Lived Experience of the Family Members of Person with Mental Illness: A Qualitative Phenomenological Study

By
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Statement of Authorship

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

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Dedication

Dedicated to My Precious Family

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List of Abbreviations

BMD	Bipolar Mood Disorder
IPA	Interpretative Phenomenological Approach
IRB	Institutional Review Board
NGO	Non Governmental Organisation
NIMH	National Institute of Mental Health
OCD	Obsessive Compulsive Disorder
PWMI	Person with Mental Illness
PTSD	Post-traumatic Stress Disorder
SMI	Severe Mental Illness
WHO	World Health Organisation
COREQ	Consolidated Criteria for Reporting Qualitative Research

Abstract

Background: It is well recognized that mental illness is a significant health issue in Bangladesh. Family members often play a critical role in managing people with mental illness. By understanding family members' contextualized perspectives, needs, and coping strategies, mental health providers can develop more effective strategies for engaging and collaborating with families. Several studies have examined the lived experiences of family members living with mental illness worldwide. To date, there has not been any related literature available, in particular, in the context of Bangladesh.

Aim: The study aimed to explore and describe the lived experience of the first-degree family members of a person with mental illness.

Method: This exploratory study used descriptive qualitative methodology and an interpretive phenomenological approach. Participants were recruited through the registry of the National Institute of Mental Health. Eight participants were selected purposively and interviewed face-to-face using a semi-structured interview guide. The interview guide had two parts: demographics and open-ended inquiry with probing questions. The participants chose the interview site according to their preferences. All interviews were conducted for 30–60 minutes. Descriptive notes were taken during interview. Data collection continued until saturation. A reflective journal was maintained from the beginning of the study. The interviews were audio-recorded as first-person narratives in Bangla, then transcribed and translated into English. Braun and Clark's six-step thematic analysis framework was used to identify, analyze, and present the data. Member checking was ensured to improve trustworthiness.

Result: Seven over-reaching themes were found that summarize the lived experiences of family members: "Initial Consequences", "Interpersonal Relationship", "Social Response", "Financial Condition", "Coping Strategy", "Increased Resiliency" and "Daily Life Experience". Subthemes were also identified with the varied responses and experiences of family members.

Conclusion: The study examined these family members' contextualized perspectives, needs, and coping methods using qualitative techniques and interpretive phenomenology. The identified themes show the initial effects of mental illness, family relationships, societal responses, financial difficulties, coping strategies, increased resiliency, and the impact on daily life. These findings demonstrate the complexity of family experiences and the necessity for comprehensive support systems.

Keyword: Mental Illness, Coping Strategies, Resiliency, Positive Experiences, Daily Life Experience, Family Relationship

CHAPTER I: INTRODUCTION

1.1 Background

The issue of mental illness is a significant and challenging subject both globally and within the context of Bangladesh. According to estimates, a staggering 450 million individuals across the globe are currently experiencing the effects of mental illness. The figures above denote 121 million individuals affected by depression, 24 million individuals diagnosed with schizophrenia, and 37 million with dementia. According to the World Health Organisation (WHO), in 2011, mental illness constituted 12.3% of the worldwide disease burden in 2001. Furthermore, it is projected that depressive disorders will rank as the second most prevalent cause of disability by 2020.

Family members play a crucial role in providing care, rehabilitation, and treatment for individuals with mental illness who are part of their family (Chadda, 2014; Kusumawaty et al., 2021). The provision of ongoing care by a family member is a challenging and demanding task, despite the familial relationship (Chadda, 2014). The presence of an individual with mental illness within a family unit has a significant impact, resulting in a notable reduction in overall quality of life (Behere et al., 2017; Phillips et al., 2022; Robinson et al., 2008; Subu et al., 2021). Individuals with a family member with a mental illness may experience negative impacts on their self-esteem, social relationships, and employment opportunities (Eckardt, 2021; Kamal, 2014; Nenobais et al., 2019; Ntsayagae et al., 2013). They may often exhibit reluctance to acknowledge the presence of mental illness (Vermeulen et al., 2015). The experience of being raised within a family unit can present challenges. Nonetheless, atypical challenges may arise in cases where one or more members of a

family have a mental disorder. The family members of PWMI experience prolonged and distressing life events that significantly affect their capacity to engage in and manage various life roles, including those related to work, family, and social interactions (Nenobais et al., 2019; Ntsayagae et al., 2013; Shimange et al., 2022; Vermeulen et al., 2015).

Individuals belonging to these familial units frequently encounter circumstances characterized by a lack of stability or predictability. Frequently, there is difficulty regarding the allocation of responsibilities within families. In certain circumstances, offspring or other kin may be required to assume many duties typically fulfilled by their progenitors, including but not limited to tending to younger siblings or managing domestic tasks (Wipt & George, 2008). They might be responsible for attending to their parent's emotional or physical requirements. In such circumstances, providing adequate care and education to children and other family members may only sometimes be ensured (Wipt & George, 2008).

Furthermore, individuals who have family members with mental illness may experience a sense of shame when discussing their condition with others, leading them to distance themselves from loved ones or acquaintances who could offer support or solace. Individuals may encounter challenges in identifying and articulating their own needs, both internally and externally. Consequently, individuals experiencing such circumstances encounter seclusion and solitude (Mccowan, 2022). Numerous studies from various nations demonstrate the stigma, discrimination, and other difficulties faced by families of people with mental illness. According to a United Kingdom study, family members who experienced rejection felt grief, frustration, and embarrassment. The lack of diversity in family relationships with

relatives, the limited blame and avoidance of racism by others, and the limited voice gaps of men (father, son, and brother) are all research findings (Karnieli-Miller et al., 2013). According to data from numerous developing countries, many people with mental illnesses live with family members who serve as their primary carers (WHO, 2011). Due to the growing severity of poverty, this load is anticipated to be greater in low-income nations. As a result of having to provide care for a family member with a person with mental illness, family members suffer psychologically and socially (Shimange et al., 2022). In a different study from Ghana, prejudice was only evident at the economic and social levels, while other forms of discrimination were seen at the psychological and social levels (Tawiah et al., 2015). Families could be required to take on the carer job for a member with a mental illness. Many families were hesitant or unwilling to accept this role, as in Malaysia. Families are expected to care for a family member with a mental illness. Still, they appear to encounter several difficulties, including a lack of knowledge and expertise (Monyaluoe et al. 2014)

Family members must learn how to control the mental illness patient's shifting skills. Conditions in the physical, psychological, social, and environmental realms jeopardise the health, wellness, and well-being of people and communities everywhere. The lived experience study will allow people to look at their families and develop an understanding supporting more significant participation in carer education. Understanding the care provider's perspective facilitates the development of effective and efficient techniques to strengthen the therapeutic alliance, resulting in a stronger and more reliable bond between the therapist, the client, and the client's family (Kamal, 2014; Kusumawaty et al., 2021; Phillips et al., 2022; Shamsaei et al., 2015;).

Without knowing specifics about the lived experience of having a family member with mental illness, it will be impossible to provide a suitable treatment setting; nonetheless, there is a shortage of contextual research on this topic (Phillips et al., 2022; Shamsaei et al., 2015; Shimange et al., 2022; Vermeulen et al., 2015).

In general, there hasn't been much qualitative research to explore family members' lived experiences, particularly in the context of Bangladesh, regarding their knowledge of mental illness, care giving abilities, and stress-reduction strategies related to people's physical and emotional changes with mental illnesses. The study aimed to understand better how family members of people with mental illnesses experience their lives. This information will aid in the development of an intervention for effective mental health practice that is evidence-based and identifies the needs of family carers. The family member mental health assistance programme will be more sensitive to cultural differences and aggressively acknowledge the numerous problems frail family systems face.

1.2 Justification of the Study

Researching the lived experience of family members of individuals with mental illness holds significant importance in Bangladesh for multiple reasons.

To begin with, mental illness poses a substantial public health concern in Bangladesh, given the considerable prevalence of mental health disorders among its populace. As per the report by the World Health Organisation, mental disorders contribute to 12% of the overall disease burden in Bangladesh. Additionally, the nation has one of the highest suicide rates globally. Notwithstanding, mental health care provisions in Bangladesh are constrained, a shortage of mental health practitioners exists, especially

in remote regions. Investigating family members' encounters can facilitate identifying obstacles and difficulties in obtaining mental health care and support services. This can further aid in creating interventions that enhance the quality of care and accessibility to such services.

Furthermore, mental health conditions are frequently subjected to social stigmatization in Bangladesh, resulting in marginalization, prejudicial treatment, and limited availability of healthcare services. The insights gained from the experiences of family members of individuals with mental illness can be of great value in understanding the impact of stigma on both individuals and families. Such insights can also be utilized to develop effective strategies to reduce stigma and enhance mental health literacy within the community.

Moreover, the involvement of family members is of utmost importance in providing care and support to individuals with mental illness in Bangladesh. In numerous instances, familial individuals serve as the principal caretakers and may encounter substantial obstacles and psychological strain when caring for their beloved ones. The investigation of the personal encounters of family members can facilitate the identification of caregivers' necessities and viewpoints and contribute to the creation of interventions that mitigate caregiver strain and enhance mental health outcomes for both the mentally ill individual and their family members.

Furthermore, scholarly investigation into the encounters of family members can contribute to the formulation of mental health care frameworks that give precedence to the requirements and outlooks of family members. This may encompass tactics for effectively involving and cooperating with families in providing care for their relatives alongside measures that target the psychological anguish and caregiver strain

family members' encounter.

Researching the lived experiences of family members can contribute to developing mental health policies and practices in Bangladesh. The inclusion of viewpoints and personal encounters of family members can aid policymakers and mental health practitioners in devising policies and programmes that are more efficient and adaptable, catering to the requirements of individuals and families impacted by mental illness.

1.3 Operational Definition

1.3.1 Lived Experience

The term "lived experience" refers to the direct knowledge and comprehension of the world an individual has acquired through personal encounters. The term pertains to compiling an individual's experiences, viewpoints, and insights constituting their distinct approach to understanding and engaging with their surroundings (Kamal, 2014; Shimange et al., 2022).

The term "lived experience" can refer to diverse personal encounters, such as one's cultural heritage, familial upbringing, educational background, social interactions, relationships, occupational experiences, health status, and other related factors. In general, the concept of lived experience acknowledges the significance of personal accounts and the unique viewpoint of individuals in shaping their understanding of the world. It emphasises the importance of attentively considering and gaining knowledge from diverse perspectives (Kamal, 2014; Shimange et al., 2022).

1.3.2 First-Degree Relative

Family Members include a person's parents, siblings, and children because they are the individual's nearest blood relatives. They are considered "first-degree" relatives due to the fact that they share approximately half of their genetic material with the individual under investigation (Ntsayagae et al., 2013).

Family member of person with mental illness refers to parents, siblings and offspring of the with mental illness person suffers from psychosis type of a disorder in mental health (Sapp, 2022).

1.3.3 The Person with Mental Illness (PWMI)

"The person with mental illness" is a way of describing an individual who has been diagnosed with a mental health condition or illness. This term emphasizes the personhood of the individual and acknowledges that mental illness is just one aspect of their identity, rather than defining them as a whole. (Ntsayagae et al., 2013; Robinson et al., 2008; Shimange et al., 2022; Vermeulen et al., 2015).

1.4 Study Question and Aim, Objectives

1.4.1 Overarching Research Question

How was the lived experience of the family members of a person with mental illness?

1.4.2 Aim

To explore and describe the lived experience of the first-degree family members of a person with mental illness

1.4.3 Objectives

a) To know about the family member's thoughts about mental illness.

b) To investigate the way they dealt with themselves during the period of onset of mental illness.

c) To explore their family support system during the time.

d) To capture the challenges and positive aspects of being a family member of a person with mental illness.

