilphamari, Bangladesh.

3.4 Participant Selection Procedure

A total of 10 parents of children with CP were selected to conduct this study. Out of them, half of them were fathers and half of them are mothers. Four parents (two fathers and two mothers) and six parents (three fathers and three mothers) were selected for in-depth interviews and focus group discussions respectively. The purposive sampling technique was employed to select parents with at least one child with CP aged between 3 and 8 years old. The selection ensured that participants could understand and respond to interview questions effectively, and share their perceptions and practices related to nurturing a child with CP.

3.5 Data Collection Methods

Data for this study was collected using two main methods: In-depth interviews (Alzbutas, #102) and focus group discussion (FGD) guidelines was developed and reviewed by the experts. The IDIs were allowed individual parents to express themselves freely and ensure that key issues were covered. Focus group discussions were bring together small groups of parents to discuss their experiences and challenges in a more interactive environment. These helped capture perspectives and reveal common themes and experiences shared by parents. It was designed not only to collect complete data but also to made parents feel supported and valued throughout the research process. If additional or follow-up information was needed, audio or video calls were used to stay in touch and address any issues as they raised. Before the data collection, the oral consent was taken from the participants. The researcher explained the objectives to the participants and collected the data by herself. The IDIs and FGDs were conducted at a convenient time and place for the participants. The length of each IDI and FGD were 45 to 60 minutes and the data were recorded using an audio recorder and manually with the permission of the participants. The researcher thanked the participants and completed the IDIs and FGDs.

3.6 Data Management and Analysis

In a qualitative study, data analysis was started at the beginning of the data collection. Analysis of the findings of this study required a careful and systematic approach to gain a deeper understanding of parents’ experiences of caring for children with CP. The process began with the formatting of the summary. Recordings were generated from recordings of in-depth interviews (IDIs) and focus group discussions (FGDs). Backup copies were securely stored to prevent any data loss.

Once the data was sorted, a full content analysis technique was performed. This involved reading the transcripts repeatedly to identify important issues and issues that provided insight into the participants’ experiences. This step helped capture the complexities and nuances of parental narratives, laying the foundation for in-depth analysis.

Data were transcribed by the researcher. After the transcription, the data were read several times and identify the themes and issues. Reviewed the themes and understand deeper insights.

The findings of the IDIs and FGDs were then be interpreted. This interpretation aimed to capture the essence of the participants’ stories in an unbiased way, providing a reflective and descriptive account of their experiences. The insights gained were linked to the broader context of existing research and literature on cerebral palsy in Bangladesh. After that, the findings were shared.

3.7 Ethical Issues

To ensure the safety and validity of the study, prior ethical approval was obtained from the BRAC Institute of Educational Development (BRAC IED), BRAC University and then participants’ oral consent was collected for in-depth interviews and focus group discussions. The researcher maintains confidentiality and anonymity which were the essential part of conducting IDIs and FGD. The objectives, time and process were explained to the participants before data collection. The researcher also points out that participation was voluntary and that one could terminate participation at any time with no negative consequences. The researcher also stated how confidentiality and anonymity was protected.

3.8 Validity & Reliability

The validity and reliability of this study were kept in consideration since it consists of the experiences of parents with children affected by CP in Bangladesh, using a qualitative research design. The interview questions were developed to cover all aspects of the research objectives to ensure that the data collection instruments yield the intended results. This involves altering the initially asked questions to those that provided relevant data regarding the themes under investigation, such as parents' understanding of CP, their mental health issues, the challenges they face, and their coping strategies. The interview guide was reviewed to ensure that the questions were clear, unbiased, and comprehensively cover the research topics. Additionally, since the interviews were semi-structured, there was a certain degree of flexibility, allowing participants to fully express their experiences, and the validity of the data collected was, therefore, high.

In order to ensure the reliability of the study, a pilot study was also carried out before undertaking the main data collection exercise. This pilot was carried out using a small sample of parents from the target group, so that the interview questions to be further developed and the problems with data collection to be examined. Pilot interviews facilitated the identification of slight changes regarding the wording of some questions in order to make them understandable by all stakeholders. All these changes helped enhance the stability of the data collection process. In addition, member validation was carried out with a few of the participants involvement to ensure that their views were captured correctly as the data were transcribed from the recorded data collected from the participants.

Furthermore, the use of data triangulation was implemented by using parents from different cultures and backgrounds thus, having different views towards the same problems. This method complemented the narrative data by adding a number of important concerns that the parents of children with CP have to endure. Original participants' quotes were appreciated in the process of analysis and their efforts were made to remain as genuine as possible to provide the validity & reliability of the study.

3.9 Limitation

This study aimed to explore the parental experiences of parenting practices of children with CP. However, there were several limitations. At first when the data collection started, the political situation in the country started to deteriorate. It was very difficult to collect data in such a situation. Participants did not want to come because of the overall situation of the country. Secondly, the study was geographically confined to urban areas like Saidpur and Nilphamari, potentially missing the unique challenges faced by families in rural settings where healthcare access was more limited. Furthermore, qualitative methods such as in-depth interviews (IDIs) and focus group discussions (FGDs) provided deep, personal perspectives but did not capture broader a way of thinking could provide it. This reliance on subjective narrative meant that the findings were influenced by the personal experiences of the participants, who might not be representative of the general population

The study also targeted parents from middle-class, urban areas who were at least at the Secondary School Certificate (SSC) level. This focus excluded the perspectives of parents from lower socioeconomic and educational backgrounds, who might face unique or other challenges.

In conclusion, the methodology used in this study was carefully designed to integrate the experiences of parents raising children with cerebral palsy in Bangladesh. The method of qualitative research, which involved in-depth interviews and focus group discussions, guarantees the collection of extensive, detailed information from a varied range of participants. Emphasizing validity, reliability, and ethical factors could boost the study's credibility even more. Although there were some limitations, the methodology laid a solid groundwork for the study's results, guaranteeing that the data gathered was trustworthy, credible, and aligned with the research objectives.

Chapter IV: Results & Discussion

This section explores results from the qualitative research conducted with parents of children diagnosed with cerebral palsy in Bangladesh. The primary goals of the research are to comprehend how parents view CP, recognize the mental health obstacles caregivers deal with, investigate the daily struggles they experience, and delve into ways to cope with caregiver stress. Through qualitative methods, researchers gained detailed information by conducting interviews and focus group discussions with ten parents, comprising of five fathers and five mothers. The results are categorized under four primary themes: parents' comprehension of CP, mental health obstacles, difficulties in caregiving, and methods for managing stress. The themes originate from direct quotes, showcasing the authentic feelings of the individuals involved. The names of the interviewees have been changed and pseudonyms are being used to safeguard their privacy. The in-depth interviews and focus group discussion are conducted between August 14 and August 26, 2024.

4.1 Parents' Understanding of Cerebral Palsy

Many parents, at the onset, were unfamiliar with CP, illustrating a significant gap in public awareness and education. It was found that parents' understanding of CP varied, with most recognizing it as a lifelong condition but they were not very clear about medical aspects and treatments.

One parent said, for example, shared her experience:

> *"No, I didn't know much about cerebral palsy before. I only learned about it when my daughter's problem was diagnosed" (In-Depth Interview #1, 14.08.24).*

Similarly, other parents expressed a similar experience, with one parent saying,

> *"No, I didn't know much about cerebral palsy before. I first learned about it when my son was diagnosed" (In-Depth Interview #2, 20.08.24).*

These examples reflect the sudden shift in parents' understanding once their children were diagnosed.

The initial ignorance led many parents to experience a period of emotional upheaval. Some of the parents described this transition:

> *"At first, it felt like the world had stopped. I couldn't understand anything" (Focus Group Discussion #1: 26.08.24).*

This sense of disorientation is further echoed by some other parents stated,

> *"My heart was completely broken when I heard the news. I had many dreams, but then it felt like they would never be fulfilled" (Focus Group Discussion #1: 26.08.24).*

These accounts emphasize the emotional toll the diagnosis had on the parents, shifting their understanding of CP while confronting a new reality.

As time passed and parents sought medical advice, their understanding of CP began to evolve. Most of the parents mentioned,

> *"No, I didn't know much about cerebral palsy. I first learned about this disease through the doctors when my daughter started having problems" (In-Depth Interview #3, 21.08.24).*

This highlights the pivotal role healthcare professionals play in educating parents about CP, helping them navigate the complexities of the condition.

The journey from ignorance to awareness underscores the critical need for early education and support for parents. These experiences illustrate the importance of timely information and support systems in helping parents manage the emotional and practical adjustments required after a CP diagnosis.

4.2 Mental Health Issues of Parents of Children with CP

The theme "Mental Health Issues" highlights the significant psychological impact of the caregivers of children with CP. Parents frequently described experiencing stress, anxiety, and depression, which were often triggered by the ongoing demands of caregiving

Most of the parents spoke candidly about her mental health struggles:

> *“It is affecting my mental health a lot. Sometimes I feel depressed and think that everything is very difficult” (In-Depth Interview #1, 14.08.24).*

Her situation is frequently seen in parents who are attempting to juggle the difficulties of providing care while also looking after their own mental health. Some caregivers also expressed similar feelings:

> *“Sometimes I feel tired, anxious, and depressed. But I try my best to do everything for my daughter” (In-Depth Interview #3, 21.08.24).*

These accounts highlight the dual pressure of fulfilling parental responsibilities while managing personal mental health struggles.

Other parents, described the anxiety and stress they experience as constant companions. Most of the parents explained,

> *“Yes, it is affecting my mental health. I am always worried and anxious about the future” (In-Depth Interview #2, 20.08.24).*

while some other parents shared,

> *“Yes, it has greatly affected my mental health. Worries about my daughter, family pressure, and social challenges make me mentally exhausted” (In-Depth Interview #2, 20.08.24).*

These narratives show how caregiving responsibilities, coupled with societal pressures, create an environment filled with emotional strain.

Some parents recalled moments of initial mental health crises and eventual adaptation. Some parents stated,

> *“I became very depressed and lost faith in myself” (Focus Group Discussion #1: 26.08.24),*

while some parents discussed his path towards acceptance, saying,

> *“I was completely broken mentally, but over time I learned to adapt to this situation” (Focus Group Discussion #1: 26.08.24).*

This evolution from initial despair to gradual adaptation reflects the resilience required by parents in the face of ongoing caregiving challenges.

In sum, the theme of mental health issues emphasizes the considerable emotional strain parents endure. The combination of daily caregiving demands, societal expectations, and personal worries underscores the need for robust mental health support systems.

4.3 Challenges of Parents with CP Children

The theme “Challenges” explores the difficulties that parents experience in taking care of children with cerebral palsy. These challenges take on practical caregiving duties, financial constraints, limited services, and cultural hindrances.

Practical caregiving tasks are one of the primary challenges parents faces, as they must provide extensive support for their children’s daily needs. Most of the parents described their routine, saying,

> *“My daughter’s daily activities take a bit more time. I help her with walking and try to keep her muscles active through therapy. We also need to take special care for her eating” (In-Depth Interview #1, 14.08.24).*

Similarly, some parents illustrate the demands of caregiving, explaining,

> *“I have to help Tasnim with her movement and eating. I feed her, clean her, and help her with general tasks. It takes a lot of patience to help her” (In-Depth Interview #3, 21.08.24).*

These accounts illustrate the physical and emotional toll of caregiving, requiring constant attention and effort.

