Exploring Psychological Functioning and Occupational Participation among Caregivers of Individuals with Mental Illness: A Qualitative Study

By

Jannatul Ferdous Alo

February 2025

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

Bachelor of Science in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Faculty of Medicine
University of Dhaka

Thesis completed by:

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

……..……
Signature

Supervisor's Name, Designation, and Signature

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

……
Signature

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

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

……
Signature

Board of Examiners

Prof. Sk. Moniruzzaman
Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh.

.....
Signature

Dr. Md. Shakhaoat Hossain, PhD
Chairman & Associate Professor
Department of Public Health and Informatics
Jahangirnagar University
Savar, Dhaka-1342, Bangladesh.

.....
Signature

Statement of Authorship

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

Jannatul Ferdous Alo

4th year, B.Sc. in Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka: 1343

…….……

Signature

Acknowledgement

Alhamdulillah! I am very happy to have completed my thesis. All praise goes to Almighty Allah who keeps me fit both physically and mentally and provides knowledge, patience, and capability to accomplish this journey. I expressed my deepest gratitude to my parents and all my family members who supported me unconditionally throughout my academic journey. I would like to show my heartiest gratitude to my honorable supervisor, Mohuya Akter, Lecturer in Occupational Therapy Department, for her guidance, valuable suggestions, and support throughout my research journey. I am also thankful to my respected teacher, Professor Sk. Moniruzzaman, Head of the Department, and other faculty members, Kaniz Fatema, and Arifa Jahan Ema, for their guidance and support, and all BHPI teachers for their academic support throughout the study time. A heartfelt thanks to Farhana Haque Boisakhi, clinical OT, for helping me to get permission from the authority of the National Institute of Mental Health (NIMH). A am thankful to my sister Eshika Akter Nilima for her help in supporting the Bangla transcription. I am also thankful to my seniors who gave suggestions and guidance to complete this study. I am also thankful to my friends who gave me emotional support throughout my academic journey. I also wanted to gratify the authority of the National Institute of Mental Health (NIMH) to collect data and thank the participants who provided their valuable information to accomplish my study. Without their willingness to share their experiences and insights, this research would not have been possible.

Dedication

I have dedicated my research to the Almighty Allah, my family members, and to myself for my hard work.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ADL	Activities of Daily Living
AOTA	American Occupational Therapy Association
APA	American Psychological Association
BHPI	Bangladesh Health Professions Institute
CBI	Caregiver Burden Inventory
CRP	Center for the Rehabilitation of the Paralysed
IRB	Institutional Review Board
LMIC	Low and Middle Income Country
NHMRC	National Health and Medical Research Council
NIMH	National Institute of Mental Health
OT	Occupational Therapy
QoL	Quality of Life
WHO	World Health Organization

Abstract

Background: Mental disorders represent a significant global and national public health concern, affecting millions of individuals worldwide Mental illness may cause a variety of problems such as experience psychological distress, social isolation, financial strain, and reduced quality of life due to caregiving responsibilities of the patient's family members as well as increased social distance for the patient and the family caring for the patient.

Aim: To explore the psychological functioning and occupational participation of caregivers of individuals with mental illness and how caregiving influences their daily occupational participation.

Methods: This study was designed using a qualitative, phenomenological approach. Participants were recruited from the National Institute of Mental Health and Hospital. Data gathered from twelve family caregivers among individuals with mental illness involved conducting in-depth face-to-face interviews using semi-structured interview guidelines and the age of the caregiver above 18. The sample size was based on achieving data saturation. The study employed audio-recording techniques to capture first-person narratives in Bangla, which were transcribed and translated into English. The present study integrated thematic analysis, utilizing Braun and Clark's six-step approach.

Result: Four main themes emerged with emotional and psychological burden, physical health and self-care impact, disruption in daily functioning and finances, and changes in social relationships, identity, and coping. This study shows caregivers experienced persistent emotional distress, physical exhaustion, reduced occupational participation, financial strain, and social isolation. Despite these challenges, caregivers relied on

coping strategies such as religious faith, acceptance, and emotional endurance, which helped them continue caregiving but did not substantially reduce the overall burden.

Conclusion: Family caregivers of individuals with mental illness experience significant psychological, physical, social, and occupational challenges. Although coping strategies support endurance, the findings underscore the urgent need for caregiver-centered mental health services, psychosocial support, respite care, and policy-level interventions to address caregivers' psychological functioning and occupational participation.

Keywords: Caregivers, Mental Illness, Psychological Functioning, Occupational Participation, Caregiver Burden.

CHAPTER I: INTRODUCTION

1.1 Background

Mental disorders are a major global public health concern because of their high prevalence and their wide-ranging effects on health, functioning, and well-being. Earlier estimates suggested that around 450 million people worldwide were affected by mental disorders at any given time, including approximately 121 million individuals with depression, 24 million with schizophrenia, and 37 million with dementia (Iseselo et al., 2016). More recent estimates indicate that in 2019, about one in eight people globally approximately 970 million individuals were living with a mental disorder, with anxiety and depressive disorders identified as the most common conditions (World Health Organization [WHO], 2022). According to the World Health Organization, mental disorders are characterized by a combination of abnormal thoughts, perceptions, emotions, behaviors, and interpersonal relationships (WHO, 2022). Clinically, they involve significant disturbances in cognition, emotional regulation, or behavior and are typically associated with distress or impairment in important areas of functioning. The term also covers a broad range of mental health conditions, including psychosocial disabilities and other mental states linked to substantial distress or risk of self-harm (WHO, 2022). The burden of mental illness is not limited to affected individuals; it also extends to families, particularly those who provide day-to-day care.

In Bangladesh, mental disorders represent a significant public health challenge. The prevalence of psychiatric disorders among Bangladeshi adults has been reported as 18.7%, with higher rates among women than men (21.5% vs. 15.7%). The National Mental Health Survey (2024) further reported that mental disorders

affect approximately 16.8% of adults and 13.6% of children. Among individuals receiving care, commonly reported mental illnesses include schizophrenia (31.5%), bipolar disorder (25.5%), autism spectrum disorder (14.9%), and depressive disorders (8.6%) (Yao et al., 2024). Within this context, informal caregivers play a central role in supporting individuals living with mental illness. Informal caregivers are individuals who provide unpaid, ongoing assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) to persons with chronic illness or disability (Roth et al., as cited in Yao et al., 2024).

However, caregiving for a person with mental illness is frequently associated with psychological, emotional, social, physical, and financial challenges. Evidence indicates that caregivers often experience emotional distress, reduced social contact, financial strain, lower life satisfaction, and compromised physical and mental health due to caregiving responsibilities (Jeyagurunathan et al., 2017). In addition, mental illness within a family can negatively affect parental mental health, marital relationships, and overall family functioning. Primary caregivers may experience ongoing stress while managing unpredictable behaviors, treatment demands, and social stigma. These pressures can influence caregivers' psychological functioning and may also disrupt their participation in everyday occupations such as self-care, work, leisure, and social roles. Despite the increasing reliance on family caregiving in Bangladesh, research examining caregivers' psychological functioning and occupational participation in the Bangladeshi context remains limited.

Therefore, this study aims to explore the psychological functioning and occupational participation of caregivers of individuals with mental illness and how caregiving influences their daily occupational participation.

1.2 Justification of the study

Caregiving for individuals with mental illness is widely recognized as burdensome; however, much of the existing literature has predominantly employed quantitative research designs focusing on measurable outcomes such as caregiver burden, depression, anxiety, and quality of life (e.g., Liu et al., 2024; Karambelas et al., 2022; Jeyagurunathan et al., 2017). While these studies provide important statistical evidence, they offer limited insight into caregivers' in-depth psychological experiences and how caregiving influences their everyday occupational lives. Moreover, most caregiving research has been conducted in high-income countries, limiting the applicability of findings to low- and middle-income countries (LMICs) such as Bangladesh. The Bangladeshi caregiving context is shaped by unique cultural, religious, socioeconomic, and family dynamics, including strong family obligations, stigma surrounding mental illness, and limited access to formal mental health services. These contextual factors may influence caregivers' psychological functioning, coping strategies, and occupational participation in ways that are not adequately captured in existing literature. From an occupational therapy perspective, there remains a notable gap in understanding how caregiving affects engagement in daily occupations, routines, and roles. Although studies by (Isobel et al.2021) and (Fairfax et al.2019) have discussed coping and occupational identity, they do not sufficiently detail the impact of mental health caregiving on everyday occupational participation. Additionally, there is limited exploration of how caregivers develop coping strategies, adapt routines, and sustain caregiving roles within their daily lives and sociocultural contexts. Therefore, this qualitative study seeks to contribute uniquely by exploring caregivers' psychological functioning and occupational participation within the Bangladeshi context from an

occupational therapy perspective. By focusing on caregivers' lived experiences, this study aims to generate context-specific and culturally relevant evidence that can inform mental health services, caregiver support programs, occupational therapy interventions, and policy development in Bangladesh

1.3 Operational Definition

1.3.1: Mental Illness

Mental illness refers to a clinically significant disturbance in an individual's cognition, emotional regulation, or behavior that is associated with distress or impairment in important areas of functioning (World Health Organization [WHO], 2022). In this study, mental illness refers to diagnosed mental health conditions requiring ongoing caregiving support.

1.3.2: Caregiver

A caregiver is defined as a family member who provides unpaid, ongoing assistance with activities of daily living and/or instrumental activities of daily living to an individual with a chronic illness or disability (Yao et al., 2024; Roth et al., 2015). In this study, caregivers are family members providing primary care to individuals with mental illness.

1.3.3: Psychological Functioning

Psychological functioning refers to an individual's emotional and mental state, including their ability to regulate emotions, cope with stress, and maintain psychological well-being in response to life demands (American Psychiatric Association [APA], 2013). In this study, psychological functioning reflects caregivers' emotional experiences within the caregiving role.

1.3.4: Occupational Participation

Occupational participation is defined as engagement in meaningful daily life activities,

including self-care, work, leisure, and social roles, within one's sociocultural context (American Occupational Therapy Association [AOTA], 2020). In this study, occupational participation refers to caregivers' involvement in daily occupations while managing caregiving responsibilities.

1.3.5: Caregiver Burden

Caregiver burden refers to the perceived physical, psychological, social, and financial strain experienced by individuals who provide long-term care to a family member with illness or disability (Zarit et al., 1980). In this study, caregiver burden is considered as a factor influencing caregivers' psychological functioning and occupational participation.

1.3.6: Coping Strategies

Coping strategies are defined as cognitive and behavioral efforts used to manage internal or external demands that are perceived as stressful or exceeding an individual's resources (Lazarus & Folkman, 1984). In this study, coping strategies refer to the ways caregivers manage caregiving-related stress within their daily lives and occupations.

1.4 Aim of the study

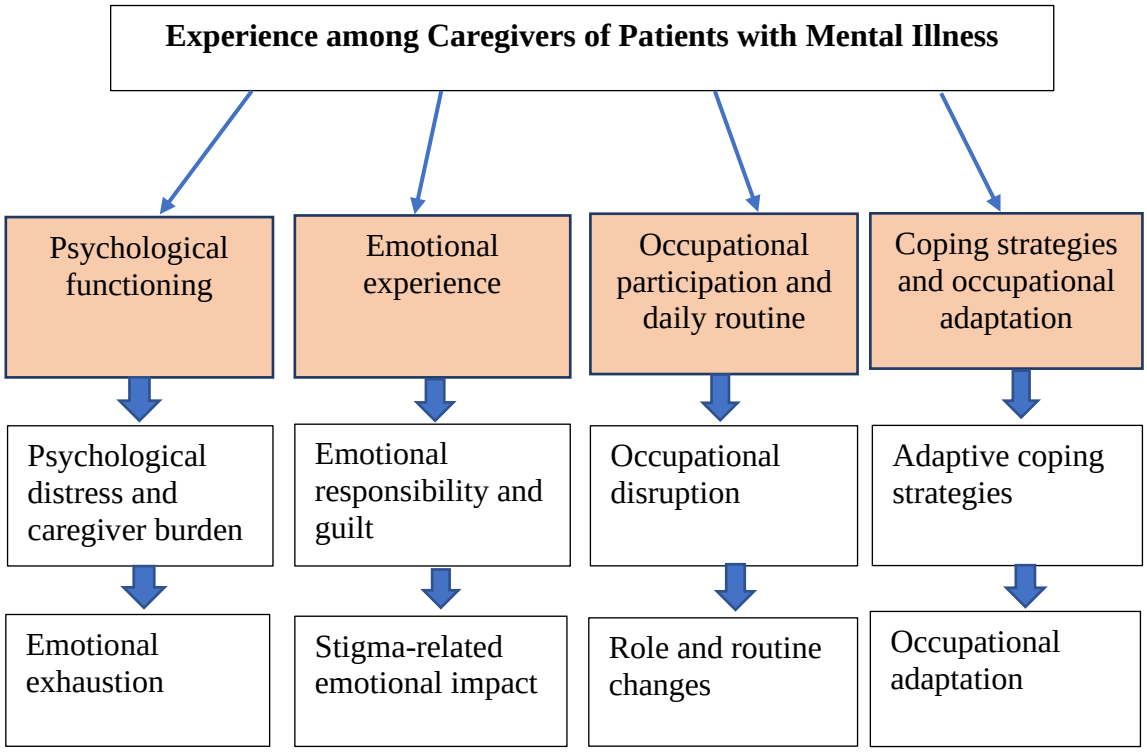
To explore the psychological functioning and occupational participation of caregivers of individuals with mental illness and how caregiving influences their daily occupational participation.