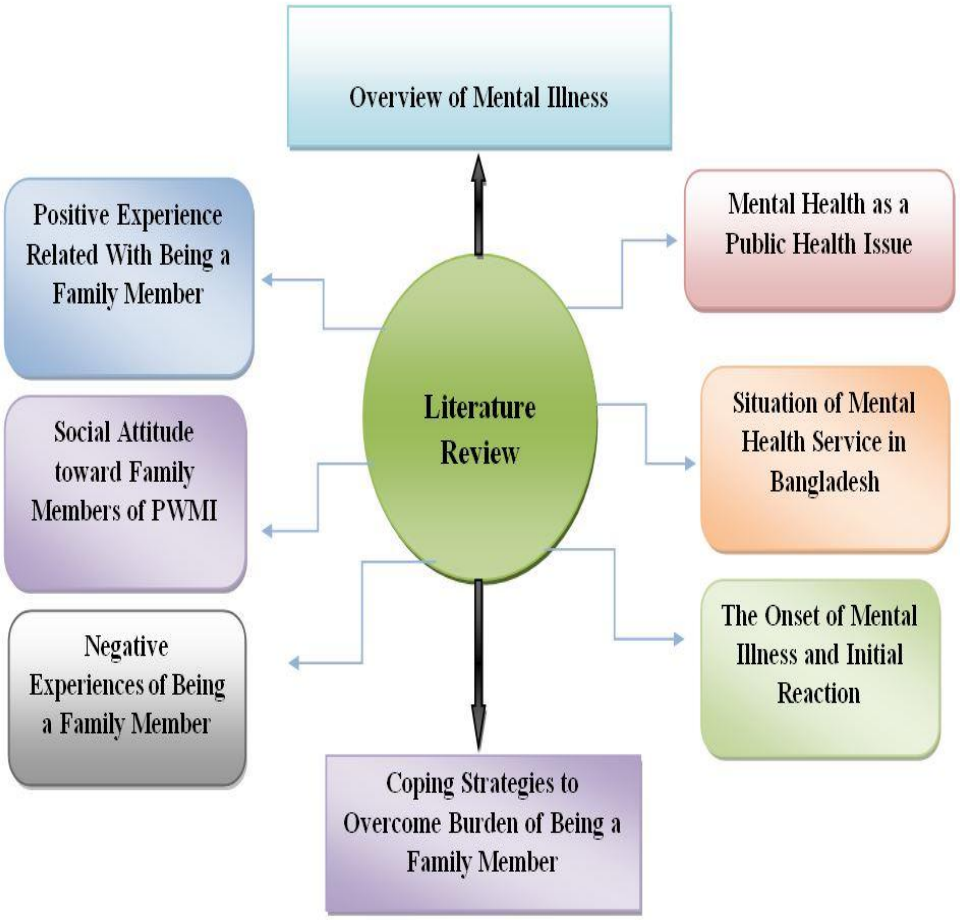
e) To explore the manner of coping with the challenges.

CHAPTER II: LITERATURE REVIEW

In the chapter on literature review, through some findings demonstrated about the life experience of the family members of a person with mental illness. There is little literature in Bangladesh about family members' experiences of a person with mental illness. Little is known about the topic from Bangladesh's perspective. Other countries like the United Kingdom, China, Netherlands, etc., have many kinds of literature and in-depth information about the experience of a family member of a person with mental illness.

Figure 2.1

Literature Review Framework



2.1 Overview of Mental Illness

Mental illness encompasses a spectrum of disorders that impact an individual's cognitive, affective, and behavioral capabilities, as well as their overall level of functioning. The spectrum of mental illnesses encompasses a broad range of severity levels, which can substantially influence an individual's overall well-being, social connections, and capacity to carry out routine activities (World Health Organization (WHO), 2017).

Prevalent mental illnesses encompass depression, anxiety disorders, bipolar disorder, schizophrenia, personality disorders, eating disorders, and post-traumatic stress disorder (PTSD). Distinctive symptoms are associated with each mental illness. However, some shared symptoms include alterations in mood, impaired concentration, modifications in behavior or social seclusion, and physical manifestations such as exhaustion, migraines, or sleep patterns (World Health Organization (WHO), 2017).

The etiology of mental illness can be attributed to a multi-factorial interplay of genetic, environmental, and lifestyle determinants. Individuals with a familial predisposition to mental illness or who have been exposed to traumatic or stressful experiences are at an elevated risk for developing mental illness. Moreover, the abuse of substances and other physical health issues may serve as contributing factors to the onset of mental illness. Men who have been exposed to trauma tend to report more traumatic incidents on average than women (Breslau, 2002).

The negative societal attitudes and beliefs towards mental illness can pose significant obstacles for individuals in accessing and obtaining adequate mental healthcare

services. Individuals who have mental illness may experience feelings of shame or embarrassment regarding their condition, resulting in social isolation and a reluctance to pursue treatment. The act of seeking assistance for mental illness is crucial in enhancing symptoms and overall quality of life (Subu et al., 2021)

The therapeutic interventions for mental illness encompass pharmacotherapy, occupational therapy, psychotherapy, and modifications in lifestyle choices such as physical activity, nutrition, and stress coping mechanisms. The primary objective of treatment is to assist individuals in effectively coping with their symptoms, enhancing their general level of functioning and quality of life, and averting subsequent occurrences of mental illness (Walsh, 2011).

To conclude, mental illness is a prevalent and substantial health concern that can profoundly influence an individual's well-being. Obtaining assistance and proper medical care is crucial for managing symptoms and enhancing the quality of life. Family members' involvement in providing support and care for individuals with mental illness is crucial. However, it is imperative to prioritise these family members' mental and emotional well-being by adopting effective coping strategies and seeking appropriate support when necessary. Enhancing access to treatment and mitigating the stigma associated with mental illness can facilitate improved outcomes for individuals with mental illness and their families (Kusumawaty et al., 2021; Monyaluoe et al., 2014; Ntsayagae et al., 2013; Phillips et al., 2022).

2.2 Mental Illness as a Public Health Issues

The public's mental health awareness has grown over the past several years. The World Health Organization (WHO) describes mental health as "a state of well-being

in which the individual realizes his or her abilities, can cope with the normal stresses of life, can work productively and fruitfully, and can contribute to his or her community." As a result, a mental disorder is any ailment that makes it difficult for a person to handle everyday stresses or a mental or social imbalance.

According to Tawiah et al. (2015) stigma and prejudice towards those who have mental illness are spreading worldwide. Worldwide, 450 million people had mental health issues in 2001, according to the World Health Organization (World Health Organization, 2001). The cumulative lifetime prevalence of common mental illnesses in individuals aged 16 to 65 is estimated to be 29.2%, according to a meta-analysis of mental health surveys conducted in 59 countries between 1980 and 2013 (Leng et al., 2018). According to a national study conducted in 2003–2005, 16.1% of Bangladesh's adult population had a mental disorder (National mental health survey of Bangladesh, 2018–19). At least 160 million years of healthy living are lost yearly due to mental diseases, of which 30% might be prevented using already available therapies (Tawiah et al., 2015).

2.3 Situation of Mental Health Service in Bangladesh

The prevalence of mental health disorders in Bangladesh is a matter of great concern, as approximately 20% of the population is estimated to encounter such conditions at some point. Despite the notable incidence rate, the mental healthcare system in Bangladesh is encountering several obstacles, such as limited resources, insufficient infrastructure, and societal discrimination against individuals with mental health disorders. Nonetheless, there have been favourable advancements in recent times, characterised by endeavours to enhance mental health services and diminish the negative perception surrounding them through awareness campaigns and community

outreach programmes. The Bangladesh government's current mental health spending accounts for 0.44% of the total health care budget. Less than 0.11% of the population has access to free essential psychotropic drugs (Hasan et al., 2021).

In Bangladesh, mental health services are impacted by a lack of trained specialists, poor coordination and collaboration between professionals, patients, and their families, few resources, and high social stigma (Islam & Biswas, 2015).

The lack of skilled mental health professionals in Bangladesh is a significant issue. Mental health services are inaccessible due to a shortage of psychiatrists and clinical psychologists. Rural residents lack access to mental health services due to their concentration in cities. Mental health specialists are few due to low financing for education and training (Hasan et al., 2021).

Lack of coordination and collaboration within mental health system sectors is another major challenge in Bangladesh. Private companies and NGOs help the government provide mental health treatments. However, coordination between these varied sectors creates a disorganised and unproductive structure (Islam & Biswas, 2015).

In Bangladesh, mental health services lack infrastructure and funding. Many mental health facilities lack psychiatric beds and crucial supplies. The lack of psychiatric drugs, which are expensive and not covered by insurance, makes treatment unaffordable for many, especially people experiencing poverty (Alam et al., 2021).

Social stigma is society's disapproval of those who break from cultural norms. Mental health services are hindered by social stigma and discrimination. Mental illness is blamed on supernatural forces or human frailty in Bangladesh. Thus, mental health patients may face social stigma. Stigma can delay medical treatment and reduce social

support, worsening isolation and illness (Hasan et al., 2021; Islam & Biswas, 2015).

However, the National Mental Health Policy, mental health institutes, NGOs, and private organisations promoting mental health services are beneficial achievements.The National Mental Health Policy describes national mental health strategies. It guides mental health programme development and implementation to improve individual and community mental health. The strategy encourages mental health stakeholders to collaborate and coordinate using evidence-based research and best practices. It prioritises mental health over physical health and ensures prompt and adequate care and support for mental health patients. In 2006, the Bangladeshi government created a National Mental Health Policy. The policy emphasises community-based mental health services, primary healthcare integration, and stigma and discrimination reduction ("Bangladesh WHO Special Initiative for Mental Health Situational Assessment," 2020).

The National Institute of Mental Health (NIMH) was established in 2013 founding improved Bangladesh's mental health infrastructure. The institute provides mental health care, research, and practitioner training. Awareness programmes and community engagement programmes help the centre reduce mental illness stigma.NGOs and private organisations operate outside government control. NGOs and private organizations improve mental health in Bangladesh. Friendship NGO conducts rural mobile mental health clinics, while Basic Needs provides community-based mental health help. These organisations provide affordable and accessible mental health services to those who cannot afford them (Islam & Biswas, 2015).

In recent times, there has been a notable increase in efforts to advocate for mental health rights in Bangladesh. These efforts have been focused on raising awareness

about the crucial role that mental health plays in promoting the overall well-being of both individuals and communities. The recognition of mental health rights as a fundamental human right is currently gaining momentum. Advocacy efforts have led to increased financial allocations for mental health services and improved availability of care (Alam et al., 2021).

2.4 The Onset of Mental Illness and Initial Reactions

The beginning of a mental illness can be difficult for the affected person and their family. In order to get through this trying time, family members may go through a range of emotions and narratives as they try to understand and accept the signs of mental illness. It's essential to comprehend and address these narratives in order to offer the impacted person the best support system available (Phillips et al., 2022;Shimange et al., 2022).

Denial is one of the most frequent emotional reactions that family members may go through. Particularly if the symptoms are not visible or if there is a lack of knowledge about mental illness in the family, family members may find it difficult to acknowledge that their loved one is dealing with a mental health condition. This denial may be very intense in societies where mental illness is stigmatised and taboo (Monyaluoe et al., 2014).

Guilt is another typical emotion encountered. Family members may feel responsible for their loved one's mental illness and question what they could have done to stop it. The guilt may be very severe if the family member has a history of mental illness or feels that they might have genetically transmitted it to their loved one (Karnieli-Miller et al., 2013).

Another frequent occurrence that family members could encounter is fear. Fear can appear in various ways, such as worrying about the safety of a loved one, pondering how the mental illness will affect a loved one's future, or feeling overburdened by the responsibilities of caring for a person with a mental illness (Chadda, 2014; Robinson et al., 2008).

Another typical reaction is anger. Family members could feel angry or dissatisfied with the circumstance or their loved one for delaying obtaining assistance. They might be upset with society or the mental health system for not offering enough assistance and resources (Wankiiri et al., 2013). As family members learn more about mental illness and the available therapies, they respond positively with hope and empathy. Family members can begin to feel hopeful about their loved one's future and hopeful that they can assist them in navigating the difficulties of mental illness with knowledge and support. Family members may begin to better comprehend their loved one's situation as they begin to put themselves in their place. They can offer more effective and sympathetic support as a result. Finally, as a family works together to support a member, a story of resilience may develop. Despite the difficulties associated with mental illness, family members can grow stronger and more resilient as they figure out how to deal with the situation and help their loved ones (Kusumawaty et al., 2021).

2.5 Negative Experiences of Being a Family Member

Living with an individual with a mental illness can present a demanding and burdening experience. Mental illness has the potential to impact various domains of an individual's life, encompassing their affective state, conduct, and capacity to perform activities. The illness of a loved one can pose challenges for family members,

resulting in various difficulties that may affect the entire family system (Wankiiri et al., 2013).

One of the main difficulties associated with cohabiting with an individual with a mental illness is the erratic nature of their conduct. Individuals with mental illness may experience mood swings, agitation, and erratic behavior, which can pose difficulties in maintaining a stable and consistent living environment. Relatives may experience persistent unease, uncertain of their kin's conduct, resulting in elevated levels of tension and apprehension (Dalky, 2012).

An additional obstacle pertains to the influence on familial relationships. The presence of mental illness has the potential to exert pressure on interpersonal relationships, resulting in discord and stress among kin. The illness of a loved one can elicit feelings of helplessness and distress among family members, potentially resulting in emotions of guilt, hatred, and exasperation. Furthermore, the provision of care for individuals with mental illness can be a demanding and fatiguing task, resulting in sentiments of burnout and weariness among kin (Corrigan et al., 2006).

The co-occurrence of mental illness in a household can potentially give rise to financial difficulties. The presence of mental illness can pose difficulties for individuals in their efforts to sustain employment or engage in educational pursuits, resulting in financial burdens for their families. Furthermore, the expenses associated with medical treatment and medication can be substantial, resulting in further economic strain on the household (Wankiiri et al., 2013).

Social isolation can be a potential difficulty when cohabiting with an individual with a mental illness. The experience of isolation and stigmatisation may be encountered by

family members, potentially resulting in shame and embarrassment. Individuals with mental illness may encounter difficulties engaging in group activities or sustaining social relationships, resulting in restricted social involvement (Subu et al., 2021; Vermeulen et al., 2015).

Ultimately, navigating the mental healthcare system can pose a considerable obstacle for individuals closely related to the patient. The mental healthcare system is often intricate and challenging to navigate, resulting in frustration and confusion for relatives endeavoring to secure treatment for their beloved. Furthermore, obtaining suitable medical intervention and attention can be difficult, especially in regions with limited resources (Sanden et al., 2015).