Limited access to services for children with CP is another significant challenge. Some parent pointed out,

> *“There are few services available for children with cerebral palsy in our country. There are some therapy centers and hospitals, but their number is low and the costs are very high” (In-Depth Interview #1, 14.08.24).*

Other parents also echoed this concern, with one parent mentioning,

> *"There are some special therapy centers and schools for children with cerebral palsy in our country, but they are limited in number and facilities" (In-Depth Interview #4, 21.08.24),*

and some parents shared,

> *"The opportunities for treatment and therapy are limited, and the costs are quite high" (In-Depth Interview #2, 20.08.24).*

These statements reflect the systemic barriers that limit access to critical services, placing additional strain on families.

The financial burden associated with managing medical and therapeutic costs is a prominent challenge for parents. Some parents highlighted this issue, stating,

> *"The biggest challenge was financial expenses and mental stress" (Focus Group Discussion #1: 26.08.24).*

This reflects the economic pressures many families face while trying to provide adequate care for their children (Focus Group Discussion #1: 26.08.24).

Finally, societal attitudes and stigma create additional challenges for parents. Some parents discussed the lack of understanding from society and the pressure it adds to their caregiving experience. Most of the parents also highlighted the complexity of meeting their children's needs, saying,

> *"Meeting my son's physical and mental needs is always difficult" (Focus Group Discussion #1: 26.08.24).*

These statements underscore the social barriers that parents must navigate while caring for their children with CP.

4.4 Ways to Cope with Stress

This theme explores the different approaches parents take to deal with the difficulties of caregiving. These tactics encompass assistance from family, connections with others, individual coping skills, and help from professionals. Family assistance is crucial in aiding parents in handling their caregiving duties. Some of the mother emphasized the importance of her family's assistance, stating,

> *"My family and husband's support make me mentally strong" (In-Depth Interview #1, 14.08.24).*

Similarly, most of the parents appreciated the help from her family and friends, saying,

> *"My family and a few friends help a lot" (Focus Group Discussion #1: 26.08.24).*

This shows that a solid family support system aids parents in managing the emotional and practical responsibilities of caregiving.

Social relationships, especially with fellow parents facing similar challenges, also play a role in helping parents deal with stress. Parents found that talking to other parents provided comfort:

> *"I also do yoga sometimes and talk to other parents, which helps me stay calm" said one parent (In-Depth Interview #1, 05.07.23).*

Similarly, other parent highlighted the importance of seeking advice from professionals and friends to manage stress. These interactions allow parents to share their experiences and gain emotional support.

Personal practices, such as spirituality and self-care, also help parents manage their mental health. For instance, most parents mentioned,

> *“Regular prayers help me stay mentally calm” (In-Depth Interview #4, 21.08.24),*

while some other parent stated that yoga helps her maintain emotional balance (In-Depth Interview #1, 14.08.24). These actions give parents a feeling of authority and calmness in the face of caregiving difficulties.

Finally, receiving professional help such as therapy and medical guidance is essential for parents to effectively balance their mental well-being and caregiving responsibilities. Parents highlighted the importance of getting professional advice (In-Depth Interview #2, 20.08.24) as some parents routinely sought assistance from medical experts (Focus Group Discussion #1: 26.08.24). These external resources help parents navigate the complexities of both caregiving and their personal well-being.

In general, parents' strategies to address a problem involve an approach that includes family support, social connections, personal habits, and seeking help from professionals. These methods help parents manage the challenges of caregiving while looking after their own health and giving their children the best possible care.

This thematic analysis uncovers the deep and diverse experiences of parents caring for children with CP in Bangladesh. The themes focus on the development of knowledge about CP, the important mental health issues, the challenges of providing care practically and emotionally, and the different ways parents handle the situation. The analysis highlights the importance of having thorough support systems and resources available to help parents handle the responsibilities of caregiving while also looking after their mental well-being. By thoroughly examining these themes, the analysis offers a more profound insight into parents' experiences and the resilience they show when dealing with challenges.

4.5 Discussion

The discussion chapter is here to present a connection between the findings of the parents' experiences analysis with the social, healthcare, and policy aspects in Bangladesh. Using a thematic analysis of the parents' experiences, four themes were formed: Parents' Understanding about CP, Mental Health Issues, Challenges, and How to Mitigate. This part will delve into the details of these themes, looking at the situation of CP care in Bangladesh, the wishes and desires of the respondents for improvement, and proposals for policy initiatives.

This investigation has brought out very important points about parents who have to take care of their children with CP in Bangladesh. The data collected highlight significant mental, emotional, and social struggles these parents endure while caring for their children. The study finds that the parents' interpretations of CP, their mental health problems, the daily difficulties they face, and their coping strategies reveal both the system's weaknesses and the strengths of the family and social support.

The findings indicate that parents don't seem to have a lot of knowledge about CP at its onset, according to the responses where many say they only learnt about the condition after their child was diagnosed. For instance, most parent shared they were unfamiliar with cerebral palsy until their child received a diagnosis, highlighting a general lack of awareness about the condition.

This reinforces the fact that there is a dire need for public education and awareness regarding disabilities such as CP. The fact that parents are not aware of the knowledge that help in early intervention, and therefore they are also subjected to the emotional shock of the diagnosis of the disease, is a major contributing factor.

An important revelation of the study is that parents are the ones seriously affected by mental health issues. Most of the participants expressed feeling anxious, depressed, and drained owing to the pressure of parenthood for a kid with CP.

The study reveals that this mental strain is further caused by societal pressure and the shortcomings of the available services. This finding is in line with the literature that says the parents of the children with disabilities are under more stress and mental health problems than the parents of the children without disabilities. Studies done by Chu Chen et al. (2023), Ekhlas Al-Gamal & Long (2013), Hung et al. (2010), & Marquis et al. (2019), all reveal that parents of children with disability had high levels of psychological distress and overall mental health issues compared to parents of children with no disability. Parental stress is caused by child’s impairment severity, his/her full dependence on caregivers, and child’s young age (Hung et al., 2010). Similar to the case with the family factors, other parent related factors like; low income, no religious practice, perceived parental distress also influenced mental health adversely (Hung et al., 2010). The emotional cost that this study demonstrates indicates a necessity for the development of complete mental health support services tailored to these parents.

The results also underline the everyday difficulties of parents in caring for their children. Physical tasks such as feeding, therapy, and mobility assistance occupy a crucial part of the day.

These data show a serious shortcoming in service provision parents are often the only ones taking care of a child, with almost no outside help. Nevertheless, there are some therapy centers and special schools, as stated by several respondents, the rather small number of such facilities and their high cost are the main hindrances. This denotes that the current infrastructure is not sufficient to meet the demands of the parents of these children.

As per the strategies to mitigate the effects, the study shows the strength of the parents, most of whom depend on the family support and self-made coping methods to regulate their mental and emotional health.

This indicates that even though there may be a lack of formal support systems, the informal family networks offer a vital lifeline for many parents. Besides, a lot of parents have been using personal coping strategies, which include doing yoga or praying, as some participants noted. In addition, several parents have recently been employing personal coping strategies including yoga or prayer, as some of the participants reported. These outcomes clearly demonstrate the necessity of promoting support mechanisms that are culturally and contextually relevant and also point to the fact that mental health interventions should necessarily include family dynamics and traditional coping tactics to be successful.

Derived from the existing studies, the challenges pointed out in this research have a very close relationship with the worldwide findings stating that parents of children with disabilities suffer from a number of physical, emotional, and financial problems. Researchers show the increased rate of depression, anxiety, and stress in parents of children with disability (Chu Chen et al., 2023; Ekhlas Al-Gamal & Long, 2013). Nevertheless, what emerged is that there are potentially unmet health care needs with certain subgroups and for certain conditions such as parents of children age 4-11 year, and this is during a period when there are heightened mental health issues (Chu Chen et al., 2023). On the other hand, this research provides a fundamental aspect of the topic by viewing these challenges on the local socio-economic background of Bangladesh. It is known that international studies have talked about the necessity of professional support and government aid, but this research revealed that both are lacking in Bangladesh which further makes it difficult for parents. The present results underscore the urgent need for more establishing mental health prevention and educational programs for the parents of children with disabilities (Chu Chen et al., 2023; Marquis et al., 2019).

The findings are very useful and detailed; however, they also show that yet more research is required, particularly with a focus on the long-term effect on the parents' mental health and family dynamics. In addition, future findings should look into how effective the existing support services are and the ways that they can be expanded or improved to meet the needs of more families. As an example, exploring the community-based support systems approach and what can be done to include it in the policy's formal framework can be one of the possible alternatives for the institutional support shortages.

To sum up, this research shows the main obstacles for parents who have CP children in Bangladesh. They face real hardships not just on mental health but also the daily issues they have to deal with. The results of the study imply, without a doubt, that boosting public awareness, making the healthcare services more easily available, and providing thorough mental health assistance for parents are necessary for the betterment of their quality of life. The results presented here are part of a collection of literature about parents of disabled children and are thereby a solid basis for further research and policy development that will aim to tackle the issues.

4.6 Conclusion

This study aimed to identify the daily experiences of parents in raising children with CP this included their understanding about CP, mental health issues, challenges and coping up process as resident from Bangladesh. The aim of the study was to explore emotional, psychological and social aspects of caregiving for children with CP in-depth based on ten parents (two mothers and two fathers). By analyzing the findings through key thematic areas, this research has illuminated the knowledge, struggles, strengths, and resilience of parents navigating this journey.

This indicates that the research has successfully served its purpose of giving a nuanced insight into these parents' often complex realities. Key themes about caregiving were the lack of knowledge, personal distress or burden and sometimes illegitimacy associated with caregiver perceptions; additional financial demands to their homes resulting in role changes as a result of unemployment/ loss, and family contributors not being sufficient. Our results highlight the relevant lacunae in healthcare availability and social support systems in Bangladesh, demanding immediate policy interventions to ensure improved access to medical care as well emotional & financial resources for families with suffering children living with CP.

This was a very enlightening experience for me personally when this research work was done. Perspective of a caregiver was learned, understood and showed more human features behind Parent (mostly from developing country where resources are scarce like Bangladesh), who seeks care for their children with CP. It has shown the emotions that never even thought existed: where to be tough and where the importance of family supporting each other in every little step we take as parents, grandparents. That also showed we need to be brighter in society to allow those disability children. The research also emphasizes the necessity of appropriate interventions, pathways and support to mental health for these families' aged children with additional needs. The experiences of those parents are a moving testimony to the fact that public policies and community support efforts can bring about life-changing benefits when they are designed in such a way as to meet the needs families with chronic health care problems.

4.7 Recommendations

Based on the findings of this study, we should take some initiatives to improve the current situation of the parents of children with Cerebral Palsy in Bangladesh. Here are some recommendations:

- **Increase Awareness and Education**: It is important to educate the public about cerebral palsy to enhance comprehension. This would help minimize discrimination and define an atmosphere that is conducive for such families.

- **Improve Access to Healthcare Services**: The country ought to build more directories of health centers that are only dedicated to the provision of therapy, rehabilitation and medical services specifically for children suffering from CP. Such services ought to be within reach of families from all parts of the country The country ought to build more directories of health centers that are only dedicated to the provision of therapy, rehabilitation and medical services specifically for children suffering from CP. Such services ought to be within reach of families from all parts of the country.

- **Mental Health Support for Parents**: Psychological services should be targeting the parents with children, whom they have been identified have CP.