CHAPTER II: LITERATURE REVIEW

This literature review chapter is an overview of articles that highlight the experiences of family caregivers among individuals with mental illness patient in the previous literature. Caregiving for individuals with mental illness is widely recognized as a complex and demanding role that significantly affects caregivers' psychological functioning and daily occupational participation. Existing qualitative literature consistently demonstrates that caregivers experience emotional strain, disrupted occupational roles, and ongoing adaptation in response to caregiving demands. A search strategy is used to locate relevant articles from different databases, including CHINAIL, Embase, Scopus, PubMed, Google Scholar, and Google.

Figure 2.1

Overview of literature review



2.1 Psychological Functioning

Across diverse settings, caregiving for individuals with mental illness is consistently associated with compromised psychological functioning. Qualitative evidence shows recurring experiences of stress, anxiety, depressive symptoms, and emotional strain, often linked to prolonged responsibility, symptom management, and limited time for self-care. For example, caregivers reported psychological distress connected to continuous supervision and lack of personal time (Howes & Ellison, 2021) Another study carried out a qualitative study in Beijing, China, and reported that primary family caregivers of individuals with schizophrenia experienced high levels of psychological burden. The study revealed that caregivers frequently suffered from emotional stress and depressive symptoms, which negatively affected their psychological functioning. Limited access to community mental health services further intensified caregiver burden (Chen et al., 2019).

A study in Canada and found that caregivers of adults with mental illness experienced persistent psychological distress and emotional exhaustion. The authors reported that prolonged caregiving without adequate support led to chronic stress and reduced psychological resilience among caregivers (Cruz et al., 2024). Most studies are context-specific and commonly cross-sectional or small-sample qualitative designs, which limits transferability and understanding of change over time in Bangladesh. These findings support the need to explore caregivers' psychological functioning and emotional experiences in Bangladesh.

2.1.1 Psychological distress and caregiver burden

Psychological distress and caregiver burden emerge as central, interconnected themes. Evidence indicates that long-term caregiving contributes to chronic stress, anxiety, and emotional strain, particularly where caregivers lack adequate social and professional

support (Chen et al., 2019). A multi-country systematic review further suggests caregiver burden negatively affects mental health regardless of diagnosis, indicating psychological distress is a broad caregiving outcome (Karambelas et al., 2022). A study conducted in Tanzania by (Iseselo et al., 2016) further reported that caregivers experienced psychological burden due to financial strain, lack of social support, and stigma. These stressors significantly affected caregivers' psychological functioning and overall well-being.

Caregiver burden is shaped not only by individual demands but also by structural and contextual factors. This is particularly relevant to Bangladesh, where resource constraints and limited formal support may heighten caregiver burden and distress.

2.1.2 Emotional exhaustion

Emotional exhaustion is frequently reported as a consequence of sustained caregiving with limited opportunities for rest and recovery. Caregivers describe fatigue and burnout when caregiving requires constant vigilance and reduces time for self-care (Howes and Ellison, 2021).

Similarly, a qualitative study in Canada and reported that emotional exhaustion was a common experience among caregivers of adults with mental illness. The study revealed that prolonged caregiving without recognition or support resulted in emotional fatigue and burnout (Cruz et al. 2024).

In Australia, also reported that caregivers of individuals with bipolar disorder experienced emotional exhaustion due to unpredictability of symptoms and fear of relapse, which further compromised their psychological functioning (Speirs et al. 2023).

Emotional exhaustion appears to function both as a psychological outcome and

a sign of occupational imbalance, with potential implications for daily occupational engagement. This reinforces examining how psychological strain (including exhaustion) influences caregivers' everyday occupational participation.

2.2 Emotional Experiences of Caregiving

This section of the literature review provides an overview of Emotional responsibility, guilt and Stigma-related emotional impact. Understanding these emotional experiences is essential for exploring caregivers' psychological and emotional functioning.

2.2.1 Emotional responsibility and guilt

A study was carried out in Australia by (Speirs et al. 2023) and established that caregivers often felt strong emotional responsibility toward the individual with mental illness. Caregivers reported feelings of guilt when they perceived themselves as unable to adequately support the care recipient, which contributed to emotional stress.

Similarly, (Issac et al. 2023) conducted a qualitative study in India and reported that caregivers of individuals with paranoid schizophrenia experienced guilt and self-blame related to caregiving expectations. Emotional responsibility was intensified by cultural expectations and family obligations.

In a study conducted in Uganda, also reported that caregivers experienced guilt and emotional pressure when caregiving demands interfered with other family roles, particularly among caregivers of adolescents with bipolar disorder (Amanyire et al. 2025).

2.2.2 Stigma-related emotional impact

A study was carried out in Beijing, China Stigma related to mental illness consistently emerges as a major emotional stressor. Caregivers report shame, embarrassment, and emotional isolation due to negative societal attitudes (Pan et al., 2024)

A study in Tanzania and established that caregivers experienced stigma and

discrimination, which negatively affected their emotional well-being. Fear of social judgment often led caregivers to withdraw from community interactions (Iseselo et al. 2016). Stigma contributed to feelings of emotional invisibility and helplessness among caregivers, further exacerbating emotional distress (Cruz et al. 2024).

This supports examining how social stigma affects both psychological functioning and participation in daily occupations, particularly in settings where stigma remains high and supports are limited.

2.3 Occupational Participation and Daily Routines

This section of the literature review covers information related to the Occupational disruption, Role and routine changes. This directly aligns with examining how caregiving influences occupational participation and meaningful roles

2.3.1 Occupational disruption

Across studies, occupational disruption appears as a consistent consequence of mental health caregiving, affecting leisure, employment, and self-care. Caregivers report reduced engagement in meaningful occupations due to caregiving demands and emotional strain (Howes and Ellison, 2021; Chen et al., 2019; Mandani et al., 2018;). These findings indicate that psychological burden and occupational disruption are interconnected outcomes rather than separate experiences.

This underscores the relevance of exploring caregivers' occupational participation and the occupational consequences of caregiving within the Bangladeshi context.

2.3.2 Role and routine changes

Caregiving often requires substantial changes in daily routines and roles. Evidence suggests caregivers re organize schedules around monitoring, care tasks, and safety needs, which can result in occupational imbalance (Pan et al., 2024). Role overload is

also reported in low-resource settings where caregivers assume multiple responsibilities with minimal external support (Amanyire et al., 2025).

Over time, caregivers may alter work and family roles to accommodate caregiving demands (Speirs et al., 2023), suggesting longer-term occupational role transformation with implications for well-being and identity.

These findings support exploring how caregiving reshapes meaningful occupational roles and daily routines, especially where formal respite and services are limited.

2.4 Coping Strategies and Occupational Adaptation

Despite challenges, caregivers actively develop coping strategies and adaptive routines to manage caregiving demands. Coping and adaptation appear influenced by cultural beliefs, social support, and available resources.

2.4.1 Adaptive coping strategies

A study was carried out in Malaysia by (Azman et al. 2016) and established that caregivers used adaptive coping strategies such as acceptance, emotional regulation, and seeking family support. These strategies helped caregivers manage psychological distress.

Similarly, (Ntsayagae et al. 2019), through a qualitative meta-synthesis in Sub-Saharan Africa, reported that caregivers relied on emotional coping and social support to manage caregiving stress. In LMIC contexts, religious coping is commonly described as a key strategy (Iseselo et al., 2016). These strategies highlight the culturally embedded nature of coping and the importance of understanding coping within local contexts.

2.4.2 Occupational adaptation

A study was carried out in the United Kingdom by (Howes and Ellison et al. 2021) and established that caregivers gradually developed occupational adaptation by modifying daily routines and redefining meaningful activities.

Caregivers adapted occupational roles over time, allowing them to maintain caregiving responsibilities while preserving some level of occupational balance (Speirs et al. 2023). However, lack of professional guidance may limit effective adaptation (Pan et al., 2024), suggesting a potential role for occupational therapy support to promote healthier occupational engagement. This supports examining everyday occupational adaptation and the challenges that shape it among caregivers.

2.5 Key Gaps of the Study

- Most existing studies on caregivers of individuals with mental illness have used quantitative or systematic review designs, which limit in-depth understanding of caregivers lived psychological and occupational experiences (Tulek et al., 2020).
- Many studies focus mainly on caregiver burden or stress**,** with limited integration of occupational participation and daily routines**,** particularly from an occupational therapy perspective (Howes and Ellison, 2021).
- Several studies provide insufficient information on caregivers' general health conditions, comorbidities, and social support, limiting holistic understanding of caregiving experiences (Tsai et al., 2021).
- A large number of studies employed cross-sectional designs, which do not allow examination of changes over time or causal relationships between caregiving and psychological outcomes (Abdollahpour et al., 2018; Huang et al., 2012).
- In some studies, convenience sampling and limited demographic data reduced

the transferability of findings and failed to reflect diverse caregiving contexts (Connors et al., 2020).

- The majority of studies are based in high-income countries (Singapore, UK, Australia, Canada), offering little cultural relevance to the Bangladeshi context. There is a significant lack of research capturing the unique sociocultural, and caregiving experiences in Bangladesh or similar LMICs.

CHAPTER III: METHODS AND MATERIALS

3.1 Study Question, Aim, Objective

3.1.1 Study Question

How does caring for a relative with mental illness influence caregivers' psychological functioning and occupational participation?

3.1.2 Aim

To explore the psychological functioning and occupational participation of caregivers of individuals with mental illness and how caregiving influences their daily occupational participation.

3.1.3 Objective

• To explore the psychological and emotional experiences of caregivers in relation to their care giving.

• To understand how caregiving influences caregivers' participation in occupation and meaningful occupational roles.

• To identify perceived challenges coping strategies and adaptation in everyday occupational routines.

3.2 Study Design

3.2.1 Study Method

This study followed a qualitative research method that is appropriate for this study as it allows for in depth exploration of psychological functioning and occupational participation among caregivers of mental illness patients. Because qualitative study focuses on human experience, perceptions, motivations, intentions, behaviors, and meanings which are based on description and observation. And a naturalistic

interpretative approach to a subject and its contextual setting. This study requires an exploration of the experience of real-life situations (Creswell, 2018).

3.2.2 Study Approach

A phenomenological approach is suitable for this study which is focused on understanding people's lived experiences and how they perceive the psychological and occupational consequences of caregiving (Creswell and Poth, 2018). Phenomenology is particularly suitable for examining shared meanings and common patterns across participants who experience the same phenomenon. In this case, the focus is on the participants' views on psychological functioning and occupational participation. By using this approach, the researcher is trying to capture the shared feelings, thoughts, and experiences of caregivers (van Manen, 2016). Thematic analysis was used in order to gain a deeper and clearer understanding and a formation of themes. The unit of analysis was the themes expressed in the text about social and psychological problems found in families caring for persons with mental illness (Guest, MacQueen, & Namey, 2012).

3.3 Study Setting and Period

3.3.1 Study Setting

The study was conducted at The National Institute of Mental Health & Hospital (NIMH). As this institute served as the principal source of participants for the study, the student researcher chose this setting.

3.3.2 Study Period

The study period was from 15 June 2025 to 15 December 2025 and the data collection period was from 15 August, 2025 to 15 September, 2025.

3.4 Study Participant

3.4.1 Study Population

The target population for this study consists of caregivers who came to the National Institute of Mental Health (NIMH) for treatment purposes among individuals with mental illness.

3.4.2 Sampling Techniques

Purposive sampling, a form of non-probability sampling, was used in this study to recruit participants who could provide rich and relevant information about the phenomenon. This method relies on the researcher's informed judgment when selecting individuals who satisfy specific inclusion and exclusion criteria (Galloway, 2005). Because the study required participants with particular characteristics, purposive sampling was considered appropriate, allowing the researcher to intentionally recruit those who were most capable of offering meaningful insights (Banerjee and Chaudhury, 2010; Rai and Thapa, 2015). For these, the student researcher uses this sampling because there are some inclusion and exclusion criteria in this study and after judgment of all the criteria the researcher would select the participants.

3.4.3 Inclusion Criteria

- Primary caregivers (informal or family) of individuals diagnosed with a mental illness (e.g., schizophrenia, bipolar disorder, depression, generalized anxiety disorders etc).
- Participant age 18-60 years
- Caregiver living with relative who had been suffering from mental illness for at least 6 months
- Able and willing to share personal experiences in an in-depth interview

3.4.4 Exclusion Criteria

- Professional or paid caregivers (e.g., nurses, domestic workers) who are not family members.
- Individuals who themselves have a diagnosed severe mental illness, which may interfere with participation or data quality.
- Persons unable or unwilling to provide informed consent.
- Participants who are unable to participate in an in-depth interview due to cognitive, hearing, or language difficulties that affect communication.

3.4.5 Study Sample Size

The study included 12 participants because saturation was reached through iterative data collection and analysis.