Living with an individual with a mental illness can present difficulties and induce stress. The challenges associated with caring for an individual with mental illness can be attributed to various factors, including the unpredictability of their behavior, the impact on family dynamics, financial constraints, social isolation, and the complexities of navigating the mental healthcare system. Acknowledging the challenges associated with mental illness and seeking assistance from healthcare providers, community resources, and support groups is crucial in effectively managing the impact of mental illness on the family unit. Collaborative efforts and seeking assistance can enable families to secure adequate care and support for their beloved ones while preserving their welfare (Kusumawaty et al., 2021)

2.6 Positive Experiences Related With Being a Family Member

Coping with a family member who has a mental illness can present a set of difficulties. However, it can also offer a multitude of rewards. As a member of a

family unit, one may encounter a multitude of difficulties and hindrances, such as the complexities of navigating the mental health system, effectively managing challenging behaviors, and confronting the negative societal attitudes towards mental illness. Despite these obstacles, there are also numerous affirmative encounters that may ensue from being a relative of an individual with mental illness. One of the foremost favorable encounters is offering assistance and nurturing to a beloved individual. This may encompass rendering emotional support, aiding in everyday tasks, and advocating for their requisites (Karnieli-Miller et al., 2013).

Caring for a family member with a mental illness has the potential to facilitate personal growth and development. One has the potential to acquire novel proficiencies and approaches towards proficient communication, resolving challenges, and managing stress. The acquisition of these competencies has the potential to be transferable to various domains of existence, thereby improving one's overall state of being and capacity to adapt to adversity (Monyaluoe et al., 2014).

Apart from individual development, providing care for individuals with mental illness can also result in a favorable influence on the community. In the capacity of a familial relation, one may advocate for promoting mental health awareness, education, and access to resources. Through sharing personal experiences, it is possible to mitigate the negative connotations often attached to mental illness, while simultaneously promoting greater comprehension and compassion (Wankiiri et al., 2013).Another positive experience of being a family member of a person with mental illness is witnessing their resilience and strength. Despite their challenges, mentally ill individuals can demonstrate incredible courage and determination. Seeing this can inspire and uplift family members and provide hope and motivation during difficult

times. Recognizing these positive experiences and seeking support and resources to help manage the challenges that may arise is essential. This can include seeking professional help, joining a support group, or finding other ways to care for their well-being (Chadda, 2014)

2.7 Social Attitude toward Family Members of PWMI

Mental illness is stigmatized worldwide. According to Sartorius and Schulze (2005) mental health research, stigma can hinder daily life and lead to adverse effects if not addressed. Mental illness stigma has been documented in numerous studies. Stigmatizing mental illness can harm family members, according to research. Schizophrenia, mood problems, and obsessive compulsive disorder OCD were most associated with familial stigma. The parent's disease determines family stigma. However, several factors, including the family member's role and personal experience, contribute to discriminatory behavior. Families with Severe Mental Illness (SMI) reported being accused, excluded, or disparaged (Dalky, 2012).

A lack of social support from friends during a vital time intensified the psychological load of coping with a family member's diagnosis. Karnieli-Miller et al. (2013) found that some families felt angry and unfairly blamed for some events. A recent study found that cohabiting with a mentally ill family member produces various societal reactions. One respondent said society lacks empathy for mental illness households. Mentally sick families were unappreciated by the community. Discrimination was another response. The family understood that others shun, avoid, or reject families, dwellings, and resources related to the mentally ill family member. Mental illness produces misconceptions in society. Family members believed mental illness was contagious and caused by supernatural forces like demons and witchcraft. This study

also revealed that by not taking proper medication for depression female carers experience financial hardship, social isolation, and the strain of giving care (Wankiiri et al., 2013).

According to Plessis et al. (2021), family members said mental illness remains stigmatized due to a lack of family and community understanding. In another study, stigma affected family members as well as PWMI patients. The authors note that their community often simplifies mental illness, including PWMI and their families.Community members also discriminated against PWMI and their families. Blaming, criticism, and denial can have detrimental effects. Several studies have found that many family members have complained about professional neglect and treatment exclusion. Specialists have denied them treatment (Sanden et al., 2015; Sartorius & Schulze, 2005).

2.8 Coping Strategies to Overcome Burden of Being a Family Member

According to a study conducted in Ghana, most mental health patients (88%) reported utilizing social strategies as their primary coping mechanism. The factors above encompass assistance from one's partner and relatives (23%), religious practices (21%), assertiveness and response (14%), abstention from matrimony (13%), and miscellaneous factors (16%). The economic strategy comprises a mere 7%, while the psychological strategy accounts for 5%. Other studies have reported on the various coping strategies employed by families of individuals with mental illnesses. The most commonly reported behaviors were concealment of the illness, silence, abandonment, isolation, and social avoidance or secrecy (Tawiah et al., 2015).

Furthermore, the study revealed the presence of constructive coping mechanisms.

Caring involves a collaborative and adaptable dynamic among family members, their ailing loved ones, and the healthcare provider. The provision of spiritual assistance through the utilization of traditional or religious healers, prayer, acceptance of the situation, and receiving support from family members were also identified (Dalky, 2012).

Living with a family member with a mental illness can be difficult and negatively affect one's mental and emotional health. Feelings of anxiety, stress, guilt, and isolation may negatively impact a family member's general quality of life. Coping mechanisms are crucial for dealing with these difficulties and preserving one's mental and emotional well-being. The results show that carers experience bad quality of life in a variety of areas, including role-physical, role-emotional, and mental health. This is relevant to family members of persons with mental illness. Additionally, caregivers assessed their own levels of prior support as being low and their number of support-seeking actions as being low. The findings also indicate that carers who get supportive coworkers, friends, neighbors, and family members enjoy a higher quality of life. Different facets of social support have varying relationships with both mental and physical well-being (Leng et al., 2018).

2.9 Key Gap of the Evidence

The study focuses on examining stigma experienced by family members of individuals with mental illness across ten literary works, with particular emphasis on five of these works. An additional five individuals have focused on exploring their lived experiences and assessing their overall quality of life.

- ✓ The main time frame of the research publication spans from 2006 to 2021. As of 2021, only a few researches have been identified for review. There has been a shortage of published research in recent times.
- ✓ Lack of research conducting in broader community. Most of the research conducts in hospital setting with small sample size.
- ✓ Several studies have been conducted in South Africa, the United States, China, Jordan, Malaysia, the Netherlands, and Ghana. However, there is a lack of research conducted in South Asia and specifically in Bangladesh on this topic.
- ✓ Most studies have not addressed the family members' educational attainment, employment status, and economic circumstances.
- ✓ Certain studies have neglected significant factors such as coping mechanisms and the individual's physical and psychological state.

The research suggests that further investigation is required in this particular field. Exploring the life experiences of family members of PWMI is a crucial undertaking.

CHAPTER III: METHODS

3.1 Study Design

3.1.1 Study Method

The study employed a qualitative methodology. Qualitative research provides insight into individuals' perceptions and interpretations of the world. This study aims to provide a detailed account of the participants' lived experiences of cohabiting with individuals with mental health issues. Qualitative research is a methodology that entails gathering and examining non-numerical data to comprehend concepts, opinions, or experiences. This approach can facilitate a comprehensive understanding of a given issue or stimulate novel avenues for scholarly investigation.

3.1.2 Study Approach

The study approach is Interpretative Phenomenological Approach (IPA). The Interpretative Phenomenological Approach is commonly employed in research endeavours that seek to comprehend intricate, unclear, and emotionally charged phenomena experienced by participants. The utilisation of a qualitative methodology can facilitate an understanding of the cognitive and affective processes involved in the formation of thoughts, emotions, and memories, as well as how individuals derive meaning from their lived experiences of a specific life event (Larkin & Thompson, 2011).

The study design was structured by the theoretical framework of Interpretative Phenomenological Analysis (IPA) in three discernible manners. The primary objective of IPA research is to gain insight into the personal experiences of

individuals from a novel standpoint, as opposed to elucidating such experiences through preconceived theoretical constructs (Alase, 2017; Clarke, 2009; Larkin & Thompson, 2011; Noon, 2018; Smith & Osborn, 2015). Secondly, the utilisation of IPA enables researchers to analyse and comprehend the outcomes derived from the data provided by the participants. Finally, this methodology was deemed most appropriate for the present investigation as it allows the researcher to scrutinise and comprehend the intricate nuances of the participants' experiences, thereby identifying overarching themes. The utilisation of IPA is prevalent in occupational therapy literature as it aids in attaining a comprehensive comprehension of the client and care provider's experience, thereby facilitating the provision of more holistic care (Clarke, 2009).

3.2 Study Setting and Period

The National Institute of Mental Health (NIMH) served as the principal source of participants for the study. The National Institute of Mental Health is a primary governmental organisation committed to addressing mental health concerns through the development of mental health policies, research initiatives, and the provision of training opportunities for mental health practitioners.

The study period was April 2022 to February 2023 and the period of data collection spanned from November 2022 to December 2022.

3.3 Study Participants

3.3.1 Study Population

The study's population consisted of first-degree relatives of individuals with mental

illness. The immediate family members of an individual may include their parents, siblings, or children. Furthermore, it is pertinent to identify the individuals who satisfy the established inclusion and exclusion criteria.

3.3.2 Sampling Techniques

Purposive sampling will be utilised to select participants from a defined population. The selection of participants is based on specific inclusion and exclusion criteria. Purposive sampling is the deliberate and intentional selection of individuals who can provide insight into a particular theme, concept, or phenomenon (Robinson, 2014). The purposive sampling technique is a non-probability sampling approach that involves the researcher making decisions regarding selecting individuals to be included in the sample. These decisions are based on various criteria, such as the researcher's specialist knowledge of the research issue or the individual's willingness and ability to participate (Rai & Thapa, 2015). By utilising Purposive sampling, the student researcher was able to collect qualitative responses, resulting in more precise research outcomes.

3.3.3 Inclusion Criteria

- The person who was 1st-degree relative of a person with mental illness(currently in treatment)
- Age between 18 years and 65 years
- Live in a household where only one family member has a psychosis type of mental illness.
- Have no history of mental illness themselves

3.3.4 Exclusion Criteria

- Family member with a chronic physical illness.
- Have speaking difficulty and language problems.

3.3.5 Sample Size

Eight family members participated in this study. The saturation of the data determined the sample size.Throughout the study, the researchers compared new data with previously collected data to identify any emerging information or recurring findings. This iterative process allowed them to gauge if additional data contributed new insights or if it repeated existing information. The data collection and analysis continued until a point was reached where no new or relevant information emerged from the analysis. At this stage, the researchers concluded that data saturation had been achieved. This ensured that the research findings were comprehensive, reliable, and representative of the participants' experiences, as the researchers had thoroughly explored and captured the relevant aspects of the lived experiences of family members of individuals with mental illness.

3.3.6 Participants Overview

Eight participants are included in this study. The participants have no history of mental illness. Six participants were female; two participants were male.

Table 3.1

Participants' Overview

Pseudo Name of Participants	Age	Sex	Condition of PWMI	Relation with PWMI	Occupation of Family Members	Marital Status
Sophia	30	Female	Schizophrenia	Mother	Housewife	Married
Rifat	60	Male	Schizophrenia	Father	Job holder	Married
Boby	40	Female	Schizophrenia	Mother	Housewife	Married
Jerin	40	Female	BMD	Mother	Housewife	Married
Rihana	40	Female	Schizophrenia	Mother	Housewife	Married
Riya	30	Female	BMD	Daughter	Housewife	Married
Jesmin	35	Female	BMD	Daughter	Housewife	Married
Rocky	24	Male	BMD	Son	Student	Unmarried

*Bipolar Mood Disorder (BMD)

3.4 Ethical Consideration

Firstly, BHPI's institutional ethical review board granted ethics approval through occupational therapy containing the ethics number CRP/BHPI/IRB/09/33/625.The National Institute of Mental Health director authorises data collection.

Secondly, informed consent was obtained from all participants, ensuring that they had a comprehensive understanding of the study's purpose, procedures, potential risks, and benefits. Participants were made aware of their right to voluntary participation, the option to withdraw from the study at any time, and the confidentiality measures in place to safeguard their personal information. The researchers took into account the potential vulnerability of the participants and ensured that informed consent was obtained in an empathetic and culturally sensitive manner.

In addition, confidentiality and anonymity were maintained. Strict protocols were established to protect the privacy of participants' data, ensuring that information gathered during the study was securely stored and only accessible to authorized

personnel. Data was anonymized and presented in a manner that prevented identification of individual participants. The researchers also considered the potential psychological impact of the study on participants and provided appropriate support or referral services if needed.

Verbal and written approval was obtained. Participants can utilise a withdrawal form to withdraw their data within a defined timeframe. Participants and student researchers were equal. The interview guide had no sensitive questions, and as it is a self-funded study, the participants did not get any money.