Provision for regular groups and psychologist attention would enable parents deal with emotional upheaval and prevent mental deterioration.

- **Financial Assistance for Families**: The government and NGOs should offer financial aid or subsidies to families facing high costs for therapy, healthcare, medication, and special education for their children with CP.
- **Training for Healthcare Professionals**: Healthcare professionals need specific training in diagnosing, treating, and supporting children with CP. This would improve the quality of care provided to these families.
- **Expand Special Education Opportunities**: Much like other educational infrastructure, special education facilities must be expanded so that children with CP have access to the right kind of curriculum and staff support.
- **Further Research**: This study needs to be further extended in later years on long term impact of children with CP on family dynamics and psychological status of parents. Future research can also investigate the impact of existing OER support services and how they could be further developed.
- **Policy Recommendations for Inclusive Policies**: Policymakers should develop inclusive education and health care policies that ensures equal access to resources, facilities and services to children with disability. Thousands of children with CP fall often prey to discrimination and exclusion, modern family life practices may bring practical opportunities for integrative education where they can improve their lives.

Families raising children with cerebral palsy could significantly ease the challenges faced if these recommendations are put into action. This would lead to improved healthcare, greater social inclusion, and better mental well-being for both the parents and their children.

References

Ahmed, S. M. (2013). Harnessing pluralism for better health in Bangladesh. *The Lancet*, 382(9906), 1746-1755.

Ahsan, M. T. (2012). Challenges to prepare teachers to teach students with disabilities in inclusive classrooms: A perspective from Bangladesh. *International Journal of Inclusive Education*, 16(10), 1137-1154.

Al-Gamal, E., & Long, T. (2013). Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: A cross-sectional study. *Scandinavian journal of caring sciences*, 27(3), 624-631.

Chen, C., Bailey, C., Baikie, G., Dalziel, K., & Hua, X. (2023). Parents of children with disability: Mental health outcomes and utilization of mental health services. *Disability and Health Journal*, 16(4), 101506.

Davis, E. &.-P. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with cerebral palsy. *Journal of Intellectual & Developmental Disability*, 34(2), 153-162.

Davis, K. &.-P. (2009). The impact of child, family, and professional support characteristics on the quality

Gray, P. H. (2012). Parenting stress in mothers of preterm infants during early infancy. *Early human development*, 88(1), 45-49.

Gray, P. H. (2016). Parenting stress in mothers of preterm infants during early infancy. *Early Human Development*, 94, 1-6.

Halder, A. S. (2007). Inequalities in reproductive healthcare utilization: evidence from Bangladesh Demographic and Health Survey 2004. *World health & population*, 9 2, 48-63. doi:https://doi.org/10.12927/WHP.2007.18853.

Hung, J. W., Wu, Y. H., Chiang, Y. C., Wu, W. C., & Yeh, C. H. (2010). Mental health of parents having children with physical disabilities. *Chang Gung Med J*, 33(1), 82-91.

Jamie C. Brehaut, P., Dafna E. Kohen, P., Parminder Raina, P., Stephen D. Walter, P., Dianne J. Russell, M., Marilyn Swinton, B., . . . Peter Rosenbaum, M. (2004). The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics*, 114(2).

K Davis, S. G.-P. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability*, 34(2), 153-162.

Karim, S. M. (2020). Understanding the impact of social support on families with children with disabilities in Bangladesh. *Bangladesh Journal of Disability Studies*, 10(2), 34-45.

Marquis, S. M., McGrail, K., & Hayes, M. (2020). Mental health of parents of children with a developmental disability in British Columbia, Canada. *J Epidemiol Community Health*, 74(2), 173-178.

Miles, M. (2002). Disability in South Asia: Millennium to millennium: An overview of development trends and their effects on disabled people, with particular reference to South Asia. *Asia Pacific Disability Rehabilitation Journal*, 13(2), 10-30.

Oskoui, M. C. (2013). An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 55(6), 509-519.

Raina, P. O. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 5(1), 1-13.

Rosenbaum, P. P. (2007). A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology*, 49(S109), 8-14.

Shields, N. M. (2006). A systematic review of the self-concept of children with cerebral palsy compared with children without disability. *Developmental Medicine & Child Neurology*, 48(2), 151–157. doi:doi:10.1017/S0012162206000326

UNICEF. (2014). *The state of the world's children 2013: Children with disabilities.* New York, NY: United Nations Children's Fund.

Appendices A

Focus Group Discussion (FGD) Questions

1. How is your experience of parenting a child with cerebral palsy?
2. What did you feel when you heard that your children were cerebral palsy?
3. What was your mental health condition at that time?
4. How did you manage your children? Did you send them any schools or services? Do you have any support system available at your homes to look after the children with cerebral palsy?
5. Have you consulted with a doctor regarding your child's condition?
6. Can you describe a typical day for you and your child with cerebral palsy?
7. Did you feel stressed to manage the children with cerebral palsy? Please tell me more.
8. How does your community treat your child with cerebral palsy, and how does this affect you?
9. What kinds of support do you receive from family, friends, community, hospital / doctors or organizations?
10. What are the challenges that you faced as parents of children with cerebral palsy?
11. How did you mitigate those?
12. What advice or recommendations would you give to other parents or caregivers who are nurturing a child with cerebral palsy?

13. What would be your expectations from the family/ community / government to manage the children with cerebral palsy?

In-Depth Interview (Alzbutas, #102) Questions

1. Did you know anything about cerebral palsy before?
2. Can you describe the moment when you first heard about your child's diagnosis of cerebral palsy?
3. How did you feel, and what were your initial thoughts and concerns?
4. How did the doctors explain the diagnosis to you? Did they give you enough information and support?
5. How did you manage your child's daily activities such as walking, feeding, and personal care?
6. How do your family members support you?
7. What are the biggest challenges you face as a parent of a child with cerebral palsy?
8. Do you face any social and financial challenges?
9. What difficulties do you encounter with your child's education as a parent?
10. Is nurturing a child with cerebral palsy affecting your feelings and mental health?
11. What helps you to deal with the stress and challenges of nurturing a child with cerebral palsy?
12. What kind of services are available in our country to deal with the children with cerebral palsy?

13. What changes would you like to see in healthcare and education for children with cerebral palsy?
14. What would be your expectations from the family/ community / government to manage the children with cerebral palsy?

Appendices B

Focus Group Discussion Transcript (FGD)

ফোকাস গ্রুপ ডিসকাশন ট্রান্সক্রিপ্ট (FGD)

ফ্যাসিলিটেটর: আজকের আলোচনায় অংশ নেওয়ার জন্য আপনাদের সবাইকে ধন্যবাদ। চলুন, প্রথম প্রশ্নটি দিয়ে শুরু করি। আপনারা যারা সেরেব্রাল পালসি আক্রান্ত সন্তানের বাবা-মা, তাদের জন্য অভিজ্ঞতা কেমন?

মিনা: প্রথমে আমি খুব দ্বিধান্বিত ছিলাম। মেয়েকে সামলানো কঠিন ছিল, কিন্তু ধীরে ধীরে শিখেছি। এখন, যদিও এটি চ্যালেঞ্জিং, মেয়ের ছোট ছোট উন্নতি আমাকে অনুপ্রাণিত করে।

আব্দুল্লাহ: বাবা হিসেবে দায়িত্বগুলো অনেক বেশি। আমি কাজের বাইরে সময় দিলে ছেলেকে যত্ন করি। মাঝে মাঝে মনে হয় আমি আরও ভালো করতে পারতাম, কিন্তু আমি আমার সাধ্যমতো চেষ্টা করছি।

ফ্যাসিলিটেটর: শেয়ার করার জন্য ধন্যবাদ। যখন শুনলেন যে আপনার সন্তান সেরেব্রাল পালসিতে আক্রান্ত, তখন আপনার অনুভূতি কেমন ছিল?

আলো: প্রথমে মনে হয়েছিল যেন পৃথিবী থমকে গেছে। আমি কিছু বুঝতেই পারছিলাম না।

বকুল: খবরটি শুনে মনটা একদম ভেঙে পড়েছিল। অনেক স্বপ্ন ছিল, কিন্তু তখন মনে হচ্ছিল সেগুলো আর পূরণ হবে না।

ফ্যাসিলিটেটর: আমি বুঝতে পারছি কতটা কঠিন সময় ছিল সেটা। তখন আপনার মানসিক অবস্থা কেমন ছিল?

বিলকিস: আমি খুব হতাশ হয়ে পড়েছিলাম, নিজের প্রতি বিশ্বাস হারিয়ে ফেলেছিলাম।

রবিউল: মানসিকভাবে একদম ভেঙে পড়েছিলাম, কিন্তু সময়ের সাথে সাথে আমি এই পরিস্থিতির সাথে খাপ খাইয়ে নিতে শিখেছি।

ফ্যাসিলিটেটর: এই অনুভূতিগুলোকে স্বীকার করা গুরুত্বপূর্ণ। আপনি কিভাবে আপনার সন্তানকে সামলেছেন? আপনি কি তাদের কোনো স্কুল বা সেবায় পাঠিয়েছেন? আপনার বাড়িতে সেরেব্রাল পালসি আক্রান্ত সন্তানদের দেখাশোনা করার জন্য কোনো সাপোর্ট সিস্টেম আছে?

মিনা: আমি ছেলেকে একটি বিশেষ স্কুলে ভর্তি করিয়েছি যেখানে তার জন্য বিশেষ সুবিধা আছে।

আব্দুল্লাহ: পরিবারের কয়েকজন সাহায্য করে, তবে মূলত আমি আর আমার স্ত্রীই সবটা সামলাই।

ফ্যাসিলিটেটর: শুনে ভালো লাগলো যে কিছু সাপোর্ট আছে। আপনার সন্তানের অবস্থা সম্পর্কে কি আপনি ডাক্তার দেখিয়েছেন?

আলো: হ্যাঁ, প্রথম থেকেই একজন নিউরোলজিস্টের সঙ্গে যোগাযোগ করেছি।

বকুল: অবশ্যই, নিয়মিত ডাক্তার দেখাই এবং থেরাপির ব্যবস্থা করি।

ফ্যাসিলিটেটর: শেয়ার করার জন্য ধন্যবাদ। আপনি এবং আপনার সেরেব্রাল পালসি আক্রান্ত সন্তানের জন্য একটি সাধারণ দিন কেমন কাটে তা কি আপনি বর্ণনা করতে পারেন?

বিলকিস: আমার দিন শুরু হয় ছেলের থেরাপি দিয়ে। এরপর তাকে স্কুলে নিয়ে যাই। বিকেলে তাকে কিছু খেলা শেখাই যাতে তার মানসিক বিকাশ হয়।

রবিউল: দিনটা বেশিরভাগ সময় ছেলের সেবা নিয়েই কাটে। মাঝে মাঝে তার সঙ্গে খেলি, গল্প করি।

ফ্যাসিলিটেটর: শুনে মনে হচ্ছে আপনাদের দিনটা বেশ পূর্ণ থাকে। সেরেব্রাল পালসি আক্রান্ত সন্তানদের সামলাতে গিয়ে কি আপনি কখনও স্ট্রেস অনুভব করেছেন? দয়া করে একটু বিস্তারিত বলুন।

মিনা: অনেক স্ট্রেস হয়, বিশেষ করে যখন সবকিছু একসঙ্গে সামলাতে হয়।

আব্দুল্লাহ: স্ট্রেস আছে, তবে চেষ্টা করি নিজের শান্তি বজায় রাখতে।

ফ্যাসিলিটেটর: স্ট্রেস ম্যানেজমেন্ট অনেক গুরুত্বপূর্ণ। আপনার সন্তানকে নিয়ে আপনার সম্প্রদায় কেমন আচরণ করে, এবং এটি আপনাকে কিভাবে প্রভাবিত করে?