Table 3.4.6

Participant Overview

Participant Pseudo name	**Age**	**Occupation**	**Relation with Mentally ill Patient**	**Duration of Caregiving**
Rahima	40 years	Housewife	Mother	2 years
Salma	35 years	Housewife	Wife	3 years
Khadija	22 years	Student	Daughter	1.5 years
Abdul Karim	50 years	Business	Father	4 years
Rita	38 years	Housewife	Mother	2 years
Shemoly	35 years	Housewife	Wife	4 years
Rina Begum	38 years	Housewife	Mother	6 years
Tamanna	33 years	Garments worker	Mother	2.5 years
Konika	37 years	Housewife	Mother	3 years
Lamiya	39 years	Housewife	Mother	4 years
Shiuli	28 years	Housewife	Mother	2.5 years
Roma	36 years	Housewife	Wife	3 years

3.5 Ethical Consideration

3.5.1 Ethical clearance

The ethical clearance has been approved by the Institutional Review Board of BHPI, explaining the purpose of the research, through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), The IRB number CRP-BHPI/IRB/07/2025/1125 (See Appendix A for details). Permission from the National Institute of Mental Health (NIMH). All the participants were informed that their information was used in the research, but their names and addresses were confidential. The ethics was maintained according to the World Medical Association,2013 Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects.

3.5.2 Informed Consent

• Information sheet

The student researcher informed each participant about the details of the information sheet. Every participant was given an information sheet from the student researcher, which includes the goal, purposes, and risks or benefits of the study. The information was provided to participants in a language and format that was easy to understand (World Medical Association., 2013). (Please see Appendix B).

• Consent form

The student researcher explained the purpose and procedure to the participants, inviting them to participate in the study. The student researcher did not force the participants to participate in the survey against their interests. The participants, who felt willingly interested in participating in the study, their data was collected. Written consent was obtained from the participant during the face-to-face survey (World Medical Association., 2013). (Please see Appendix B).

• Withdrawal Form

Participants had complete freedom to choose whether to participate or not in this study. The withdrawal form was attached with the consent form, so that the participants could withdraw their participation from the study within two (02) weeks from the time of collecting data (World Medical Association., 2013). (Please see Appendix B).

3.5.3 Unequal Relationship

The student researcher maintained an equal and neutral relationship with all participants, ensuring that no power imbalances or biases influenced the study results. (NHMRC, 2023)

3.5.4 Risk & Beneficence

There were no direct risks or benefits involved in this study. There was no monetary or any other benefit involved in this study. Although no physical risk was expected, participation involved minimal psychological risk, such as emotional discomfort or distress when discussing personal caregiving experiences. Direct benefits were not guaranteed; however, participants may experience indirect benefits such as the opportunity to share their experiences, and the findings may contribute to improving caregiver support services in the future.

3.5.5 Power Relationships

The student researcher ensured that there were no unequal relationships among the participants and that the dynamics remained neutral and equitable throughout the study (NHMRC, 2023).

3.5.6 Confidentiality

The participants' information was kept strictly confidential. Their names and identities were shared solely with the supervisor and clearly displayed on the information sheet. Participants were assured that their identities would be kept anonymous in any

subsequent reports, publications, presentations, or other written or spoken materials (NHMRC, 2023).

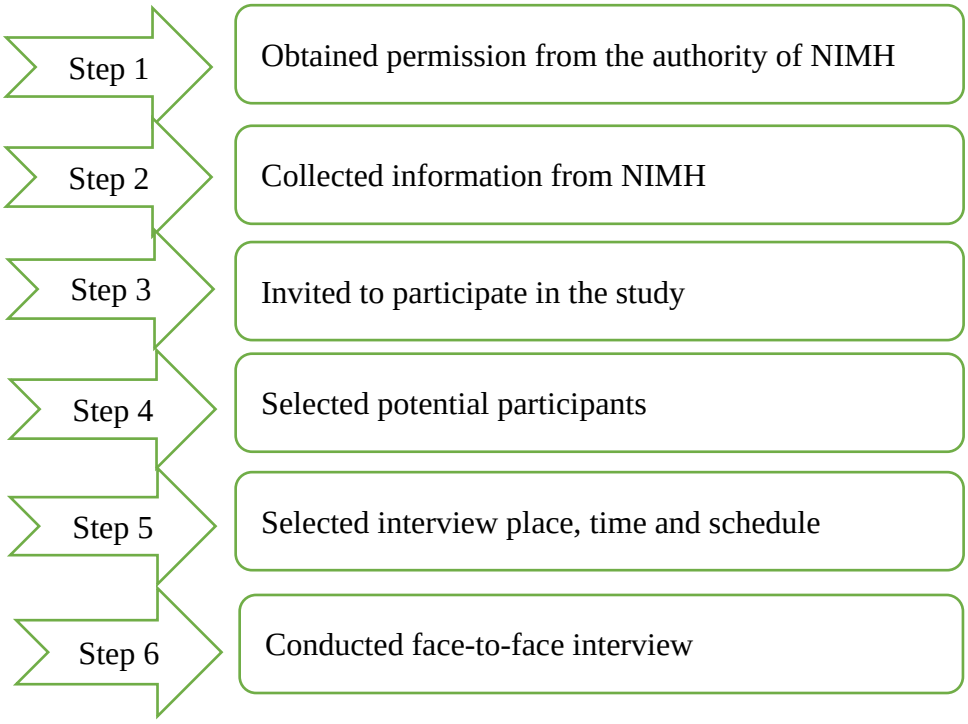
3.6 Data Collection Process

3.6.1 Participant Recruitment Process

Figure 3.6.1 shows the participant recruitment process

Figure 3.6.1

Overview of participant recruitment process



The student researcher obtained the ethical consideration letter and subsequently proceeded to the National Institute of Mental Health to gather data from the NIMH database. After obtaining permission from the relevant authority investigator to collect population data, caregivers among individuals with mental illness were invited to participate in the study. Interested participants received an information sheet, consent form, and withdrawal form.

3.6.2 Data Collection Method

The student researcher conducted face-to-face, in-depth, semi-structured interviews to collect data, which provided flexibility to explore participants' experiences and obtain detailed responses. At first, the student researcher introduced with the participants before data collection. The student researcher also verbally presented the details of the study, including the aim, objectives, and purpose of the study. The interviews were held in Bengali using a semi-structured questionnaire to gather comprehensive information from each participant. Consent forms and information sheets in Bengali were provided to ensure that participants felt comfortable and could express themselves accurately and no non-participants were present during interviews. Observation techniques were used to note participants' facial expressions, and each interview was audio-recorded, with written transcriptions prepared afterward following the method described by (Liamputtong et al.;2017). The duration of each interview was approximately 30–40 minutes.

3.6.3 Data Collection Instrument

A self-developed interview guide was used by the student researcher to collect data from the participants. A semi-structured interview guide was developed by a student researcher. Because it encouraged a more in-depth response from research participants and helped to keep the interview and the subject focused. There are 14 open-ended questions in the interview guide. The student researcher developed an interview guide by reviewing literature related to this study and according to the research aim and objectives ((Issac et al., 2023; Howes and Ellison, 2022; Jeyagurunathan et al., 2017; Von Kardorff et al., 2016; Iseselo et al., 2016, Azman et al., 2016) and in discussion with the supervisor. The student researcher also developed a sociodemographic information sheet, which was included in the semi structured interview guide. Phone

recorder, was also used as instruments for the study. The data collection instrument was a self-developed interview guide and flowchart following the literature review. (Please see the Appendix C)

Field Test: Before the data collection process a field test is done by student researcher for ensuring an effective data collection and measuring the reliability of interview guide.

3.7 Data Management and Analysis

The student researcher used thematic analysis according to Braun and Clarke's six steps of thematic analysis to analyze the data (Braun & Clarke, 2021). The six steps are given below:

1. **Familiarizing with data:** At first the student researcher transcribed data verbatim in Bengali as their first language and translated them into English. She translated interviews by herself. After that, the respected supervisor re-checked all the transcription and translation. Then the student researcher read the data two times thoroughly to understand the meaning of data and noted down initial ideas.
2. **Generating initial codes:** In this step, the student researcher generated interesting features of the data by highlighting interesting sentences and generated some initial codes from the interesting sentences and named them. The initial codes were checked by the supervisor.
3. **Searching for themes:** The student researcher wrote down all the codes on paper and highlighted the similar codes by reading the translation. and discussing them with a supervisor. Then the student researcher collated codes into potential themes, wrote them. Through this gathered all data relevant to each potential theme.
4. **Reviewing themes:** In this fourth step the student researcher re-checked if the

themes worked about the coded extracts and the entire data set, generated a thematic 'map' of the analysis, and discussed it with the supervisor. Four themes emerged from the study.

5. **Defining and naming themes:** Here, the student researcher refined the specifics of each theme, and the overall story the analysis tells, generated clear definitions, and named each theme. The respected supervisor rechecked all the themes.
6. **Producing the report:** Finally, the student researcher produced a scholarly report in the dissertation by writing the results chapter with verbatim quotes from participants.

3.8 Trustworthiness and Rigor

Trustworthiness was maintained by following methodological and interpretive rigor.

3.8.1 Methodological rigor

Congruence

The following steps-maintained congruence:

- The study followed a phenomenological qualitative research design, which was appropriate for exploring the lived experiences of family caregivers of individuals with mental illness.
- The research design, objectives, data collection method, and analysis were aligned to maintain internal consistency.

Responsiveness to Social Context

The following steps ensured responsiveness:

- Face-to-face interviews were conducted in a private and comfortable setting to encourage open communication.
- The student researcher spent time engaging with participants and becoming familiar with the caregiving context, which fostered rapport and deeper

understanding.

Appropriateness

The following steps ensured appropriateness:

- Purposive sampling was used to include participants who were best suited to address the research questions.
- Twelve participants were selected based on clear inclusion and exclusion criteria to ensure relevance and adequacy of the sample.

Adequacy

The following steps supported adequacy:

- A semi-structured interview guide in Bangla was used to conduct in-depth interviews.
- All interviews were audio-recorded for accuracy and later transcribed.
- Participants' experiences were presented through verbatim quotations to maintain the authenticity of the data.
- The methodological description was sufficiently detailed so readers could understand how the study was conducted.

Transparency

The following steps ensured transparency:

- All interviews were first transcribed verbatim in Bangla and then translated into English.
- Data analysis followed Braun and Clarke's six-phase thematic analysis framework.
- The respected supervisor rechecked all the transcriptions and data analysis, which provided multiple views on the data.

3.8.2 Interpretive rigor

Authenticity

The following steps ensured authenticity:

- Participants' views were preserved through the use of verbatim quotations.
- After each interview, the student researcher verbally clarified and confirmed the meaning of participants' statements to enhance accuracy.
- Due to time limitations, participants were not involved in reviewing transcripts or findings, but their perspectives were accurately represented.

Coherence

The following steps ensured coherence:

- The student researcher transcribed the data verbatim in Bangla, (the first language) listening to the audio in Bengali, and then translated them into English, maintaining conceptual consistency between languages.
- All transcripts and thematic interpretations were reviewed by supervisor and refined to ensure the findings logically reflected the data.

Reciprocity

The following steps ensured reciprocity:

- The student researcher developed initial codes from the similar data, which were reviewed by the supervisor to minimize bias and enhance analytical depth.
- After completing coding, similar codes were clustered into potential themes and discussed with the supervisor for validation.

Typicality

The following considerations ensured typicality:

- The experiences of caregivers in this study reflect common caregiving patterns in South Asian cultural contexts.

- Readers from regions with similar sociocultural and healthcare structures may find the findings transferable.

Permeability of the Researcher

The following steps ensured permeability:

- The student researcher reflected on personal assumptions, values, and preconceptions throughout the study to minimize bias.
- The student researcher and the supervisor reviewed and there was no chance of bias in this study.

CHAPTER IV: RESULTS

The results chapter provides a deeper understanding of the findings of this research, about the experiences of family caregivers among individuals with mental illness. Four main themes emerged from the data analysis, which are: Emotional & psychological burden, Physical health & self-care impact, Daily functioning, work & finances, social relationships, identity & coping resources. Each theme is sorted with some sub-themes shown in Table 4.1. They are given below in this chapter:

Table 4.1

Overview of the result

Theme	Sub-theme
Theme 1: Emotional & psychological burden	Anxiety & fear
	Anger & frustration
	Sadness, hopelessness & emotional numbing
Theme 2: Physical health & self-care impact	Sleep disturbance & fatigue
	Self-care & health neglect
Theme 3: Daily functioning, work & finances	Household routines & time use
	Work & economic consequences
	Leisure & personal interests
Theme 4: Social relationships, identity & coping strategies	Social isolation & stigma
	Family role changes
	Coping & resilience

4.1 Theme One: Emotional and psychological burden

Caregivers described caregiving as emotionally demanding and psychologically consuming. Their accounts showed persistent hypervigilance, uncertainty, and a sense that their inner emotional life was reorganized around managing crises. Importantly, emotional distress was not only a feeling state but also a functional force shaping occupational participation when anxiety or hopelessness intensified, caregivers reported reduced ability to sleep, work, maintain household routines, or participate in leisure and social occupations.

4.1.1 Sub-theme: Anxiety and fear

Caregivers expressed ongoing worry regarding illness progression, safety, and the future. Anxiety appeared both anticipatory (future-focused fear) and situational (fear triggered by aggression or unpredictability), creating continuous psychological threat and reducing perceived control over everyday life.

Rahima (mother) said that, “If a child is sick, the mother will naturally worry.” This framing normalized worry as part of motherhood, yet also revealed how caregiving worry becomes taken-for-granted and constant. Salma (mother) said that,

> *“The way my child behaves, it feels like he will kill me. He is very stubborn; he tries to hit me with a knife. I live in fear inside my own home. I cannot breathe properly when he gets uncontrollable; my whole chest trembles until I fall asleep.”*

Fear here functioned like an occupational barrier in home, which is typically a place of rest and routine, became a site of threat that disrupted basic occupations (sleep, breathing regulation, daily tasks). And another father Abdul Karim said that,

> *“I have not slept for three days because he does not sleep. Even when he takes medicine, he wakes up again and again. I feel like I must stay awake every moment because I don’t know when something will happen. Every minute I am afraid that he will hit someone or create trouble, and I will have to run to save him…”*

This illustrates how fear leads to constant monitoring, limiting rest and replacing discretionary time with caregiving surveillance. Roma, caring for a husband, she said that “I live in fear that he might kill me at any moment… he threatens divorce, scolds, fights.”

