LEVEL OF CAREGIVER BURDEN: A STUDY ON CAREGIVERS OF PATIENT WITH SCHIZOPHRENIA AT THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) IN BANGLADESH

By

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Statement of Authorship

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Abstract

Background: Schizophrenia is a chronic, severe and disabling mental disorder that causes serious consequences for those with the illness, as well as those who care for them. It has significant physical, emotional and socio-economic costs for those with the condition as well as their families.

Objectives of the study: To explore the socio-demographic picture of the caregivers of PWS in Bangladesh, explore the level of burden of caregivers, identify the caregiver’s burden in the relationship, emotional well-being, social and family life, finances and loss of control over one's life and determine the association between age, sex, occupation, relation, duration of care giving and level of care giving

Methodology: The study conducted through cross-sectional design among 121 participants who were selected from National Institute of Mental Health by a structure questionnaire with face to face interview. Data was analyzed by using Statistical Package for social science.

Result and Discussion: After analyzing data, it was found that most of the caregivers (63.6%) of PWS faced moderate to severe level of burden and in terms of all five domains. Most of the caregivers faced with also moderate to severe burden about Burden in the relationship (65.3%), Emotional wellbeing (57.9%), Social and family life (42.1%), Finances (38.8%) and Loss of control over one's life (63.6%). Caregivers’ burden level was significantly associated with caregiver characteristics: Sex ($P <0.001$), relationship with patient ($P <0.000$), care giving duration ($P <0.030$). Female caregivers who were housewives, mother in relationship with the PWS giving long duration of care exhibit severe burden.

Conclusion: The study findings will be helpful for occupational therapists to know the situation of care given to Schizophrenic Patient in Bangladeshi perspective and in future caregiver will be benefited to reduce burden as much as possible. Occupational therapists have an important role to promote a better social and psychological support for quality life of caregiver and PWS.

Key words: *Burden, Caregiver, NIMH, Patient with schizophrenia*

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List of Acronyms

ADLs: Activities of Daily Living
BAS: Burden assessment schedule
BHPI: Bangladesh Heath Professions Institute
MAPI: Marche Prospective International
NIMH: National Institute of Mental Health
OT: Occupational Therapy
PWS: Patient with schizophrenia
SPSS: Statistical Package for social science
WHO: World Health Organization
ZBI: Zarit Burden Interview

CHAPTER 1
INTRODUCTION

1.1. Introduction

Schizophrenia is a critical mental disorder. It is a chronic and disabling mental condition. It requires long term care. The consequences of having schizophrenia are associated with significant and long-lasting health, social, and financial burdens, not only for patients but also for families and caregivers. Patient's symptoms and their personal (self-care, productivity, leisure activity) and social functioning have a great impact on their own quality of life as well as the caregiver (Bevan *et al*., 2013).

Schizophrenia affects the physical, psychological, emotional, social and financial life of patient's caregivers. According to Jungbauer *et al.* (2004), 41% of patients with schizophrenia still live with their parents, or have moved back in with their parents. 12% of caregivers are the patient's siblings; and 7% of caregivers are a spouse or partner. Caregiver's burden can be associated with work overload, sleep disturbance, financial problems, less spare time etc. Stigmatization and social isolation by neighbors or other acquaintances can be seen as a substantial part of the caregiver burden. It was reported that many neighbors are fearful of violence caused by patients with schizophrenia. A reported 32% of the burden related to caregiver problems arises from young patient age, awareness of the patient's suicidal attempts, and concern about family resources (Millier *et al.*, 2014).

Various studies have confirmed that family caregivers of persons with a severe mental illness suffer from significant stresses, experience high levels of burden, and often receive inadequate assistance from mental health professionals (Saunders, 2003).

Martens and Addington (2001) observe that, family members are significantly distressed as a result of having a family member with schizophrenia. Ivarsson *et al.* (2004) stated that, family caregiver burden is complex and includes several areas such as activities in daily life, worry and social strain. Effective family functioning in families with schizophrenia may be influenced by a variety of psychosocial factors. Family conflict and family intimacy have been found to reflect the degree of burden or reward experienced and it is recommended that the family system (Stanley and Shwetha, 2006).

The patient with schizophrenia (PWS) has behavioral, cognitive and functional problems. So the caregiver of PWS has a higher risk to fall in burden because the caregiver faces difficulty to manage those problems and fell stress. For this reason the researcher wants to know the level of caregiver of PWS.

1.2. Background

Schizophrenia is a severe form of mental illness that affects about 7 per 1,000 of the adult population. Most of patients are between 15 to 35 years. According to World Health Organization (WHO) (2010), it is estimated that globally about 29 million people have schizophrenia (Chan, 2011). In Bangladeshi situation Schizophrenia is the single largest cause of admission to government and private mental hospitals. About 1.3 million people (1% of the population) of Bangladesh suffer from schizophrenia. The illness usually appears in adolescence and early adulthood. In most of the cases the onset is between 17 and 25 years of age but it can occur at any age (Begum, 2012).

Many studies presented that in western countries about 25% – 50% of PWSs stay with their family after discharge from hospital. They become dependent on the assistance and continued involvement of their families. Studies of Asian country show that about 70% of clients with schizophrenia live with their family. They depend on the family for care provision. Acceptance of people with mental illness as members of society is limited by cultural and social factors (Chan, 2011).

Marsh (2001) recommended that, families are often served as an extension of the mental health system. It is now recognized globally that caregivers will continue to play an important and ever expanding role, as health and social services systems. Caregiver has many tasks such as ensuring patients prescribed medications, sufficient food and sleep. Ensure other daily living activities, as well as preventing them from possibly dangerous behaviour. The families are also challenged with additional problems including financial problems and worry about the general health and repetitive illness of the patients in addition to management of the patient's behaviour. The families have to take other roles in their life and family, including financial, employment, social life, physical health, marital and family relationships, and daily household activities. Caregiver’s lives may be disrupted by providing more care activities.

Care activities for patients with schizophrenia may have a significant impact on all aspects of individual lives as well as the entire family and this may have a dysfunctional impact on the family. Care provisions for patients with schizophrenia are difficult and often long-term responsibilities of the caregiver. The families have to deal with a challenging situation in order to balance between providing care for their relative with schizophrenia, others members in their family as well as themselves (Tungpunkom *et al.*, 2012). The lifetime consequence of emotional, social, and financial burden experienced by individuals with schizophrenia and it has significant effects on their families. Family member with schizophrenia relative has care burden, fear and embarrassment about illness, signs and symptoms, insecurity, lack of social support, and stigma (Brady, 2004).

The investigator completed his 3rd year placement at National Institute of Mental Health (NIMH) in Dhaka. The researcher had experience of working with PWS and the caregiver for a certain period. The researcher observed the physical, psychological, emotional, social and financial burden of the caregiver. From that concept, the researcher felt interested to conduct a study for measuring the level of caregiver burden of PWS. According to the course curriculum researcher has to conduct a study in 4th year as a compulsory project. At that time the investigator tried to find out the level of caregivers burden of PWS at NIMH.

1.3. Significance of the study

The caregivers are working as the co-therapist. Caregivers take care of people with disabling diseases. Generally they are parents, wives, siblings, sons, daughters, close relatives, friends and neighbors (Chan, 2011). They have to provide care to the patient. Caregivers with a PWS have many problems during providing care, because schizophrenia is a disabling, long-lasting psychiatric illness. It poses several challenges in its management and consequences that have significant burden to the patient as well as on the caregiver. Caregivers' burden is a complex issue. Shifting burden of care from hospital to caregiver, families, and on society is direct and indirect. That includes frequent hospitalizations and the need for long-term psychosocial and economic support, as well as life-time lost productivity. Burden on caregiver is more defined by its impacts and consequences.

In addition to the emotional, psychological, physical and economic impact, the concept of ‘burden of care’ involves distressing concepts such as shame, embarrassment, feelings of guilt and self-blame (Awad, 2008).Occupational Therapist work with both patient and caregiver (CAOT, 2014). If there are no smooth relationship among patients and their caregiver it will hamper provision of intervention. An OTs can provide advice to the patient and caregiver by understanding knowing the burden of schizophrenia on their caregiver. Similarly, the caregivers will be benefited by getting Occupational Therapy (OT) management.

Bangladesh Heath Professions Institute (BHPI) organizes a clinical placement for their 3rd year B.Sc. in OT students and internship is also conducted in NIMH each year. During placement and internship, OT students and intern work with patients and their caregiver. The OT students and intern will be knowledgeable about the level of caregivers’ burden of PWS by this study. The Occupational Therapists will be introduced to the caregivers of PWSs; they will also be a mandatory part to manage the burden. The NIMH will be able to provide better quality of services.

1.4. Aim of the study

The aim of the study is to investigate the burden level on the caregivers of PWS

1.5. Objectives of the study

- To explore the Socio-demographic picture of the caregivers of PWS at NIMH in Bangladesh
- To explore the level of burden (mild, moderate and severe) of the caregivers
- To identify the caregivers’ Burden in the relationship, Emotional well-being, Social and family life, Finance and Loss of Control over one's life
- To determine the association among caregiver age, sex, occupation, relationship with patient and duration of care giving with the level of the caregivers’ burden

CHAPTER 2
LITERATURE REVIEW

This chapter will focus on the key words of this study: Definition, etiology, epidemiology, symptoms, prognosis and OT intervention of Schizophrenia. Besides the caregiving role in treatment and rehabilitation of PWSs, various problems are faced by the caregivers also described in this chapter.

2.1. Schizophrenia

At the beginning of this century the Swiss psychiatrist Bleuler introduced schizophrenia in the medical language (Barbato, 1998).

According to Office of Mental Health (2003) *“Schizophrenia is a mental illness that affects one person in every hundred. Schizophrenia interferers with the mental functioning of a person and, in the long term, may cause change to a person’s personality. First start is generally in adolescence or early childhood. It can develop in older people, but this is not nearly as common. Some people may experience only one or more brief episodes in their lives. For others, it may remain are current or life-long condition”.*

Family responses to have a family member with schizophrenia that include care burden, fear and embarrassment in illness signs and symptoms, uncertainty about course of the disease, want of social support, and stigma (Talwar and Matheiken, 2010).

There is no specific cause of this condition. But it characterized by psychotic symptoms that significantly impair functioning and involve disturbances in feeling, thinking and behavior (Firoz, 2001).

2.2. Etiology of schizophrenia

The probable causes of schizophrenia are not fully understood. Research has attempted to determine the causal role of biological, psychological and social factors. The evidence does not point to any single reason. Gradually, it is thought that schizophrenia and related psychoses result instead from a complex interaction of multiple factors (Bhugra, 2010).

The etiology of schizophrenia is complex. It is probably a combination of several different things, man to man which may vary. About 1 in 10 PWSs have a parent with the illness. Along with other mental disorders, deprivation or physically or sexually abuse in childhood may cause schizophrenia (Royal College of psychiatrist, 2011). Pre-morbid abnormalities of speech and behaviour may be present during childhood. Enlarged ventricles and abnormalities of the temporal lobes are common findings from neuroimaging (Davies and Craig, 2009).

2.3. Incidence and prevalence

Lifetime occurrence is approximately 1-1.5% and 2 million new cases seem each year worldwide. Prevalence morbidity and severity of presentation are greater in urban areas than rural. Schizophrenia is equally prevalent in men and female. The male & female ratio is 1:1 in Bangladesh (Firoz, 2001). Keplan *et al.* (1994) mentioned that, men have an earlier onset of schizophrenia than women. The peak ages of onset for men and women are 15 to 25; and 25 to 35.

The lifetime prevalence of schizophrenia is between 0.4 and 1.4%. Worldwide, it has been estimated that schizophrenia falls into the top ten medical disorders causing disability (WHO, 2010).

Firoz (2001) stated that, lower socioeconomic groups are more vulnerable for this condition. Schizophrenic people died 10 years earlier than usual.

2.3.1. Prevalence of schizophrenia in Bangladesh

Population	**Percentage (%)**
General population	1-1.5
First degree Relative	10-12
Second degree Relative	5 - 6
Child of two Schizophrenic parents	40
Child of one Schizophrenic parents	14
Dizygotic twins	12-15
Monozygotic	45-50

Table 1: Prevalence of Schizophrenia in Bangladesh (Firoz, 2001).

Schizophrenia is a major problem in Bangladesh. The rising trends are evident in both urban and rural areas. Young people are commonly affected by schizophrenia. In national survey on mental health the prevalence of schizophrenia was found 0.63% (Firoz, 2007).

2.4. Symptoms of schizophrenia

The DSM-V (2013) diagnostic criteria for schizophrenia describe a wide range of symptoms, classified as either positive or negative. Positive symptoms include delusions, hallucinations, cognitive and disorganized or abnormal behaviour. Negative symptoms include diminished emotional expression, reduced motivation, and lack of pleasure. Cognitive deficits are also common and can persist when other symptoms are in remission, causing long-term disability (Pike, 2013).