আলো: বেশিরভাগ লোকজন সহানুভূতি দেখায়, কিন্তু কেউ কেউ অবহেলা করে, যা মন খারাপ করে দেয়।

বকুল: কিছু মানুষ নেতিবাচক মন্তব্য করে, তবে আমি তাদের এড়িয়ে চলি।

ফ্যাসিলিটেটর: এই ধরনের মনোভাবের সাথে মানিয়ে নেওয়া কতটা কঠিন তা বুঝতে পারছি। আপনি পরিবার, বন্ধু, সম্প্রদায়, হাসপাতাল/ডাক্তার বা সংগঠন থেকে কী ধরনের সহায়তা পাচ্ছেন?

বিলকিস: আমার পরিবার এবং কয়েকজন বন্ধু অনেক সাহায্য করে। হাসপাতাল থেকেও নিয়মিত চিকিৎসা সহায়তা পাই।

রবিউল: সাপোর্ট সিস্টেম থাকলেও সেটা পর্যাপ্ত নয়। তবে যারা পাশে দাঁড়িয়েছে, তাদের কাছে কৃতজ্ঞ।

ফ্যাসিলিটেটর: এটা শুনে ভালো লাগলো যে কিছুটা হলেও সাপোর্ট আছে। সেরেব্রাল পালসি আক্রান্ত সন্তানের পিতামাতা হিসেবে আপনি কী কী চ্যালেঞ্জের সম্মুখীন হয়েছেন?

মিনা: সবচেয়ে বড় চ্যালেঞ্জ ছিল আর্থিক ব্যয় এবং মানসিক চাপ।

আব্দুল্লাহ: ছেলের শারীরিক এবং মানসিক চাহিদা মেটানো সবসময় কঠিন।

ফ্যাসিলিটেটর: আমি বুঝতে পারছি এই সমস্যাগুলো কতটা বিশাল হতে পারে। আপনি কীভাবে এই চ্যালেঞ্জগুলো মোকাবিলা করেছেন?

আলো: পরিবার এবং থেরাপির মাধ্যমে কিছুটা কাটিয়ে উঠেছি।

বকুল: ধৈর্য্য ধরে পরিস্থিতির সঙ্গে মানিয়ে নিতে শিখেছি।

ফ্যাসিলিটেটর: খুবই গুরুত্বপূর্ণ পরামর্শ। অন্যান্য পিতামাতা বা সেরেব্রাল পালসি আক্রান্ত শিশুর যত্নশীলদের জন্য আপনি কী পরামর্শ বা সুপারিশ করবেন?
বিলকিস: কখনোই হাল ছাড়বেন না। তাদের ভালোবাসা এবং যত্ন দিতে থাকুন।

রবিউল: নিজেদের মানসিক স্বাস্থ্যের দিকে খেয়াল রাখুন। এটা অনেক গুরুত্বপূর্ণ।

ফ্যাসিলিটেটর: খুবই গুরুত্বপূর্ণ পরামর্শ। শেষ প্রশ্ন, আপনার পরিবার, সম্প্রদায় বা সরকারের কাছ থেকে সেরেব্রাল পালসি আক্রান্ত শিশুদের পরিচালনা করার ক্ষেত্রে আপনার কী ধরনের প্রত্যাশা রয়েছে?

মিনা: আমি আশা করি সরকার থেকে বিশেষ সুবিধা এবং সহায়তা পাওয়া যাবে।

আব্দুল্লাহ: কমিউনিটি আরও সহানুভূতিশীল এবং সহায়ক হবে বলে আশা করি।

ফ্যাসিলিটেটর: আপনাদের সবাইকে ধন্যবাদ আপনার মতামত এবং অভিজ্ঞতা শেয়ার করার জন্য। আপনারা যে ইনসাইটগুলো দিয়েছেন তা অত্যন্ত মূল্যবান।

এই ট্রান্সক্রিপ্ট ফোকাস গ্রুপ ডিসকাশনে অংশ নেওয়া পিতামাতার অভিজ্ঞতা, অনুভূতি এবং চ্যালেঞ্জগুলোর সারমর্ম তুলে ধরে।

Focus Group Discussion Transcript (FGD)

Facilitator: Thank you all for participating in today's discussion. Let's start with the first question. For those of you who are parents of children with cerebral palsy, what has your experience been like?

Mina: At first, I was very hesitant. It was difficult to manage my daughter, but I learned slowly. Now, although it's challenging, my daughter's small improvements motivate me.

Abdullah: As a father, the responsibilities are much greater. When I'm not at work, I take care of my son. Sometimes I feel like I could do better, but I'm trying my best.

Facilitator: Thank you for sharing. How did you feel when you first heard that your child had cerebral palsy?

Alo: At first, it felt like the world had stopped. I couldn't understand anything.

Bokul: My heart was completely broken when I heard the news. I had many dreams, but then it felt like they would never be fulfilled.

Facilitator: I can understand how difficult that must have been. How was your mental state back then?

Bilkis: I became very depressed and lost faith in myself.

Rabiul: I was completely broken mentally, but over time I learned to adapt to this situation.

Facilitator: It's important to acknowledge these feelings. How have you managed your child? Have you sent them to any schools or services? Is there any support system at home for taking care of children with cerebral palsy?

Mina: I've enrolled my son in a special school where there are special facilities for him.

Abdullah: A few family members help, but mostly my wife and I handle everything.

Facilitator: It's good to hear that there is some support. Have you consulted a doctor about your child's condition?

Alo: Yes, I've been in touch with a neurologist from the beginning.

Bokul: Of course, I see a doctor regularly and arrange for therapy.

Facilitator: Thank you for sharing. Can you describe what a typical day is like for you and your child with cerebral palsy?

Bilkis: My day starts with my son's therapy. Then I take him to school. In the afternoon, I teach him some games to develop his mental skills.

Rabiul: Most of the day is spent taking care of my son. Sometimes I play with him, talk to him.

Facilitator: It sounds like your days are quite full. Have you ever felt stressed while taking care of a child with cerebral palsy? Please elaborate.

Mina: I feel a lot of stress, especially when everything has to be managed at once.

Abdullah: There is stress, but I try to maintain my peace.

Facilitator: Stress management is very important. How does your community treat your child, and how does it affect you?

Alo: Most people are sympathetic, but some neglect, which makes me sad.

Bokul: Some people make negative comments, but I avoid them.

Facilitator: I can understand how difficult it is to cope with this kind of attitude. What kind of support do you get from family, friends, community, hospital/doctor, or organizations?

Bilkis: My family and a few friends help a lot. I also get regular medical support from the hospital.

Rabiul: Although there is a support system, it's not enough. But I am grateful to those who stand by me.

Facilitator: It's good to hear that there is some support. What challenges have you faced as parents of children with cerebral palsy?

Mina: The biggest challenge was financial expenses and mental stress.

Abdullah: Meeting my son's physical and mental needs is always difficult.

Facilitator: I can understand how big these issues can be. How have you dealt with these challenges?

Alo: I've overcome it somewhat through family and therapy.

Bokul: I've learned to be patient and adapt to the situation.

Facilitator: Very important advice. What advice or recommendations would you give to other parents or caregivers of children with cerebral palsy?

Bilkis: Never give up. Keep loving and caring for them.

Rabiul: Take care of your own mental health. It's very important.

Facilitator: Very important advice. Last question, what kind of expectations do you have from your family, community, or government in managing children with cerebral palsy?

Mina: I hope to get special facilities and support from the government.

Abdullah: I hope the community will be more sympathetic and supportive.

Facilitator: Thank you all for sharing your opinions and experiences. The insights you have provided are invaluable.

Appendices C

In-Depth Interview #1, 14.08.24

Name: Marufa
Age: 25
Educational qualification: S.S.C
Occupation: Housewife
Children: 1
Children age: 5
Area: Saidpur
Socio-economic status: Lower middle class
Husband occupation: Businessmen
family structure: Nuclear family

শিশুর মায়ের সাথে কুশল বিনিময়ের পর মায়ের সম্মতিক্রমে ইন্টারভিউ শুরু হয় এবং রেকর্ড হয়।

সাক্ষাৎকারগ্রহীতা: আসসালামু আলাইকুম আপা,কেমন আছেন???? আমরা শুরু করার আগে, আপনি কি একটু আপনার সম্পর্কে বলতে পারবেন?

শিশুর মা: আমার নাম মারুফা। আমি এসএসসি পর্যন্ত পড়াশোনা করেছি। আমার স্বামী একজন ব্যবসায়ী এবং পাঁচ বছরের একটি মেয়ে আছে যার নাম তাসনিম, সে সেরিব্রাল পালসিতে আক্রান্ত।

সাক্ষাৎকারগ্রহীতা: ধন্যবাদ, শিশুর মা। তাহলে আমরা প্রথম প্রশ্নটি দিয়ে শুরু করি। আপনি কি আগে সেরিব্রাল পালসি সম্পর্কে কিছু জানতেন?

শিশুর মা: না, আমি সেরিব্রাল পালসি সম্পর্কে তেমন কিছু জানতাম না। যখন আমার মেয়ের সমস্যা দেখা দিতে শুরু করল, তখনই ডাক্তারদের মাধ্যমে আমি প্রথম এই রোগ সম্পর্কে জানতে পারি।

সাক্ষাৎকারগ্রহীতা: যখন প্রথম জানতে পারলেন আপনার সন্তান সেরিব্রাল পালসিতে আক্রান্ত, তখন সেই মুহূর্তটি কেমন ছিল?

শিশুর মা: প্রথমবার যখন জানতে পারলাম,নিজেকে কিছুতেই ঠিক রাখতে পারছিলাম না। মনের মধ্যে অনেক ভয় আর চিন্তা ছিল, কীভাবে ওকে সুস্থ রাখব, কীভাবে আমরা সামলাব—এইসব প্রশ্ন মনে আসছিল।

সাক্ষাৎকারগ্রহীতা: আপনি কেমন অনুভব করেছিলেন, এবং আপনার প্রাথমিক চিন্তা এবং উদ্বেগগুলি কী ছিল?

শিশুর মা: আমি খুবই ভীত আর দিশেহারা অনুভব করছিলাম। আমার প্রধান উদ্বেগ ছিল ওর ভবিষ্যত নিয়ে—ও কি স্বাভাবিকভাবে বড় হতে পারবে? ওকে কীভাবে সাহায্য করব?

সাক্ষাৎকারগ্রহীতা: ডাক্তাররা কীভাবে আপনাকে এই নির্ণয়টি ব্যাখ্যা করেছিলেন? তারা কি আপনাকে যথেষ্ট তথ্য এবং সমর্থন দিয়েছিলেন?