3.5 Data Collection Method

3.5.1 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, having obtained permission from the relevant authority. After collecting population data, family members of individuals with mental illness were invited to participate in the study. Interested participants received an information sheet, consent form, and withdrawal form. The study utilised purposive sampling to select a sample of eight participants from whom data were collected.

3.5.2 Data Collection Process

The study employed semi-structured face-to-face interviews with open-ended questions, conducted within a single session lasting 30 to 40 minutes, with a mean duration. The interviews are characterised by their individual and semi-structured nature. They are conducted thoroughly and comprehensively, allowing participants to elaborate on sensitive information while preserving anonymity and confidentiality.

Semi-structured interviews are valuable for various tasks, especially when multiple open-ended questions necessitate follow-up inquiries. This particular interview format involves the interviewer posing inquiries to extract insights about the participants' prior experiences(Adams, 2015). This type of interview is capable of gathering comprehensive information. The interview was carried out utilising an interview guide in the Bengali language of the participants during the period spanning from November 2022 to December 2022. The interview guide comprised two distinct components: demographic data and open-ended semi-structured questions accompanied by probing inquiries. The demographic section comprised information about the age, gender, profession, and marital status of the family members.

Initially, the student researcher engaged in rapport-building activities with the participants. During the interview, it is essential to allow sufficient time for the participant to respond to each question. The entire interview was conducted in the Bengali language. The researcher provided the participants with a comprehensive explanation of all the questions to ensure their comprehension of the inquiry. The investigator verifies each response's accuracy to ensure the information's validity. Before conducting the interview, the interviewer obtained consent from each participant. Participants' safety and emotional well-being were carefully upheld during the interview process, and no coercion was employed to elicit responses to any inquiries. Initially, demographic data is gathered from the participants; then, comprehensive information is collected through the interview protocol. The interviewer recorded and documented the participant's emotional expressions in the field notes. All of the data was adequately saturated during the interview. The duration of the interview was between 20 and 25 minutes. In conclusion, the interviewer thanked the participant for generously contributing their time.

Field Notes. The student researcher took field notes during the interview through pen and paper. Noted every specific important information and emotion of participant's as much as possible.

Member Checking. The student-researcher returned the recordings and transcript to the participants, who reviewed the information to see if the content matched their experiences. There was also an option to update or delete the information.

3.5.3 Data Collection Instrument

Self-developed Interview Guide. A self-developed interview guide used for data collection. The interview guide has been developed according to study objective. There are 24 open ended questions in the guide. The interview guide has two parts, first one is demographic information and second one is qualitative information. The qualitative questions arranged with personal, social, emotional, financial and physical aspects. The interview guide is placed in Appendix C for better understand.

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.

3.6 Data Analysis

Following the interview, the researcher analysed the collected data using thematic analysis. Currently, this is the most commonly utilised approach for data analysis. The present study employed Braun and Clarke's six-step thematic analysis method to conduct data analysis. Initially, the data is encoded during the interview process and transcribed and translated through auditory and written means. Subsequently, it is

recommended to thoroughly review and analyse the data to become acquainted with its contents and record any preliminary insights that may arise. The user proceeded to identify significant data points and subsequently produced preliminary codes. The task involves categorising the codes by searching for common themes and assigning a descriptive name to each identified theme. The process involves analysing the main themes and generating sub-themes, followed by a thorough review of the codes before report production. Finally, a comprehensive report detailing the results of the data analysis is to be written. The thematic analysis aims to elicit participants' perspectives, viewpoints, insights, and familiarity regarding a subject matter (Braun & Clarke, 2006). This study pertains to the lived experiences of family members of individuals with mental illness. This analytical approach facilitates the attainment of accurate and concise outcomes.

3.7 Trustworthiness and Rigour

According to Fossey et al. (2002), the preservation of trustworthiness was achieved by implementing methodological and interpretive rigour. The steps are maintained as follows:

- The study aimed to identify the lived experience, and as such, a phenomenological approach utilising a qualitative design was deemed appropriate to accomplish the research objectives.
- The student researcher collected primary data through in-person interactions within the study environment.
- The researcher should make observations and record the emotional responses of the participants.
- The student researcher conducted a field test before data collection.
- The data was gathered through semi-structured interviews, and the researcher gained familiarity with the context through verbal communication with the participants.
- The researcher maintained no power dynamic between themselves and the participant.
- Participants are chosen based on the research topic's criteria.
- The verbatim quotations of participants' views and voices are presented, thereby preserving the originality of the data.
- The results section lacks self-observation data and only includes participants'

statements.

- The data undergoes analysis through Braun and Clarke's six-step thematic analysis.
- The supervisor's involvement in each data analysis stage ensured a comprehensive examination of the data, and minimising the possibility of bias.

CHAPTER IV: RESULTS

Seven themes are created through thematic analysis. The themes are broken into several subthemes. The themes are the Initial consequences of family members, Inter-personal relationship among family members, Social response, Financial condition, Coping strategy, Increased resiliency and Daily life experience.

Table 4.2

Overview of Result

Theme	**Sub-theme**
Initial Consequences of Family Members	Stress Factors due to Unusual Changes in PWMI
	Emotional Factors
	Superstition
	Negative Circumstance
Inter-personal Relationship among Family Members	
Social Response	Stigmatize Behavior
	Helpful Circumstance
	Expectations from Society
Financial Condition	
Coping Strategy	Seclusion to PWMI
	Treatment Provision
	Response to Negative Situation
Increased Resiliency	
Daily Life Experience	Physical and Psychological Factors
	Self-Maintenance

4.1 Theme One: Initial Consequences of Family Members

Nearly all family members describe the initial state of individuals with psychiatric and mental illness. The initial phase elicited a significant surprise for the individuals in question. Physical and psychological changes were identified in individuals with mental illness. The individual conveyed their circumstances and how the person with mental illness behaved towards them. The family members also experienced challenging life circumstances alongside their loved ones impacted by mental illness. Individuals may experience emotional breakdowns and situations that are beyond their control. Most individuals characterize the situation as disgusting, shameful, and anxiety-inducing.

4.1.1 Sub-theme one: Stress Factors due to Unusual Changes in PWMI

Each participant initially described about some mental stress caused by initial emotional and physical changes in PWMI. Some claimed that the PWMI was frightened, agitated, and hostile. They stayed awake all night. Some of them were feverish and easily passed out. Sophia said,

> "He (PWMI) came from Dhaka with this fever. When coming home, he feels restless, going here and there, and said that he feels scary. When we asked him why he felt scared, he said he felt wired… He didn't recognize the path to his home."

Approximately 80% of the participants reported aggressive behavior exhibited by individuals with psychiatric and/or mental illness. According to reports, the PWMI exhibited disruptive behavior by physically assaulting their family members, causing bodily harm, and damaging property within the household. Several participants

reported that individuals with psychiatric and mental illness tended to flee their place of residence. The individual has expressed a desire to self-harm and has exhibited suicidal ideation. Boby shared,

> "She (PWMI) does the things that she wants to do. She beat on her head as long as she wanted. Then when we go to catch her, she bites, pinches, and twinges me. She vandalizes everything with stubbornness and anger… She will throw away everything that comes in front of her."

Rihana added,

> “I felt awful when I saw my mum engaging in some bizarre action with total strangers. She questioned the strangers, and by doing so, she horrified them, about what had been done to her brothers.”

According to them, these behaviors of PWMI and the sudden changes of them become awful and stressful for them.

Conversely, one participant asserted that the PWMI exhibited positive conduct towards them. According to the participant, there appears to be no significant issue in living together with him. Rifat added,

"he (PWMI) showed good behavior with us… There is no major problem living with him".

4.1.2 Sub-theme two: Emotional Factors

The family members exhibited a range of emotions. Sure participants reported experiencing emotional distress characterized by feelings of pain and frustration upon witnessing their loved one in such a state. A paternal figure expressed that the

experience is challenging to articulate, and despite its negative emotions, there are no viable solutions. At times, individuals may experience a sense of hopelessness. Rifatshared that,

"I can't explain it; it's a challenging thing; even if it feels bad, there's nothing to do. Sometimes there is a feeling of despair."

Jerin said,

> "I feel awful. I had high hopes for the boy. I will educate the eldest son in the family, and he will get married; which was different. My boy was good in all aspects, good in education. He suddenly became ill. I feel horrible for him."

A few family members also express their desire for individuals with psychiatric and mental illness to achieve a state of recovery. Sophia expresses her aspiration by stating that there is some degree of optimism that if her condition improves marginally, she will attain good health.

> "There is a little hope; if she can be a little better, she will be healthy. It takes a little hope. The tension is for the girl to get well. If the girl gets well, I can take her from here(hospital)."

4.2.3 Sub-theme three: Superstition

Except for a single participant, all individuals asserted that they initially sought the assistance of a kaviraj and Hujur to recover PWMI. Initially, it was believed that this phenomenon was attributed to the influence of jinn. After some time, they realized that this condition was a disease. Their trust in the Kaviraj and other matters has been lost. Boby shared,

> "I bring him to many kinds of hujur and others. Now, I don't believe them. Because who solves the Jin-related problem, I bring him to them, but the result is zero. I got nothing. At first, I believed in this type of thing, but slowly the faith is gone."

Jesmin added,

> "Everyone said the evil eye of Jin cursed my mother. Yes, these things still occur today. At first, I didn't believe it, but now I have serious doubts. Why was this happening to her? Why did she get sick like that? Before this, her life was better. (crying)I believe she was cursed and charmed by evil magic."

Riya describe as,

> "There was no conflict in her family, and she had good prospects. She recovered from being in poverty. She had three intelligent kids. She suddenly fell unwell. She crossed a graveyard on her way to a wedding ceremony. She bit me and beat my other siblings a short while later. She kept us out of her way. Kaviraj, was called immediately and he enchanted her. The traditional treatment was continued. She then went silent and stopped caring for herself or performing any housework."

4.2.4 Sub-theme four: Negative Circumstance

Family members encountered numerous adverse circumstances while cohabiting with a PWMI. The participants provided accounts of various circumstances, such as the potential danger of sustaining injuries from individuals with mental illness, challenges in upholding daily living activities, and the end of productive work and academic pursuits. The individuals resided in a state of distressing circumstances. Rihana said,

> "When I see him now, I am afraid. My body trembles with fear, and when he gets angry, he talks a lot. Like, I will kill you, I will kill people, I am studying to kill people. He says that I will kill a lot of people. And to you, I will decorate your home with your skeleton. Bury you inside the house."

Rifat shared,

"It is affecting me, such as I have to leave my job and live here, I have to be down to my boss, I have to plead with them."

Jesmin added,

> "I took custody of my mother's two children after her illness. I hardly ever find time to study and go to university. My bachelor's degree took eight years to accomplish. I was unable to get accepted into the master's programme either. I never considered working since I knew she needed me."

4.2 Theme Two: Inter-personal Relationship among Family Members

The study's participants provided insights into the interpersonal dynamics within families and their attitudes towards individuals with mental illness. Most participants recounted narratives of having a family that provided them with ample support. The individual conveyed the manner in which additional members of the family provide assistance to persons with mental illness and adjust to the circumstances. Rifat said,

> "I have other family member who fills the gap for me… I have two sons, and they are also studying and they help me and fill the gaps for me."

Conversely, certain participants also divulged details regarding familial ostracism. The individual conveyed that their family members exhibited disregard towards

PWMI and demonstrated disrespectful conduct towards them.

Families exhibit a range of reactions with varying degrees of positivity and negativity. Certain family members exhibit supportive behavior, while others display discourteous and unsupportive conduct. Riya shared,

> “My in-laws refused to acknowledge that my mother had a mental illness. My husband and I's relationship is getting worse every day. My mother's strange behaviour was the root of the problem. She reprimanded her son-in-law and engaged in strange, unacceptable behaviour to others not close to her.They believed she acted in this way out of an egotistical problem and to demonstrate the influence of excessive money.”

4.3 Theme Three: Social Response

Family members report experiencing significant social reactions directed towards them. The majority of instances exhibited unfavorable conduct by society. They also assisted family members and individuals with psychiatric and mental illnesses in certain circumstances. The individuals within the familial unit provided a comprehensive account of the responses elicited from members of the broader societal community.

4.3.1 Sub-theme one: Stigmatize Behavior

The majority of the participants discussed the stigmatizingbehavior exhibited by members of society. The people use insulting talk and exhibit inappropriate behavior towards an individual with a mental health condition. Instances have been reported where individuals subject a child with mental illness to physical abuse, attributing their condition to a sign of sin. Sophia expressed the condition as follows,

> "If she disturbs people, people curse. Throw her away, saying that you should not come here. They abuse, and rude the face. I feel ashamed, but she does not understand. People titter, push her away, and slap her, that's it. People don't like her. People threatened her, saying not to come here again. Sometimes, they hit her. I feel pain and cry. She annoys people, so people beat her, and drive her away. Even if she does not come, then they oppress her."

Another family shared mixed reactions from the society. They experience various reactions from the society. Rocky said,

> "Everyone is doing good things. There are some people, some negative people in the society. Everyone is doing well on average except for them. It means that everyone wants to help. We have good and bad average reactions."

Jesmin said,

> "There have been occasions when I've thought I should talk to friends about this (my mother's illness), but I'm afraid they won't accept me. Additionally, they will criticise it. I was reluctant to bring my friend inside because of what had happened."