These statements show that caregivers often function under continuous psychological

threat, reflecting high emotional arousal and chronic stress.

4.1.2 Sub-theme: Anger & frustration

Caregivers described anger as emerging from long-term strain, helplessness, and lack of support. Anger was not only directed toward the care recipient's behavior, but also toward the unending nature of responsibility and the collapse of caregivers' own routines and valued roles. Abdul Karim said that,

> *"My mental state is becoming worse day by day because of him. I become so frustrated that sometimes I cannot even pray or do my own work. I have only one son, and all my suffering is coming from him. Sometimes I cry while eating. I become so angry but I cannot do anything."*

This account directly links emotional strain to occupational disruption (prayer, work, eating). Another participant Lamiya (mother) said,

> *"I feel irritated all the time. The work I want to do, I cannot do. I feel frustrated because I have to spend so much time behind him. Even then, no one wants to look after him and all the burden falls on me."*

This reflects role overload and restricted co-care, where caregiving dominates time use and blocks meaningful occupations.

4.1.3 Sub-theme: Sadness, hopelessness, and emotional numbing

Many narratives conveyed profound sadness, emotional depletion, and loss of interest in life activities. These experiences resembled depression-like states and were strongly connected to occupational withdrawal (reduced engagement in grooming, socializing, leisure, and productive roles). Importantly, while emotional distress also appears in Theme stigma, this sub-theme emphasizes the internal erosion of emotional energy, whereas Theme 4 focuses on social mechanisms (stigma, rejection) that intensify distress. Some participants in this regard stated: Rita (mother) said that,

> *"Look at me. I am exhausted from crying. I feel like hanging myself. I am educated but now I cannot do any work because of him. There is so much sorrow in my heart that I feel like dying every day."*

Her statement illustrates severe psychological suffering alongside occupational loss (cannot do any work). Rina Begum (mother) said that,

> *"I feel like a living dead person. I used to dress nicely, meet people, and enjoy life. Now I do not even feel like combing my hair. The illness of my daughter has taken away all the joy from my life; even the days feel long and empty."*

This shows disrupted self-care (grooming) and reduced social and leisure participation. Another mother Shiuli said that,

> *"All peace in my life has vanished. I feel helpless and cry often. I do not feel like talking to anyone. Now I do not even feel like watching TV. I have lost interest in everything because my daughter became sick."*

This reflects occupational disengagement across communication, leisure, and daily routine.

4.2 Theme Two: Physical health and self-care impact

Caregivers described a clear physical toll, where chronic fatigue and health neglect emerged as consequences of prolonged emotional stress, night-time caregiving, and constant monitoring. Physical depletion further reduced occupational capacity, caregivers reported being unable to maintain consistent sleep, hygiene, nutrition, and medication routines, intensifying occupational imbalance.

4.2.1 Sub-theme: Sleep disturbance and fatigue

Caregivers reported fragmented sleep due to the care recipient's irregular sleep patterns and the caregiver's night-time vigilance. Abdul Karim (father) said that, "I haven't slept

for three days because he doesn't sleep. Even when I lie down, I cannot sleep because when he wakes up, I must get up too. I am always alert at night."

Such sleep deprivation contributed significantly to physical and psychological exhaustion. Another participant Rita(mother) stated that, "I cannot sleep or rest now. He keeps saying 'outside, outside' all the time. I cannot even sleep for one hour properly."

Sleep deprivation here acts as both a health issue and an occupational barrier, reducing energy for daytime roles such as household management, income generation, and caregiving continuity.

4.2.2 Sub-theme: Self-care and health neglect

Caregivers frequently reported neglecting bathing, eating, clothing changes, and medical adherence. Abdul Karim (father)said that,

"I have three rings in my heart, and still, I cannot take care of myself. I have worn the same shirt for three days even though I have more than 40 shirts. I cannot even take my medicine regularly."

Self-care was frequently compromised, as caregivers described neglecting their own hygiene, nutrition, and medical needs.

Another participant Shiuli (mother) said that, "I cannot bathe properly, cannot eat properly. My work does not get done. My daughter's illness has broken my whole routine. I have suffered so much that it cannot be expressed in words." Another participant Tamanna (mother) said that, "Today I could not even brush my teeth. I was running after him from the morning. I forget my own health completely."

These accounts show that caregiving transforms self-care from a routine occupation into a neglected activity, reflecting occupational disruption and decreased performance capacity.

4.3 Theme Three: Daily functioning, work, and finances

This theme most directly addresses occupational participation, illustrating how caregiving reorganizes time use across domestic tasks, paid employment, and leisure. The data show a pattern of caregiving-centered routines, where caregivers' productive and restorative occupations are reduced or abandoned.

4.3.1 Sub-theme: Household routines and time use

Caregivers described constant interruptions that prevented organized completion of cooking, bathing, and eating. The participants illustrate how caregiving responsibilities severely disrupt daily routines and household functioning**.** Another participant Rita (mother) said that,

> *"Everything gets disrupted. If I cook, he goes outside and I have to run after him. Then when will I cook, when will I bathe, when will I eat? Everything gets messed up. I have to run after him all the time."*

Abdul Karim (father) said that, "When I go to take a bath, suddenly I hear he has hit someone. Then I have to run there immediately. I can't do any work properly." Lamiya (mother) said that, "My daily routine never stays right. Cooking, bathing, eating everything gets delayed. I cannot do my work on time because most of my time goes behind him." These accounts reflect occupational imbalance, caregiving demands consume time, producing delayed or unfinished household occupations and reducing predictability needed for daily functioning.

4.3.2 Sub-theme: Work and economic consequences

Caregivers reported treatment costs, reduced work capacity, and job insecurity.

Rita (mother) said that, "I had to quit my job because of him. I cannot earn anymore. All work has stopped. If I had a job, I could earn money but now I have

nothing.” Tamanna (mother) stated that, “If I don’t go to work for long, they will remove me. I am the only earner for my children. If I lose my job, I cannot survive.” Here, caregiving creates work–care conflict, worsening psychological stress and limiting occupational choices. In the Bangladeshi context, where families often rely on a single income and informal support systems, job loss can threaten basic security, intensifying role strain.

4.3.3 Sub-theme: Leisure and personal interests

Caregivers described losing leisure, hobbies, and restorative activities key occupations that support mental health and balance.

Tamanna (mother) said that, “I don’t get any leisure time. I am always doing something for him. I stay busy with him every minute.” Lamiya(mother) said that, “Before, I loved singing, cooking, doing creative work. Now I have no time or energy. My mind does not stay well enough to sing anymore.” Shiuli(mother) said that, “I used to enjoy talking, watching TV, praying. But now I don’t feel like doing anything. All my interest is gone.”

This sub-theme illustrates occupational deprivation, where caregivers are structurally blocked from engaging in meaningful leisure due to time pressure and emotional exhaustion.

4.4 Theme Four: Social relationships, identity, and coping resources

This theme addresses how caregiving reshapes social participation and identity. Caregivers described stigma-driven isolation, changes in family roles, and coping strategies that support endurance. Notably, coping often helped caregivers continue rather than meaningfully reduce burden, indicating adaptive but limited resources. Caregivers prioritize caregiving roles over their own needs, resulting in changes to their

sense of self. Although they rely on coping strategies such as acceptance, spirituality, and learned skills, these mainly help them endure caregiving demands rather than reduce the overall burden.

4.4.1 Sub-theme: Social isolation and stigma

Caregivers reported being judged and labeled, leading to withdrawal.

Abdul Karim (father) said that, “Relatives call me ‘the madman’s father.’ They look down on me. I don’t socialize anymore.” Rina Begum (mother) said that, “People say my daughter is mad. It hurts a lot. No one helps, no one communicates with us.” Roma (wife) said that, “People talk harshly. They say I should leave him. I feel small in public, so I avoid going anywhere.”

These experiences highlight how stigma restricts community participation and reduces support, reinforcing emotional distress and limiting caregivers’ occupational roles outside the home.

4.4.2 Sub-theme: Family role changes

Caregivers described role absorption, where identity becomes centered on caregiving at the expense of other roles (parent, spouse, worker). Rahima (Mother) stated that, “My whole life has changed since my child became mentally ill. I cannot maintain the home, cannot rest, and cannot care for myself. I feel like the person I used to be has disappeared.” Roma (wife) said that,

> *“I had to give up caring for my other child because all my time goes to my husband. I do everything for him but no one appreciates it. Their expectations never end, and I feel like I am no longer a mother to my own child.”*

Shiuli (mother) said that, “My entire focus is only on my daughter now. I cannot do any other work in the house. My whole life has changed, and I sometimes feel like I exist only to take care of her.” These accounts demonstrate identity disruption and

role overload, shaped by cultural expectations that women especially mothers and wives provide intensive family care, often silently.

4.4.3 Sub-theme: Coping and resilience

Caregivers described coping through prayer, acceptance, and endurance.

Abdul Karim (Father) said that, “I pray; there is no other way. Only talking to Allah gives me peace. Whenever I feel like breaking down, I remind myself that Allah is watching me.” Tamanna (Mother) stated that, “Even when I feel exhausted, I remind myself that I am the only one my son has. Thinking this way gives me strength to continue.” Rita (Mother) said that, “I have accepted everything. This is my fate. I do not fight with destiny anymore. I just try to stay calm and continue doing what I have to do.”

These coping strategies reflect culturally meaningful resources (faith, destiny, family duty). However, they mainly support emotional regulation and persistence rather than restoring occupational balance or reducing care demands suggesting resilience is present but constrained by structural and social barriers.

CHAPTER V: DISCUSSION

The present qualitative study explored the psychological functioning and occupational participation of caregivers of individuals living with mental illness in Bangladesh. The findings portray caregiving as a complex, demanding occupation that reshapes caregivers' emotional well-being, physical health, daily routines, social relationships, and engagement in meaningful activities. Although these experiences align with existing qualitative literature on caregiver burden, this study extends understanding by highlighting how caregiving is intensified within a low- and middle-income country context, where stigma, limited-service availability, and economic vulnerability reduce support options and restrict participation.

Interpreted through Stress Coping Theory, participants' anxiety, fear, frustration, sadness, and emotional numbing reflect sustained appraisal of threat (e.g., relapse, aggression, uncertainty) alongside constrained coping resources (Lazarus & Folkman, 1984). Similar patterns of psychological distress and unmet support needs are widely reported among family caregivers in mental illness contexts (Chen et al., 2019; Karambelas et al., 2022). The prominent "always on alert" state described by caregivers suggests chronic stress activation; over time, such prolonged strain plausibly contributes to emotional exhaustion and burnout, consistent with reviews of caregiver burden in serious mental illness (Karambelas et al., 2022).

From an occupational therapy perspective, findings are well explained by the Model of Human Occupation (MOHO)**.** Caregiving demands disrupted volition (reduced sense of choice and enjoyment), altered habituation (collapsed routines, role overload), and constrained performance capacity (sleep disruption, fatigue, reduced self-care), collectively diminishing occupational competence and participation

(Kielhofner, 2008). Caregivers' neglect of sleep, rest, and health management mirrors occupational imbalance and occupational deprivation, increasing long-term vulnerability. Empirically, caregiving has been shown to reshape occupational participation and occupational identity, with caregivers often experiencing role absorption and diminished engagement in meaningful occupations (Howes and Ellison, 2021).

Participants also described social isolation, stigma, and altered family roles. These experiences can be interpreted through Occupational Justice, where stigma, gendered expectations, and limited community resources restrict access to valued occupations and participation on equitable terms. Stigma "by association" can amplify self-blame and reduce help-seeking, reinforcing exclusion from work, education, and community life (Ong et al., 2024). In low-resource settings, these structural constraints may intensify occupational disruption and financial strain. Related qualitative work documents economic burden and limited social support as key stressors for caregivers (Chen et al., 2019; Iseselo et al., 2016).

Despite high burden, caregivers demonstrated resilience through acceptance, faith, endurance, and emotional regulation. These strategies align with coping literature indicating that caregivers commonly use emotion-focused and meaning-based coping when stressors are persistent and resources are scarce (Hawken et al., 2018). However, our findings suggest these strategies often supported endurance rather than sustained recovery of occupational balance highlighting a gap between coping and genuine restoration of well-being. Similar qualitative evidence notes that caregivers may rely on religious and acceptance-based coping while still needing structured support (Jamir Singh et al., 2016)

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Strength of the Study

- The qualitative phenomenological approach was appropriate for exploring the lived experiences of family caregivers of individuals with mental illness.
- In-depth, face-to-face semi-structured interviews allowed caregivers to share rich, detailed, and emotional experiences.
- Data were collected from caregivers attending both inpatient and outpatient services at NIMH, which increased variation in participants' caregiving backgrounds.
- The study captured multiple dimensions of caregiver burden, including emotional strain, physical exhaustion, social stigma, financial challenges, and role changes.
- Importantly, the study also identified positive adaptations (resilience, coping, acceptance, and skill-building), offering a balanced understanding rather than a deficit-only account.
- Braun and Clarke's thematic analysis enhanced rigor by identifying clear patterns and themes across the data.
- Ethical procedures such as informed consent, confidentiality, and pseudonyms were strictly maintained, supporting trustworthiness and participant safety.
- Verbatim quotations preserved the accuracy and authenticity of participants' voices and experiences.