শিশুর মা:: ডাক্তাররা প্রথমে আমাকে রোগের ব্যাপারে ব্যাখ্যা দিয়েছিলেন এবং বলেছিলেন যে এর জন্য দীর্ঘমেয়াদি চিকিৎসা ও থেরাপি প্রয়োজন। তারা কিছুটা তথ্য দিয়েছিলেন, কিন্তু আমি মনে করি, আমার আরও বেশি সমর্থন আর পরামর্শ দরকার ছিল।

সাক্ষাৎকারগ্রহীতা: আপনি কীভাবে আপনার সন্তানের দৈনন্দিন কার্যকলাপ যেমন হাঁটাচলা, খাওয়াদাওয়া, এবং ব্যক্তিগত যত্ন পরিচালনা করেন?

শিশুর মা: তাসনিমের চলাফেরা এবং খাওয়াদাওয়া করতে সাহায্য করতে হয়। তাকে খাওয়ানো, পরিষ্কার করা, এবং সাধারণ কাজ করতে সহায়তা করি। অনেক ধৈর্য নিয়ে ওকে সাহায্য করতে হয়।

সাক্ষাৎকারগ্রহীতা: আপনার পরিবারের সদস্যরা কীভাবে আপনাকে সমর্থন করে?

শিশুর মা: আমার পরিবার থেকে কিছুটা সমর্থন পাই, তবে অনেক সময় আমাকে একাই সবকিছু সামলাতে হয়। আমার স্বামী কাজের কারণে বেশিরভাগ সময় বাইরে থাকে, তাই আমি বেশিরভাগ দায়িত্ব একাই পালন করি।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে একটি সন্তানের বাবা-মা হিসাবে আপনার সবচেয়ে বড় চ্যালেঞ্জগুলি কী?

শিশুর মা: সবচেয়ে বড় চ্যালেঞ্জ হলো তাসনিমের শারীরিক এবং মানসিক উন্নতির জন্য প্রয়োজনীয় সবকিছু প্রদান করা। পাশাপাশি, আর্থিকভাবে এই চিকিৎসা চালিয়ে যাওয়া আমাদের জন্য কঠিন।

সাক্ষাৎকারগ্রহীতা: আপনি কি কোনো সামাজিক এবং আর্থিক চ্যালেঞ্জের মুখোমুখি হচ্ছেন?

শিশুর মা: হ্যাঁ, সামাজিকভাবে অনেক সময় লোকজন বুঝতে পারে না আমাদের পরিস্থিতি। আর্থিকভাবে তাসনিমের চিকিৎসা, থেরাপি এবং অন্যান্য প্রয়োজনীয়তার খরচ চালানো আমাদের জন্য কঠিন হয়ে দাঁড়ায়।

সাক্ষাৎকারগ্রহীতা: একজন বাবা-মা হিসাবে আপনার সন্তানের শিক্ষার ক্ষেত্রে আপনি কী ধরনের অসুবিধার সম্মুখীন হন?

শিশুর মা: তাসনিমের শারীরিক অবস্থা অনুযায়ী তাকে বিশেষ শিক্ষা দরকার। কিন্তু আমাদের এলাকায় তেমন সুযোগ নেই, তাই ওর শিক্ষা নিয়ে আমি খুব চিন্তিত।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালন করছেন। এটা কি আপনার অনুভূতি এবং মানসিক স্বাস্থ্যের উপর প্রভাব ফেলছে?

শিশুর মা: হ্যাঁ, এটি আমার মানসিক স্বাস্থ্যের উপর প্রভাব ফেলে। অনেক সময় আমি ক্লান্ত, দুশ্চিন্তাগ্রস্ত এবং হতাশ বোধ করি। তবে আমার মেয়ের জন্য সবকিছু করার চেষ্টা করি।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালনের চাপ এবং চ্যালেঞ্জগুলি মোকাবিলা করতে আপনাকে কীভাবে সাহায্য করে?

শিশুর মা: আমার পরিবারের সমর্থন, কিছু বন্ধুবান্ধব এবং স্থানীয় স্বাস্থ্যকেন্দ্র থেকে কিছু সহায়তা পাই। তবে মানসিকভাবে নিজেকে শক্ত রাখার চেষ্টা করি এবং তাসনিমের জন্য যতটা সম্ভব ভাল করতে চেষ্টা করি।

সাক্ষাৎকারগ্রহীতা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য কী ধরনের সেবা পাওয়া যায়?

শিশুর মা: আমাদের দেশে এই ধরনের শিশুদের জন্য সেবা অনেক সীমিত। কিছু বিশেষ স্কুল আর স্বাস্থ্যকেন্দ্র আছে, কিন্তু তাসনিমের মতো বাচ্চাদের জন্য পর্যাপ্ত সুযোগ নেই।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য স্বাস্থ্যসেবা এবং শিক্ষার ক্ষেত্রে আপনি কী ধরনের পরিবর্তন দেখতে চান?

শিশুর মা: আমি চাই আরও বিশেষজ্ঞ ডাক্তার, থেরাপিস্ট এবং শিক্ষকদের সমন্বয়ে সেবা প্রদান হোক। তাসনিমের মতো শিশুদের জন্য বিশেষ স্কুল এবং শিক্ষা পদ্ধতি উন্নত করা উচিত।

সাক্ষাৎকারগ্রহীতা: পরিবার/সমাজ/সরকার থেকে আপনি কী ধরনের প্রত্যাশা করবেন যাতে সেরিব্রাল পালসি রোগে শিশুদের পরিচালনা করা সহজ হয়?

শিশুর মা: আমি চাই পরিবার, সমাজ এবং সরকার আমাদেরকে আরও বেশি সমর্থন দিক। যেমন: আর্থিক সহায়তা, বিশেষ শিক্ষা এবং থেরাপির ব্যবস্থা করা হোক, যাতে আমরা আমাদের সন্তানদের ভালোভাবে গড়ে তুলতে পারি।

সাক্ষাৎকারগ্রহীতা: আপনার অভিজ্ঞতা এবং চিন্তাভাবনা আমাদের সাথে শেয়ার করার জন্য অনেক ধন্যবাদ।

শিশুর মা: আপনাকেও ধন্যবাদ আমার কথা শোনার জন্য।

In-Depth Interview #1, 14.08.24

Name: Marufa
Age: 25
Educational qualification: s.s.c
Occupation: Housewife
Children: 1
Children age: 5
Area: Saidpur
Socio-economic status: Lower middle class
Husband occupation: Businessmen
family structure: Nuclear family

Interviewer: Assalamualaikum, Apa. How are you? Before we start, could you tell us a little about yourself?

Marufa: My name is Marufa. I've completed my secondary school education. My husband is a businessman, and we have a five-year-old daughter named Tasnim. She has cerebral palsy.

Interviewer: Thank you, Marufa. Let's start with the first question. Did you know anything about cerebral palsy before?

Marufa: No, I didn't know much about cerebral palsy. I first learned about this disease through the doctors when my daughter started having problems.

Interviewer: How did you feel when you first learned that your child had cerebral palsy?

Marufa: When I first heard it, I couldn't keep myself steady. My mind was filled with fear and worry. How would I keep her healthy? How would we manage? These questions kept coming to my mind.

Interviewer: How did you feel, and what were your initial thoughts and concerns?

Marufa: I felt very scared and lost. My main concern was her future. Would she be able to grow up normally? How can I help her?

Interviewer: How did the doctors explain this diagnosis to you? Did they provide you with enough information and support?

Marufa: The doctors first explained the disease to me and said that it requires long-term treatment and therapy. They gave me some information, but I think I needed more support and advice.

Interviewer: How do you manage your child's daily activities like walking, eating, and personal care?

Marufa: I have to help Tasnim with her movement and eating. I feed her, clean her, and help her with general tasks. It takes a lot of patience to help her.

Interviewer: How do your family members support you?

Marufa: I get some support from my family, but I often have to handle everything alone. My husband is out most of the time due to work, so I take on most of the responsibilities alone.

Interviewer: What are the biggest challenges you face as a parent of a child with cerebral palsy?

Marufa: The biggest challenge is providing everything necessary for Tasnim's physical and mental development. Additionally, it's difficult for us to continue this treatment financially.

Interviewer: Are you facing any social and financial challenges?

Marufa: Yes, socially, many people don't understand our situation. Financially, it's difficult for us to manage the costs of Tasnim's treatment, therapy, and other necessities.

Interviewer: As a parent, what kind of difficulties do you face in your child's education?

Marufa: Tasnim needs special education according to her physical condition. But there are not many such opportunities in our area, so I am very worried about her education.

Interviewer: Raising a child with cerebral palsy is affecting your feelings and mental health. Is that true?

Marufa: Yes, it is affecting my mental health. Sometimes I feel tired, anxious, and depressed. But I try my best to do everything for my daughter.

Interviewer: What helps you cope with the stress and challenges of raising a child with cerebral palsy?

Marufa: I get support from my family, some friends, and the local health center. But I also try to stay strong mentally and do my best for Tasnim.

Interviewer: What kind of services are available in our country for children with cerebral palsy?

Marufa: Services for such children are very limited in our country. There are some special schools and health centers, but there are not enough opportunities for children like Tasnim.

Interviewer: What kind of changes do you want to see in healthcare and education for children with cerebral palsy?

Marufa: I want to see more specialized doctors, therapists, and teachers providing services. Special schools and education methods should be improved for children like Tasnim.

Interviewer: What kind of expectations do you have from family, society, and the government to make it easier to manage children with cerebral palsy?

Marufa: I want family, society, and the government to provide more support. For example, financial assistance, special education, and therapy arrangements should be made so that we can raise our children well.

Interviewer: Thank you for sharing your experiences and thoughts with us.

Marufa: Thank you for listening to me.

In-Depth Interview #2, 20.08.24

Name: Shofiq Rahman
Age: 32
Educational qualification: H.S.C
Occupation: job Holder
Children: 2
Children age: 5,8
Area: Saidpur
Socio-economic status: Lower Middle class
Wife occupation: Housewife
family structure: Nuclear

শিশুর মায়ের সাথে কুশল বিনিময়ের পর মায়ের সম্মতিক্রমে ইন্টারভিউ শুরু হয় এবং রেকর্ড হয়।

সাক্ষাৎকারগ্রহীতা: আপনি কি আগে সেরিব্রাল পালসি রোগটি সম্পর্কে কিছু জানতেন?

শিশুর বাবা: না, আমি আগে সেরিব্রাল পালসি সম্পর্কে তেমন কিছু জানতাম না। আমার ছেলের রোগ নির্ণয়ের পরই আমি প্রথমবারের মতো এই রোগ সম্পর্কে জানতে পারি।

সাক্ষাৎকারগ্রহীতা. আপনি যখন প্রথমবার জানতে পারলেন আপনার সন্তান সেরিব্রাল পালসি রোগে আক্রান্ত, তখন সেই মুহূর্তটি কেমন ছিল?

শিশুর বাবা: যখন আমি প্রথম জানতে পারলাম,সেই মুহূর্তটা আমার জন্য খুবই কষ্টকর ছিল, কারণ আমি কখনো ভাবিনি যে আমার সন্তান এমন একটি সমস্যায় ভুগতে পারে।

সাক্ষাৎকারগ্রহীতা: আপনি কেমন অনুভব করেছিলেন, এবং আপনার প্রাথমিক চিন্তা এবং উদ্বেগগুলি কী ছিল?

শিশুর বাবা: আমি খুবই উদ্বিগ্ন ছিলাম। আমার প্রথম চিন্তা ছিল, আমার ছেলে স্বাভাবিক জীবন যাপন করতে পারবে কিনা। আমি ভাবছিলাম, তার ভবিষ্যৎ কেমন হবে এবং আমরা কীভাবে তাকে সাহায্য করতে পারব।

সাক্ষাৎকারগ্রহীতা:ডাক্তাররা কীভাবে আপনাকে এই নির্ণয়টি ব্যাখ্যা করেছিলেন? তারা কি আপনাকে যথেষ্ট তথ্য এবং সমর্থন দিয়েছিলেন?