This disorder disrupts the day to day life functioning of the person. Self-care, interpersonal relationships, social involvement, and vocational life are all affected. Disabilities in various areas such as educational performance, vocational activities, independent living skills, activities of daily life are recognized as part of psychotic illnesses (Raj, 2013). Caregivers often become the nucleus for support for a person living with schizophrenia especially during the most difficult times that are caused by the symptoms of the disease (Roberts and Writer, 2008). The symptoms of schizophrenia fall into three broad categories:

2.4.1. Positive symptoms

Positive symptoms are usually involving a loss of contact with reality, including hallucinations (person sees, hears, smells, or feels that no one else can see, hear, smell, or feel). Delusions (false personal beliefs that are not part of the person’s culture and do not change, even when other people present proof that the beliefs are not true or logical), thought disorder, and disorders of movement. Positive symptoms can come and go. Sometimes they are severe and at other times hardly noticeable, depending on whether the individual is receiving treatment (NIMH, 2009). PWSs have difficulty with concentration, attention and memory. Trouble in understanding information and making decisions, expressions like smiling or laughing for no appropriate reason, loss of interest or pleasure in activities, lack of interest in eating, disturbances in sleep patterns, and abnormal movements like pacing or rocking are major problems.

For this hallucination and delusion symptoms of PWSs they face difficulties in concentrating to their activities of daily living (ADL's) such as self-care, productivity, leisure. The caregiver always stays in a stress during managing the patient. They cannot maintain their ADL's properly, so it makes their life very much problematic.

2.4.2. Negative symptoms

Negative symptoms are referred to reductions in normal emotional and behavioral states. These include the following:

- Flat affect (immobile facial expression, monotonous voice)
- Lack of pleasure in everyday life
- Diminished ability to initiate and sustain planned activity
- Speaking infrequently, even when forced to interact

These symptoms are called "negative" because they have been deducted from that person's normal behavior. Sometimes they can be mistaken for depression or other disorders. These symptoms can affect a person's relationship, employment; finances, schooling, and overall enjoyment of life. It tends to form difficulties in home, in relationships with family and sometimes in basic self-care eating, grooming and toileting. The caregivers have to help the patients in patient's ADL's. For this reason the caregivers cannot take rest, take care of their own health. These problems decrease their quality of life (NIMH, 2009).

2.4.3. Cognitive symptoms

Cognitive symptoms are not noticeable like negative symptoms. Cognitive deficits can also be difficult to recognize as part of the disorder. Often, they are detected only when other tests are performed. Cognitive symptoms include the following:

- Poor "executive functioning" means the ability to understand information and use it to make decisions
- Trouble focusing or paying attention
- Problems with "working memory" that means the ability to use information immediately after learning it (NIMH, 2009).

Cognitive symptoms often make it hard to lead a normal life and earn a living. PWSs may lose their ability to use their time properly, relax, concentrate or sleep and they may withdraw the reality. About half of PWSs cannot recognize that they are sick.

This symptom, called anosognosia, has serious consequences and they won’t seek treatment. Caregivers are always busy with providing care and it is burden for them (Brichford, 2014).

2.5. Effect of schizophrenia

When the signs and symptoms of schizophrenia are ignored or improperly treated, the effects can be devastating both to the individual with the disorder and their caregiver. Some of the possible effects of schizophrenia are:

- **Relationship problem:** Problem in good relationship may be seen because PWSs often withdraw and isolate themselves.
- **Disruption to normal daily activities:** Schizophrenia causes significant disruptions to daily functioning because of social difficulties and because everyday tasks become hard like bathing, eating, or leisure activities.
- **Alcohol and drug abuse:** PWSs frequently develop problems with drugs or alcohol, which are often used in an attempt to self-medicate, or relieve symptoms. They may also be heavy smokers, a complicating situation as cigarette smoke can interfere with the effectiveness of medications prescribed for the disorder.
- **Increased suicide risk:** PWSs have a high risk of suicidal tendency. They are committed for suicide during psychotic episodes, during periods of depression (Smith and Segal, 2014).
- **Social and occupational dysfunction:** The onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations or self-care are markedly disrupted. When the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement (Viertio, 2011).

2.6. Prognosis

There is no absolute cure for schizophrenia. An effective treatments can reduce symptoms, decrease the likelihood that new episodes of psychosis. Shorten the duration of psychotic episodes and in general, offer the majority of people with suffering from schizophrenia the possibility of living more productive and satisfying lives.

- Approximately 50% of people diagnosed with schizophrenia are completely recovered or improved to the point of being able to function independently
- 20% are improved, but require a strong support network
- Additional 15% remain unimproved and are typically hospitalized
- Unfortunately 10% of the affected population sees no way out of their pain they go through to death and ends up by committing suicides.

The family members and relatives as caregiver need to be informed by the health professionals about prognosis for avoiding to expect unexpected recovery. Besides the health professional should advice the caregivers and make therapeutic plan for PWSs (Nemade and Dombeck, 2009).

2.7. OT intervention for PWSs

Psychosocial treatments: Although medications are the cornerstone of schizophrenia treatment, once psychosis recedes, psychosocial treatments also are important. These may include:

- **Social skills training:** This focuses on improving communication and social interactions.
- **Family therapy:** This provides support and education to families dealing with schizophrenia.
- **Vocational rehabilitation and supported employment:** This focuses on helping PWSs find and keep jobs.
- **Individual therapy:** Learning to cope with stress and identify early warning signs of relapse can help PWSs manage their illness. Many communities have programs to help people with schizophrenia with jobs, housing, self-help groups and crisis situations. A case manager or someone on the health care team can help find one. Most PWSs can manage their condition with an appropriate treatment.

Coping and support: Coping with an illness as serious as schizophrenia can be challenging, both for the person with the condition and for friends and family. Here are some ways to cope with schizophrenia:

- **Learn about schizophrenia:** Education about the condition can help motivate the PWSs to stick to the treatment plan. Education can help friends and family understand the condition and be more compassionate with the person who has it.

- **Join a support group:** Support groups for PWSs can help them reach out to others facing similar challenges. Support groups may also help family and friends to cope with these types of patient.
- **Stay focused on goals:** Recovery from schizophrenia is an ongoing process. Keeping recovery goals in mind can help the PWS stay motivated. Help your loved one remember to take responsibility for managing the illness and working toward goals.
- **Learn relaxation and stress management:** The person with the disease and loved ones may benefit from stress reduction technique such as meditation, yoga etc. (Royal College of psychiatrist, 2011).

2.8. Caregiver

According to Oxford Advanced Learner's Dictionary (2014) "*a person who takes care of a sick or old person at home"*

According to Collins English Dictionary (2012) *"a person who has accepted responsibility for looking after a vulnerable neighbour or relative is called carer"*

Caregiving is an occupation that can encompass 24 hours a day, 7 days a week, with no sick family, and caregiving responsibilities simultaneously. These challenges put caregivers at risk for experiencing caregiver burden (Naguwa, 2010).

The terms family caregiver and informal caregiver refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard *et al.*, 2014).

Caregivers are more likely to be women in many country of the world. Asian studies such as Japan, Taiwan, Malaysia, Philippines, Indonesia and India found about 70% of family caregivers are females. Globally about 80% of the caregivers are women. They are mother, wife, or daughter of the patients. Usually their socioeconomic condition is not better (Chan, 2011).

Caregivers of PWSs are very essential part for long-term supervision and successful delivery of effective interventions for PWSs (Bhugra, 2010).

2.9. Caregiver responsibilities

Caregiving responsibilities can make a burden on caregivers' daily lives, physical health, and emotional well-being. High levels of caregiver burden can have considerable consequences for patients and wider society as a whole as well as for caregivers themselves. For instance, the impact on the caregiver becomes too great, and then there could be some consequences on the delivery of care to patients, an increase in unmet needs of overburdened caregivers and an increasing reliance on formal, paid assistance resulting in costs to healthcare systems and wider society. In addition, caregiving has a significant impact on informal caregivers' own physical and psychological health (Gater, 2014).

2.10. Caregiver burden

Caregiver burden has been widely researched and is defined as *"a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"*. Many studies have found that caregiving is related to physical and psychosocial issues, such as depression, illness, and decreased quality of life (Naguwa, 2010).

The caregivers have to deal with patients' symptoms, and help patients in ADL's. Caregivers look at several stressors including financial, family structure, and physical health demands among many others. Care giving could be stressful. Caregivers of persons with schizophrenia and other disorders experience high levels of burden. Burden of care can be conceptualized into two distinct components are objective and subjective. Objective burden of care is meant to indicate its effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the caregivers perceived the burden of caregiving. Subjective burden means the positive and negative feelings and perceptions of the caregiver associated with providing caregiving function. Caregiver burden include financial strain, being confined to the home, change in the relationship, the demands of caregiving and having little time for oneself. The relationship between coping styles and perceived burden of care is complex because caregivers subjectively report "burden." The burden of caregivers is more dependent on their judgment of the situation of their patients rather than the actual illness (Talwar and Matheiken, 2010).

2.11. Impact of caregiving role on caregivers

The burden that is often placed on families or other living in close contact with a mentally ill person has only recently been recognized. Various aspects of impact on caregivers should be considered these include:

- The economic burden related to the need to support the patient and the loss of productivity of the family unit;
- Emotional reactions to the patient’s illness, such as guilt, a feeling of loss and fear
- The stress of coping with disturbed behaviour;
- Disruption of household routine;
- Problems of coping with social withdrawal or awkward interpersonal behaviour;
- Curtailment of social activities (Barbato, 1998).

2.12. Schizophrenia in the family: the caregiver

Each family divides up the tasks of caregiving differently. The majority of families, parents and step-parents are primary caregivers. The primary caregiver also worries about patient future. 90% of primary caregivers express concern about what their death would mean for the PWS in their care. Caregivers spend much of their time regarding to the medical needs of their loved one, often leaving them no time left over to tend to their own needs. 63% of caregivers report not having time for them, and 55% don't have time to perform their daily living activities. There mental also affected, including an increased likelihood of depression, insomnia, and anxiety. Schizophrenia can cause relationships within the family to suffer. Family members who do not understand the nature of mental illness may feel embarrassed or ashamed of their sick loved one. The primary caregiver may have no time left to spend with other family members. Partners and other children often feel neglected by the primary caretaker, which can lead to resentment of the PWS. Shifting the responsibility from one caregiver to the whole family including younger member in family negotiations can help foster a sense of group contribution. The right support group can help families sort out their early feelings of guilt, misperception, and anger, as well as help them. People with mental illness such as PWSs face discrimination, misunderstanding and stigma. Often, their families and parents are blamed for mental illness (Brichford, 2014).

2.13. Caregiver’s burden for PWS

Care activities for schizophrenic patients affect the general and mental health of caregivers. Burden refers to the negative impact of the individual's mental disorder on the entire family. It is possible to distinguish between objective burden, negative consequences on family routines, and subjective burden that relates to emotional disturbances experienced by the caregivers (Grandon, 2008).

Caregiver, relatives and friends of PWSs are important both in the process of assessment and engagement in treatment and, in the long-term, successful delivery of effective interventions for PWSs (Bhugra, 2010).

Pratima (2011) found that, Burden was to be lower at 6-months follow-up in relatives of PWSs with predominantly positive symptoms, and it was found to be stable among those of patients with predominantly negative symptoms. During a 5- year follow- up period high distress of the relatives of first-admission patients was related to poor outcome of the patients. Relatives’ burden was found to be stable at a 15- year follow-up in a sample of relatives who had not received any specific intervention as well as in one year follow up. Families have assumed a greater role in providing care for relatives with severe mental illness. Impact of managing disturbing behavior on caregivers is greatest. Disturbing behaviors refers to behaviors that actively violate household or social rules. Common disturbing behaviors reported by relatives include unusual ideas, social withdrawal, and violent behaviors. That behaviour has consistently been reported as an important correlate to caregiver burden. Negative symptoms have been posited to be more burdensome than positive ones. However, in another study, relatives reported having more difficulties with problems related to typical positive symptoms (e.g., poor insight, delusions, and hallucinations) than typical negative symptoms like anergia, apathy, social withdrawal.

CHAPTER 3
METHODOLOGY

In this chapter the researcher discusses study design, study setting, participants and sampling procedure, measuring instruments, field test of Zarit Burden Interview (ZBI), data collection procedure and technique, variables, data analysis, ethical issues, reliability and validity.

3.1. Study design

To conduct this study the researcher used the cross sectional survey method. Quantitative method was appropriate for this study as the issue is known about, relatively simple and clear-cut. Under the quantitative method the researcher used cross sectional methods that is one type of observational study, involves data collection from a population, or a representative subset, at one specific point in time. According to Levin (2006), Cross-sectional study is an analysis of the present situation and is carried out at one specific time, or over a short period. Data can also be collected on individual characteristics, including exposure to risk factors, along with information about the outcome. In this way cross sectional studies provide a snapshot of the outcome and characteristics associated with it, at a specific point in time. Usually there is no hypothesis as such, but the aim is to describe a population or a subgroup within the population with respect to an outcome and set risk factors.

The purpose of the study is to find out the burden level of caregivers of PWS at any one particular period of time. Data has been collected within two months. In this present study the researcher has also to investigate the association between the burden level and demographic factors of the respondents and patients with schizophrenia. Cross sectional studies are useful to identify associations that can then be more rigorously studied using a cohort study or randomized controlled study (Mann, 2003).