- Using an interview guide in Bangla enhanced cultural relevance and helped participants express experiences naturally, supporting context-sensitive interpretation**.**

6.1.2 Limitations of the study

- Participants were recruited from a single mental health institution (NIMH), which may limit the diversity of caregiving contexts represented. This limits insight into caregiving realities in settings where services are unavailable or avoided.
- Due to purposive qualitative sampling, the study findings cannot be generalized to all caregivers of mentally ill individuals in Bangladesh.
- Self-report and emotional sensitivity may have influenced data quality. Some participants may have under-reported stigma, family conflict, or coping difficulties due to fear of judgment or distress, which could result in partial accounts.
- Community-based caregivers who do not visit hospitals were not included, limiting the range of caregiving experiences.
- Time constraints prevented follow-up interviews or participant checking, which might have strengthened the credibility of interpretations.
- As this was the student researcher's first field study, limited experience may have influenced probing depth, handling of sensitive topics, and refinement of themes. This may have affected the richness of some narratives and the analytical complexity of interpretation.
- Translation from Bangla to English may have resulted in subtle loss of meaning despite careful transcription and checking.

- Observational data were limited because the main focus was on interviews, restricting triangulation opportunities.

6.2 Practice Implication

This study highlights the need for mental health professionals, service providers, and policymakers to recognize and address the complex realities faced by family caregivers of individuals with mental illness. Understanding caregivers' emotional, physical, social, and financial challenges is essential to designing effective and culturally relevant support systems.

• Developing caregiver-centered interventions

Based on the findings of this study, mental health services should design targeted interventions such as counseling, stress-management programs, and caregiver support groups. Such structured support can reduce emotional distress, psychoeducation, stress management, enhance coping skills, and improve caregivers' overall well-being. Interventions that acknowledge caregivers' fear, anxiety, sleep disturbance, and role overload can better meet their needs.

• Providing caregiver education and training

Caregivers often struggle due to a lack of knowledge about mental illness, crisis management, medication adherence, and behavioral management. Training programs and educational materials delivered in simple Bangla can equip caregivers with practical strategies for managing aggressive behaviors, maintaining safety, and supporting treatment adherence. This may reduce caregiver burden and improve patient outcomes.

• Strengthening awareness and reducing stigma

Findings revealed widespread stigma, social judgment, and isolation experienced by

caregivers. Mental health campaigns, community workshops, and outreach programs are needed to reduce stigma and enhance public understanding of mental illness and caregiving roles. Reducing social stigma may help caregivers feel more supported and less socially excluded.

• Integrating caregiver needs into mental health policy

Caregivers' emotional strain, financial burden, and lack of formal support highlight the need for policy-level initiatives such as caregiver allowances, respite care services, workplace support policies, and accessible mental health facilities. Policymakers should prioritize caregiver well-being as part of a comprehensive mental health care model.

• Enhancing multidisciplinary collaboration

Healthcare providers including psychiatrists, psychologists, social workers, and nurses should engage family caregivers as partners in care. Strengthening communication and collaborative planning can improve both caregiver confidence and patient outcomes.

6.2.1 Recommendation for Future Practice

- Implement structured support programs for caregivers at mental health institutions, such as psychoeducation sessions, peer support groups, and skill-based training workshops.
- Provide brief counseling and stress-management support, including coping-skills training and referral pathways for caregivers experiencing high distress
- Introduce community level caregiver support services**,** including home-visits, crisis helplines, and respite programs to reduce caregiver overload.
- Run community awareness programs to reduce stigma and normalize mental health help-seeking.
- Strengthen coordination between hospitals and families by ensuring follow-up

counseling, behavioral management guidance, and accessible communication channels.

6.2.2 Recommendation for future research

- Future research should examine caregiving experiences across multiple settings, including community-based caregivers, rural populations, and caregivers not connected to hospital services. This will broaden understanding beyond a single institution.
- Consider longitudinal to explore how caregiver burden and coping change over time.
- Future research will recommend conducting the study with large samples to enhance the transferability of findings across different socioeconomic and cultural groups. As it is an undergraduate research student researcher could not include large sample size because of time limitation.

6.3 Conclusion

This study explored the lived experiences of family caregivers of individuals with mental illness using a qualitative phenomenological approach. The findings revealed that caregivers face significant emotional, physical, social, and financial challenges, including fear, anxiety, frustration, sleep disturbance, role overload, stigma, and economic strain. Despite these burdens, many caregivers demonstrated resilience through coping strategies such as acceptance, prayer, patience, and learning from experience.

The findings suggest that caregiver burden is intensified by interacting conditions: limited structured caregiver support within services, social stigma that isolates families, and resource constraints that increase financial and daily-life disruption.

At the same time, caregivers' resilience expressed through acceptance, prayer, patience, and learning through experience shows that caregiving is not solely a story of suffering but also one of adaptation. These coping patterns are not simply individual traits; they point to opportunities for structured support systems that strengthen what caregivers are already trying to do.

The study highlights the urgent need for caregiver-centered support programs, psychoeducation, counseling services, and stigma reduction initiatives. The results also emphasize the importance of including caregivers' perspectives in mental health policies and service development. Although the study was limited to a small, single-site sample, it provides valuable insights into the realities of caregiving within the Bangladeshi context and guide future research across broader populations.

Overall, the research underscores that family caregivers play a crucial but often overlooked role in mental health care, and supporting their well-being is essential for improving outcomes for both caregivers and individuals with mental illness. If caregivers' physical, emotional, or daily lives are disrupted, patients' quality of life will decrease.

CHAPTER VII: REFERENCE

Amanyire, P., Namagga, J. K., Nambozi, G., Nakanjako, S., Rubega, A., & Maling, S. (2025). Lived experiences of informal caregivers of adolescents with bipolar disorder at Masaka Regional Referral Hospital. *PLOS Mental Health, 2*(7), e0000351. https://doi.org/10.1371/journal.pmen.0000351

American Occupational Therapy Association. (2020). *Occupational therapy practice framework: Domain and process* (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), 7412410010. https://doi.org/10.5014/ajot.2020.74S2001

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Azman, A., Singh, P. S. J., & Sulaiman, J. (2017). Caregiver coping with the mentally ill: A qualitative study. *Journal of Mental Health, 26*(2), 98–103. https://doi.org/10.3109/09638237.2015.1124395

Banerjee, A., & Chaudhury, S. (2010). Statistics without tears: Populations and samples. *Industrial Psychiatry Journal*, *19*(1), 60–65. https://doi.org/10.4103/0972-6748.77642

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. SAGE Publications.

Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., & Lu, X. (2019). The burden, support and needs of primary family caregivers of people experiencing

schizophrenia in Beijing communities: A qualitative study. *BMC Psychiatry, 19*, 75. https://doi.org/10.1186/s12888-019-2052-4

Connors, M. H., Seeher, K., Teixeira-Pinto, A., Woodward, M., & Ames, D. (2020). Dementia caregiver outcomes: The role of sampling and measurement limitations. *International Journal of Geriatric Psychiatry, 35*(8), 870–878. https://doi.org/10.1002/gps.5313

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). SAGE Publications.

Cruz, E., Paré, M. A., Stan, C., Voth, J., Ward, L., & Taboun, M. (2024). Caring for the caregiver: An exploration of the experiences of caregivers of adults with mental illness. *SSM – Qualitative Research in Health, 5*, 100406. https://doi.org/10.1016/j.ssmqr.2024.100406

Family Caregiver Alliance. (2019). *Caregiver statistics: Demographics*. https://www.caregiver.org/resource/caregiver-statistics-demographics/

Galloway, A. (2005). Non-probability sampling. In K. Kempf-Leonard (Ed.), *Encyclopedia of social measurement* (Vol. 2, pp. 859–864). Elsevier.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. SAGE Publications.

Howes, M. L., & Ellison, D. (2021). Understanding the occupational identity of caregivers for people with mental health problems. *British Journal of Occupational Therapy, 84*(4), 274–282. https://doi.org/10.1177/03080226211018153

Iseselo, M. K., Kajula, L., & Yahya-Malima, K. I. (2016). The psychosocial problems of families caring for a relative with mental illness in Tanzania. *BMC Psychiatry, 16*, 146. https://doi.org/10.1186/s12888-016-0857-y

Issac, M. S., Varghese, S., & Thomas, S. P. (2023). Development of qualitative interview guides: Insights from practice. *Journal of Qualitative Research in Health Sciences, 5*(2), 45–52.

Jeyagurunathan, A., Sagayadevan, V., Abdin, E., Zhang, Y., Chang, S., & Shafie, S. (2017). Psychological status and quality of life among primary caregivers of individuals with mental illness: A hospital-based study. *Health and Quality of Life Outcomes, 15*, 106. https://doi.org/10.1186/s12955-017-0676-y

Karambelas, A., Lazarus, A., & Stuart, G. W. (2022). Caregiver burden in severe mental illness: A systematic review. *Archives of Psychiatric Nursing, 36*, 45–54. https://doi.org/10.1016/j.apnu.2021.10.005

Karambelas, G. J., Filia, K., Byrne, L. K., et al. (2022). A systematic review comparing caregiver burden and psychological functioning in caregivers of individuals with schizophrenia spectrum disorders and bipolar disorders. *BMC Psychiatry, 22*, 422. https://doi.org/10.1186/s12888-022-04069-w

Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4th ed.). Lippincott Williams & Wilkins.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.

Liamputtong, P. (2017). *Research methods in health: Foundations for evidence-based practice* (2nd ed.). Oxford University Press.

Liu, Z., Heffernan, C., & Tan, J. (2024). Caregiver burden and mental health outcomes: A systematic review. *BMC Psychiatry, 24*, 210. https://doi.org/10.1186/s12888-024-05678-9

Mandani, B., Ghasemi, E., & Khankeh, H. (2018). Barriers to leisure activities among family caregivers of people with chronic psychiatric disorders. *Electronic Physician, 10*(6), 6516–6524. https://doi.org/10.19082/6516

Ntsayagae, E. I., Poggenpoel, M., & Myburgh, C. P. H. (2019). Experiences of family caregivers of persons living with mental illness: A meta-synthesis. *Curationis, 42*(1), a1900. https://doi.org/10.4102/curationis.v42i1.1900

Ong, W. J., Goh, C. M. J., Tan, G. T. H., Shahwan, S., & Subramaniam, M. (2024). A qualitative enquiry on the impact of mental illness stigma on caregiving role and experiences in Singapore. *Frontiers in Psychiatry, 15*, 1417514. https://doi.org/10.3389/fpsyt.2024.1417514

Pan, Z., Li, T., Jin, G., & Lu, X. (2024). Caregiving experiences of family caregivers of patients with schizophrenia in a community: A qualitative study in Beijing. *BMJ Open, 14*(4), e081364. https://doi.org/10.1136/bmjopen-2023-081364

Rai, N., & Thapa, B. (2015). A study on purposive sampling method in research. *Kathmandu School of Law Review, 3*(1), 1–12.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal. *The Gerontologist, 55*(2), 309–319. https://doi.org/10.1093/geront/gnu177

Speirs, B., Hanstock, T. L., & Kay-Lambkin, F. J. (2023). The lived experience of caring for someone with bipolar disorder: A qualitative study. *PLOS ONE, 18*(1), e0280059. https://doi.org/10.1371/journal.pone.0280059

Tulek, Z., Polat, A., & Tuncay, T. (2020). Caregiver burden and the need for qualitative approaches in mental health caregiving research. *Archives of Psychiatric Nursing, 34*(2), 87–94. https://doi.org/10.1016/j.apnu.2019.12.006

van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). Routledge.

von Kardorff, E., Steinke, I., & Flick, U. (2016). Qualitative research methods in social sciences. In U. Flick (Ed.), *The SAGE handbook of qualitative data analysis* (pp. 69–84). SAGE Publications.

World Health Organization. (2022). *Mental disorders*. https://www.who.int/news-room/fact-sheets/detail/mental-disorders

World Health Organization. (2025). *Mental disorders*. https://www.who.int/news-room/fact-sheets/detail/mental-disorders

Yao, H., Li, K., Li, C., Hu, S., Huang, Z., Chen, J., & Xu, Y. (2024). Caregiving burden, depression, and anxiety in informal caregivers of people with mental illness in China: A cross-sectional survey. *BMC Psychiatry, 24*(1), 824. https://doi.org/10.1186/s12888-024-06239-4

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

APPENDICES

Appendix A: Ethical Approval Form and Permission Letter

Ethical Approval Letter from IRB

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

BANGLADESH HEALTH PROFESSIONS INSTITUTE

Ref: CRP-BHPI/IRB/07/2025/1125 Date: 21.07.2025

To
Jannatul Ferdous Alo
4th Year B.Sc. in Occupational Therapy
Session: 2020-2021 Student ID: **122200457**
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal **Exploring Psychological Functioning and Occupational Participation among Caregivers of Individuals with Mental Illness: A Qualitative Study** by ethics committee.