ডাক্তাররা আমাদের বুঝিয়েছিলেন যে সেরিব্রাল পালসি একটি দীর্ঘমেয়াদী সমস্যা, তবে এটি নিয়ন্ত্রণ করা সম্ভব। তারা আমাদেরকে কিছু পরামর্শ এবং তথ্য দিয়েছিলেন, তবে আমি তখনও অনেক কিছুই বুঝতে পারছিলাম না।

সাক্ষাৎকারগ্রহীতা: আপনি কীভাবে আপনার সন্তানের দৈনন্দিন কার্যকলাপ যেমন হাঁটাচলা, খাওয়াদাওয়া, এবং ব্যক্তিগত যত্ন পরিচালনা করেন?

আমার স্ত্রী এবং আমি মিলে আমাদের ছেলের দৈনন্দিন কার্যকলাপগুলোতে সাহায্য করি। হাঁটাচলা, খাওয়াদাওয়া, এবং অন্যান্য কাজগুলো আমরা সমন্বিতভাবে করি, কারণ সে নিজে থেকেই এসব করতে পারে না।

সাক্ষাৎকারগ্রহীতা: আপনার পরিবারের সদস্যরা কীভাবে আপনাকে সমর্থন করে?

আমার পরিবারের সদস্যরা আমাদেরকে মানসিকভাবে এবং মাঝে মাঝে আর্থিকভাবে সহায়তা করে। তারা আমাদের সাথে সবসময় থাকেন এবং যখনই দরকার হয় তখন পাশে থাকেন।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে একটি সন্তানের বাবা-মা হিসাবে আপনার সবচেয়ে বড় চ্যালেঞ্জগুলি কী?

সবচেয়ে বড় চ্যালেঞ্জ হলো, তার জন্য প্রয়োজনীয় থেরাপি এবং সেবা নিশ্চিত করা, যা অনেক সময় আমাদের পক্ষে সহজ হয় না। এছাড়া, তাকে নিয়ে বাইরে বের হওয়া এবং তার ভবিষ্যৎ নিয়ে চিন্তা করাও একটি বড় চ্যালেঞ্জ।

সাক্ষাৎকারগ্রহীতা: আপনি কি কোনো সামাজিক এবং আর্থিক চ্যালেঞ্জের মুখোমুখি হচ্ছেন?

হ্যাঁ, আমি আর্থিকভাবে অনেক চ্যালেঞ্জের মুখোমুখি হই, কারণ থেরাপি এবং অন্যান্য চিকিৎসা সেবার খরচ অনেক বেশি। এছাড়া, সমাজের অনেকেই এ বিষয়ে সঠিক ধারণা না থাকার কারণে নানা প্রশ্ন করে, যা মানসিকভাবে কষ্ট দেয়।

সাক্ষাৎকারগ্রহীতা: একজন বাবা-মা হিসাবে আপনার সন্তানের শিক্ষার ক্ষেত্রে আপনি কী ধরনের অসুবিধার সম্মুখীন হন?

আমার সন্তানকে সাধারণ স্কুলে ভর্তি করানো কঠিন। বিশেষ চাহিদা সম্পন্ন শিশুদের জন্য নির্ধারিত স্কুলের খরচ এবং সুযোগ সুবিধাও সীমিত, যা আমাদের জন্য একটি বড় সমস্যা।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালন করছেন। এটা কি আপনার অনুভূতি এবং মানসিক স্বাস্থ্যের উপর প্রভাব ফেলছে?

হ্যাঁ, এটা আমার মানসিক স্বাস্থ্যের উপর প্রভাব ফেলছে। আমি সবসময় চিন্তিত থাকি এবং ভবিষ্যৎ নিয়ে অনেক দুশ্চিন্তা করি। তবে আমার স্ত্রী এবং পরিবারের সমর্থন আমাকে মানসিকভাবে শক্ত রাখে।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালনের চাপ এবং চ্যালেঞ্জগুলি মোকাবিলা করতে আপনাকে কীভাবে সাহায্য করে?

আমি আমার পরিবারের সাথে সময় কাটাই, তাদের সাথে কথা বলি, এবং কখনও কখনও সামাজিকভাবে অন্যদের সাথে যুক্ত হই। এছাড়া, নিয়মিত প্রার্থনা আমাকে মানসিকভাবে শান্ত রাখতে সাহায্য করে।

সাক্ষাৎকারগ্রহীতা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য কী ধরনের সেবা পাওয়া যায়?

আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য কিছু বিশেষ থেরাপি কেন্দ্র এবং স্কুল রয়েছে, তবে সেগুলোর সংখ্যা এবং সুযোগ-সুবিধা অনেক সীমিত। অনেক ক্ষেত্রে, এই সেবাগুলো পেতে অনেক কষ্ট করতে হয়।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য স্বাস্থ্যসেবা এবং শিক্ষার ক্ষেত্রে আপনি কী ধরনের পরিবর্তন দেখতে চান?

আমি চাই সেরিব্রাল পালসি আক্রান্ত শিশুদের জন্য আরও বেশি বিশেষায়িত সেবা এবং থেরাপি কেন্দ্র প্রতিষ্ঠিত হোক। এছাড়া, তাদের জন্য আরও অনেক বিশেষ শিক্ষা প্রতিষ্ঠানের প্রয়োজন, যেখানে তারা যথাযথভাবে শিক্ষা গ্রহণ করতে পারবে।

সাক্ষাৎকারগ্রহীতা: পরিবার/সমাজ/সরকার থেকে আপনি কী ধরনের প্রত্যাশা করবেন যাতে সেরিব্রাল পালসি রোগে শিশুদের পরিচালনা করা সহজ হয়?

আমি চাই সরকার থেকে আর্থিক সাহায্য এবং সমাজের সদস্যদের সচেতনতা বৃদ্ধির জন্য উদ্যোগ নেওয়া হোক। আমাদের মতো পরিবারগুলোর জন্য সহজলভ্য সেবা ও সহায়তা প্রয়োজন, যাতে আমরা আমাদের সন্তানদের যথাযথভাবে প্রতিপালন করতে পারি।

In-Depth Interview #2, 20.08.24

Name: Shofiq Rahman
Age: 32
Educational qualification: H.S.C
Occupation: job Holder
Children: 2
Children age: 5,8
Area: Saidpur
Socio-economic status: Lower Middle class
Wife occupation: Housewife
family structure: Nuclear

Interviewer: Did you know anything about cerebral palsy before?

Shofiq Rahman: No, I didn't know much about cerebral palsy before. I first learned about it when my son was diagnosed.

Interviewer: How did you feel when you first learned that your child had cerebral palsy?

Shofiq Rahman: It was a very difficult moment for me. I never thought my child would suffer from such a problem.

Interviewer: How did you feel, and what were your initial thoughts and concerns?

Shofiq Rahman: I was very worried. My first thought was whether my son would be able to live a normal life. I was wondering about his future and how we could help him.

Interviewer: How did the doctors explain this diagnosis to you? Did they provide you with enough information and support?

Shofiq Rahman: The doctors explained to us that cerebral palsy is a long-term condition, but it can be managed. They gave us some advice and information, but I didn't understand much at the time.

Interviewer: How do you manage your child's daily activities like walking, eating, and personal care?

Shofiq Rahman: My wife and I together help our son with his daily activities. We do everything together, as he cannot do these things on his own.

Interviewer: How do your family members support you?

Shofiq Rahman: My family members support us mentally and sometimes financially. They are always with us and are there for us whenever we need them.

Interviewer: What are the biggest challenges you face as a parent of a child with cerebral palsy?

Shofiq Rahman: The biggest challenge is ensuring necessary therapy and services for him, which is often difficult for us. Additionally, going out with him and worrying about his future are also big challenges.

Interviewer: Are you facing any social and financial challenges?

Shofiq Rahman: Yes, I face many financial challenges, as the costs of therapy and other medical services are very high. Additionally, due to lack of proper understanding, many people ask various questions, which can be mentally distressing.

Interviewer: As a parent, what kind of difficulties do you face in your child's education?

Shofiq Rahman: It's difficult to enroll my child in a regular school. The costs and facilities of schools designated for children with special needs are also limited, which is a big problem for us.

Interviewer: Raising a child with cerebral palsy is affecting your feelings and mental health. Is that true?

Shofiq Rahman: Yes, it is affecting my mental health. I am always worried and anxious about the future. However, my wife and family's support keep me mentally strong.

Interviewer: What helps you cope with the stress and challenges of raising a child with cerebral palsy?

Shofiq Rahman: I spend time with my family, talk to them, and sometimes socialize with others. Additionally, regular prayers help me stay mentally calm.

Interviewer: What kind of services are available in our country for children with cerebral palsy?

Shofiq Rahman: There are some special therapy centers and schools for children with cerebral palsy in our country, but they are limited in number and facilities. In many cases, it is difficult to access these services.

Interviewer: What kind of changes do you want to see in healthcare and education for children with cerebral palsy?

Shofiq Rahman: I want to see more specialized services and therapy centers established for children with cerebral palsy. Additionally, more specialized educational institutions are needed where they can receive proper education.

Interviewer: What kind of expectations do you have from family, society, and the government to make it easier to manage children with cerebral palsy?

Shofiq Rahman: I want the government to provide financial assistance and raise awareness among society members. We need easily accessible services and support for families like ours so that we can raise our children appropriately.

In-Depth Interview #3, 21.08.24

Name: Moni
Age: 23
Educational qualification: S.S.C
Occupation: Housewife
Children: 1
Children age: 6
Area: Saidpur
Socio-economic status: Lower Middle class
Husband occupation: Business
family structure:

শিশুর মায়ের সাথে কুশল বিনিময়ের পর মায়ের সম্মতিক্রমে ইন্টারভিউ শুরু হয় এবং রেকর্ড হয়।

সাক্ষাৎকারগ্রহীতা: আপনি কি আগে সেরিব্রাল পালসি রোগটি সম্পর্কে কিছু জানতেন?

শিশুর মা: আগে সেরিব্রাল পালসি সম্পর্কে তেমন কিছু জানতাম না। যখন মিলির সমস্যা ধরা পড়ে, তখনই এই রোগ সম্পর্কে জানতে শুরু করি।

সাক্ষাৎকারগ্রহীতা: আপনি যখন প্রথমবার জানতে পারলেন আপনার সন্তান সেরিব্রাল পালসি রোগে আক্রান্ত, তখন সেই মুহূর্তটি কেমন ছিল?

শিশুর মা: জানার পর সেই মুহূর্তটি আমার জন্য খুবই কঠিন ছিল। মনে হচ্ছিল যেন সবকিছু ধসে পড়ছে। মিলির ভবিষ্যৎ নিয়ে খুব চিন্তিত হয়ে পড়েছিলাম।

সাক্ষাৎকারগ্রহীতা: আপনি কেমন অনুভব করেছিলেন, এবং আপনার প্রাথমিক চিন্তা এবং উদ্বেগগুলি কী ছিল?