3.2. Study setting

The study was conducted in the Indoor and Outdoor unit of the NIMH at Dhaka in Bangladesh. This institute was established in 2001 with the aim of providing quality care to people with mental illness in Bangladesh. As a result patients are representative all over the country.

3.3. Sample

3.3.1. Sampling procedure

Hicks (1999) stated that, *"Findings the appropriate number and types of people take part in your study called sampling"*. The researcher used non-probability sampling throughout the process of participant selection. The convenience sampling method was used in this study. Convenience sampling is a process in which a sample is drawn from the conveniently available subjects. The procedure included all the caregivers of patients with schizophrenia who met the inclusion and exclusion criteria.

3.3.2. Sample size estimation

This is an essential part of good research design of any sort, whether it is surveys or experimental approaches. For quantitative research, it is better to meet as many subjects as possible relative to the size of the ideal population (Bowling, 1997). Sometimes sample size may big and sometimes it may small, depending the population and characteristics of the study. The convenience sampling is used to meet the desired sample size until they are not reachable (Depoy and Gitlin, 1998). This method helps to save time, money and energy (Bailey, 1997). On the other hand, Heiman (1995) stated that, it would be better to choose the convenience sampling method rather than random sampling, in order to select the sample for conducting research when the population is small. The study population is caregivers of PWSs in Bangladesh. Researcher selected 121 appropriate caregivers in order to conduct this study. The researcher has chosen convenience sampling to select the participants for this study in order to reach the desired sample size. Here the researcher used the formulation of sample size determination: $(n) = z^2.pq/r^2$. The researcher used 95% confidence interval and 5% sampling error for this study. Here, the confidence interval is $(z) = 1.96$ and the sampling error is $(r) = 0.05$. At the start of the survey The Researcher did not know the precise number of caregivers of patients with schizophrenia in Bangladesh. So, the researcher assumed that the prevalence of caregivers was $(p) = 0.5$ and (q) means $(1-p) = 0.5$. According to this calculation the standard sample was 384. But the researcher selected only selected 121 caregivers (both male and female) of PWSs who received treatment from NIMH (indoor and outdoor) for time limitation. The participants were selected based on inclusion and exclusion criteria.

3.3.3. Inclusion criteria

- The participants were the caregivers of PWSs.
- The participants were the primary caregivers, taking care of the patient.
- The Participants age range is 15-80 years (Talwar and Matheiken, 2010; Stanley and Shwetha, 2006).
- Caregivers must be selected from those patients who took the treatment from NIMH.

3.3.4. Exclusion criteria

- A caregiver with any mental illness.
- A caregiver who was unable to provide information properly.
- A caregiver who was not interested to give data.

3.4. Field test of ZBI

The researcher accomplished the field test after starting the data collection with the participants. The questionnaire adopted was from the Marche Prospective International (MAPI) research trust that was originally developed by Zarit, Reever and Bach-Peterson in 1980. The scale is a popular caregiver's self-administered questionnaire which is used in translation many countries. To make the questionnaire feasible the researcher translated (forward and backward) the main questionnaires in Bengali with three different people. The researcher had given the information to the participants about the aim and objective of the study. Then the researcher had performed field testing with two caregivers of patients with schizophrenia. It was conducted to check the wording was both appropriate and understandable.

3.5. Data collection

3.5.1. Data collection technique

In order to collect data the researcher conducted face to face interviews about the level of caregiver burden through a structured questionnaire. Using face to face interviews the researcher developed rapport with the caregiver to collect accurate data.

Bailey (1997) stated that, *"Interview conducted face to face is more innovate allowing the interviewer to indirect directly and develop rapport with the interview"*.

3.5.2. Data collection procedure

Firstly, in order to collect data the researcher obtained permission from the Head of the OT Department and Director of NIMH. The researcher fixed a date and time with the participant, according to his availability. The aim of the study, and study procedure was explained to participants before collecting data. The participant was given information sheets and consent forms and these were explained by the researcher. Participants had an opportunity to ask question, and they signed the consent form after being if they were satisfied. The researcher completed the signed questionnaire on the consent form with regards to demographic data. After that, the researcher collected the demographic information from the participant. Once it had been completed, the researcher completed the "ZBI" questionnaire through face to face interview in a silent place rather than the work place. Through this face to face interview the interviewer had a chance to understand the nonverbal cues given by the interviewee who may indicate confusion or lack of understanding. The interviewer helped the interviewee to understand the questions by changing some words with the same meaning (Bailey, 1997). The entire interview was conducted in Bengali whereas questionnaire was translated into Bengali following Linguistic validation guidelines of MAPI Research Institute for translation. The researcher was explained the question into local language that will be helpful to the participant.

3.5.3. Data collection instrument

The Researcher used three types of data collection instruments. These are:

- Socio demographic profile sheet: This questionnaire was developed by the researcher and included items related to the personal characteristics, such as age, sex, marital status, education, occupation, duration of illness and relationship with patient
- ZBI: This was developed to assess caregivers' burden of patients with chronic mental illnesses. The burden interview used in many countries in translated version. It is 22-item instrument that include the factors most frequently mentioned by caregivers as problem areas in providing care for mentally ill patients. The factors include the caregiver's health, psychological wellbeing, finances, social life, stigma details, and relationship between patient and caregiver. The instrument has a possible score of 0-88, depending on the caregiver's responses. Responses are rated from 0-4, based on the level of distress.

The ZBI scores were converted into categorical responses in this study. Scores ranging from 0 to 1 were regarded as negative, while scores ranging from 2 to 4 were regarded as positive.

- Paper, pen, pencil, eraser, sharpener, writing board, information sheet and consent form.

3.6. Data analysis

Data were analyzed through data entry, and analysis was performed using the Statistical Package for social science (SPSS), by using descriptive statistic method, version 17, and Microsoft excel spreadsheet. The presentation of data was organized in SPSS and in Microsoft Office Word. All data were input within the variable of SPSS. The ZBI and Demographic questionnaire were analyzed. Demographic factors were discussed such as sex, age, occupation, marital status, relationship and duration of caregiving. The SPSS was used to calculate all statistical data. Data was analyzed through descriptive statistical analysis and it is presented by using tables, figures, bar and pie charts.

The chi-square test (χ^2), also called Pearson's chi-square test of association, is used to discover if there is a relationship between two categorical variables. This (χ^2) test was done to measure the association among related variables. By (χ^2) test, the researcher determines the association among age, sex, occupation, relation, duration of care giving with the level of burden.

Total Caregiver Burden Scale questionnaire score is 88, and ranges from 0-88. There were four different categories of total score in ZBI scale. Score (0-20) mentions little or no burden, mild to moderate burden (21-40), moderate to severe (41-60) and finally severe burden (61-88). ZBI discussed the level of caregiver burden in five domains and clusters .These are the questions no. 1, 8, 11, 14, 18, 20 indicate the Burden in the relationship, question no. 2, 4, 5, 9, 10, 21, 22, illustrate emotional well-being, question no. 3, 6, 12, 13 shows social and family life, question no.15 indicates finances and finally loss of control over one's life is indicated by question no.7, 16, 17, 19. In the case of these five domains, firstly Burden in the relationship minimum score is 0 and maximum is 32, secondly Emotional well-being ranges from 0-28, thirdly Social and family life strain range from 0-16, fourthly Economic strain range 0-4. Finally Loss of control over one's life score ranges from 0-16.

Most of the caregivers were mothers (n=57), the rest were brothers (n=18), fathers (n=10), wives (n=7), sisters (n=6), aunties (n=10), uncles (n=6), daughters (n=3) and sons (n=4). Among all the patients, Married are (n=65), the others are unmarried (n=54) and the rest are divorced (n=2).

3.7. Ethical consideration

"In all research in the human sciences the rights; privacy and welfare of the participants should be respected" (Berg, 2009).

- The Researcher obtained permission from the Head of OT Department in BHPI.
- The Researcher obtained permission from the authority of the "ZBI" to use for the dissertation.
- The Researcher obtained permission from the authority of the NIMH.
- The Researcher maintained confidentiality about service information of the institutes.
- Informed consent was collected from the participants.
- The Researcher ensured that the confidentiality is maintained about the participants.
- All participants were informed about the aim of the study.
- The participant was allowed to leave from the study at any time.
- The Researcher also ensured that their participation would not cause any harm but would benefit them but in future.

3.8. Reliability and validity

- The ZBI explores the negative physical, mental, social, and economic impacts of caregiving on the life of the caregivers.
- The instrument has been widely used to assess caregiver burden on family members of patients with schizophrenia in Asia, South America and Africa. The popularity of the ZBI in these settings has been attributed to its ability to characterize the sociocultural dynamics of the population to which it is applied and the clarity of the items (Adeosun, 2013).
- The instrument has been used to assess caregiver's burden not only in dementia but also in schizophrenia (Yusuf, 2009).

- The ZBI is a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire. The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using 5-point scale. Response options range from 0 to 4 where 0 indicates never and 4 mentions nearly always (Zarit, Reever and Bach-Peterson, 1980).

3.9. Variables

- Dependent Variables: Types and course of Schizophrenia
- Independent Variables: Age, sex, occupation of the caregivers and caregiving duration

3.10. Dissemination of results

This academic research must be done for completing the Degree of B.Sc. in OT. The research will be published in the BHPI library which is the academic institute of Centre for the Rehabilitation of the Paralysed and a printed copy will go to OT Department.

Result At a Glance

Aim of the study	Objectives of the study	Findings
The aim of the study is to investigate the burden level on the caregivers of PWS	1. To explore the Socio-demographic picture of the caregivers of PWS at NIMH in Bangladesh	1. Most of the participants (64.5%) were femal and their age range was between 46-60 years. They were house wife (56.2%) and majority were mothers (47.1%) of the PWS.
	2. To explore the level of burden (mild, moderate and severe) of the caregivers	2. The burden of caregivers were moderate to severe (63.6%) rest of them had severe (25.6%) and mild to moderate burden (10.7%) due to caregiving.
	3. To identify the caregivers' Burden in the relationship, Emotional well-being, Social and family life, Finance and Loss of Control over one's life	3. There were moderate to severe burden on maximum caregivers (63.6%) in every domain.
	4. To determine the association among caregiver age, sex, occupation, relationship with patient and duration of care giving with the level of the caregivers' burden	4. The level of caregiver burden has strongly associated with caregiver sex ($P < 0.001$), relationship with the patient ($P < 0.000$) and caregiving duration ($P < 0.030$).

CHAPTER 4
RESULT

This segment provides statistical analysis in a systematic way and interpretation of analyzed data with the aim and objectives of the study. All of the participants had experience of caring PWS. The demographic information of the participants is summarized in Table 2.

4.1. Socio-demographic characteristics of the caregivers (N=121)

Characteristics		Frequency	Percentage (%)
Sex of caregiver	Male	43	35.5
	Female	78	64.5
Age of Caregiver	15-30 year	30	24.8
	31-45 year	39	32.2
	46-60 year	45	37.2
	61-80 year	7	5.8
Occupation of caregiver	Housewife	68	56.2
	Service holder	12	9.9
	Student	9	7.4
	Farmer	6	5.0
	Others	26	21.5
Religion of caregiver	Muslim	118	97.5
	Hindu	3	2.5
Relationship with PWS	Mother	57	47.1
	Wife	7	5.8
	Sister	6	5.0
	Brother	18	14.9
	Father	10	8.3
	Daughter	3	2.5
	Son	4	3.3
	Others	16	13.2
Duration of caregiving	Less than 01month	26	21.5
	01-06 months	25	20.7
	06months -01year	17	14.0
	01-02year	8	6.6
	02 years or more	45	37.2

Table 2: Socio-demographic characteristics of the caregivers

Demographic data of caregiver are listed in Table 2. The Table showed that among 121 participants, most of the participants were 64.5% female (n=78) and 35.5% were male (n=43) where 97.5 (n=118) were Muslim and only 2.5% (n=3) were Hindu religion.

The most of the caregiver's age ranges were from 46-60 years and mean age were 41.45 years and the Table 2 described 37.2% (n=45) were of 46-60 years, 32.2% (n=39) were of 31-45 years, 24.8% (n=30) were of 15-30 years, 5.8% (n=7) participants' age were from 61 years and more.

In table 2, among all the participants (n=121), 56.2% (n=68) were housewives, 9.9% (n=12) were service holders, 7.4% (n=9) were students, 5.0% (n=6) were farmers, and 21.5% (n=26) had other occupations such as businessmen, driver, day laborer, and unemployed.

With regard to their relationship with the PWS, most of the caregivers were mothers 47.1% (n=57), 14.9% (n=18) were brothers, 13.2% (n=16) were other relatives (nephew, mother-in-law, daughter-in-law, sister-in-law, brother-in-law and aunty) 8.3% (n=10) were fathers, 5.8% (n=7) were wives, 5.0% (n=6) were sisters, 3.3 % (n=4) were sons, and 2.5% (n=3) were daughters.

Again, table 2 shows that most of the participants 37.2% (n=45) were providing care for about 2 years or more, 21.5% (n=26) were providing care less than 1 month, 20.7% (n=25) 1- 6 months, 14.0% (n=17) 6 months-1 year and 6.6% (n=8) 1-2 years.