Dear Jannatul Ferdous Alo,
Congratulations.
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator and Mohuya Akter, Lecturer, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP as thesis supervisor. The Following documents have been reviewed and approved:

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

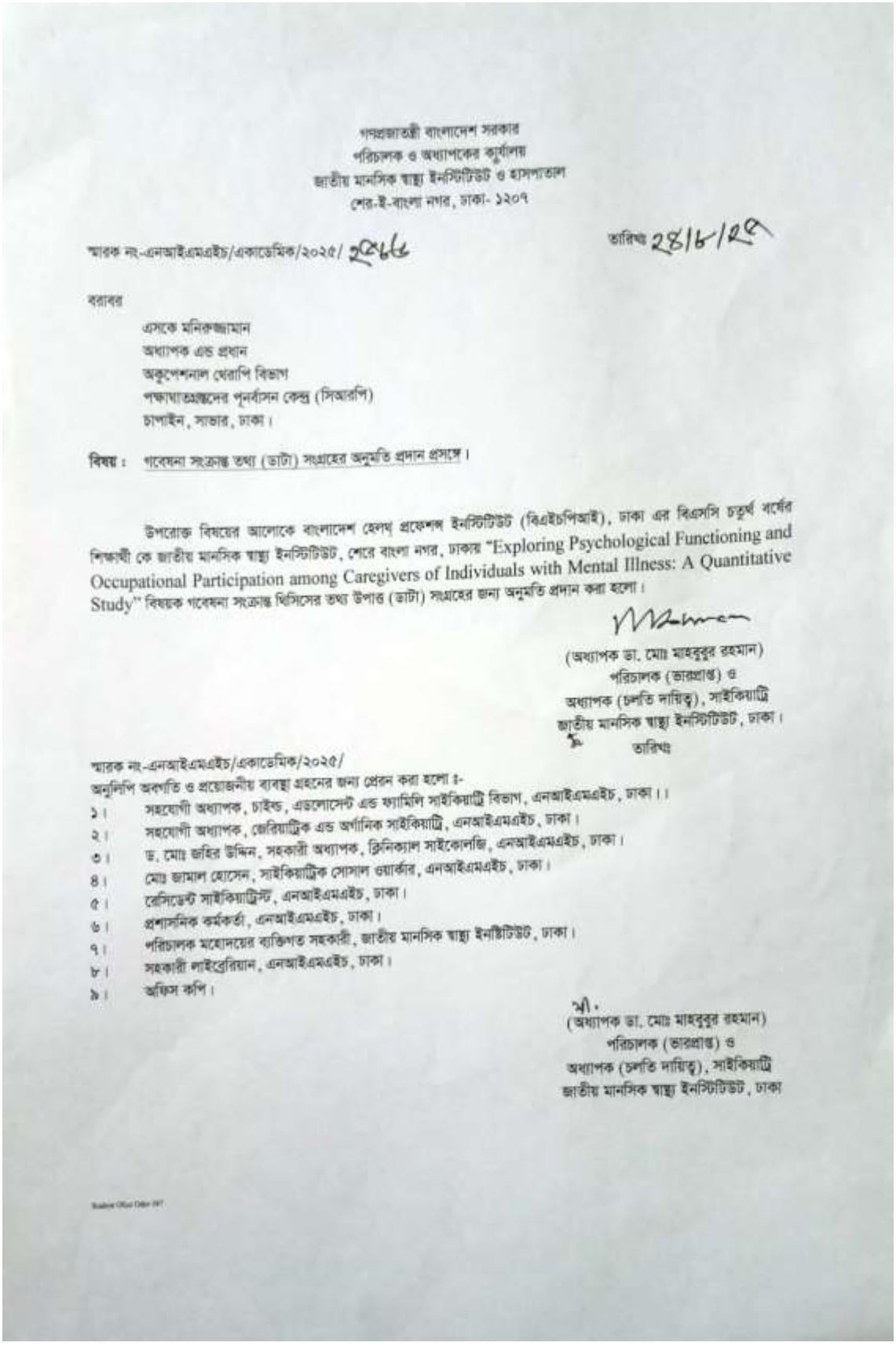
The purpose of the study is to explore how caregiving affects the psychological health and daily occupational engagement (e.g., work, self-care, social roles) of caregivers of individuals with mental illness, through qualitative exploration. The study involves use of a self –developed interview guide to explore how caregiving affects the psychological health and daily occupational engagement (e.g., work, self-care, social roles) of caregivers of individuals with mental illness, through qualitative exploration that may take approximately 60 minutes to answer the Interview Guide and there is no likelihood of any harm to the participants .There is no benefit to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8:30 AM on 17 June, 2025 at BHPI (50th IRB Meeting) .

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

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

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭
CRP-Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd

Permission Letter for data collection from NIMH



গণপ্রজাতন্ত্রী বাংলাদেশ সরকার
পরিচালক ও অধ্যাপকের কার্যালয়
জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট ও হাসপাতাল
শের-ই-বাংলা নগর, ঢাকা- ১২০৭

স্মারক নং-এনআইএমএইচ/একাডেমিক/২০২৫/ ২৫৬৬ তারিখঃ 28/8/25

বরাবর

এসকে মনিরুজ্জামান
অধ্যাপক এন্ড প্রধান
অকুপেশনাল থেরাপি বিভাগ
পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি)
চাপাইন, সাভার, ঢাকা।

বিষয়ঃ গবেষনা সংক্রান্ত তথ্য (ডাটা) সংগ্রহের অনুমতি প্রদান প্রসঙ্গে।

উপরোক্ত বিষয়ের আলোকে বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), ঢাকা এর বিএসসি চতুর্থ বর্ষের শিক্ষার্থী কে জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, শেরে বাংলা নগর, ঢাকায় "Exploring Psychological Functioning and Occupational Participation among Caregivers of Individuals with Mental Illness: A Quantitative Study" বিষয়ক গবেষনা সংক্রান্ত থিসিসের তথ্য উপাত্ত (ডাটা) সংগ্রহের জন্য অনুমতি প্রদান করা হলো।

(অধ্যাপক ডা. মোঃ মাহবুবুর রহমান)
পরিচালক (ভারপ্রাপ্ত) ও
অধ্যাপক (চলতি দায়িত্ব), সাইকিয়াট্রি
জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
তারিখঃ

স্মারক নং-এনআইএমএইচ/একাডেমিক/২০২৫/
অনুলিপি অবগতি ও প্রয়োজনীয় ব্যবস্থা গ্রহনের জন্য প্রেরন করা হলো ঃ-

১। সহযোগী অধ্যাপক, চাইল্ড, এডলোসেন্ট এন্ড ফ্যামিলি সাইকিয়াট্রি বিভাগ, এনআইএমএইচ, ঢাকা।।
২। সহযোগী অধ্যাপক, জেরিয়াট্রিক এন্ড অর্গানিক সাইকিয়াট্রি, এনআইএমএইচ, ঢাকা।
৩। ড. মোঃ জহির উদ্দিন, সহকারী অধ্যাপক, ক্লিনিক্যাল সাইকোলজি, এনআইএমএইচ, ঢাকা।
৪। মোঃ জামাল হোসেন, সাইকিয়াট্রিক সোসাল ওয়ার্কার, এনআইএমএইচ, ঢাকা।
৫। রেসিডেন্ট সাইকিয়াট্রিস্ট, এনআইএমএইচ, ঢাকা।
৬। প্রশাসনিক কর্মকর্তা, এনআইএমএইচ, ঢাকা।
৭। পরিচালক মহোদয়ের ব্যক্তিগত সহকারী, জাতীয় মানসিক স্বাস্থ্য ইনষ্টিটিউট, ঢাকা।
৮। সহকারী লাইব্রেরিয়ান, এনআইএমএইচ, ঢাকা।
৯। অফিস কপি।

(অধ্যাপক ডা. মোঃ মাহবুবুর রহমান)
পরিচালক (ভারপ্রাপ্ত) ও
অধ্যাপক (চলতি দায়িত্ব), সাইকিয়াট্রি
জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা

Appendix B: Information Sheet & Consent Form

Information Sheet (English Version)

Information Sheet (English Version)

I am Jannatul Ferdous Alo, a 4th year student of B.Sc. in Occupational Therapy Department at Bangladesh Health Professions Institute (BHPI) the educational institution of Centre for the Rehabilitation of the Paralyzed (CRP).

To fulfill the requirements of the course, I must conduct research as a part of the 4th year course curriculum. This research is about "Exploring Psychological Functioning and Occupational Participation Among Caregivers of Individuals with Mental Illness in Bangladesh: A Qualitative Study". The purpose of this study to explore the psychological functioning and occupational participation of caregivers of individuals with mental illness and how caregiver influences their daily occupations and engagement.

I would like to invite you to participate in this research, your valuable participation will strengthen my research. Your participation in this research is voluntary. You are free to not participate at all or withdraw from the research any of the time. All the details of the research are given on this sheet. After reading this if you want to know more about something, you are welcomed to ask a question.

Neither any gift/reward nor money is not given to you for your participation in this research. The confidentiality of your given information will be highly maintained.

Where to contact to know about this research?

If you have any question/enquiry or any objection and if you want to know the result of the research, you can contact the researcher:

Jannatul Ferdous Alo

4th year, B.Sc. in Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka: 1343

Email: jannatulferdousalo307@gmail.com

Phone no:01784007843

Mohuya Akter

Lecturer in Occupational Therapy Department

Bangladesh Health Professions Institute (BHPI)

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka: 134

Email: mohuya15_ot@yahoo.com

Information Sheet (Bangla Version)
তথ্যপত্র

আমি জান্নাতুল ফেরদৌস আলো, বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি)-এর শিক্ষা প্রতিষ্ঠান – এর অকুপেশনাল থেরাপি বিভাগের তৃতীয় বর্ষের একজন শিক্ষার্থী।শিক্ষাক্রমের অংশ হিসেবে, চতুর্থ বর্ষের পাঠ্যসূচি পূরণের জন্য আমাকে একটি গবেষণা পরিচালনা করতে হচ্ছে। আমার গবেষণার শিরোনাম হলো: **বাংলাদেশে মানসিক রোগে আক্রান্ত ব্যক্তিদের সেবাদানকারীদের মানসিক কার্যকারিতা এবং পেশাগত অংশগ্রহণ অন্বেষণ: একটি গুণগত গবেষণা**

এই গবেষণার উদ্দেশ্য হলো: মানসিক রোগে আক্রান্ত ব্যক্তিদের সেবাদানকারীদের মানসিক অবস্থা ও পেশাগত অংশগ্রহণ কেমন, এবং সেবাদানের অভিজ্ঞতা কীভাবে তাদের দৈনন্দিন কাজ ও সম্পৃক্ততাকে প্রভাবিত করে—তা অনুসন্ধান করাআমি আপনাকে এই গবেষণায় অংশগ্রহণের জন্য আন্তরিকভাবে আমন্ত্রণ জানাচ্ছি। আপনার মূল্যবান অংশগ্রহণ আমার গবেষণাকে সমৃদ্ধ করবে।এই গবেষণায় অংশগ্রহণ সম্পূর্ণ স্বেচ্ছাসেবামূলক। আপনি চাইলে অংশগ্রহণ না করতেও পারেন কিংবা যে কোনো সময় গবেষণা থেকে নিজেকে প্রত্যাহার করে নিতে পারেন। গবেষণা সংক্রান্ত সকল তথ্য এই পৃষ্ঠায় প্রদান করা হয়েছে। এটি পড়ে যদি আপনার কোনো প্রশ্ন থাকে বা কোনো বিষয়ে আরও জানতে চান, তাহলে আপনি প্রশ্ন করতে পারেন।এই গবেষণায় অংশগ্রহণের জন্য আপনাকে কোনো উপহার/পুরস্কার বা অর্থ দেওয়া হবে না। আপনার প্রদত্ত সকল তথ্য কঠোরভাবে গোপন রাখা হবে।

গবেষণা সম্পর্কে জানতে কোথায় যোগাযোগ করবেন?

যদি আপনার কোনো প্রশ্ন, অনুসন্ধান বা আপত্তি থাকে অথবা আপনি গবেষণার ফলাফল জানতে চান, তাহলে আপনি গবেষকের সঙ্গে যোগাযোগ করতে পারেন:

গবেষক:

জান্নাতুল ফেরদৌস আলো

বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সেশন: ২০২০–২১

রোল নম্বর: ৪৭

সিআরপি, সাভার, ঢাকা-১৩৪৩

ইমেইল: jannatulferdousalo307@gmail.com

ফোন নম্বর: ০১৭৮৪০০৭৮৪৩

তত্ত্বাবধায়ক

মহুয়া আক্তার

প্রভাষক, অকুপেশনাল থেরাপি

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)

সিআরপি, সাভার, ঢাকা।

Consent form (English version)

(English Version)

Research Title: Exploring Psychological Functioning and Occupational Participation among Caregivers of Individuals with Mental Illness: A Qualitative Study

Student investigator: Jannatul Ferdous Alo

I have been asked to take part in the research of Bangladesh Health Professions Institute (BHPI). I have been asked to read the information sheet and hereby I consent to participate in this project.