4.3.2 Sub-theme two: Helpful Circumstance

Some individuals within the family unit have reported beneficial conduct exhibited by members of the broader community. Under adverse circumstances, individuals receive mental and, in certain instances, financial assistance from others. Rifat stated,

> "They also look like they feel sorry for me, equally they think for me. They have shown no negative reaction. They are also a little sorry that a good boy has become sick like this. They are also tensed about him."

Boby informed me,

> "They behave well with us. What else they will behave? Everyone is in tension with their child. They behave well and do not show any bad behavior. Many people are helping with money, who can help me is helping. They help by buying things for us".

4.3.3 Sub-theme three: Expectations from society

The participants asserted that they held certain expectations from members of the community. They desire an empathetic community that provides amenities for individuals with physical and mental impairments. said,

> "If people help me to make a allowance card, then I can spend money on her, I can't buy medicine, if they give me a card and money every month, I could feed her food and medicines. That would have been beneficial for me."

Several participants reported having no expectations from individuals in society. The community met the individual's expectations. They do not possess any additional expectations or requirement.

4.4 Theme Four: Financial Condition

The majority of the participants discussed the financial crisis resulting from the presence of PWMI. The individual conveyed that they have experienced various difficulties due to the ongoing financial crisis. Individuals with mental illness struggle to sustain their daily routines and adhere to medication regimens. The prevalent issue among individuals is that of indebtedness. Several people take loans from friends and family to sustain their medical care. Jerin conveyed,

> "If she were healthy, I would have been able to work; if I worked, I would have earned money. I can save my money. I could eat what her father was earning and give rent on the house. I can't do that now. Her father could not pay properly even for her medical treatment. After coming to this place, I could not even eat and drink properly. I can't be able to give her what she wants. I have no money or debt; I think I owe like one and a half lakh taka. I am in turmoil because of this debt problem, child problem, etc."

Some family members have good financial conditions. They are willing to spend money to treat PWMI as much as needed. Sophia shared,

"I have not had any financial problems by the grace of Allah. I will give my son more treatment where he will be better."

4.5 Theme Five: Coping Strategy

Families of people with mental illnesses have a variety of difficulties. The PWMI has brought about a few uncontrollable circumstances in their lives. To get through these challenges, they must modify some coping mechanisms.

4.5.1 Sub-theme one: Seclusion to PWMI

Family members' first action is trying to stop PWMI from progressing. They disclosed that, they initially secluded PWMI, keeping them under monitoring, locking them in a room, tying them up, and occasionally hitting and scolding them. Sophia stated,

> "I locked her so that she could not spoil anything. A person is always staying with her." Another participant said, "I kept her by tie up with a chain at home."

4.5.2 Sub-theme two: Treatment Provision

Bringing the patient to a medical facility is yet another approach that may be utilized during the rehabilitation process for PWMI. Everyone who took part in the study stated that they were the ones who brought the PWMI to the hospital during the early stage. Boby said,

"We will take him to the doctor later. After consulting the doctor, he felt better."

Rocky added,

> "Immediately, I was taken him to Chittagong Medical; they pushed the injection. Means was pushing the injection when he was over-excited. After that, I tried many ways, with good behavior, to see if it could be maintained without injection. I couldn't see a good result. When the injection was being pushed, then he became senseless."

4.5.3 Sub-theme three: Response to the negative situation

The family members responded to the stigmatizing behavior directed towards them by members of society. According to the participants, they tend to remain silent in response to negative behavior exhibited by others. The individuals maintain a state of silence and depart from the premises. The majority of the participants reported that they tend to avoid social functions. Typically, individuals pray to Allah and express emotional distress through tears within the confines of their homes. Jerin shared,

> "I do not abuse anyone. As Allah had given her such a condition, I brought my girl, so they beat her. If she were well, then they would not have done it again. I don't say anything, shut my mouth and leave with my child. Allah has given

> me, so I come back without saying anything."

Some participants showed some positive reactions. Rocky said,

> "When someone makes a negative comment like this, I will take it normally, didn't mind. I mean, I didn't take it as such that someone is telling me something because my father is sick. I think it's his weakness that he doesn't realize he's sick. I think so."

4.6 Theme Six: Increased Resiliency

The present study explores the experiences of family members in coming to terms with the reality of mental illness affecting their loved ones. The individuals in question have successfully adjusted and dealt with the given circumstances. They believe in Allah, and right now, all they hope for is the recovery of their loved one. Rihana expresses her situation as,

> "I enter the network site; I see people worse than me and then console myself. Then I think again that the people on my street, It is Allah's decision. Besides, I think there is someone worse than me. My son has straight arms and legs. If Allah wants, Allah can give the brain. Many people do not have straight arms and legs."

4.7 Theme Seven: Daily Life Experience

The disruption of the quality of life of a family member of PWMI can be attributed to many factors. The individuals exhibited infrequent adherence to their self-care routines. All participants reported experiencing high levels of stress and leading busy lifestyles. They have limited time available for recreational activities.

4.7.1 Sub-theme one: Physical and psychological factors

The majority of the participants exhibited poor physical and psychological well-being. The physical condition of persons with mental illness may deteriorate over time due to the care giving process. The individuals in question are experiencing physical fatigue and psychological stress. Boby Shared,

"I have many problems. I have a physical problem. The body is fragile. I have a waist problem. Again, the bones in my waist have decayed."

Jerin said,

> "I have given up eating and drinking. I think I don't eat rice for six months. I don't sleep because I think about it; I feel restless. When we go home, my son doesn't talk to me for a month."

4.7.2 Sub-theme two: Self-maintenance

The study's participants shared strategies for maintaining physical and mental well-being. Most individuals asserted they needed more time to execute self-care practices adequately. Several participants provided details about their daily activities. Rifat said,

> "I am much good at taking care of myself. I took a daily bath, took my doctor's pills, ate and drank according to a timetable, and cared for my health. I always follow a sleeping time. And mentally, I have a grandson, spending time with him, playing sports with him and spending some good time."

Boby talks about some techniques of her daily care. She added,

"How do I care about myself? I care, Like farming in the land. Pick the pepper. Let's eat then a little. If my body feels good, I tend cows, if I don't feel good, I sleep for a while. That's how my day goes. I pray to Allah, my mind calms down (crying)."

CHAPTER V: DISCUSSION

The present research was undertaken to explore the lived experiences of family members of individuals with mental illness. The study involved the participation of eight individuals from the same family. Based on the data provided by the participant, the findings were categorized into seven distinct themes.

The study investigated the stress factors of family members due to behavioral changes exhibited by PWMI. Individuals with Persistent and Severe Mental Illness exhibited hostile conduct and impropriety towards their relatives. The family members exhibit fear and irritation towards this particular form of conduct. A study conducted in a foreign nation also demonstrated the alteration in behavior among PWMI. The study revealed that a family member with a mental illness poses significant challenges for the family unit due to their behavioral patterns. One of the challenges carers encounter is the persistent anger of mentally ill family members (Wankiiri et al., 2013). According to Wankiiri et al. (2013), PWMI may exhibit disinterest, increased appetite, irritability, or erratic behavior, as noted by their family members. This creates a huge stress on them. The present investigation has revealed that the family members exhibited diverse emotional reactions. The individual is experiencing negative emotions such as sadness, stress, and distress. According to Chadda, (2014), due to the chronic nature and high demands of mental illness, caregivers who are caring for the patient experience stress, anxiety, and depression. Long-term effects including burnout and emotional weariness are possible. Others studies also support this fact of emotional exhaustion. The belief in superstition may serve as an initial stage in the recovery process for individuals with mental illness. This research has

yielded a remarkable discovery. There is a relative lack of literature on this particular superstition. The individual experiences a multitude of adverse outcomes in their life. The individual in question is experiencing difficulties with their academic pursuits and is also leading a lifestyle that poses potential hazards. A study revealed that individuals experienced embarrassment as an emotional response to residing with a family member with a mental illness. According to Wankiiri et al. (2013), individuals with family members experiencing mental illness often report distress, discomfort, and inconvenience. Sanden et al. (2015) reported that parents have consistently claimed responsibility for initiating and continuing their family member's mental illness. This study explores the intersection of family perceptions and interpersonal relationships among family members. The family members exhibited a significant amount of support and expressed a keen interest.

On the contrary, certain families exhibited disapproval and lack of knowledge. Maternal figures tend to exhibit high support for children experiencing mental health challenges. Studies conducted in various nations have revealed that family members have developed the ability to acknowledge and coexist with their kin who suffer from mental illness, despite experiencing a sense of inadequacy in fulfilling their familial support obligations. According to Monyaluoe et al.(2014), family members often perceive themselves as having limited options but to accommodate a family member experiencing a mental illness.

The primary discovery of this research pertains to the phenomenon of social response. This study has identified several social attitude. Family members experienced significant stigmatization, discrimination, and adverse treatment from various sources. Conversely, specific households asserted the excellent conduct of their surrounding

community and neighbors. According to the study's results, varying or moderate associations exist between family members and society. The research findings corroborated these results. The majority of families examined in these studies experienced feelings of shame and embarrassment due to the unusual behaviors' exhibited by their family members. Carers often experience a sense of isolation and loneliness and may harbor feelings of guilt and blame for the mental illness of their loved ones (Dalky, 2012).

Another study has reported a favorable response from families. According to Wankiiri et al. (2013), a positive correlation exists between the familial unit of an individual with a mental illness and their neighbors. This is attributed to the neighbor's polite, kind, tolerant, or cordial behavior towards the mentally ill individual. Family members employ diverse coping strategies to manage their circumstances. A recent study revealed that individuals with psychiatric and neurological conditions were subjected to confinement, preventing them from participating in various events. They were administering medical intervention and engaging in religious devotion to Allah. Another study has revealed that individuals with mentally ill family members tend to limit their social interactions and avoid discussing their family member's condition with friends and acquaintances (Sanden et al., 2015). According to Sanden et al. (2015), participants reported refraining from attending social gatherings due to the fear of encountering stigmatizing responses from their peers. A recent study has revealed that most carers frequently employ diverse techniques, tactics, and assets to manage and endure their responsibilities as carers. Chang and Horrocks (2006) have identified several conventional methods and tactics for addressing mental health issues, such as hospitalization, respite care, pharmacological interventions, mindfulness practices, psychosocial assistance, and

familial assistance.

The financial status of the family members is moderate. The majority of households belong to the middle-class socioeconomic group. Following the COVID-19 situation, their financial condition has been adversely impacted. The economic burden has had an impact on their daily lives. Scholars in the field have also researched this particular subject matter. A family's financial resources, including income, proceeds, earnings, and profits, are utilized to cover the costs of providing care for a family member with a mental illness.

Similarly, Wankiiri et al. (2013) discovered that families of individuals with mental illness face a significant financial burden. The present study reveals that resilience and acceptance are predominant characteristics among most family members. One must accept and adapt to the situation while maintaining faith in Allah. A similar finding has been reported in another study regarding South Africa. According to Monyaluoe et al.(2014), the participants reported acquiring the ability to acknowledge and coexist with family members who have a mental illness, despite frequently experiencing a sense of inadequacy in fulfilling their role as a source of familial support. According to recent research, when discussing the daily experiences of family members, it was discovered that they do not allocate sufficient time to uphold their daily self-care and personal maintenance routines. The phenomenon under consideration involves both physiological and psychological stressors. According to Dalky (2012) research conducted in a foreign country, family members have reported experiencing feelings of being overworked, stressed, angry, and dissatisfied with the management of day-to-day care. The study found that carers experienced a decreased quality of life across various domains, such as physical, emotional, and psychological

roles. According to Leng et al. (2018), the findings indicate that carers who received adequate support from their colleagues, friends, neighbors, and relatives experienced an enhanced quality of life. The overarching discovery facilitates the identification of the requirements of individuals who are family members of PWMI and may aid in preserving their standard of living.

CHAPTER VI: CONCLUSION

6.1 Strength of the Study

- The qualitative interpretative phenomenological approach adopted in this study enables a thorough exploration of the lived experiences of family members of individuals with mental illness. It allows for a deep understanding of the complexities, emotions, and challenges faced by these family members, providing a holistic view of their experiences.

- The study's qualitative nature acknowledges that the impact of mental illness on families is shaped by cultural, social, and familial dynamics. By considering these contextual elements, the study can provide a detail understanding of how these factors intersect with the lived experiences of family members.
- The use of rigorous data collection methods, such as in-depth interviews, face-to-face interview allows for a comprehensive exploration of participants' experiences.
- Additionally, employing thematic analysis helps identify recurring patterns and themes, contributing to the study's credibility and trustworthiness, for example: member checking, peer debriefing.
- The findings of this study have the potential to inform clinical practice, support services, and policies related to mental health care.

- This study maintained consolidated criteria for reporting qualitative research (COREQ) standard in reporting throughout the study.