4.2. Socio-demographic characteristics of the PWSs

Characteristics		Frequency	Percentage (%)
Sex of Patient	Male	89	73.6
	Female	32	26.4
Marital status of Patient	Married	65	53.7
	Unmarried	54	44.6
	Divorce/Separation	2	1.7
Sickness before or after marriage	Unmarried	54	44.6
	Before marriage	16	13.2
	After marriage	51	42.2
Hospital identity	Indoor	88	72.7
	Outdoor	33	27.3

Table 3: Socio-demographic characteristics of PWSs

Demographic data of PWS are listed in Table 3. This Table shows that among 121 PWS, most of the patient were 73.6% male (n=89) and 26.4% were male (n=32) where 53.7% (n=65) were Married, 44.6% (n=54) were unmarried and others are 1.7% (n=2) were divorced. Most of the patients 72.7% (n=88) were having treatment from Indoor and 27.3% (n=33) were taken from Outdoor service of NIMH.

4.3. Overall Caregiver Burden

Score of ZBI	Frequency	Percentage (%)
21-40 (Mild to Moderate burden)	13	10.7
41-60 (Moderate to Severe burden)	77	63.6
61-88 (Severe Burden)	31	25.6
Total	121	100.0

Table 4: Overall caregiver burden

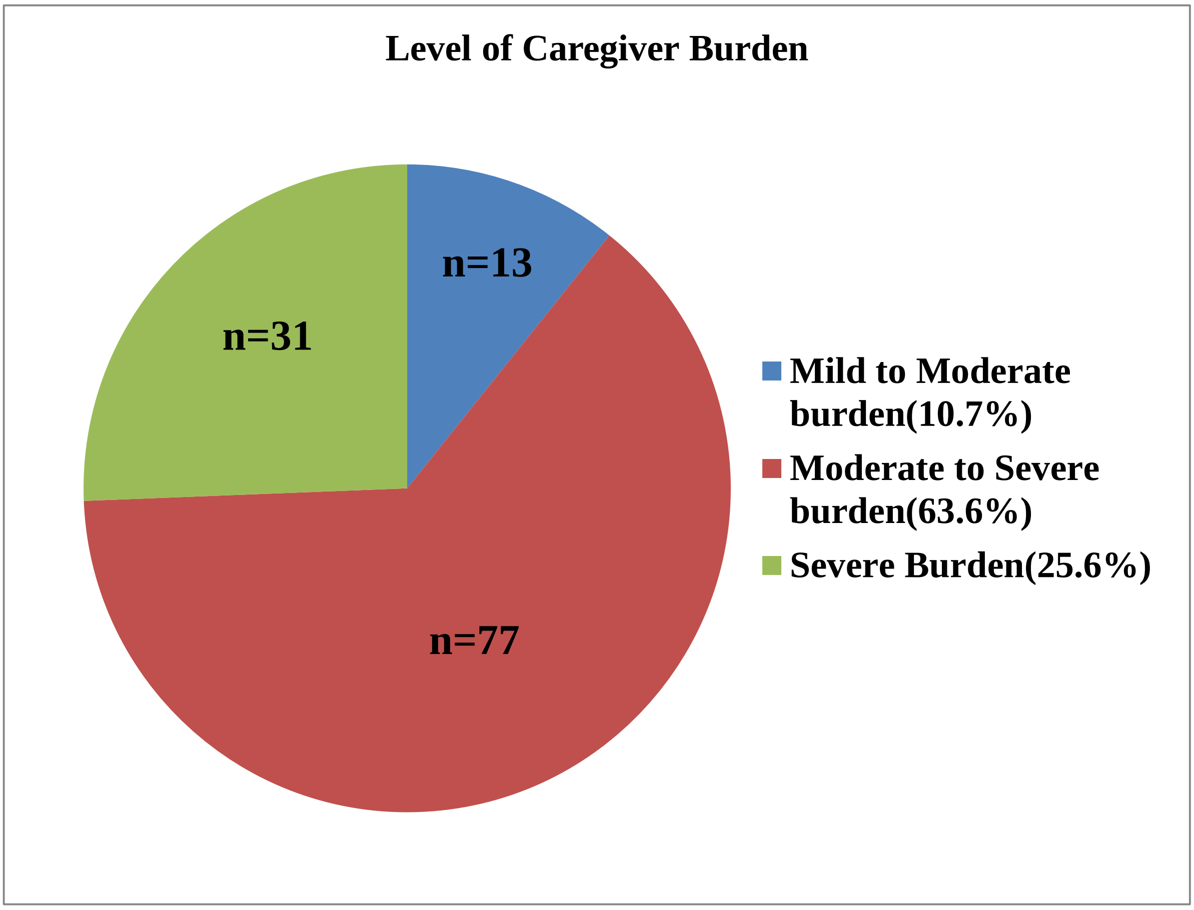

Figure 1: Level of caregiver burden

The study surveyed the caregiver burden of PWS by using ZBI which consist 22-questions. This scale analyzed the total caregiving burden as well as its five domains-Burden in the relationship, Emotional wellbeing, Social and family life, Finances and Loss of control over one's life. Analyzing Caregiver Burden scale the researcher found out the overall burden.

Table 4 and figure 1 shows that most 63.6% (n=77) of the caregivers of PWS have Moderate to Severe burden, where as 25.6% (n=31) of caregivers have Severe Burden and only 10.7% (n=13) of caregivers have low burden respectively.

4.4. Caregiver burden according to ZBI domains

The ZBI is composed of 22 items investigating in 5 domains (Rankin *et al*., 1994). These domains are Burden in the relationship, Emotional wellbeing, Social and family life, Finances and finally Loss of control over one's life.

Score	**Frequency**	**Percentage (%)**
6-11 (mild to moderate burden)	29	24.0
12-17 (moderate to severe burden)	79	65.3
18-24 (severe burden)	13	10.7
Total	121	100.0

Table 5: Domain 1 (Burden in the relationship)

In domain 1, table 5 shows that the moderate to severe burden is maximum 65.3% (n=79), severe burden is minimum 10.7% (n=13) and between them mild to moderate burden which is 24.0% (n= 29).

Score	**Frequency**	**Percentage (%)**
0-6 (little or no burden)	01	0.8
7-13 (mild to moderate burden)	24	19.8
14-20 (moderate to severe burden)	70	57.9
21-28 (severe burden)	26	21.5
Total	121	100.0

Table 6: Domain 2 (Emotional wellbeing)

In table 6, domain 2 shows that the moderate to severe burden is maximum 57.9% (n=70), little or no burden is minimum 0.8% (n=1) and between them mild to moderate burden and severe burden are 19.8 % (n=24) and 21.5% (n=26).

Score	**Frequency**	**Percentage (%)**
0-3 (little or no burden)	06	5.0
4-7 (mild to moderate burden)	38	31.4
8-11(moderate to severe burden)	51	42.1
12-16 (severe burden)	26	21.5
Total	121	100.0

Table 7: Domain 3 (Social and family life)

In domain 3, table 7 shows that the frequency of moderate to severe burden is the most 42.1 % (n=51).Secondly mild to moderate burden 31.4% (n=38).Thirdly severe burden 21.5% (n=26) and finally little or no burden is minimum 5.0% (n=6).

Score	**Frequency**	**Percentage (%)**
0-1 (little or no burden)	25	20.7
2 (mild to moderate burden)	30	24.8
3 (moderate to severe burden)	47	38.8
4 (severe burden)	19	15.7
Total	121	100.0

Table 8: Domain 4 (Finances)

Table 8 describes the finance domain. It shows the moderate to severe burden is 38.8% (n=47), mild to moderate is 24.8% (n=30), little or no burden is 20.7% (n=25), and lastly severe burden is 15.7% (n=19).

Score	**Frequency**	**Percentage (%)**
0- 3 (little or no burden)	01	0.8
4-7 (mild to moderate burden)	11	9.1
8-11 (moderate to severe burden)	77	63.6
12-16 (severe burden)	32	26.4
Total	121	100.0

Table 9: Domain 5 (Loss of control over one's life)

In domain 05, table 9 represents the loss of control over one’s life. This shows that maximum participants are in the moderate to severe phase 63.6% (n=77) and the rest are severe burden 26.4% (n=32), mild to moderate burden 9.1% (n=11) and little or no burden is 0.8% (n=1).

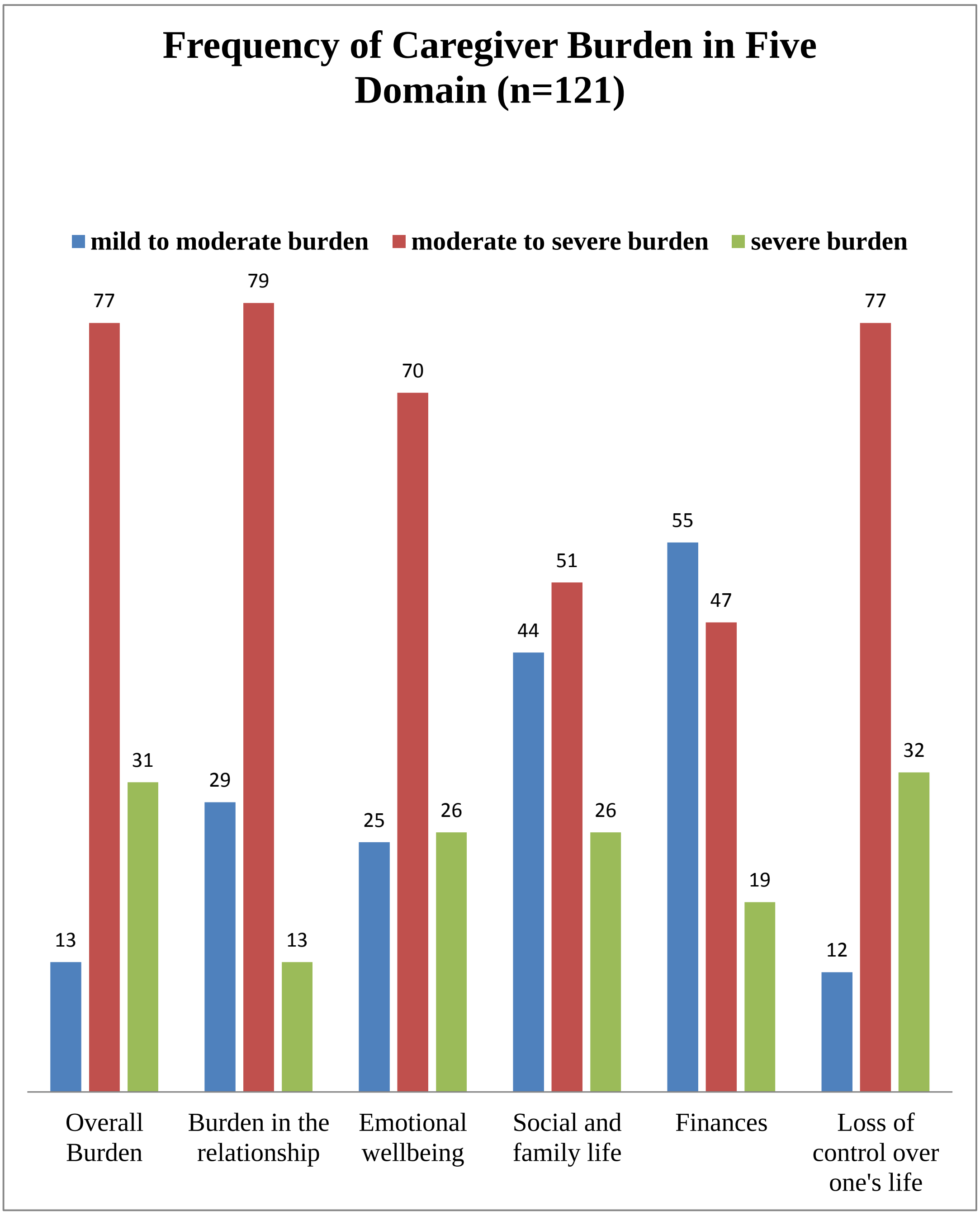

Figure 2: Level of caregiver burden according to five domains

4.5. Association between caregiver’s socio-demographic factors and level of caregiver burden among caregivers of PWS at NIMH in Bangladesh

Parameters	**Level of caregiver burden**			**Total N=121**	**χ^2 Value**	**P-value**
	Mild to Moderate burden n=13	**Moderate to Severe burden n=77**	**Severe Burden n=31**			
Age of Caregivers (in year)						
15-30 year	4.1% (5)	17.4% (21)	3.3% (4)	24.8% (30)	8.718	0.367
31-45 year	4.1% (5)	20.7% (25)	7.4% (9)	32.2% (39)		
46-60 year	2.5% (3)	20.7% (25)	14.0% (17)	37.2% (45)		
61-75 year		5.8% (7)	.8% (1)	6.6% (8)		
Caregivers Sex						
Male	7.4% (9)	24.8% (30)	3.3% (4)	35.5% (43)	13.769	0.001
Female	3.3% (4)	38.8% (47)	22.3% (27)	64.5% (78)		
Occupation of Caregiver						
Housewife	3.3% (4)	33.1% (40)	19.8% (24)	56.2% (68)	13.448	0.097
Service holder	1.7% (2)	5.8% (7)	2.5% (3)	9.9% (12)		
Student	1.7% (2)	5.8% (7)		7.4% (9)		
Farmer		4.1% (5)	.8% (1)	5.0% (6)		
Others	4.1% (5)	14.9% (18)	2.5% (3)	21.5% (26)		
Relationship with Patient						
Mother	1.7% (2)	26.4% (32)	19.0% (23)	47.1% (57)	50.696	0.000
Wife	.8% (1)	3.3% (4)	1.7% (2)	5.8% (7)		
Sister		4.1% (5)	.8% (1)	5.0% (6)		
Brother	2.5% (3)	10.7% (13)	1.7% (2)	14.9% (18)		
Father	.8% (1)	6.6% (8)	.8% (1)	8.3% (10)		
Daughter	.8% (1)	1.7% (2)		2.5% (3)		
Son	3.3% (4)			3.3% (4)		
Others	.8% (1)	10.7% (13)	1.7% (2)	13.2% (16)		
Caregiving Duration						
Less than 1month	4.1% (5)	16.5% (20)	.8% (1)	21.5% (26)	17.000	0.030
1-6 month	1.7% (2)	12.4% (15)	6.6% (8)	20.7% (25)		
6 month-1 year	1.7% (2)	10.7% (13)	1.7% (2)	14.0% (17)		
1-2 year	.8% (1)	5.0% (6)	.8% (1)	6.6% (8)		
2 year or more	2.5% (3)	19.0% (23)	15.7% (19)	37.2% (45)		

Table 10: Association between caregiver’s socio-demographic factors and level of caregiver burden

In the following Table 10 shows the association between level of burden and demographic characteristics of the caregiver and PWS. A Pearson Chi-square test was performed to show association between these variables.