Consent of the following	Yes	No
Participating in one semi-structured in-depth interview		
Audio recording of interview		
Being able to participate in the future research related to this research		

Name of participant:

Signature of participant/

Thumb print:

Date:

Consent form (Bangla version)

সম্মতিপত্র

(বাংলা সংস্করণ)

গবেষণার শিরোনাম:

বাংলাদেশে মানসিক রোগে আক্রান্ত ব্যক্তিদের সেবাদানকারীদের মানসিক কার্যকারিতা এবং পেশাগত অংশগ্রহণ অন্বেষণ: একটি গুণগত গবেষণা

গবেষক শিক্ষার্থী: জান্নাতুল ফেরদৌস আলো

আমাকে বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (BHPI)-এর একটি গবেষণায় অংশগ্রহণের জন্য অনুরোধ করা হয়েছে। আমি তথ্যপত্রটি পড়েছি এবং স্বেচ্ছায় এই গবেষণায় অংশগ্রহণে সম্মতি প্রদান করছি।

নিম্নলিখিত বিষয়ে সম্মতি	**হ্যাঁ**	**না**
একটি আধা-সংগঠিত গভীর সাক্ষাৎকারে অংশগ্রহণ	☐	☐
সাক্ষাৎকারটি অডিও রেকর্ড করার অনুমতি	☐	☐
ভবিষ্যতে এই গবেষণার সাথে সম্পর্কিত অন্য কোনো গবেষণায় অংশগ্রহণের অনুমতি	☐	☐

অংশগ্রহণকারীর নাম: _____

অংশগ্রহণকারীর স্বাক্ষর / আঙুলের ছাপ: _____

তারিখ: _____

Withdrawal form (English Version)

Withdrawal form

Research Title: Exploring Psychological Functioning and Occupational Participation among Caregivers of Individuals with Mental Illness: A Qualitative Study.

Researcher's Name: Jannatul Ferdous Alo ,4th year, Occupational Therapy. I, ...(Participant's Name) wish to withdraw from participating myself as a participant in this study.

Reason for withdrawing: .....

Name of the participant: ..... Date: .....

Signature of the participant: ..... Date: .....

Name of the researcher: ..... Date: .....

Withdrawal form (Bangla Version)

অংশগ্রহণ প্রত্যাহার ফর্ম

গবেষণার শিরোনাম: মানসিক রোগে আক্রান্ত ব্যক্তিদের যত্নকারীদের মনস্তাত্ত্বিক কার্যকারিতা ও পেশাগত অংশগ্রহণ অনুসন্ধান: একটি গুণগত গবেষণা

গবেষকের নাম:

জান্নাতুল ফেরদৌস আলো

৪র্থ বর্ষ, অকুপেশনাল থেরাপি

আমি, ... (অংশগ্রহণকারীর নাম), এই গবেষণায় একজন অংশগ্রহণকারী হিসেবে আমার অংশগ্রহণ প্রত্যাহার করতে ইচ্ছুক।

অংশগ্রহণ প্রত্যাহারের কারণ:

অংশগ্রহণকারীর নাম:

অংশগ্রহণকারীর স্বাক্ষর:

তারিখ:

গবেষকের নাম:

তারিখ:

Appendix C: Questionnaire

Sociodemographic Questionnaire (English)

1. Age: _____
2. Gender: ☐ Male ☐ Female ☐ Other
3. Education Level:

   ☐ No formal education ☐ Primary ☐ Secondary ☐ Higher Secondary ☐ Graduate and above
4. Occupation: _____
5. Relationship to the patient:

   ☐ Parent ☐ Spouse ☐ Sibling ☐ Child ☐ Other: _____
6. Duration of caregiving: _____(in months/years)
7. Living arrangement with the patient:

   ☐ Yes ☐ No
8. Monthly household income:_____(in BDT)
9. Area of residence:

   ☐ Urban ☐ Semi-urban ☐ Rural
10. Patient's diagnosis:

Sociodemographic Questionnaire (Bangla)

সামাজিক ও জনসংখ্যাতাত্ত্বিক প্রশ্নমালা (Bangla)

১. বয়স: _____

২. লিঙ্গ: ☐ পুরুষ ☐ নারী ☐ অন্যান্য

৩. শিক্ষাগত যোগ্যতা:

☐ কোনো শিক্ষা নেই ☐ প্রাথমিক ☐ মাধ্যমিক ☐ উচ্চমাধ্যমিক ☐ স্নাতক ও এর উপরে

৪. পেশা: _____

৫. রোগীর সঙ্গে সম্পর্ক:

☐ পিতা/মাতা ☐ জীবনসঙ্গী ☐ ভাই/বোন ☐ সন্তান ☐ অন্যান্য: _____

৬. যত্ন নেওয়ার সময়কাল: _____ (মাস/বছর)

৭. রোগীর সঙ্গে বসবাস করেন কি?

☐ হ্যাঁ ☐ না

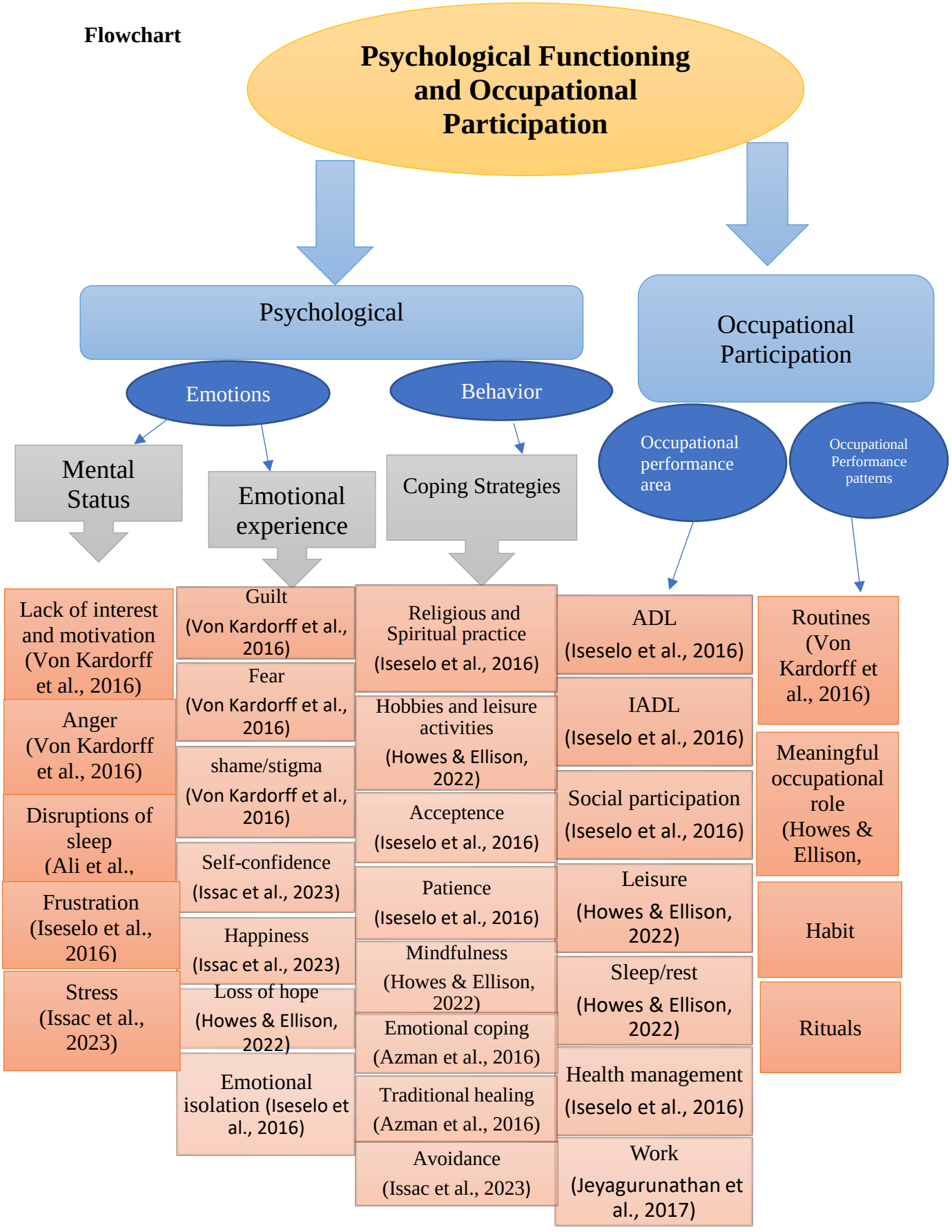
৮. মাসিক পারিবারিক আয়: _____ (BDT)

৯. বসবাসের স্থান:

☐ শহর ☐ আধা শহর ☐ গ্রাম

১০. রোগীর রোগ নির্ণয় : _____

Flowchart


Psychological Functioning and Occupational Participation
Psychological
Occupational Participation
Emotions
Behavior
Occupational performance area
Occupational Performance patterns
Mental Status
Emotional experience
Coping Strategies
Lack of interest and motivation (Von Kardorff et al., 2016)
Anger (Von Kardorff et al., 2016)
Disruptions of sleep (Ali et al.,
Frustration (Iseselo et al., 2016)
Stress (Issac et al., 2023)
Guilt (Von Kardorff et al., 2016)
Fear (Von Kardorff et al., 2016)
shame/stigma (Von Kardorff et al., 2016)
Self-confidence (Issac et al., 2023)
Happiness (Issac et al., 2023)
Loss of hope (Howes & Ellison, 2022)
Emotional isolation (Iseselo et al., 2016)
Religious and Spiritual practice (Iseselo et al., 2016)
Hobbies and leisure activities (Howes & Ellison, 2022)
Acceptence (Iseselo et al., 2016)
Patience (Iseselo et al., 2016)
Mindfulness (Howes & Ellison, 2022)
Emotional coping (Azman et al., 2016)
Traditional healing (Azman et al., 2016)
Avoidance (Issac et al., 2023)
ADL (Iseselo et al., 2016)
IADL (Iseselo et al., 2016)
Social participation (Iseselo et al., 2016)
Leisure (Howes & Ellison, 2022)
Sleep/rest (Howes & Ellison, 2022)
Health management (Iseselo et al., 2016)
Work (Jeyagurunathan et al., 2017)
Routines (Von Kardorff et al., 2016)
Meaningful occupational role (Howes & Ellison,
Habit
Rituals

Interview Questions (English)

Objective	Questions
Warm up questions	**1. Can you tell me a little about yourself (e.g., age, family, occupation)?**
Objective-1: To explore the psychological and emotional experiences of caregivers in relation to their caregiving. Mental status: • Lack of interest and motivation • Anger • Disruptions of sleep • Frustration • Stress Emotional experience: • Guilt • Fear • shame/stigma • Self confidence • Happiness • Loss of hope • Emotional isolation	**2.Can you describe how your caregiving experience affects your mental state?** • How have your day-to-day feelings or energy levels changed since you started caregiving? **3.What is the experience of caring for your mentally ill relative?** • Can you give an example of a situation that deeply affected your emotions? • Can you describe any positive and negative feelings while caregiving?
Objective-2: To understand how caregiving influences caregivers' participation in occupation and meaningful occupational roles. Occupations: • ADL (e.g: eating, bathing, dressing, toileting, Transferring, continence) • IADL (e.g: Preparing meals, managing finance, shopping, housekeeping, managing medication, caring for others)	**4.How has caregiving influenced your daily life and routines?** • What changes (if any) have occurred in your usual activities, like self-care? • Are there any tasks you do more, less, or differently now and explain these? **5.Can you describe how caregiving has impacted your ability to handle household tasks or responsibilities?**

• Social participation • Leisure • Sleep/rest • Health management • Work Performance patterns: • Routines • Habit • Rituals • Meaningful occupational role	• Have you reduced or stopped any tasks/responsibilities or doing extra task/responsibilities because of caregiving, explain these? **6.How has caregiving affected your involvement in social relationships or community activities?** • Can you describe any changes in the way you connect with friends, relatives, or neighbors? • Do you feel more connected or isolated from your social circle since you became a caregiver and how? **7.How do you currently spend your leisure time, and has that changed since you became a caregiver?** • Are there any enjoyable or relaxing activities you engage in more or less now, explain these? • Have you discovered any new hobbies or interests through caregiving if yes, explain these? **8.How has caregiving influenced your ability to take care of your own health/ well-being and personal needs?** • How has caregiving affected your attention to your own health? • How do you usually manage rest and sleep while caring for your relative? **9.Can you describe how caregiving affects your participation in work or productivity related activities?** • In what ways have your work hours or responsibilities been influenced by your caregiving tasks? **10. Can you describe how your caregiving experience has affected your life roles and**

	sense of meaning? • Have there been any positive, negative, or meaningful outcomes from this experience for you in life roles (like parent, worker, or family/community member) explain these? **11.Since you started caregiving, have there been any changes in your daily routine, habits, or personal rituals? Can you tell me about these?** • How do these changes or new experiences influence your everyday life and the way you manage your time?
Objective-3: To identify perceived challenges coping strategies and adaptation in everyday occupational routines. • Religious and Spiritual practice • Hobbies and leisure activities • Acceptance • Patience • Mindfulness • Emotional coping • Traditional healing • Avoidance	**12. How do you experience challenges in your daily life while caring for your mentally ill relative?** • Can you describe a situation in your daily life that feels particularly difficult or overwhelming? **13.What coping strategies or adaptations have you developed to manage these challenges in your everyday life?** • Can you share any methods, routines, or techniques you use for coping or make your tasks easier?
Closing Questions/Ended questions:	**14.How did you feel talking about your experiences today?** • Did this conversation remind you of anything significant?

Interview Questions (Bangla version)

১)আপনার সম্পর্কে একটু বলবেন? (যেমন: বয়স, পারিবারিক অবস্থা, পেশা ইত্যাদি)

২)মানসিক ভাবে অসুস্থ আত্মীয়ের যত্ন নেওয়ার অভিজ্ঞতা কীভাবে আপনার মানসিক অবস্থাকে প্রভাবিত করেছে?

*যত্ন নেওয়া শুরু করার পর আপনার দৈনন্দিন অনুভূতি বা মনের অবস্থায় কী ধরনের পরিবর্তন এসেছে?