6.2 Limitations of the Study

- The study's findings may be limited by the sample's characteristics and the specific context in which the research is conducted. While efforts will be made to recruit a diverse range of participants, including individuals from different backgrounds and cultural contexts, the sample may not fully represent the entire population of family members of individuals with mental illness.
- Interpretative phenomenological studies involve the researcher's interpretation and analysis of participants' narratives, which introduces the possibility of subjectivity and bias.
- Due to the qualitative and interpretative nature of the study, the findings may not be easily generalize to other contexts or populations.
- Participants may have difficulty recalling and accurately representing past experiences or emotions related to their loved one's mental illness. Memories can be influenced by time, personal biases, and the impact of ongoing experiences.
- The study continued to collect data from hospitals. The community-based data gathering is not possible due to time constraints and issues with permission.

6.3 Practice Implications

The study emphasizes the importance of mental health providers and policymakers considering the perspectives and needs of family members when developing care and treatment strategies. By understanding the unique challenges faced by family members, tailored interventions can be developed to provide appropriate support and resources.

By acknowledging their needs, promoting understanding, and involving them in the

care process, mental health providers can foster a collaborative and supportive environment that positively impacts the well-being of both individuals with mental illness and their families.

6.3.1 Recommendation for future practice and research

It is recommended that future research should focus on conducting longitudinal, studies as these are suggested to explore the dynamic nature of family members' experiences over time. Such studies would provide a deeper understanding of how their experiences evolve and the long-term impact of mental illness on families, as well as the effectiveness of interventions and support systems.

The future research should taking into account factors such as gender, race, ethnicity, socioeconomic status, and cultural background. Investigating how these intersecting identities influence their experiences and support needs would contribute to a comprehensive understanding of the diverse challenges within this population.

Comparative studies across different mental health conditions are recommended to uncover condition-specific challenges, coping mechanisms, and support needs.

Future research should consider a broader range of family relationships, including spouses, siblings, and extended family members. Understanding the unique experiences and support needs of individuals in different family relationships would provide insights into the varying dynamics within families.

The role of technology in supporting family members should be investigated, particularly in terms of accessibility, information sharing, and emotional support. Understanding the benefits and limitations of technology-based interventions and support systems can inform the development of effective tools for family members.

6.4 Conclusion

The life experiences of individuals with persistent and severe mental illness and their families are often characterized by significant pain and sorrow. The members of the family encountered numerous challenging circumstances in their everyday existence. Individuals experience various challenges that can be classified into physical, psychological, social, and financial domains. In certain instances, they experienced tremendous suffering than PWMI. The individuals in question do not avail themselves of healthcare services for their medical condition. The individual's standard of living is progressively deteriorating with each passing day. Frequently, individuals exhibit a lack of self-concern. Healthcare professionals should take serious consideration of them. The promotion of community awareness is imperative for the improvement of their well-being. Healthcare professionals should arrange additional awareness programmes and provide specialized services to the populace. In addition, professionals must work to diminish stigmatization and prejudicial attitudes.

Additionally, there is a necessity for productive domestic activities to yield revenue for individuals, as external income-generating endeavors could be more feasible. The topic of family education is also significant in this context. Family members must recognize the carer of PWMI and offer sufficient support to the PWMI.

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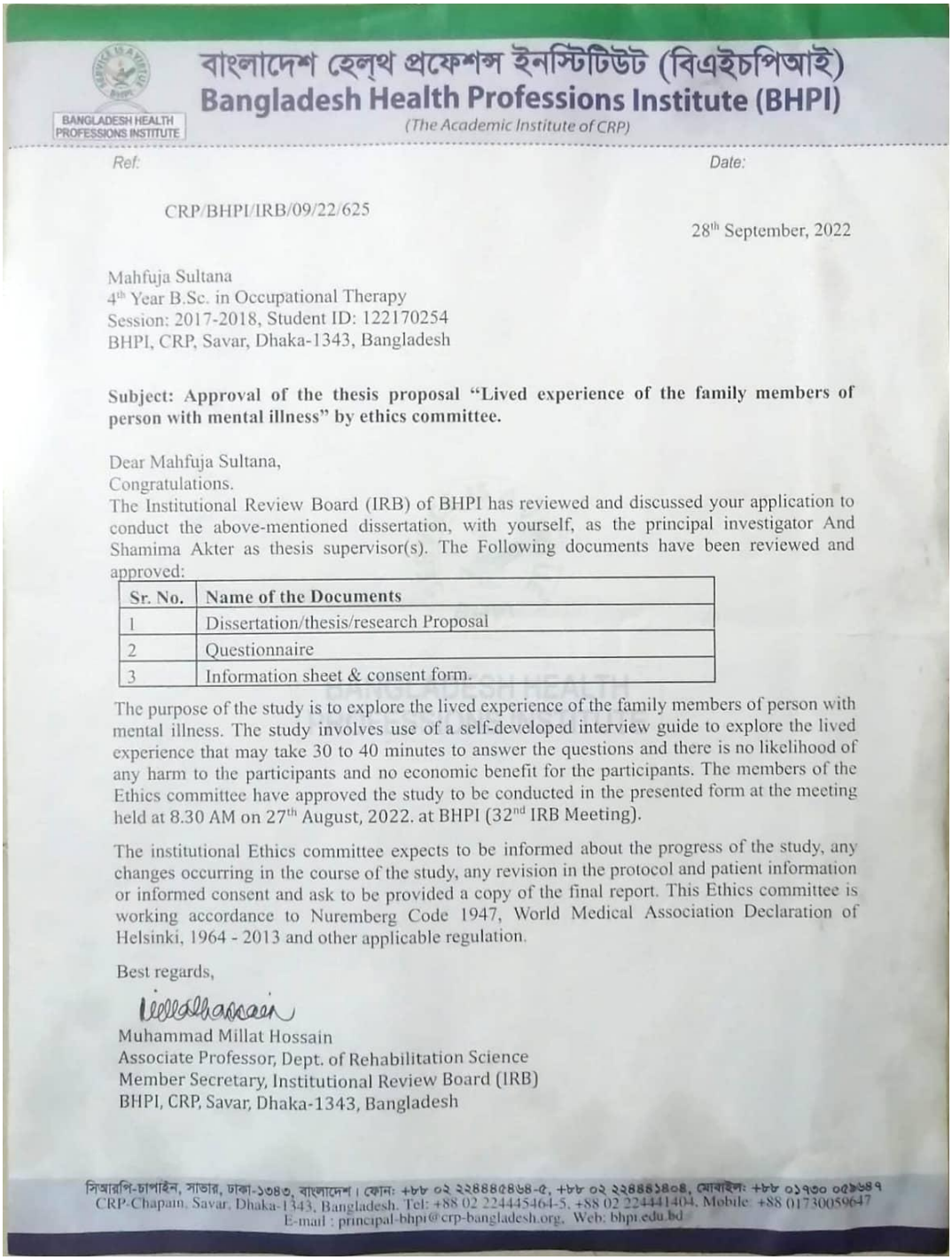
APPENDICES

Appendix A: Approval / Permission Letter

Ethical approval letter



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

BANGLADESH HEALTH PROFESSIONS INSTITUTE

Ref: CRP/BHPI/IRB/09/22/625

Date: 28th September, 2022

Mahfuja Sultana
4th Year B.Sc. in Occupational Therapy
Session: 2017-2018, Student ID: 122170254
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Lived experience of the family members of person with mental illness" by ethics committee.

Dear Mahfuja Sultana,
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 Shamima Akter as thesis supervisor(s). The Following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Dissertation/thesis/research Proposal
2	Questionnaire
3	Information sheet & consent form.

The purpose of the study is to explore the lived experience of the family members of person with mental illness. The study involves use of a self-developed interview guide to explore the lived experience that may take 30 to 40 minutes to answer the questions and there is no likelihood of any harm to the participants and no economic benefit for 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 27th August, 2022. at BHPI (32nd IRB Meeting).

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

Best regards,

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

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭
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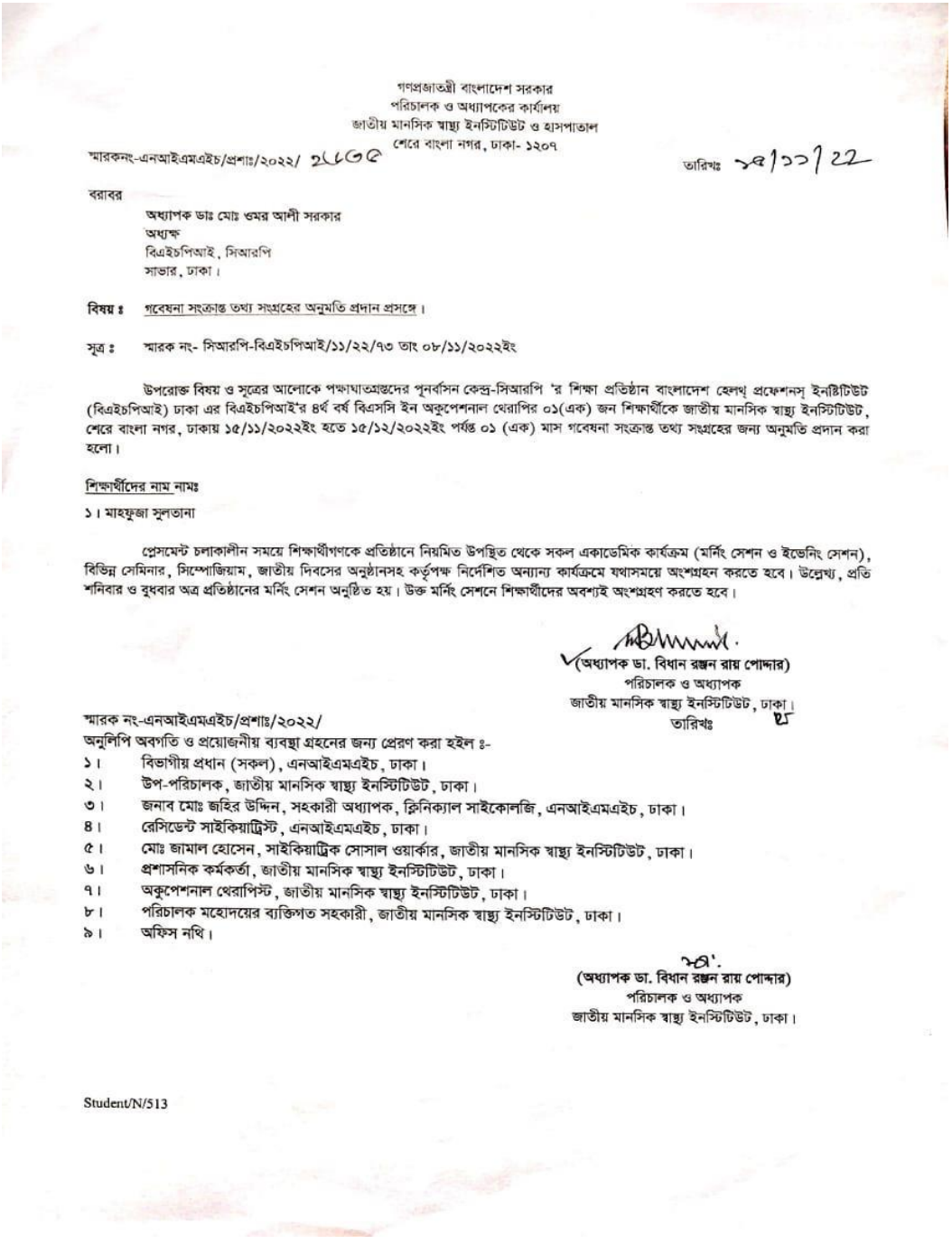
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd

Permission letter for data collection from NIMH



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

স্মারকনং-এনআইএমএইচ/প্রশাঃ/২০২২/ ২৬৬৫ তারিখঃ ১৪/১১/22

বরাবর
অধ্যাপক ডাঃ মোঃ ওমর আলী সরকার
অধ্যক্ষ
বিএইচপিআই, সিআরপি
সাভার, ঢাকা।

বিষয়ঃ গবেষনা সংক্রান্ত তথ্য সংগ্রহের অনুমতি প্রদান প্রসঙ্গে।

সূত্রঃ স্মারক নং- সিআরপি-বিএইচপিআই/১১/২২/৭৩ তাং ০৮/১১/২০২২ইং

উপরোক্ত বিষয় ও সূত্রের আলোকে পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র-সিআরপি 'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেলথ্ প্রফেশনস্ ইনষ্টিটিউট (বিএইচপিআই) ঢাকা এর বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপির ০১(এক) জন শিক্ষার্থীকে জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, শেরে বাংলা নগর, ঢাকায় ১৫/১১/২০২২ইং হতে ১৫/১২/২০২২ইং পর্যন্ত ০১ (এক) মাস গবেষনা সংক্রান্ত তথ্য সংগ্রহের জন্য অনুমতি প্রদান করা হলো।

শিক্ষার্থীদের নাম নামঃ

১। মাহফুজা সুলতানা

প্লেসমেন্ট চলাকালীন সময়ে শিক্ষার্থীগণকে প্রতিষ্ঠানে নিয়মিত উপস্থিত থেকে সকল একাডেমিক কার্যক্রম (মর্নিং সেশন ও ইভেনিং সেশন), বিভিন্ন সেমিনার, সিম্পোজিয়াম, জাতীয় দিবসের অনুষ্ঠানসহ কর্তৃপক্ষ নির্দেশিত অন্যান্য কার্যক্রমে যথাসময়ে অংশগ্রহন করতে হবে। উল্লেখ্য, প্রতি শনিবার ও বুধবার অত্র প্রতিষ্ঠানের মর্নিং সেশন অনুষ্ঠিত হয়। উক্ত মর্নিং সেশনে শিক্ষার্থীদের অবশ্যই অংশগ্রহণ করতে হবে।