There was strong association between caregiver sex and level of burden {(n=121), (χ^2 = 13.769), ($p < 0.001$)} and female were faced more moderate to severe burden than male.

Regarding to the relationship with the patient of schizophrenia there was very strong significant association with caregiver burden {(n=121), (χ^2 = 50.696), ($p < 0.000$)} that means burden were increased according to nature of relationship among caregiver and PWS and closer relatives like mother were faced more burden than others.

In case of caregiving duration {(n=121), (χ^2 = 17.000), ($p < 0.030$)} that indicate there was a strong significant association between duration of caregiving and caregiver burden which was increased with time.

Regarding to caregiver age {(n=121), (χ^2 = 8.718), ($P < 0.367$)} there was not significant association between caregiver age and level of caregivers burden.

Again caregiver occupation was not significantly associated with the level of caregiver burden {(n=121), (χ^2 = 13.448), ($p < 0.097$)} but housewives were faced moderate to severe burden than others.

CHAPTER 05
DISCUSSION

This chapter outlines the discussion among this study with others interrelated study in the world. The researcher had investigated the burden level of caregivers who are providing care to their schizophrenic family members in Bangladesh.

5.1. Socio-demographic characteristics of the caregiver

Socio-demographic characteristics are a strong predictor of perceived caregiver burden and sex is an important factor of socio-demographic characteristics. Regarding the socio-demographic status this study findings is similar to other study findings. This study finding revealed that 64.5% (n=78) caregivers were female and 35.5% (n=43) caregivers were male. The most of the caregiver's age ranges were from 46-60 years and mean age were 41.45 years. There are also some other study as like this study. In a study of Nepal Pun, He and Wang (2014) found more than 40 years age group and 57.8% female among 147 by using ZBI scale. Another study in Sri Lanka, maximum caregivers were female (Rodrigo and Silva, 2013). In India among the 100 primary care givers, 53% were female within the age range 51-60 years (Shihabuddeen, Chandran and Moosabba, 2012). Latest surveys estimate that there are 44 million caregivers over the age of 18 years (Talwar and Matheiken, 2010). 60% caregivers were women in Pakistan (Anjum, 2010). In Nigeria, 60.2% caregivers were female whereas male were 39.8%. It was also found that, the most of the caregivers were middle aged and majority of the caregivers were of 46-60 years (Adeosun, 2013). Among the 368 caregivers the majority, 77.8% were female. Their age ranged from 18 to 82 with median was 51 years (Lasebikan and Ayinde, 2013).

Care giving roles are mainly filled by women. In this study it found that most of the caregivers were female compared to male. Among all the participants 56.2% were housewives, and 21.5% (n=26) had other occupations such as businessmen, driver, day laborer, and unemployed. In Bangladesh, females are usually dedicated for managing household works and taking care of their family members. In India among the 100 primary care givers, 47% were housewives (Shihabuddeen, Chandran and Moosabba, 2012). Maximum participants (62%) were housewives in Nepal (Pun, He and Wang, 2014). Grandon (2008) showed the most participants were female 80.2% and 62.4% engaged with household activities in Chile.

The caregiver relationship with PWS is also an important factor for identifying burden. In this study most of the caregivers were mothers 47.1% (n=57), wives (5.8%), brothers (14.9%), fathers (8.3%), sisters (5.0%), daughters (2.5%), sons (3.3%), and other caregiver (13.2%) are relatives. Culturally a person is depended on their family member for caring and looking after during illness. Caregivers can be any member of the family or outside of the family but most of the cases the caregivers are parents; specially mothers in Bangladesh. Mothers usually stand by their son/daughter either they are single or married in this study. Maximum participants were parents 38.8% (Pun, He and Wang 2014). Another study in Sri Lanka, Most participants was parents and other relations were Child (Rodrigo and Silva, 2013). Gater (2014) found in his research that the most participants relationship with schizophrenia were parent, partner, sibling, child, and others. Another study in Taiwan (Lang, 2005) indicated the same findings. Among the 368 caregivers 11.7% were spouses, 81.5% were parents, and 6.8% were non-parent family members in Nigeria (Lasebikan and Ayinde, 2013).

Duration of caregiving also is an important predictor of the burden. Current study finding revealed that most of the caregivers 37.2% (n=45) were providing care for 02 years and more. Most of the patient had illness more than 5 years (Pun, He and Wang, 2014). In Sri Lanka, Most participants 56.3% had history more than 5 years of illness (Rodrigo and Silva, 2013). Two-thirds of the relatives were living with the patient (Roick *et al.*, 2007). For this reason, they cannot perform the daily living activities like eating, bathing, sleeping, taking care of other family members and leisure also.

Female caregivers of PWS report generally higher levels of the burden compared with male caregivers, specifically in terms of their levels of fear and awareness of the impact of the illness on the family (Boydell *et al.*, 2014).

The majority of studies indicate that caregiving roles are mainly filled by women. In Bangladesh, Females are usually dedicated for managing household works and taking care of their family members. In this study it found that most of the caregivers were female compared to male. Culturally a person is depended on their family member for caring and looking after during illness. Caregivers are any member of the family or outside of the family but most of the cases the caregivers are parents; specifically mothers in Bangladesh. Mothers usually stand by their son/daughter either they are single or married in this study.

5.2. Socio-demographic characteristics of the PWS

The present study exposed that majority of the PWS were male 73.6% (n=89) and female were 26.4% (n=32). The sex ratio was relatively equal in that male constituting 54% in comparison to 46% female in another study of Bangladesh (Ahammad, 2009). The socio demographic profile presented that majority Male patient 81% and female patient 19% in India (Shihabuddeen, Chandran and Moosabba, 2012). Again, Gardon, (2008) showed in his research, the gender were predominantly males (57%) rather than females 43%. Hou *et al.* (2008) reported on their study that 69% were male and rests were female (31%). But in 2009 and 2013, Yusuf and Adeosun both showed that, the female PWS were more than male.

Although the marital status of PWS was not related to burden but it is an important factor of socio-demographic characteristics and this study found that most of the patient 53.7% (n=65) were married, 44.6% (n=54) were unmarried and rest of the 1.7% (n=2) caregiver were divorcee. A study in Delhi 86% of the patient were single, 6% were married, 4% were either divorced or separated and 4% were widow (Shihabuddeen, Chandran and Moosabba, 2012). There were the same percentages of married and unmarried patients (Ahammad, 2009). In Nigerian study 16.6% were married, 44.3% were single, 32.1% separated, 3.0% divorced, and 1.4% were widowed (Lasebikan and Ayinde, 2013).

5.3. Level of burden of caregiver of PWS

Caregivers burden Level measured by the ZBI Scale. The Caregiver burden scale indicated that a higher score means severe burden and lower scores means little or no burden. In this research total level of Mild to Moderate burden only 10.7%, Moderate to Severe burden rate is 63.6% and severe Burden rate is 25.6%. So, from this study the researcher could be believed that most of the caregivers faced moderate to severe level of the burden in Bangladesh. Majority 96% of the key relatives had moderate to severe burden, and 46 % had minimal distress and 50% had moderate to marked distress (Shihabuddeen, Chandran and Moosabba, 2012).

It was found that 46.9% were perceived moderate amount burden and 36.7% experienced mild burden while 11.6% felt little burden and 4.8% were experienced severe burden during caring, their PWS (Pun, He and Wang, 2014).

The study of Arab, Zahid (2010) stated that, the majority of caregivers had mild to moderate burden experiences. A large amount of participants were experiencing a moderate to severe level of burden. This was significantly associated with family size and place of residence (Yusuf, 2009).

Caregivers who were either children or spouses of patients had a tendency to have higher burden scores than other relationship groups. Different researcher used various scale as like ZBI for assessing caregiver burden. The Burden assessment schedule (BAS) is one of them. It is a very popular and widely used scale to assess both objective and subjective burden experienced by the caregivers measuring nine different areas with 40-item . Each item has three responses “not at all,” “to some extent,” and “very much.” Scores range from 40 to 120 with higher scores indicating greater burden. The BAS score was ranging from 60 to 80.42% of the caregivers in Malaysia, while 46% of the caregivers in India had little to moderate level of burden. 58% of the caregivers in Malaysia, while 54% of the caregivers in India had high or severe level of burden (Talwar and Matheiken, 2010). Though in many countries different researchers used several scale but most of them found same result as like this study.

5.4. Caregiver burden according to ZBI domains

The researcher found the result in the five main aspects according to ZBI scale, these are Burden in the relationship, Emotional wellbeing, Social and family life, Finances and Loss of control over one's life are different in level of burden. In every domain it is seen that most of the participants had moderate to severe level of burden according to the 65.3%, 57.9%, 42.1 %, 38.8%, and 63.6% in this study. Female caregivers had significantly higher burden scores than male caregivers on the every domain in Bangladeshi perspective. The researcher investigated all of the domains but there are some other studies where specific domain was studied. In the Indian study almost 61% had severe financial burden, 19% had moderate burden, and 27 % had no burden 46% had minimal distress, 28% had moderate distress, 22% had marked distress and 4% had no distress (Shihabuddeen, Chandran and Moosabba, 2012).

Adeosun (2013) used five domains of ZBI for his study in Nigeria. He found more burden “financial/physical strain”, “time/dependence strain”, “emotional strain”, “uncertainty”, and “self-criticism” domains. Employed caregivers had significantly higher burden scores on the “self-criticism” and “time/dependence” domains. In African society, female caregivers may tend to accept the caregiver role as their exclusive preserve such that the demands on their time by the tasks of caregiving are perceived as normal, thus, accounting for the lack of association of higher burden scores in the “time/dependence” domain with being a female caregiver.

5.5. Association between caregiver’s socio-demographic factors and level of caregiver burden among caregivers of PWS at NIMH in Bangladesh

In this study the researcher found three strong associations among five socio-demographic characteristic. There was strong association between caregiver sex and level of burden {(n=121), ($\chi^2 = 13.769$), ($p < 0.001$)} and female were faced more moderate to severe burden than male. Different study showed various associations such as- Sex had highly significant $p < 0.001$ correlation with subjective burden (Anjum, 2010). Female caregivers had significantly higher burden scores than male caregivers’ $p < 0.036$ (Adeosun, 2013). The tendency for those caring for female patients to have higher burden reached significance $P < 0.004$ (Zahid, 2010). It is seen that there is a highly significant statistical difference for both male and female caregivers’ $p < 0.001$ (Stanley and Shwetha, 2006). In Germany and Britain, Family burden was associated with patients’ symptoms and male sex (Roick *et al*., 2007).

Regarding to the relationship with the patient of schizophrenia there was very significant association with caregiver burden {(n=121), ($\chi^2 = 50.696$), ($p < 0.000$)} that means burden were increased according to nature of relationship among caregiver and PWS and closer relatives like mother were faced more burden than others. Older caregivers and caregivers who were parents or spouses of the patients had significantly higher burden scores on the “uncertainty” domain (Adeosun, 2013).

Caregivers who were either children or spouses of patients had a tendency to have higher burden scores than other relationship groups $P < 0.002$ (Zahid, 2010). The correlation between ZBI score with coping strategies, emotional support.

Significant correlations with ZBI score were observed for the total score of coping strategy and emotional support both $P < 0.01$ (Hanzawa, 2008). Marital status found to be highly significant with the amount of burden level $p < 0.00$ (Pun, 2014).

In case of caregiving duration {(n=121), (χ^2 = 17.000), ($p < 0.030$)} that indicate there was a strong significant association between duration of caregiving and caregiver burden which was increased with time. Among the demographic variables duration of the illness and marital status found to be highly significant $p < 0.000$ with amount of burden (Pun, 2014).The significant associations for being depressed among caregivers were, spending more time with the patient (above the group average), being assaulted by the patient, interruption to work, disputes with children and other relations and the subjective feeling of increased psychological burden (Rodrigo and Silva, 2013).