শিশুর মা: আমি ভীষণ চিন্তিত ছিলাম। ভাবছিলাম, মিলি কখনো স্বাভাবিক জীবন যাপন করতে পারবে কিনা। তার যত্ন কীভাবে করব এবং সে কীভাবে স্বাবলম্বী হবে, তা নিয়ে নানা উদ্বেগ ছিল।

সাক্ষাৎকারগ্রহীতা: ডাক্তাররা কীভাবে আপনাকে এই নির্ণয়টি ব্যাখ্যা করেছিলেন? তারা কি আপনাকে যথেষ্ট তথ্য এবং সমর্থন দিয়েছিলেন?

শিশুর মা: ডাক্তাররা আমাদের নির্ণয়টি যথাযথভাবে ব্যাখ্যা করেছিলেন। তারা বলেছিলেন যে এটি দীর্ঘমেয়াদী সমস্যা, কিন্তু সঠিক চিকিৎসা এবং থেরাপি দিয়ে তার জীবনমান উন্নত করা সম্ভব। তারা তথ্য এবং সমর্থন দিয়েছিলেন, তবে আরও বেশি গাইডেন্স পেলে ভালো হতো।

সাক্ষাৎকারগ্রহীতা: আপনি কীভাবে আপনার সন্তানের দৈনন্দিন কার্যকলাপ যেমন হাঁটাচলা, খাওয়াদাওয়া, এবং ব্যক্তিগত যত্ন পরিচালনা করেন?

শিশুর মা: মিলির প্রতিদিনের কাজগুলো করতে একটু বেশি সময় লাগে। হাঁটাচলার জন্য তাকে সাহায্য করি এবং থেরাপির মাধ্যমে তার পেশীগুলিকে সক্রিয় রাখার চেষ্টা করি। খাওয়াদাওয়ার জন্যও আলাদা যত্ন নিতে হয়। প্রতিদিনের ব্যক্তিগত যত্নের জন্য আমাদেরকে সবসময় তার পাশে থাকতে হয়।

সাক্ষাৎকারগ্রহীতা: আপনার পরিবারের সদস্যরা কীভাবে আপনাকে সমর্থন করে?

শিশুর মা: আমার শ্বশুর-শাশুড়ি এবং স্বামী সবাই মিলে মিলির যত্নে সাহায্য করে। তারা মানসিক সমর্থনও দেয়, যা আমাকে অনেক শক্তি দেয়। একান্নবর্তী পরিবারে থাকার কারণে কাজ ভাগ করে নেওয়া সম্ভব হয়, যা অনেকটা সহজ করে তোলে।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে একটি সন্তানের বাবা-মা হিসাবে আপনার সবচেয়ে বড় চ্যালেঞ্জগুলি কী?

শিশুর মা: সবচেয়ে বড় চ্যালেঞ্জ হলো মিলির সঠিক যত্ন এবং তার উন্নতির জন্য সবরকম প্রচেষ্টা করা। অর্থনৈতিক চাপও রয়েছে, কারণ থেরাপি ও চিকিৎসার খরচ অনেক বেশি। তার ভবিষ্যৎ নিয়ে চিন্তাও সবসময় মাথায় থাকে।

সাক্ষাৎকারগ্রহীতা: আপনি কি কোনো সামাজিক এবং আর্থিক চ্যালেঞ্জের মুখোমুখি হচ্ছেন?

শিশুর মা: হ্যাঁ, আর্থিকভাবে আমাদের বেশ চাপের মধ্যে থাকতে হয়। থেরাপি এবং চিকিৎসার খরচ বহন করা কঠিন। এছাড়া সামাজিকভাবে কখনো কখনো মানুষজনের অজ্ঞতার কারণে বিচ্ছিন্নতার অনুভূতি আসে।

সাক্ষাৎকারগ্রহীতা: একজন বাবা-মা হিসাবে আপনার সন্তানের শিক্ষার ক্ষেত্রে আপনি কী ধরনের অসুবিধার সম্মুখীন হন?

শিশুর মা: মিলির শিক্ষার জন্য বিশেষ বিদ্যালয় বা শিক্ষকের প্রয়োজন। কিন্তু আমাদের এলাকায় এই ধরনের সুবিধা নেই, যা আমাদের জন্য একটি বড় অসুবিধা। তার জন্য বিশেষ শিক্ষাপদ্ধতি এবং সহায়তার প্রয়োজন, যা সবসময় পাওয়া যায় না।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালন করছেন। এটা কি আপনার অনুভূতি এবং মানসিক স্বাস্থ্যের উপর প্রভাব ফেলছে?

শিশুর মা: হ্যাঁ, মানসিকভাবে এটা অনেক চাপের। কখনো কখনো হতাশা আসে, এবং মনে হয় যেন সবকিছুই খুব কঠিন। তবে, মিলির হাসি আমাকে সবকিছু সহ্য করার শক্তি দেয়।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালনের চাপ এবং চ্যালেঞ্জগুলি মোকাবিলা করতে আপনাকে কীভাবে সাহায্য করে?

শিশুর মা: আমার পরিবার এবং স্বামীর সমর্থন আমাকে মানসিকভাবে শক্তিশালী করে তোলে। এছাড়া, মাঝে মাঝে যোগব্যায়াম করি এবং অন্য মা-বাবাদের সঙ্গে কথা বলে অভিজ্ঞতা শেয়ার করি, যা আমাকে শান্ত থাকতে সাহায্য করে।

সাক্ষাৎকারগ্রহীতা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য কী ধরনের সেবা পাওয়া যায়?

শিশুর মা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য সেবার ব্যবস্থা কম। কিছু থেরাপি কেন্দ্র এবং হাসপাতাল আছে, তবে সেগুলোর সংখ্যা কম এবং খরচ অনেক বেশি। সরকারি সাহায্যও তেমন নেই।

সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য স্বাস্থ্যসেবা এবং শিক্ষার ক্ষেত্রে আপনি কী ধরনের পরিবর্তন দেখতে চান?

শিশুর মা: আমি চাই সরকার থেকে আরও বেশি সহায়তা এবং সেবা প্রদান করা হোক। বিশেষ করে থেরাপি কেন্দ্র, বিশেষ বিদ্যালয়, এবং আর্থিক সহায়তা যেন সহজলভ্য হয়। এছাড়াও, সমাজে সচেতনতা বাড়ানোর প্রয়োজন।

সাক্ষাৎকারগ্রহীতা: পরিবার/সমাজ/সরকার থেকে আপনি কী ধরনের প্রত্যাশা করবেন যাতে সেরিব্রাল পালসি রোগে শিশুদের পরিচালনা করা সহজ হয়?

শিশুর মা: আমি আশা করি পরিবার এবং সমাজ আরও বেশি সহানুভূতিশীল এবং সহায়ক হবে। সরকার থেকে বিশেষ সহায়তা এবং সুবিধা পাওয়া যাবে, যাতে আমাদের মতো বাবা-মায়েরা আর্থিক ও মানসিকভাবে কিছুটা হলেও মুক্তি পায়।

In-Depth Interview #3, 21.08.24

Name: Moni
Age: 23
Educational qualification: S.S.C
Occupation: Housewife
Children: 1
Children age: 6
Area: Saidpur
Socio-economic status: Lower Middle class
Husband occupation: Business
family structure:

Interviewer: Did you know anything about cerebral palsy before?

Moni: No, I didn't know much about cerebral palsy before. I only learned about it when Mili's problem was diagnosed.

Interviewer: How did you feel when you first learned that your child had cerebral palsy?

Moni: It was a very difficult moment for me. It felt like everything was collapsing. I was very worried about Mili's future.

Interviewer: How did you feel, and what were your initial thoughts and concerns?

Moni: I was extremely worried. I wondered if Mili would ever be able to live a normal life. I was concerned about how to care for her and how she would become independent.

Interviewer: How did the doctors explain this diagnosis to you? Did they provide you with enough information and support?

Moni: The doctors explained the diagnosis appropriately. They said that it is a long-term problem, but with proper treatment and therapy, her quality of life can be improved. They gave information and support, but I think I needed more guidance.

Interviewer: How do you manage your child's daily activities like walking, eating, and personal care?

Moni: Mili's daily activities take a bit more time. I help her with walking and try to keep her muscles active through therapy. We also need to take special care for her eating. For daily personal care, we always have to be by her side.

Interviewer: How do your family members support you?

Moni: My in-laws and husband all help in Mili's care. They also provide mental support, which gives me a lot of strength. Being in a joint family makes it easier to share the workload.

Interviewer: What are the biggest challenges you face as a parent of a child with cerebral palsy?

Moni: The biggest challenge is providing proper care for Mili and making every effort for her improvement. There is also financial pressure, as the costs of therapy and treatment are very high. I am always worried about her future.

Interviewer: Are you facing any social and financial challenges?

Moni: Yes, we are facing financial challenges. It is difficult to bear the costs of therapy and treatment. Sometimes, due to people's ignorance, I feel a sense of isolation socially.

Interviewer: As a parent, what kind of difficulties do you face in your child's education?

Moni: Mili needs special schools or teachers for her education. But there are no such facilities in our area, which is a big inconvenience for us. She needs special teaching methods and support, which are not always available.

Interviewer: Raising a child with cerebral palsy is affecting your feelings and mental health. Is that true?

Moni: Yes, it is affecting my mental health a lot. Sometimes I feel depressed and think that everything is very difficult. But Mili's smile gives me the strength to endure everything.

Interviewer: What helps you cope with the stress and challenges of raising a child with cerebral palsy?

Moni: My family and husband's support make me mentally strong. I also do yoga sometimes and talk to other parents, which helps me stay calm.

Interviewer: What kind of services are available in our country for children with cerebral palsy?

Moni: There are few services available for children with cerebral palsy in our country. There are some therapy centers and hospitals, but their number is low and the costs are very high. There is also little government assistance.

Interviewer: What kind of changes do you want to see in healthcare and education for children with cerebral palsy?

Moni: I want the government to provide more assistance and services. Especially therapy centers, special schools, and financial assistance should be easily available. There is also a need to raise awareness in society.

Interviewer: What kind of expectations do you have from family, society, and the government to make it easier to manage children with cerebral palsy?

Moni: I hope family and society will be more compassionate and supportive. The government should provide special assistance and facilities so that parents like us can get some relief, both financially and mentally.