(অধ্যাপক ডা. বিধান রঞ্জন রায় পোদ্দার)
পরিচালক ও অধ্যাপক
জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।

স্মারক নং-এনআইএমএইচ/প্রশাঃ/২০২২/ তারিখঃ ১৫

অনুলিপি অবগতি ও প্রয়োজনীয় ব্যবস্থা গ্রহনের জন্য প্রেরণ করা হইল ঃ-

১। বিভাগীয় প্রধান (সকল), এনআইএমএইচ, ঢাকা।
২। উপ-পরিচালক, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
৩। জনাব মোঃ জহির উদ্দিন, সহকারী অধ্যাপক, ক্লিনিক্যাল সাইকোলজি, এনআইএমএইচ, ঢাকা।
৪। রেসিডেন্ট সাইকিয়াট্রিস্ট, এনআইএমএইচ, ঢাকা।
৫। মোঃ জামাল হোসেন, সাইকিয়াট্রিক সোসাল ওয়ার্কার, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
৬। প্রশাসনিক কর্মকর্তা, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
৭। অকুপেশনাল থেরাপিস্ট, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
৮। পরিচালক মহোদয়ের ব্যক্তিগত সহকারী, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
৯। অফিস নথি।

(অধ্যাপক ডা. বিধান রঞ্জন রায় পোদ্দার)
পরিচালক ও অধ্যাপক
জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।

Student/N/513

Appendix B: Information Sheet & Consent Form

Consent Form

Respected Participants, Assalamualikum / Greetings,
I am Mahfuja Sultana, 4th year B.Sc. student in Occupational Therapy department of Bangladesh Health Professions Institute (BHPI) under the medicine faculty of Dhaka University.
I want to conduct research about "lived experience of the family members of person with mental illness". The study aims to explore the lived experience of the family members of a person with mental illness. The maximum data collection time for this study will be 20- 30 minutes.
I want to inform you that, this research will not be used for any other purpose. The information will not be shared with others. Participants' names and other information will not publish. Participants of the study will not financially benefit from this study. They are free to decline to answer any question during the interview. All the information that is collected from the interview would be kept safe and maintained confidentiality. The participant can withdraw information from the study at any time.
In this study I am …….. a participant and I have been clearly informed about the purpose of the study. I am willing to participate in this study and I will have the right to refuse in taking part at any time at any stage of the study. For this reason, I will not be bounded to answer anybody. The researcher will be able available to answer any study-related question or inquiry to the participant. So, with my best knowledge, I agree to participate willingly with my full satisfaction in this study.

Participant Name and Date
Participants Signature
Researcher Signature

সম্মতিপত্র

সম্মানিত অংশগ্রহণকারীরা , আসসালামুয়ালাইকুম/নমস্কার,
আমি মাহফুজা সুলতানা, ঢাকা বিশ্ববিদ্যালয়ের অধিভুক্ত চিকিৎসা অনুষদের অধীনে পরিচালিত বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউটের (বিএইচপিআই) অকুপেশনাল থেরাপি বিভাগের ৪র্থ বর্ষের (সেশন২০১৭-১৮) শিক্ষার্থী। আমি "মানসিক অসুস্থ ব্যক্তির পরিবারের সদস্যদের জীবনযাপনের অভিজ্ঞতা" নিয়েএকটি গবেষণাপরিচালনা করতে চাই। অধ্যয়নের লক্ষ্য হল মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্যদের জীবনের অভিজ্ঞতা অন্বেষণ করা। এই গবেষণায় সর্বাধিক তথ্যসংগ্রহের সময় হবে ২০-৩০ মিনিট।
আমি আপনাকে জানাতে চাই যে, এই গবেষণা অন্য কোন উদ্দেশ্যে ব্যবহার করা হবে না।এই তথ্যসমূহ অন্যদের সাথে শেয়ার করা হবে না , অংশগ্রহণকারীদের নাম এবং অন্যান্য তথ্য প্রকাশ করা হবে না। অধ্যয়নের অংশগ্রহণকারীরা এই গবেষণা থেকে আর্থিকভাবে উপকৃত হবে না। সাক্ষাৎকারের সময় তারা যে কোনও প্রশ্নের উত্তর দিতে অস্বীকার করতে পারেন। সাক্ষাৎকার থেকে সংগৃহীত সমস্ত তথ্য নিরাপদে রাখা হবে এবং গোপনীয়তা বজায় রাখা হবে। অংশগ্রহণকারী যেকোনো সময় গবেষণা থেকে তথ্য প্রত্যাহার করতে পারেন।
এই গবেষণায় আমি ....একজন অংশগ্রহণকারী এবং

আমাকে অধ্যয়নের উদ্দেশ্য সম্পর্কে স্পষ্টভাবে অবহিত করা হয়েছে। আমি এই অধ্যয়নে অংশগ্রহণ করতে ইচ্ছুক এবং অধ্যয়নের যে কোন পর্যায়ে যে কোন সময় অংশ নিতে অস্বীকার করার অধিকার আমার থাকবে। এই কারণে, আমি কাউকে উত্তর দিতে বাধ্য হব না। গবেষক অংশগ্রহণকারীর কাছে অধ্যয়ন সম্পর্কিত যেকোনো প্রশ্ন বা অনুসন্ধানের উত্তর দিতে সক্ষম হবেন। তাই, আমার সর্বোত্তম জ্ঞানের সাথে আমি এই গবেষণায় আমার সম্পূর্ণ সন্তুষ্টির সাথে স্বেচ্ছায় অংশগ্রহণ করতে সম্মত।

অংশগ্রহণকারীর নাম এবং তারিখ :
অংশগ্রহণকারীর স্বাক্ষর :
গবেষকের স্বাক্ষর :

Information Sheet

Title of the study: Lived experience of the family members of person with mental illness.

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

WHO I AM AND WHAT THIS STUDY IS ABOUT

I am Mahfuja Sultana, a 4th year B.Sc. student in Occupational Therapy department of Bangladesh Health Professions Institute (BHPI), want to conduct research about lived experience of the family members of person with mental illness. The aim of the study is to explore the lived experience of the family members of person with mental illness. I want to know about the personal challenges, social attitude, psychosocial state and coping strategies of a family member of person with mental illness.

WHAT WILL TAKING PART INVOLVE?

I will conduct a 20-300 minutes interview with you which related to your father/child/brother (person with mental illness). The interview is about your life experience, your personal challenges, psychosocial state, social attitude and coping strategies with negative reaction. I will record the interview with your permission.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

As you are a family member of person with mental illness you have been invited to take part in the study. You have met the inclusion and exclusion criteria. I added the inclusion and exclusion criteria in below.

- **Inclusion Criteria:**
- ✓ Person who are 1st degree relative of a person with mental illness.
- ✓ Have no history of a mental illness themselves.
- ✓ live in a household where only one family member had a psychosis type of mental illness.
- ✓ Age between 18 years and 65 years.
- **Exclusion Criteria:**
- ✓ Family member with a chronic physical illness.
- ✓ Have speaking difficulty and language problem.

DO YOU HAVE TO TAKE PART?

It is up to you to decide weather or not to take part. If you do decide to take part you

will be able to keep a copy of this information sheet and you have to give consent through a consent form. You can still withdraw your information at any time through the withdrawal for. You do noy have to give a reason.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Participating in the research is not anticipated to cause you any disturbance or discomfort. There is no financial benefit for you for taking part in the study.

WILL TAKING PART BE CONFIDENTIAL?

The information will not be shared with others. your name and other information will not come out during the study. All the information that is collected from the interview would be kept safely and maintained confidentiality.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

The interview will be recorded through a smart phone.Signed consent forms and original audio recordings will be retained in my phone, which have a lock and only I have the access, until after my degree has been conferred. A transcript of interviews in which all identifying information has been removed will be retained for a further two years after this. Under freedom of information legalization, you are entitled to access the information you have provided at any time.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

You can conduct with me for further information.

Mahfuja Sultana
4th year student, Occupational therapy, BHPI, CRP
Phone: 01319044333
Email: tithitarinsultana@gmail.com
IRB NO: CRP/BHPI/IRB/09/22/625
IRB Office Address: BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

You can also contact with my supervisor.

Shamima Akter
Assistant professor, BHPI, CRP
Phone: +8801716806864
Email: shamimaakterot@gmail.com

Thank you

তথ্য পত্র

অধ্যয়নের শিরোনাম: মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্যদের জীবনের অভিজ্ঞতা।

আমি আপনাকে একটি গবেষণা গবেষণায় অংশ নিতে আমন্ত্রণ জানাতে চাই। আপনি সিদ্ধান্ত নেওয়ার আগে আপনাকে বুঝতে হবে কেন গবেষণাটি করা হচ্ছে এবং এটি আপনার সাথে কেন জড়িত। নিম্নলিখিত তথ্য মনোযোগ দিয়ে পড়ার জন্য সময় নিন দয়া করে. আপনার পড়া কিছু পরিষ্কার না হলে বা আপনি আরও তথ্য চাইলে প্রশ্ন জিজ্ঞাসা করুন। অংশ নেবেন কি না সিদ্ধান্ত নিতে সময় নিন।

আমি কে এবং এই স্টাডিটি কি সম্পর্কে?

আমি মাহফুজা সুলতানা, ৪র্থ বর্ষের বি.এসসি. বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউটের (বিএইচপিআই) পেশাগত থেরাপি বিভাগের শিক্ষার্থী , মানসিক অসুস্থ ব্যক্তির পরিবারের সদস্যদের জীবনযাপনের অভিজ্ঞতা নিয়ে গবেষণা করতে চান। অধ্যয়নের লক্ষ্য হল মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্যদের জীবিত

অভিজ্ঞতা অন্বেষণ করা। আমি মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্যের ব্যক্তিগত চ্যালেঞ্জ , সামাজিক মনোভাব, মনোসামাজিক অবস্থা এবং মোকাবেলার কৌশল সম্পর্কে জানতে চাই।

অংশগ্রহণ করার পর কি কি বিষয়থাকবে?

আমি আপনার সাথে ২০-৩০ মিনিটের একটি সাক্ষাৎকার নেব যা আপনার পিতা/সন্তান/ভাই (মানসিক অসুস্থ ব্যক্তি) সম্পর্কিত। সাক্ষাত্কারটি আপনার জীবনের অভিজ্ঞতা , আপনার ব্যক্তিগত চ্যালেঞ্জ , মনোসামাজিক অবস্থা, সামাজিক মনোভাব এবং নেতিবাচক প্রতিক্রিয়ার সাথে মোকাবিলা করার কৌশল সম্পর্কে। আমি আপনার অনুমতি নিয়ে সাক্ষাৎকার রেকর্ড করব।

কেন আপনাকে অংশ নিতে আমন্ত্রণ জানানো হয়েছে?

যেহেতু আপনি মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্য তাই আপনাকে অধ্যয়নে অংশ নিতে আমন্ত্রণ জানানো হয়েছে। আপনি অন্তর্ভুক্তি এবং বর্জনের মানদণ্ড পূরণ করেছেন। আমি নীচে অন্তর্ভুক্তি এবং বর্জনের মানদণ্ড যোগ করেছি।

●অন্তর্ভুক্তির মানদণ্ড:

- ✓ যে ব্যক্তি মানসিক রোগে আক্রান্ত ব্যক্তির ১ম শ্রেণীর আত্মীয়।
- ✓ নিজের কোন মানসিক রোগের ইতিহাস নেই।
- ✓ এমন একটি পরিবারে বাস করেন যেখানে পরিবারের শুধুমাত্র একজন সদস্যের সাইকোসিস ধরনের মানসিক রোগ আছে।
- ✓ বয়স ১৮ বছর থেকে ৬৫ বছরের মধ্যে।

●বর্জনের মানদণ্ড:

- ✓ দীর্ঘস্থায়ী শারীরিক অসুস্থতায় আক্রান্ত পরিবারের সদস্য।
- ✓ কথা বলতে অসুবিধা এবং ভাষার সমস্যা আছে।

আপনাকে কি অংশ নিতে হবে?

অংশগ্রহণ করা বা না করার সিদ্ধান্ত আপনার উপর নির্ভর করে। আপনি যদি অংশ নেওয়ার সিদ্ধান্ত নেন তবে আপনি এই তথ্য পত্রের একটি অনুলিপি রাখতে সক্ষম হবেন এবং আপনাকে একটি সম্মতি পত্রের মাধ্যমে সম্মতি দিতে হবে। আপনি যে কোনো সময় আপনার তথ্য প্রত্যাহার করতে পারেন। আপনাকে কোন কারণ দিতে হবে না।

অংশ নেওয়ার সম্ভাব্য ঝুঁকি এবং সুবিধাগুলি কী কী?