On the contrary, caregivers' occupation were not significantly associated with the level of caregiver burden {(n=121), (χ^2 = 13.448), ($p < 0.097$)} but housewives were faced moderate to severe burden than others. Occupation had a strong inverse relation with BAS (Anjum, 2010). Unemployed caregivers had higher burden scores on the "financial/physical strain" $p < 0.003$ domain, while employed caregivers scored significantly higher. Caregivers of patients working in households activities with fewer numbers of people had higher burden scores on the "financial/ physical strain" and "time/dependence" domains (Adeosun, 2013).

Regarding to caregiver age {(n=121), (χ^2 = 8.718), ($P < 0.367$)} there was not significant association between caregiver age and level of caregivers burden. Hanzawa (2008) identified that, there was no significant association with age, sex, age at disease onset, total years of hospitalization, and total number of hospital admissions or best social involvement with average score of ZBI. Pun (2014) stated that, there is no significant link among age, sex, work and relationship with the amount of burden perceived by caregivers of schizophrenia.

CHAPTER 6
LIMITATION AND RECOMMENDATION

5.1. Limitation of the study

The researcher acknowledges some limitations and barriers in this investigation. These include:

- There is few published literature available in Bangladesh regarding ‘caregiver burden’ about PWS
- The sample was selected as convenient way rather than randomly.
- The overall samples were selected from NIMH because of time limitation.

5.2. Recommendation of the study

From this study it is clearly seen that the caregivers of PWS perceived moderate to severe level of burden during caregiving. The researchers have drawn some recommendation based on the findings of the research. The researcher recommends that in future similar research might be conducted in the broader area with larger scale of sample size. A further research in this area might contribute to understand the characteristics of vulnerable caregivers and the factors or predictors that increasing caregiver burden. For ensuring effective treatment and rehabilitation of PWS, it is necessary to ensure caregiver physical, mental and socio-economic wellbeing. The current study also recommends that health professionals might contribute to minimize the caregivers’ vulnerable situation by providing proper education, patient handling training, occupational training, counseling, information for maintaining own health, and promoting social participation of the target caregivers. Researcher recommends that more male caregivers need to be encouraged to participate in care giving activities rather than only female caregivers.

CHAPTER 7
CONCLUSION

Schizophrenia is a critical mental disorder which creates harmful effects on individual who is suffering by this condition as well as their family members. This research demonstrates that the Burden level on caregivers of PWS. It is totally complex and multifaceted experience. All caregivers play a significant role. The participants are facing difficulties during providing a high level of care and support to their mentally ill family members. In this study maximum caregivers face moderate to severe burdens with burden in the relationship, Emotional wellbeing, Social and family life, Finances, Loss of control over one's life. Caregivers’ burden may consider financial burden, effect on mental and physical health of other family members, effect on family interaction, family routine, and family leisure time etc.

Caregivers may seek support from family and friends, community support groups, professional services, respite and spiritual or religious groups. Social support is particularly important for family who care for an individual with mental illness, as these caregivers are often isolated due to stigma and a lack of understanding (Boydell *et al.*, 2014).

In Bangladeshi culture people are more hospitable. Caregivers think that caring for their near ones is their responsibility and they enthusiastically take this responsibility rather than feel burden. Through this study it was also found that the degree of burden depends on several aspects, such as caregiver’s social and demographic characteristics: age, sex, relationship, caregiving duration and time and onset of PWS. The study also discovered that mother got more burden than other family members.

The caregivers are an integral part of health care system for treating the PWS all over the world. Patients’ better outcome depend on caregivers’ wellbeing. So every health care professional need to be concern about the level of caregiver burden and should take steps to prevent the burden as well as ensure better quality of life for PWS.

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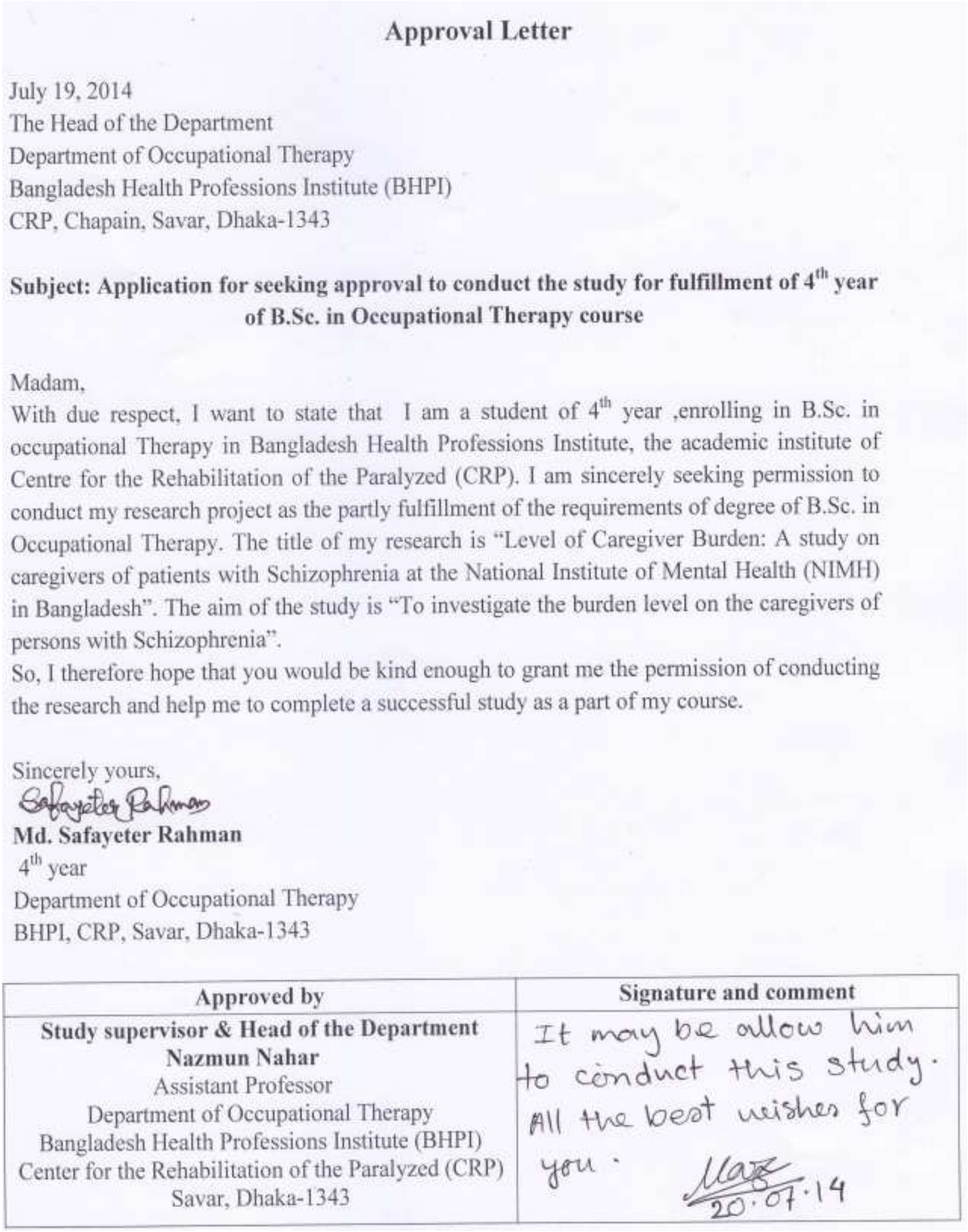
Appendix 1

Permission letter for conducting study



Approval Letter

July 19, 2014
The Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

Subject: Application for seeking approval to conduct the study for fulfillment of 4th year of B.Sc. in Occupational Therapy course

Madam,

With due respect, I want to state that I am a student of 4th year ,enrolling in B.Sc. in occupational Therapy in Bangladesh Health Professions Institute, the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). I am sincerely seeking permission to conduct my research project as the partly fulfillment of the requirements of degree of B.Sc. in Occupational Therapy. The title of my research is “Level of Caregiver Burden: A study on caregivers of patients with Schizophrenia at the National Institute of Mental Health (NIMH) in Bangladesh”. The aim of the study is “To investigate the burden level on the caregivers of persons with Schizophrenia”.

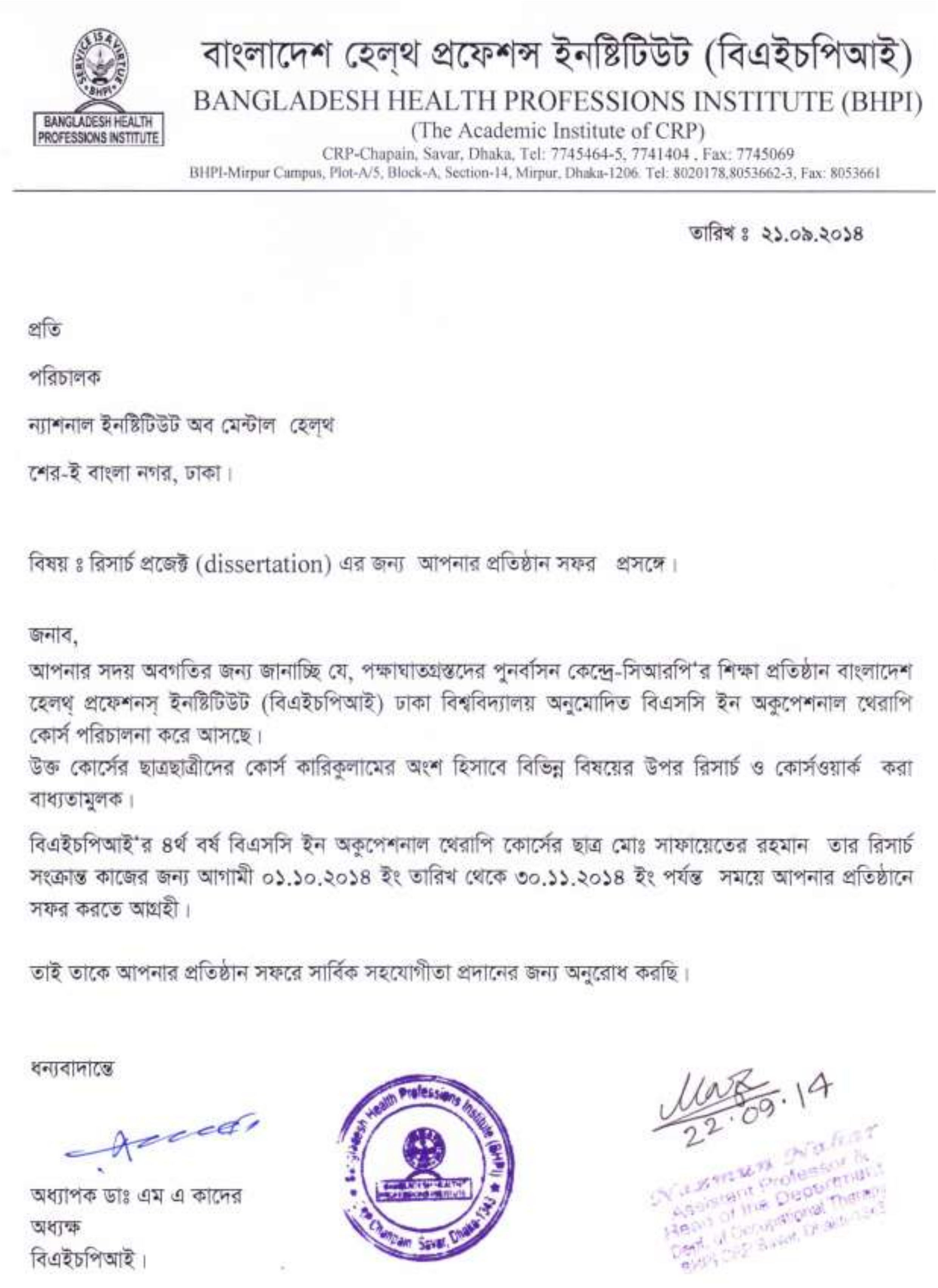
So, I therefore hope that you would be kind enough to grant me the permission of conducting the research and help me to complete a successful study as a part of my course.