৩)মানসিকভাবে অসুস্থ একজন আত্মীয়ের যত্ন নেওয়ার অভিজ্ঞতা আপনার কাছে কেমন ছিল?

* আপনার আবেগকে গভীরভাবে প্রভাবিত করেছে এমন কোনো ঘটনার উদাহরণ দিতে পারবেন?

*যত্ন নেওয়ার সময়ে ইতিবাচক ও নেতিবাচক-উভয় ধরনের অভিজ্ঞতার কিছু উদাহরণ দিতে পারবেন কি?

৪)মানসিক ভাবে অসুস্থ আত্মীয়ের যত্ন নেওয়া আপনার দৈনন্দিন জীবনকে কীভাবে প্রভাবিত করেছে?

*আপনার স্বাভাবিক কাজকর্মে (যেমন নিজের যত্ন নেওয়া) কী ধরনের পরিবর্তন এনেছে?

*এমন কোনো কাজ আছে কি যা আপনি কম, বেশি, বা ভিন্নভাবে করছেন? এ বিষয়ে উদাহরণ দিয়ে একটু বলবেন?

৫)যত্ন নেওয়া আপনার গৃহস্থালির কাজ বা পারিবারিক দায়িত্ব পালনে কীভাবে প্রভাব ফেলেছে?

*যত্ন নেওয়ার কারণে আপনি কি কোনো দায়িত্ব কমিয়েছেন বা ছেড়েছেন, অথবা অতিরিক্ত দায়িত্ব নিতে হয়েছে? এ বিষয়ে একটু বলবেন?

৬) মানসিক ভাবে অসুস্থ আত্মীয়ের যত্ন নেওয়া আপনার সামাজিক সম্পর্কে বা কমিউনিটি কার্যক্রমে অংশগ্রহণে কীভাবে প্রভাব ফেলেছে?

*বন্ধু, আত্মীয় বা প্রতিবেশীর সঙ্গে আপনার সম্পর্ক বা যোগাযোগে কী ধরনের পরিবর্তন এসেছে ?

*যত্ন নেওয়া শুরু করার পর আপনি কি সামাজিকভাবে বেশি সংযুক্ত নাকি কিছুটা বিচ্ছিন্ন বা একা বোধ করেছেন এবং কেন ?

৭)বর্তমানে আপনি অবসর সময় কীভাবে কাটান এবং একজন পরিচর্যাকারী হওয়ার পরে সেই সময় কী কী পরিবর্তন এসেছে ?

*এমন কোনো আনন্দদায়ক বা আরামদায়ক কাজ আছে কি, যা আপনি বেশি বা কম করেন বা ছেড়ে দিয়েছেন? এ বিষয়ে একটু বলবেন?

*যত্ন নেওয়ার মাধ্যমে কি আপনার কোনো নতুন শখ বা আগ্রহ তৈরি হয়েছে ? এ বিষয়ে একটু বলুন।

৮)যত্ন নেওয়া কীভাবে আপনার নিজের মানসিক স্বাস্থ্য /সুস্থতায় এবং ব্যক্তিগত প্রয়োজন পূরণে প্রভাব ফেলেছে?

*যত্ন নেওয়ার কারণে নিজের স্বাস্থ্যের প্রতি মনোযোগ কীভাবে পরিবর্তিত হয়েছে?

*এই সময় আপনি সাধারণত বিশ্রাম ও ঘুম কীভাবে পরিচালনা করেন?

৯)মানসিক ভাবে অসুস্থ আত্মীয়ের যত্ন নেওয়া কীভাবে আপনার কাজ বা উৎপাদনশীলতা সম্পর্কিত বিষয়ে প্রভাব ফেলেছে?

*কর্মক্ষেত্র বা দায়িত্ব পালনে যত্ন নেওয়া/পরিচর্চা কিভাবে প্রভাব ফেলেছে?

১০)যত্ন নেওয়ার অভিজ্ঞতা কীভাবে আপনার বিভিন্ন ভূমিকা (যেমন: পিতা/মাতা, কর্মী, পরিবারের সদস্য, কমিউনিটির অংশ) ও জীবনধারণে প্রভাব ফেলেছে?

*এই অভিজ্ঞতা আপনার জীবনের কোন কোন ক্ষেত্রে ইতিবাচক, নেতিবাচক বা অর্থপূর্ণ প্রভাব ফেলেছে? সেটি ব্যাখ্যা করুন।

১১) মানসিক ভাবে অসুস্থ আত্মীয়ের যত্ন নেওয়া শুরু করার পর, আপনার দৈনন্দিন রুটিন, অভ্যাস বা ব্যক্তিগত নিয়মে কোনো পরিবর্তন এসেছে কি?এগুলো সম্পর্কে একটু বলবেন?

*এই পরিবর্তনগুলো আপনার প্রতিদিনের জীবন বা সময় ব্যবস্থাপনাকে কীভাবে প্রভাবিত করেছে?

১২) মানসিকভাবে অসুস্থ আত্মীয়ের যত্ন নিতে গিয়ে আপনি দৈনন্দিন জীবনে কী ধরনের চ্যালেঞ্জের মুখোমুখি হন?

*এমন কোনো ঘটনার কথা বলবেন কি যা আপনাকে বিশেষভাবে কষ্ট দিয়েছে বা চাপে ফেলেছে?

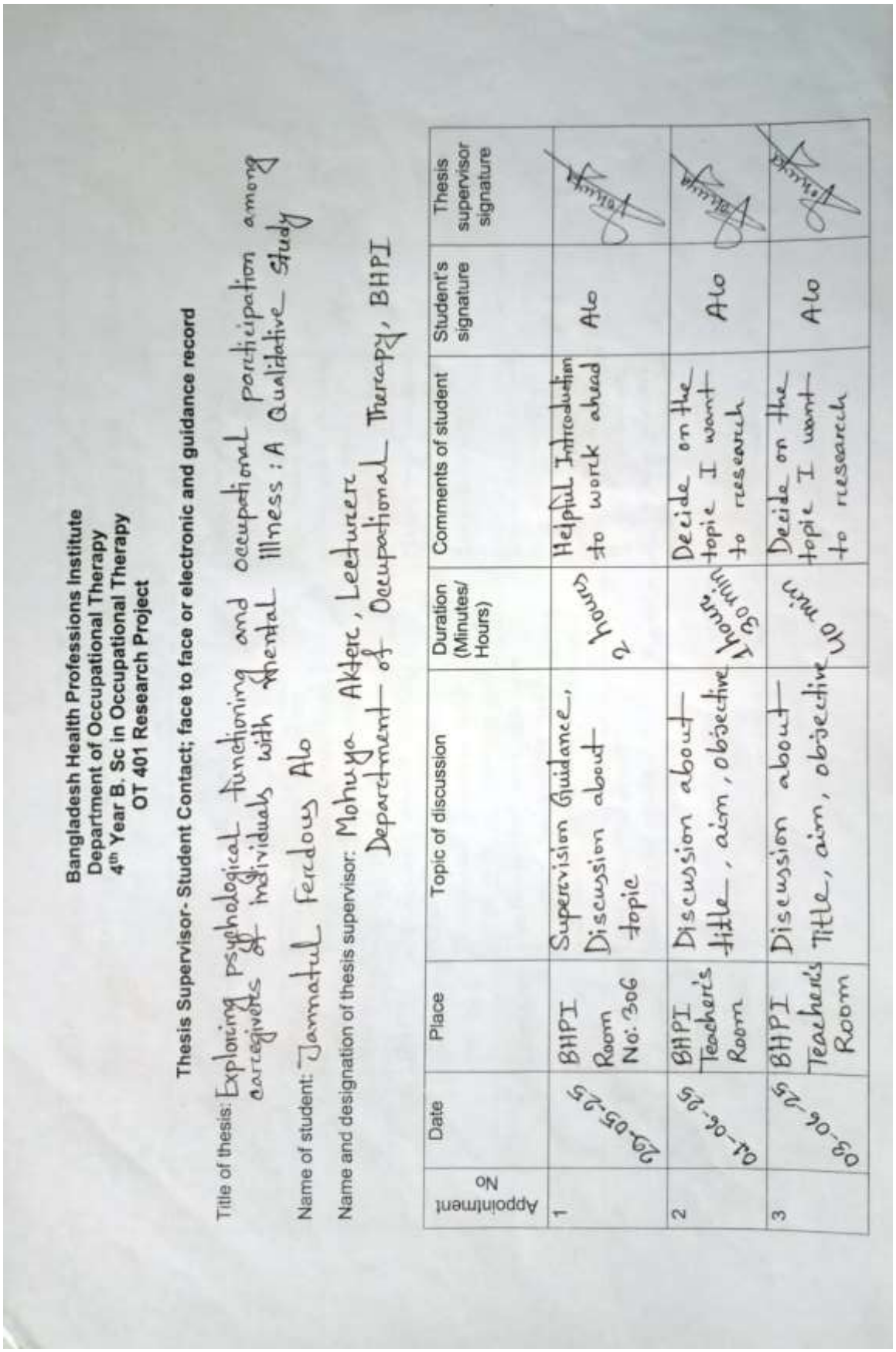
১৩)এসব চ্যালেঞ্জ মোকাবেলায় আপনি কী ধরনের কৌশল বা মানসিক সহায়তার পদ্ধতি ব্যবহার করেন?

*এমন কোনো নির্দিষ্ট নিয়ম, পদ্ধতি বা কৌশল আছে কি, যা আপনার কাজকে সহজ করে বা চাপ কমায়?

১৪)আজ আপনার অভিজ্ঞতা নিয়ে কথা বলার সময় কেমন লাগল?

*এই আলোচনার মাধ্যমে আপনি কি এমন কিছু ভেবেছেন বা শিখেছেন যা আপনার কাছে বিশেষভাবে গুরুত্বপূর্ণ?

Appendix D: Thesis Supervisor-Student Contact



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

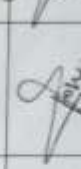
Thesis Supervisor- Student Contact; face to face or electronic and guidance record

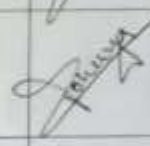
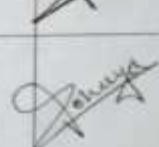
Title of thesis: Exploring psychological functioning and occupational participation among caregivers of individuals with Mental illness : A Qualitative Study

Name of student: Jannatul Ferdous Alo

Name and designation of thesis supervisor: Mohuya Akter, Leecturer Department of Occupational Therapy, BHPI

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	05-05-25	BHPI Room No: 306	Supervision Guidance, Discussion about topic	2 hours	Helpful Introduction to work ahead	Alo	
2	10-06-25	BHPI Teachers Room	Discussion about title, aim, objective	1 hour 30 min	Decide on the topic I want to research	Alo	
3	05-06-25	BHPI Teachers Room	Discussion about Title, aim, objective	1 hour	Decide on the topic I want to research	Alo	

4	05-06-25	BHPI Teacher's Room	Discussion about Method, Approach title	30 min	fixed the title and method	Alo	
5	16-06-25	BHPI Teacher's Room	Feedback on IRB Presenation and correction	45 min	I can understand the mistake	Alo	
6	23-06-25	BHPI Teachers room	New supervision plan that includes critical reading, Lab meetings and individual supervision.	45 mins	This new plan enhanced our critical thinking and collaboration among peers.	Alo	
7	17-07-25	BHPI Classroom no. 306	Discussion about COREQ reporting guideline, literature review and framework of Interview guide	1 hour 30 min	Clear my confusion and go forward structurally	Alo	
8	20-07-25	Library	Presentation and discussion on the interview guide and other progress (Jemmi)	2:30 min	I am familiar with the new method of peer discussion That was active an active participation and collaboration	Alo	
9	23-07-25	Teacher's Room	Discussion about interview guide	30 min	I got guidance about my interview guideline, framework	Alo	
10	28-07-25	Teacher's Room	Discussion about flowchart and question	30 min	Understand about flowchart	Alo	

11	25-08-25	BHPI Waiting Room	Discussion about flowchart and question	30 min	I could understand the lacking of my flowchart	Alo	
12	31-08-25	Teacher's Room	Discussion about flowchart	45 min	I can understanding about my flowchart	Alo	
13	03-09-25	Teacher's Room	Feedback on the flowchart and interview guildline	20 min	Clear about my doubt about flowchart	Alo	
14	04-09-25	Teacher's Room	Correction in flowchart and questionnaire	3 hours 45 min	Correction of questionnaire for data collection	Alo	

15	29-11-25	BHPI Teacher's room	Discussion and feedback on report writting & result	60 min	It's help to organize the result.	Alo	
16	09-12-25	BHPI Teacher's room & Library	Discussion and feedback on codes, quotes, theme and sub theme and works on it	5hours 30 min	It's help me to Reorganize my data analysis and refine the theme and sybtheme	Alo	
17	10-12-25	BHPI Teacher's room & Library	Feedback on result writing and work for result writing	2hours 30 min	I can understand the gap and find the propere guildline for result writing.	Alo	
18	03-01-26	Library Room No. 4	Feedback on first draft correction and peer review on referencing	8 hours	I get the valuable information on citation, front size, referencing	Alo	
19	11-01-26	BHPI Teacher's room	Feedback on first draft from back-ground to conclusion.	3 hours	Valuable instruction for correcting the thesis.	Alo	
20	13-01-26	Library	Work on feedback to the part of result	5 hours	Help to reccorrect the result	Alo	
21							