গবেষণায় অংশগ্রহণের ফলে আপনার কোনো সমস্যা বা অস্বস্তি হবে না । অধ্যয়নে অংশ নেওয়ার জন্য আপনার জন্য কোন আর্থিক সুবিধা নেই।

অংশ নেওয়ার পর তথ্য কি গোপনীয় রাখা হবে?

তথ্য অন্যদের সাথে শেয়ার করা হবে না. অধ্যয়নের সময় আপনার নাম এবং অন্যান্য তথ্য বেরিয়ে আসবে না। সাক্ষাৎকার থেকে সংগৃহীত সমস্ত তথ্য নিরাপদে রাখা হবে এবং গোপনীয়তা বজায় রাখা হবে।

আপনি যে তথ্য প্রদান করবেন তা কীভাবে রেকর্ড করা, সংরক্ষণ করা এবং সুরক্ষিত করা হবে?

একটি স্মার্ট ফোনের মাধ্যমে সাক্ষাৎকার রেকর্ড করা হবে। স্বাক্ষরিত সম্মতি ফর্ম এবং আসল অডিও রেকর্ডিংগুলি আমার ফোনে রাখা হবে যার একটি লক আছে এবং আমার ডিগ্রী প্রদান না হওয়া পর্যন্ত শুধুমাত্র

আমার অ্যাক্সেস আছে। সাক্ষাত্কারের একটি প্রতিলিপি যাতে সমস্ত সনাক্তকারী তথ্য মুছে ফেলা হয়েছে এর পরে আরও দুই বছর ধরে রাখা হবে। তথ্য বৈধকরণের স্বাধীনতার অধীনে , আপনি যে কোনো সময় আপনার দেওয়া তথ্য অ্যাক্সেস করার অধিকারী।

আরও তথ্যের জন্য আপনার কার সাথে যোগাযোগ করা উচিত?

আপনি আরও তথ্যের জন্য আমার সাথে যোগাযোগ করতে পারেন।

মাহফুজা সুলতানা
৪র্থ বর্ষ, অকুপেশনাল থেরাপি, বিএইচপিআই, সিআরপি
ফোন: ০১৩১৯০৪৪৩৩৩
ইমেইল: tithitarinsultana@gmail.com

IRB NO: CRP/BHPI/IRB/09/22/625

IRB Office Address: BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

আপনি আমার সুপারভাইজার এর সাথেও যোগাযোগ করতে পারেন।

শামীমা আখতার
সহকারী অধ্যাপক, বিএইচপিআই, সিআরপি
ফোন: ০১৭১৬৮০৬৮৬৪
ইমেইল: shamimaakterot@gmail.com

ধন্যবাদ.

Withdrawal Form

Title of Research: Lived experience of the family members of person with mental illness.
Name of Researcher: Mahfuja Sultana

Participant to complete this section, please initial one of the following boxes:

1. I confirm that I wish to withdraw from the study before data collection has been completed and that none of my data will be included in the study.
2. I confirm that I wish to withdraw all of my data from the study before data analysis has been completed and that none of my data will be included in the study.

Cause of Withdrawal:

Signature of participant:
Date:
Signature of researcher:
Date:

প্রত্যাহার পত্র

গবেষণারশিরোনাম: মানসিক রোগে আক্রান্ত ব্যক্তির পরিবারের সদস্যদের জীবনের অভিজ্ঞতা।

গবেষকের নাম: মাহফুজা সুলতানা

অংশগ্রহণকারী এই বিভাগটি সম্পূর্ণ করতে , অনুগ্রহ করে নিম্নলিখিত বাক্সগুলির মধ্যে একটি চিহ্নিত করুন:

১।আমি নিশ্চিত করছি যে তথ্য সংগ্রহ শেষ হওয়ার আগে আমি অধ্যয়ন থেকে প্রত্যাহার করতে চাই এবং আমার কোনও তথ্য অধ্যয়নে অন্তর্ভুক্ত করা হবে না।

২।আমি নিশ্চিত করছি যেতথ্য বিশ্লেষণ সম্পূর্ণ হওয়ার আগে আমি অধ্যয়ন থেকে আমার সমস্ত তথ্য প্রত্যাহার করতে চাই এবং আমার কোনও তথ্য অধ্যয়নে অন্তর্ভুক্ত করা হবে না।

প্রত্যাহারেরকারণ:

অংশগ্রহণকারীর স্বাক্ষর:

তারিখ:

গবেষকের স্বাক্ষর:

তারিখ:

Appendix C: Questionnaire

Self-developed Interview guide
Demographic Information
Participants Information
Name: Age: Sex:
Education: Occupation:
Relation with the person with mental illness:
Marital Status:
Address:
Information about the person with mental illness
Name: Age: Sex:
Education: Condition:
Treatment time: Hospital:
Marital Status: Number of family members:
Aggressive: Yes / No

Qualitative Information

1. Tell me about yourself and your relationship with the person with mental illness?
2. Tell me about the person with mental illness?
3. What kind of behaviors does he/she show with you and other family members?
4. What are your challenges to living with him/her. (Person with mental illness)
5. How do you overcome these challenges?
6. Have you linked this mental illness of your father/mother/sister/child (person with mental illness) with spirituality?
7. How do others react to you when they know you are a family member of a person with mental illness?
8. what kind of situation do you face when you go to any social function?
9. Is this factor affecting your relationship with community people?
10. Are you feel isolated?
11. How people support you in maintaining your everyday life in the community.
12. What kind of beneficence do you find from the community people?
13. What are you feeling (loneliness/frustration) about your father/mother/sister/child (person with mental illness)?
14. What is the cause of your negative/positive emotions?
15. Are you feeling stressed or depressed due to this situation?
16. What is your marital status? If you have another daughter or son what is his/her marital status?
17. If yes. How it affects your /their marriage life. If no. Is it affect your/their arrangement of marriage?
18. How does it is affecting your work environment and work life?
19. What is your financial condition?
20. Are you feeling financially stressed due to your father/mother/sister/child (person with mental illness)?
21. How do you respond to the negative reaction of others and cope with the situation?
22. What are the strategies you are following to overcome these situations?
23. How to you calm your mind and manage your behavior?
24. How do you take care of yourself physically and emotionally?

ইন্টারভিউ গাইড

জনতাত্ত্বিক তথ্য

অংশগ্রহণকারীদের তথ্য

নাম: বয়স: লিঙ্গ:

শিক্ষাঃ পেশাঃ

মানসিক রোগে আক্রান্ত ব্যক্তির সাথে সম্পর্ক:

বৈবাহিক অবস্থা:

ঠিকানা:

মানসিক রোগে আক্রান্ত ব্যক্তির সম্পর্কে তথ্য

নাম: বয়স: লিঙ্গ:

শিক্ষা: রোগের নাম:

চিকিৎসার সময়:

হাসপাতাল:

বৈবাহিক অবস্থা: পরিবারের সদস্য সংখ্যা:

আক্রমণাত্মক: হ্যাঁ / না

গুণগত তথ্য

1. আপনার বাবা/মা/বোন/সন্তানের (মানসিক রোগে আক্রান্ত ব্যক্তি)মানসিক রোগ সম্পর্কে বলুন
2. সে আপনার এবং পরিবারের অন্যান্য সদস্যদের সাথে কি ধরনের আচরণ দেখায়?
3. তার সাথে বসবাস করতে আপনার চ্যালেঞ্জ কি কি? (মানসিক অসুস্থ ব্যক্তি)
4. আপনি কিভাবে এই চ্যালেঞ্জগুলি অতিক্রম করেন?
5. আপনিআপনার বাবা/মা/বোন/সন্তানের (মানসিক অসুস্থ ব্যক্তি) এই মানসিক অসুস্থতাকেআপনারবিশ্বাসথেকেকিসেরসাথেসম্পর্কিতবলেমনেকরেন?
6. আপনার যদি অন্য কন্যা বা পুত্র থাকে তবে তার বৈবাহিক অবস্থা কী?
7. যদি বিবাহিত হয়, এটা কিভাবে আপনার/তাদের দাম্পত্য জীবনকে প্রভাবিত করে ? যদিঅবিবাহিতহয়, এটা কি আপনার/তাদের বিয়ের ব্যবস্থাকে প্রভাবিত করে?
8. আপনার বাবা/মা/বোন/সন্তান (মানসিক অসুস্থ ব্যক্তি) সম্পর্কে আপনি কী অনুভব করছেন (একাকীত্ব/হতাশা/আশাজনক)?
9. আপনার নেতিবাচক/ইতিবাচক মনোভাবের কারণ কি?
10. আপনি কি এই পরিস্থিতির কারণে মানসিক চাপ বা বিষণ্ন বোধ করছেন? বিস্তারিত বলুন।
11. আপনারবাবা/মা/বোন/সন্তান (মানসিক অসুস্থ ব্যক্তি)এরদেখাশুনাকরারকারণেকীভাবে আপনার কাজের পরিবেশ এবং দৈনন্দিনজীবন প্রভাবিত হচ্ছে?
12. আপনার আর্থিক অবস্থা কেমন?
13. আপনি কি আপনার বাবা/মা/বোন/সন্তানের (মানসিক অসুস্থ ব্যক্তি) কারণে আর্থিকভাবে চাপ অনুভব করছেন?বিস্তারিত বলুন।
14. অন্যরা আপনার প্রতি কেমন প্রতিক্রিয়া দেখায় যখন তারা জানে আপনি একজন মানসিক অসুস্থ ব্যক্তির পরিবারের সদস্য?
15. কোনো সামাজিক অনুষ্ঠানে গেলে আপনি কী ধরনের পরিস্থিতির সম্মুখীন হন?

16. এই বিষয়টি কি সমাজের মানুষের সাথে আপনার সম্পর্ককে প্রভাবিত করছে?
17. আপনি কি বিচ্ছিন্ন বোধ করেন? যদিহাঁহয়, বিস্তারিতবলুন।
18. সমাজেআপনার দৈনন্দিন জীবন বজায় রাখার জন্য লোকেরা কীভাবে আপনাকে সাহায্য করে?
19. সমাজের লোকদের কাছ থেকে আপনি কী ধরণের উপকার পান?
20. সমাজেরমানুষেরকাছথেকেআপনিকিপ্রত্যাশাকরেন?
21. আপনি কীভাবে অন্যদের নেতিবাচক মনোভাবের/ কথার প্রতিক্রিয়া জানান এবং পরিস্থিতি মোকাবেলা করেন?
22. এই পরিস্থিতিগুলি কাটিয়ে উঠতে আপনি কোন কৌশলগুলি অনুসরণ করছেন?
23. কিভাবে আপনি আপনার মন শান্ত করেন এবং আপনার আচরণ পরিচালনা করেন?
24. কিভাবে আপনি শারীরিক এবং মানসিকভাবে নিজের যত্ন নেন?

Supervisor-Student Contact Paper

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

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

Title of thesis: Lived experience of the family members of person with mental illness.

Name of student: Mahfuja Sultana

Name and designation of thesis supervisor: Shamima Akter, Assistant professor, Bangladesh Health Professions Institute (BHPI).

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	20.08.22	Teacher's room	Proposal Presentation	30 min	1. Literature matrix 2. Background	Mahfuja Sultana	
2	21.08.22	Teacher's room	Proposal (method)	30 min	1. Study design & Approach. 2. Population	Mahfuja Sultana	
3	22.08.22	Teacher's room	Proposal (Questions)	30 min	1. Data collection method	Mahfuja sultana	
4	28.8.22	Teachers room	Research Proposal	30 min	1. Interview guideline 2. Literature review	Mahfuja Sultana	
5	03.11.22	Teacher's room	Data collection	30 min	1. Methodology 2. Literature review	Mahfuja Sultana	
6	01.11.22	Library	Self-developed interview guide	15 min	1. Interview guide	Mahfuja sultana	
7	13.11.22	Teachers room	write-up guideline	1 hour	1. Introduction	Mahfuja Sultana	
8	22.12.22	Library	Introduction	30 min	Introduction feedback	Mahfuja sultana	
9	26.12.22	Library	Literature review	1 hour	Literature write-up	Mahfuja Sultana	
10	30.12.22	Teachers room	Methodology	1 hour	Methodology guideline	Mahfuja Sultana	
11	2.1.23	Teachers room	Literature review	1 hour	Literature final feedback	Mahfuja sultana	
12	4.1.23	Library	Methodology	1 hour	Methology feedback	Mahfuja sultana	
13	12.1.23	Library	Methodology	30 min	Methodology correction	Mahfuja Sultana	
14	24.1.23	Teachers room	Result	1 hour	Theme making	M	

15	1.02.23	Teachers room	Result	2 hour	Result correction	Mahfuja sultana	
16	13.02.23	Library	Result	1hour	Result final feedback	Mahfuja sultana	
17	17.02.23	Teachers room	Discussion	1 hour	Discussion final	Mahfuja sultana	
18	11.05.23	Library	final feedback	1 hour	final check-up	Mahfuja sultana	
19	24.05.23	Teachers room	final feedback	1hour	final feedback	Mahfuja sultana	
20	5.06.23	Teachers room	final check-up	2hour	final output	Mahfuja sultana	

Note:

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