Sincerely yours,
Safayeter Rahman
Md. Safayeter Rahman
4th year
Department of Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343

Approved by	Signature and comment
Study supervisor & Head of the Department **Nazmun Nahar** Assistant Professor Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) Center for the Rehabilitation of the Paralyzed (CRP) Savar, Dhaka-1343	It may be allow him to conduct this study. All the best wishes for you. 20.07.14

Appendix 2

Permission letter for data collection



বাংলাদেশ হেল্‌থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404 , Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ২১.০৯.২০১৪

প্রতি

পরিচালক

ন্যাশনাল ইনষ্টিটিউট অব মেন্টাল হেল্‌থ

শের-ই বাংলা নগর, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেলথ্ প্রফেশনস্ ইনষ্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামুলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্র মোঃ সাফায়েতের রহমান তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০১.১০.২০১৪ ইং তারিখ থেকে ৩০.১১.২০১৪ ইং পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

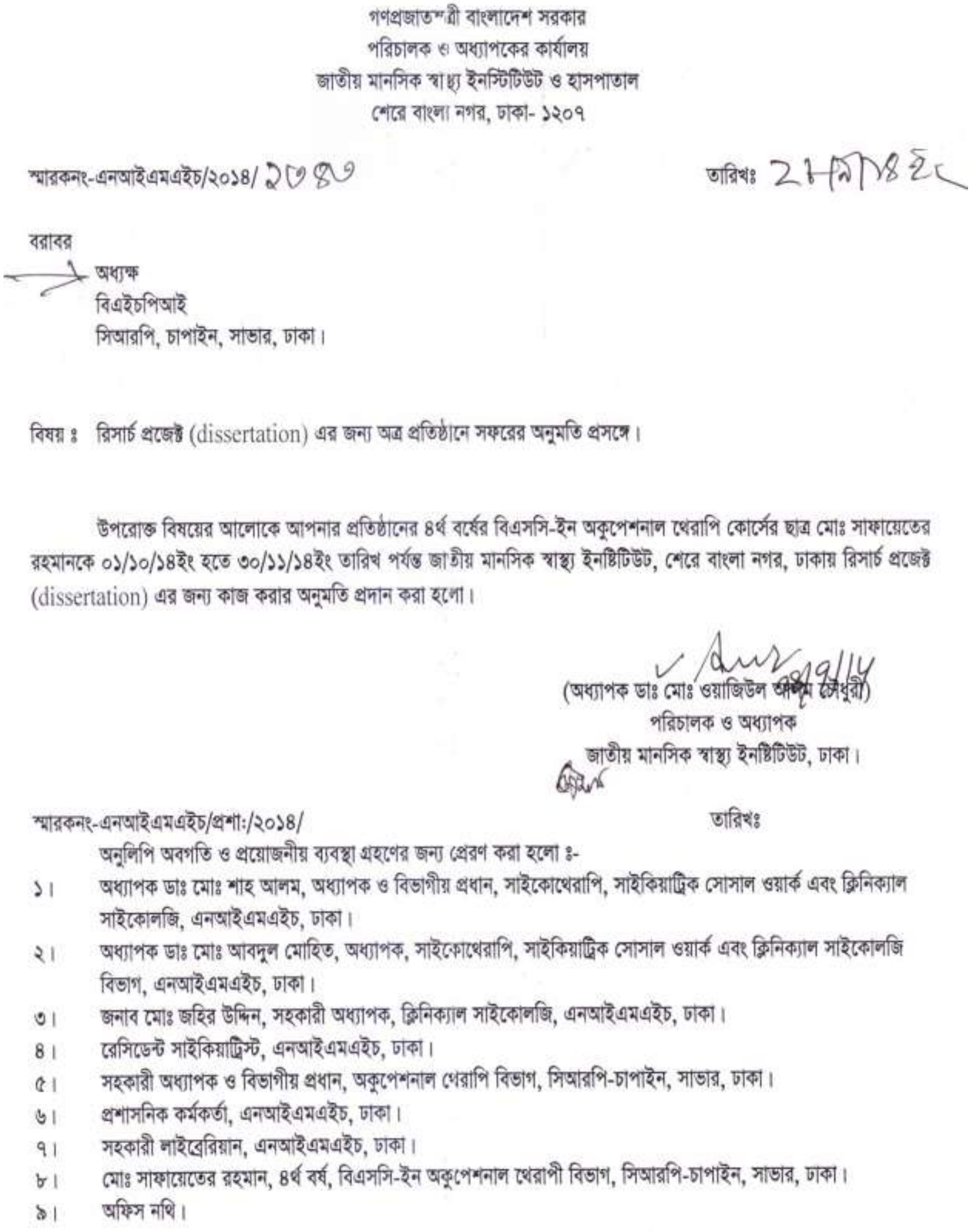
অধ্যাপক ডাঃ এম এ কাদের
অধ্যক্ষ
বিএইচপিআই।

22.09.14

[illegible]
Assistant Professor &
Head of the Department
Dept. of Occupational Therapy
BHPI, CRP, Savar, Dhaka

Appendix 3

Permission letter for data collection



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

স্মারকনং-এনআইএমএইচ/২০১৪/ ২৩৪৩ তারিখঃ ২৮/৯/১৪ইং

বরাবর
অধ্যক্ষ
বিএইচপিআই
সিআরপি, চাপাইন, সাভার, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) এর জন্য অত্র প্রতিষ্ঠানে সফরের অনুমতি প্রসঙ্গে।

উপরোক্ত বিষয়ের আলোকে আপনার প্রতিষ্ঠানের ৪র্থ বর্ষের বিএসসি-ইন অকুপেশনাল থেরাপি কোর্সের ছাত্র মোঃ সাফায়েতের রহমানকে ০১/১০/১৪ইং হতে ৩০/১১/১৪ইং তারিখ পর্যন্ত জাতীয় মানসিক স্বাস্থ্য ইনষ্টিটিউট, শেরে বাংলা নগর, ঢাকায় রিসার্চ প্রজেক্ট (dissertation) এর জন্য কাজ করার অনুমতি প্রদান করা হলো।

29/9/14
(অধ্যাপক ডাঃ মোঃ ওয়াজিউল আলম চৌধুরী)
পরিচালক ও অধ্যাপক
জাতীয় মানসিক স্বাস্থ্য ইনষ্টিটিউট, ঢাকা।

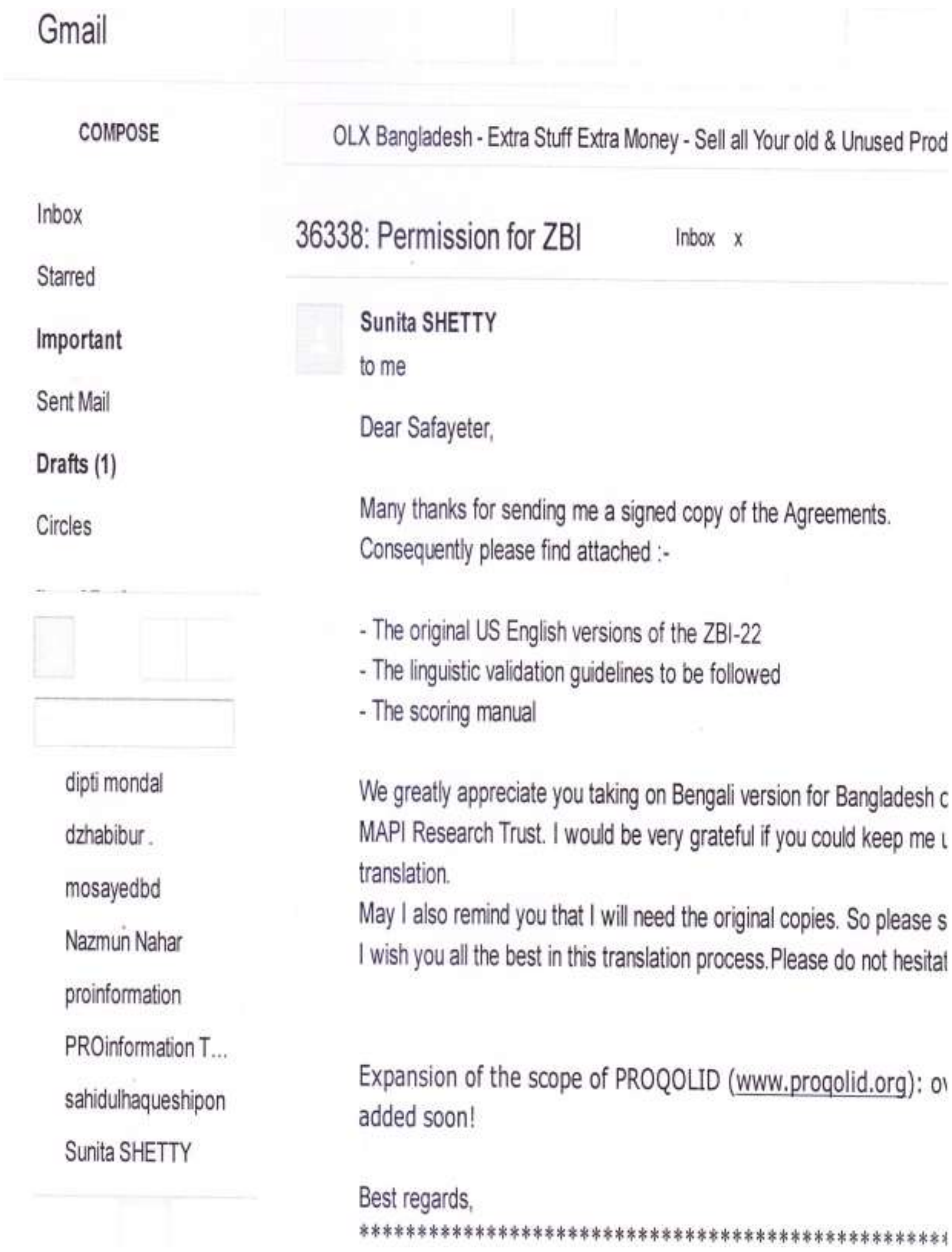
স্মারকনং-এনআইএমএইচ/প্রশা:/২০১৪/ তারিখঃ

অনুলিপি অবগতি ও প্রয়োজনীয় ব্যবস্থা গ্রহণের জন্য প্রেরণ করা হলো ঃ-

১। অধ্যাপক ডাঃ মোঃ শাহ আলম, অধ্যাপক ও বিভাগীয় প্রধান, সাইকোথেরাপি, সাইকিয়াট্রিক সোসাল ওয়ার্ক এবং ক্লিনিক্যাল সাইকোলজি, এনআইএমএইচ, ঢাকা।
২। অধ্যাপক ডাঃ মোঃ আবদুল মোহিত, অধ্যাপক, সাইকোথেরাপি, সাইকিয়াট্রিক সোসাল ওয়ার্ক এবং ক্লিনিক্যাল সাইকোলজি বিভাগ, এনআইএমএইচ, ঢাকা।
৩। জনাব মোঃ জহির উদ্দিন, সহকারী অধ্যাপক, ক্লিনিক্যাল সাইকোলজি, এনআইএমএইচ, ঢাকা।
৪। রেসিডেন্ট সাইকিয়াট্রিস্ট, এনআইএমএইচ, ঢাকা।
৫। সহকারী অধ্যাপক ও বিভাগীয় প্রধান, অকুপেশনাল থেরাপি বিভাগ, সিআরপি-চাপাইন, সাভার, ঢাকা।
৬। প্রশাসনিক কর্মকর্তা, এনআইএমএইচ, ঢাকা।
৭। সহকারী লাইব্রেরিয়ান, এনআইএমএইচ, ঢাকা।
৮। মোঃ সাফায়েতের রহমান, ৪র্থ বর্ষ, বিএসসি-ইন অকুপেশনাল থেরাপী বিভাগ, সিআরপি-চাপাইন, সাভার, ঢাকা।
৯। অফিস নথি।

Appendix 4

Permission to Use Zarit Burden Interview



36338: Permission for ZBI

Sunita SHETTY
to me

Dear Safayeter,

Many thanks for sending me a signed copy of the Agreements.
Consequently please find attached :-

- The original US English versions of the ZBI-22
- The linguistic validation guidelines to be followed
- The scoring manual

We greatly appreciate you taking on Bengali version for Bangladesh c
MAPI Research Trust. I would be very grateful if you could keep me u
translation.
May I also remind you that I will need the original copies. So please s
I wish you all the best in this translation process.Please do not hesitat

Expansion of the scope of PROQOLID (www.proqolid.org): ov
added soon!

Best regards,
****

Appendix 5

Information Sheet

This is to inform that Md. Safayeter Rahman, student of 4th year, Department Occupational Therapy, Bangladesh Health Professions Institute (BHPI), the academic institute of CRP, is doing a research project which is part of course curriculum. So the researcher would like to invite you participating in his study titled “Level of Caregiver Burden: A study on caregivers of patients with Schizophrenia at the National Institute of Mental Health (NIMH) in Bangladesh”.

Your participation in the study is voluntary. You can withdraw your participation anytime. There is no facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience about the discharge process, which is very important for the service provider to plan for their future activities. It will also be helpful for the forthcoming service users.

Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except this study and the study will certainly never reveal the name of participants.

If you have any query regarding the study, please feel free to ask to the contact information stated below:

Md. Safayeter Rahman
4th year, B. Sc. in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI),
Centre for the Rehabilitation of the Paralysed (CRP),
Chaplain, Savar, Dhaka-1343

Appendix 6

Consent Form

This research is part of Occupational Therapy course and the name of the researcher is Md. Safayeter Rahman. He is the student of 4th year, Department of Occupational Therapy in Bangladesh Health Professions Institute (BHPI). The study was entitled as "Level of Caregivers Burden: A study on caregiver of patients with Schizophrenia at the National Institute of Mental Health (NIMH) in Bangladesh" and the aim of study is to investigate the burden level on the caregivers of persons with Schizophrenia.