In-Depth Interview #4, 21.08.24

Name: Robiul.
Age: 30
Educational qualification: S.S.C
Occupation: Business
Children: 2
Children age: 6,10
Area: saidpur
Socio-economic status: Lower middle class
wife occupation: Housewife
family structure: Nuclear

শিশুর মায়ের সাথে কুশল বিনিময়ের পর মায়ের সম্মতিক্রমে ইন্টারভিউ শুরু হয় এবং রেকর্ড হয়।

প্রশ্ন ১:
সাক্ষাৎকারগ্রহীতা: আপনি কি আগে সেরিব্রাল পালসি রোগটি সম্পর্কে কিছু জানতেন?
শিশুর বাবা: না, আগে সেরিব্রাল পালসি রোগটি সম্পর্কে আমার তেমন কোনো ধারণা ছিল না। যখন আমার মেয়ের রোগ ধরা পড়ে, তখনই আমি প্রথমবার এই রোগ সম্পর্কে বিস্তারিত জানতে শুরু করি।

প্রশ্ন ২:
সাক্ষাৎকারগ্রহীতা: আপনি যখন প্রথমবার জানতে পারলেন যে আপনার সন্তান সেরিব্রাল পালসি রোগে আক্রান্ত, তখন সেই মুহূর্তটি কেমন ছিল?
শিশুর বাবা: এই সংবাদটি শোনার পর আমি সম্পূর্ণভাবে ভেঙে পড়েছিলাম। মনে হয়েছিল, পৃথিবী যেন থেমে গেছে। একদিকে নিজের মেয়ের জন্য দুশ্চিন্তা, অন্যদিকে পরিবারের চাপ—সবকিছু মিলিয়ে সেই মুহূর্তটি ছিল খুবই কষ্টের।

প্রশ্ন ৩:
সাক্ষাৎকারগ্রহীতা: আপনি কেমন অনুভব করেছিলেন, এবং আপনার প্রাথমিক চিন্তা এবং উদ্বেগগুলি কী ছিল?
শিশুর বাবা: আমি খুবই হতাশ হয়েছিলাম। প্রথম চিন্তাটি ছিল, কীভাবে আমার মেয়ের চিকিৎসা করব এবং তাকে একটি স্বাভাবিক জীবন দেওয়ার জন্য কী করতে হবে। এছাড়া, আমার মেয়ের ভবিষ্যৎ নিয়ে অনেক চিন্তা এবং উদ্বেগ ছিল।

প্রশ্ন ৪:
সাক্ষাৎকারগ্রহীতা: ডাক্তাররা কীভাবে আপনাকে এই নির্ণয়টি ব্যাখ্যা করেছিলেন? তারা কি আপনাকে যথেষ্ট তথ্য এবং সমর্থন দিয়েছিলেন?
শিশুর বাবা: ডাক্তাররা যথেষ্ট ভালোভাবে ব্যাখ্যা করেছিলেন, তবে আমি প্রথমে পুরো বিষয়টি বুঝতে পারছিলাম না। তারা আমাদেরকে রোগটি সম্পর্কে বিস্তারিত তথ্য

এবং মেয়ের জন্য কী ধরনের চিকিৎসা ও থেরাপি প্রয়োজন তা জানিয়েছিলেন। কিন্তু মানসিকভাবে এই পরিস্থিতি মেনে নেওয়া ছিল খুবই কঠিন।

প্রশ্ন ৫:
সাক্ষাৎকারগ্রহীতা: আপনি কীভাবে আপনার সন্তানের দৈনন্দিন কার্যকলাপ যেমন হাঁটাচলা, খাওয়াদাওয়া, এবং ব্যক্তিগত যত্ন পরিচালনা করেন?
শিশুর বাবা: আমার স্ত্রী এবং আমি একসাথে মিলে মেয়ের সবকিছু দেখাশোনা করি। তাকে হাঁটতে, খেতে, এবং অন্য ব্যক্তিগত কাজগুলোতে সাহায্য করতে হয়। আমরা থেরাপিস্টের পরামর্শ মেনে চলি এবং নিয়মিত থেরাপি করাই।

প্রশ্ন ৬:
সাক্ষাৎকারগ্রহীতা: আপনার পরিবারের সদস্যরা কীভাবে আপনাকে সমর্থন করে?
শিশুর বাবা: আমার পরিবার থেকে তেমন সমর্থন পাই না। বরং অনেক সময় তারা মেয়েটিকে বোঝা মনে করে, যা আমাদের জন্য আরও কষ্টকর হয়ে ওঠে। তবে কিছু ঘনিষ্ঠ বন্ধুরা মানসিকভাবে সমর্থন দেয়।

প্রশ্ন ৭:
সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে একটি সন্তানের বাবা-মা হিসাবে আপনার সবচেয়ে বড় চ্যালেঞ্জগুলি কী?
শিশুর বাবা: সবচেয়ে বড় চ্যালেঞ্জ হলো মেয়ের সঠিক যত্ন নেওয়া এবং তাকে স্বাভাবিক জীবনের জন্য প্রস্তুত করা। এছাড়া, পরিবারের মনোভাব এবং সামাজিক চাপও বড় চ্যালেঞ্জ হয়ে দাঁড়ায়।

প্রশ্ন ৮:
সাক্ষাৎকারগ্রহীতা: আপনি কি কোনো সামাজিক এবং আর্থিক চ্যালেঞ্জের মুখোমুখি হচ্ছেন?
শিশুর বাবা: অবশ্যই। মেয়ের চিকিৎসা এবং থেরাপির খরচ অনেক বেশি, যা আর্থিকভাবে আমাদের ওপর চাপ সৃষ্টি করে। সামাজিকভাবে, অনেকেই বিষয়টি বুঝতে পারে না এবং অনেক সময় নেতিবাচক মন্তব্য করে।

প্রশ্ন ৯:
সাক্ষাৎকারগ্রহীতা: একজন বাবা-মা হিসাবে আপনার সন্তানের শিক্ষার ক্ষেত্রে আপনি কী ধরনের অসুবিধার সম্মুখীন হন?
শিশুর বাবা: মেয়ের শারীরিক সমস্যার কারণে তাকে সাধারণ স্কুলে ভর্তি করা যায়নি। বিশেষ স্কুল খোঁজার জন্য অনেক কষ্ট করতে হয়েছে, আর সেখানে ভর্তির জন্য আর্থিক বিষয়গুলোও বড় সমস্যা হয়ে দাঁড়ায়।

প্রশ্ন ১০:
সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালন করছেন। এটা কি আপনার অনুভূতি এবং মানসিক স্বাস্থ্যের উপর প্রভাব ফেলছে?
শিশুর বাবা: হ্যাঁ, এটি আমার মানসিক স্বাস্থ্যের ওপর গভীর প্রভাব ফেলেছে। মেয়ের জন্য দুশ্চিন্তা, পরিবারের চাপ এবং সামাজিক চ্যালেঞ্জগুলো আমাকে অনেক

মানসিকভাবে ক্লান্ত করে দেয়।

প্রশ্ন ১১:
সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসি রোগে আক্রান্ত একটি সন্তান প্রতিপালনের চাপ এবং চ্যালেঞ্জগুলি মোকাবিলা করতে আপনাকে কীভাবে সাহায্য করে?
শিশুর বাবা: বন্ধুদের সাথে কথা বলা, থেরাপিস্টের পরামর্শ নেওয়া এবং নিজের জন্য কিছু সময় বের করার চেষ্টা করি। এই সময়ে আমি নিজের মানসিক স্বাস্থ্যের যত্ন নিতে চেষ্টা করি।

প্রশ্ন ১২:
সাক্ষাৎকারগ্রহীতা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য কী ধরনের সেবা পাওয়া যায়?
শিশুর বাবা: আমাদের দেশে সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য বিশেষ কিছু সেবা থাকলেও, তা পর্যাপ্ত নয়। চিকিৎসা ও থেরাপির সুযোগ সীমিত এবং সেগুলোর খরচও বেশ বেশি।

প্রশ্ন ১৩:
সাক্ষাৎকারগ্রহীতা: সেরিব্রাল পালসিতে আক্রান্ত শিশুদের জন্য স্বাস্থ্যসেবা এবং শিক্ষার ক্ষেত্রে আপনি কী ধরনের পরিবর্তন দেখতে চান?
শিশুর বাবা: আমি চাই শিশুদের জন্য সুলভে বিশেষ থেরাপি এবং চিকিৎসার ব্যবস্থা হোক। পাশাপাশি, বিশেষ শিক্ষাপ্রতিষ্ঠানগুলো সহজলভ্য হোক, যেখানে তারা প্রয়োজনীয় শিক্ষা পেতে পারে।

প্রশ্ন ১৪:
সাক্ষাৎকারগ্রহীতা: পরিবার/সমাজ/সরকার থেকে আপনি কী ধরনের প্রত্যাশা করবেন যাতে সেরিব্রাল পালসি রোগে শিশুদের পরিচালনা করা সহজ হয়?
শিশুর বাবা: আমি আশা করি পরিবার, সমাজ এবং সরকার একসাথে এই শিশুদের প্রতি আরো সংবেদনশীল হবে। সরকারের পক্ষ থেকে বেশি সহায়তা এবং বিশেষ সেবার ব্যবস্থা করা উচিত। সমাজের মানুষও এই শিশুদের প্রতি আরও সহানুভূতিশীল হবে বলে আশা করি।

In-Depth Interview #4, 21.08.24

Transcript 4: Robiul

Name: Robiul.
Age: 30
Educational qualification: S.S.C
Occupation: Business
Children: 2
Children age: 6,10
Area: saidpur
Socio-economic status: Lower middle class
wife occupation: Housewife
family structure: Nuclear

Interviewer: Did you know anything about cerebral palsy before?

Robiul: No, I didn’t know much about cerebral palsy before. I only learned about it when my daughter was diagnosed.

Interviewer: How did you feel when you first learned that your child had cerebral palsy?

Robiul: I was completely devastated when I heard the news. It felt like the world had stopped. I was worried about my daughter, and the family pressure was immense. That moment was very painful.

Interviewer: How did you feel, and what were your initial thoughts and concerns?

Robiul: I was very disheartened. My first thought was how I could treat my daughter and give her a normal life. Besides, I had many worries and concerns about my daughter's future.

Interviewer: How did the doctors explain this diagnosis to you? Did they provide you with enough information and support?

Robiul: The doctors explained it quite well, but I didn't understand everything at first. They gave us detailed information about the disease and the kind of treatment and therapy my daughter needed. However, it was very difficult to accept this situation mentally.

Interviewer: How do you manage your child’s daily activities like walking, eating, and personal care?

Robiul: My wife and I take care of everything together. We help her walk, eat, and with other personal tasks. We follow the therapist's advice and provide regular therapy.

Interviewer: How do your family members support you?

Robiul: I don't get much support from my family. In fact, sometimes they blame my daughter, which makes things even harder for us. However, some close friends provide emotional support.

Interviewer: What are the biggest challenges you face as a parent of a child with cerebral palsy?

Robiul: The biggest challenge is taking good care of my daughter and preparing her for a normal life. Besides, family attitude and social pressure are also big challenges.

Interviewer: Are you facing any social and financial challenges?

Robiul: Definitely. The cost of my daughter's treatment and therapy is very high, which puts a financial strain on us. Socially, many people don't understand and often make negative comments.

Interviewer: As a parent, what kind of difficulties do you face in your child's education?

Robiul: Due to my daughter's physical condition, I couldn't admit her to a regular school. It was very difficult to find a special school, and the financial aspect of admission was also a big problem.

Interviewer: Raising a child with cerebral palsy is affecting your feelings and mental health. Is that true?

Robiul: Yes, it has greatly affected my mental health. Worries about my daughter, family pressure, and social challenges make me mentally exhausted.

Interviewer: What helps you cope with the stress and challenges of raising a child with cerebral palsy?

Robiul: I talk to my friends, seek advice from therapists, and try to find some time for myself. I try to take care of my mental health during this time.

Interviewer: What kind of services are available in our country for children with cerebral palsy?

Robiul: Although there are some special services for children with cerebral palsy in our country, they are not enough. The opportunities for treatment and therapy are limited, and the costs are quite high.

Interviewer: What kind of changes do you want to see in healthcare and education for children with cerebral palsy?

Robiul: I want affordable special therapy and treatment to be available for children. Also, special schools should be easily accessible where they can get the necessary education.

Interviewer: What kind of expectations do you have from family, society, and the government to make it easier to manage children with cerebral palsy?

Robiul: I hope family, society, and the government will become more sensitive towards these children. The government should provide more support and special services. I also hope people in society will be more compassionate towards these children.