In this study I am ……………………………………………………. a participant and I have been clearly informed about the purpose and aim of the study. I will have the right to refuse in taking part any time at any stage of the study. For that reason I will not be bound to answer to anybody. This study has no connection with me and there will be no impact on me and my patient regarding treatment at present and in future. I am also informed that, all information will be collected from the interview that is used in the study will be kept safely and will maintain confidentiality. My name and address will not be published anywhere. Only the researcher and supervisor will be eligible to access in the information for his publication of the research result. I can consult with the researcher and the research supervisor about the research process or get answer of any question regarding the research project. I have been informed about the above-mentioned information and I am willing to participate in the study with giving consent.

Signature/Finger print of the Participant: Date:

Signature of the Researcher: Date:

Signature/Finger print of the witness: Date:

Appendix 7

তথ্য পত্র

আমি মোঃ শাফায়েতের রহমান, বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউটে (সিআরপির শিক্ষা প্রতিষ্ঠান) অকুপেশনাল থেরাপী বিভাগ এ ৪র্থ বর্ষে অধ্যয়নরত। আমার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলন্ত শিক্ষাবর্ষে আমাকে একটি গবেষণামূলক কাজ করতে হবে যার শিরোনাম “শুশ্রুষাকারীর বোঝা এর মাত্রা : বাংলাদেশ জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট এ সিজোফ্রেনিয়া রোগীর শুশ্রুষাকারীর উপর একটি গবেষণা”

এই গবেষণায় আপনার অংশগ্রহন সম্পূর্ণরূপে স্বেচ্ছায় আপনি যেকোন সময় গবেষণায় আপনার অংশগ্রহন করা থেকে বিরত থাকতে পারবেন। এই গবেষণায় অংশগ্রহনে গবেষক আপনাকে কোন ভাবে আর্থিক সাহায্য প্রদানে অপারগ। এই অংশগ্রহন কখনোই আপনার জন্য ক্ষতির কারণ হয়ে দাঁড়াবেনা, কিন্তু এটার মাধ্যমে সেবাপ্রদানকারী সদস্যগণ তাঁদের প্রদানকৃত সেবা সম্পর্কে আপনার অভিজ্ঞতার কথা জানতে পারবেন। প্রাপ্ত তথ্য সমূহ পরবর্তীতে সেবার মানোন্নয়নে সাহায্য করবে, যা ভবিষ্যতে রোগীদের ক্ষেত্রেও সহায়ক হবে।

আপনার কাছ থেকে প্রাপ্ত তথ্য সমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। গবেষনা ব্যতীত এগুলো অন্যথায় প্রকাশিত করা হবে না এবং গবেষণার কোথাও অংশগ্রহণকারীর নাম প্রকাশ করা হবে না। গবেষণা সম্পর্কিত যেকোন ধরনের প্রশ্নের জন্য নিম্নোলিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে:

মোঃ শাফায়েতের রহমান
৪র্থ বর্ষ
অকুপেশনাল থেরাপী বিভাগ
বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট
পক্ষাঘাতগ্রস্থদের পূনর্বাসন কেন্দ্র (সিআরপি)
চাপাইন, সাভার, ঢাকা- ১৩৪৩

Appendix 8

সম্মতি পত্র

এই গবেষণাটি অকুপেশনাল থেরাপীর একটি অংশ এবং গবেষণাকারীর নাম মোঃ শাফায়েতের রহমান। সে বাংলাদেশ হেলথ প্রফেশন্স ইন্সটিটিউট এর বি.এস.সি. ইন অকুপেশনাল থেরাপীর ৪র্থ বর্ষের ছাত্র। এই গবেষণাটির শিরোনাম “শুশ্রুষাকারীর বোঝা এর মাত্রা : বাংলাদেশ জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট এ সিজোফ্রেনিয়া রোগীর শুশ্রুষাকারী উপর একটি গবেষণা”

এই গবেষণাতে আমি একজন অংশগ্রহনকারী এবং আমি পরিষ্কারভাবে এই গবেষণার উদ্দেশ্য সম্পর্কে অবগত আছি।আমার যেকোন সময় এই গবেষণা থেকে নিজেকে সরিয়ে আনার অধিকার আছে। এজন্য আমি প্রশ্নের উত্তর প্রদান করার জন্য কারো কাছে দায়বদ্ধ না। এই গবেষনাটির সাথে আমার কোন সম্পৃক্ততা নেই। আমি আরও অবগত আছি যে,এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলি নিরাপদে এবং গোপন রাখা হবে। আমার নাম এবং ঠিকানা কোথাও প্রকাশ করা হবেনা। শুধুমাত্র গবেষণাকারী এবং তার সমন্বয়কারী এই তথ্যাবলী দেখার ক্ষমতা রাখেন।

আমি এই গবেষণাকারীর এবং তার গবেষনার সমন্বয়কারীর সাথে এই গবেষনার পদ্ধতি সম্পর্কে অথবা যেকোন প্রশ্নের উত্তর জানার জন্য কথা বলতে পারব।আমি উপরোক্ত তথ্যগুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষণায় অংশগ্রহণ করছি।

অংশগ্রহনকারীর স্বাক্ষর/ টিপসই: তারিখঃ

গবেষণাকারী রস্বাক্ষর: তারিখঃ

সাক্ষ্যপ্রদানকারীর স্বাক্ষর/ টিপসই: তারিখঃ

Appendix 9

Socio-Demographic Questionnaire

Date: ……. /……. / 2014 Code No: ………..

- Name of Patient:
- Name of Caregiver:
- Sex of Caregiver: Male / Female
- Age of Caregiver (in years):
- Duration of Care giving: ………..Month ,………..Year,…………..Hour/ Day
- Relation to the patient: Father/Mother/Brother/Sister/Wife/Uncle/Aunty/Others…
- Patient's marital status: Married/Unmarried/ /Divorce/Widow/Separated………
- If married, duration of illness after marriage:
- Is the patient suffering from illness before marriage? Yes/No. How long……
- Religion: Muslim/Hindu/Christian/Buddhist /others……………..
- Educational level: Illiterate/P.S.C/J.S.C/S.S.C/H.S.C/B.Sc./Higher/……………
- Occupation of Patient:
- Occupation of Caregiver:
- Date of admission or appointment: ……………………..….. , Indoor /Outdoor
- Others: …...……………………………………………………………………

Appendix 10

জনসংখ্যাতাত্ত্বিক তথ্যাবলী

তারিখ :............./............../২০১৪ কোড নং:...................

- রোগীর নামঃ..
- শুশ্রূষাকারীর নামঃ..
- শুশ্রূষাকারীর লিঙ্গঃ পুরুষ/মহিলা
- শুশ্রূষাকারীর বয়সঃ.....................বছর
- সেবাপ্রদানের সময়কালঃ................. বছর,................. মাস,.................ঘণ্টা/দিন
- রোগীর সাথে শুশ্রূষাকারীর সম্পর্কঃ বাবা/মা/ভাই/বোন/স্ত্রী/মামা/চাচা/খালা/ফুফু/অন্যান্য
- রোগীর বৈবাহিক অবস্থাঃ বিবাহিত/অবিবাহিত/তালাকপ্রাপ্ত/বিধবা/একাকি/ অন্যান্য.........
- যদি বিবাহিত হয় , তবে বিবাহের পরে কতদিন যাবৎ অসুস্থঃ ......বছর.......মাস........দিন
- রোগী কি বিয়ের আগে থেকেই রোগে ভুগছে কিনা? হ্যাঁ/না।
- কতদিন যাবৎ অসুস্থঃ.........বছর.......মাস........দিন
- ধর্মঃ মুসলিম/হিন্দু/খ্রিস্টান/বৌদ্ধ/ অন্যান্য........................
- শিক্ষাগতযোগ্যতা:অশিক্ষিত/স্বশিক্ষিত/প্রাথমিক/মাধ্যমিক/উচ্চমাধ্যমিক/স্নাতক/স্নাতকত্তর.
- রোগীর পেশাঃ...
- শুশ্রূষাকারীর পেশাঃ..
- ভর্তির তারিখ:.................................,অন্তর্বিভাগ/বহির্বিভাগ
- অন্যান্য:..

Appendix 11

Zarit burden interview

1. Do you feel that your relative asks for more help than he/she needs?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

4. Do you feel embarrassed over your relative's behavior?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

5. Do you feel angry when you are around your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

7. Are you afraid what the future holds for your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

8. Do you feel your relative is dependent upon you?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

9. Do you feel strained when you are around your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

17. Do you feel you have lost control of your life since your relative’s illness?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

21. Do you feel you could do a better job in caring for your relative?

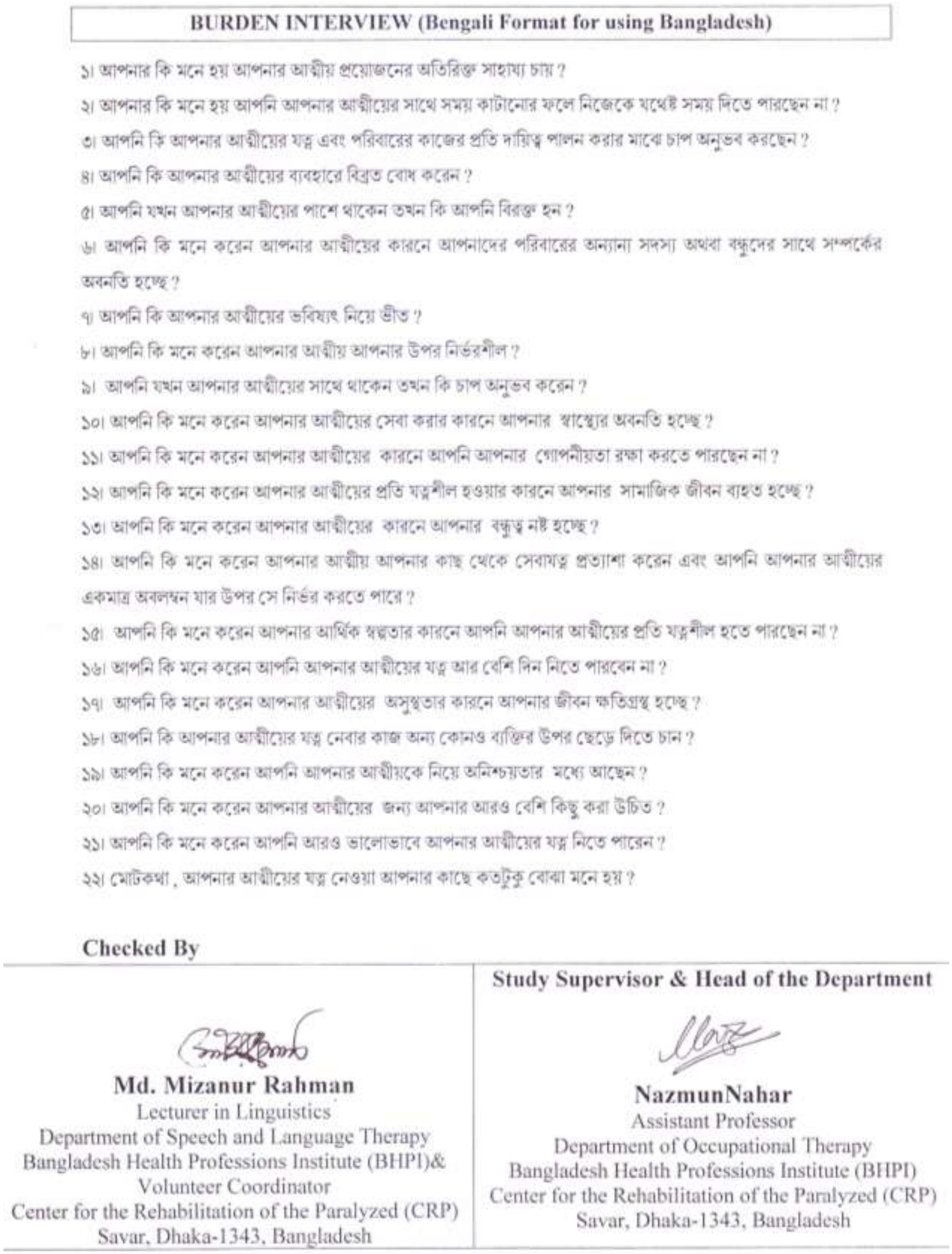
0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Never 1. Rarely 2.Sometimes 3.Quite Frequently 4.Nearly Always

Appendix 12

Zarit Burden Interview



BURDEN INTERVIEW (Bengali Format for using Bangladesh)

১। আপনার কি মনে হয় আপনার আত্মীয় প্রয়োজনের অতিরিক্ত সাহায্য চায় ?

২। আপনার কি মনে হয় আপনি আপনার আত্মীয়ের সাথে সময় কাটানোর ফলে নিজেকে যথেষ্ট সময় দিতে পারছেন না ?

৩। আপনি কি আপনার আত্মীয়ের যত্ন এবং পরিবারের কাজের প্রতি দায়িত্ব পালন করার মাঝে চাপ অনুভব করছেন ?

৪। আপনি কি আপনার আত্মীয়ের ব্যবহারে বিব্রত বোধ করেন ?

৫। আপনি যখন আপনার আত্মীয়ের পাশে থাকেন তখন কি আপনি বিরক্ত হন ?

৬। আপনি কি মনে করেন আপনার আত্মীয়ের কারনে আপনাদের পরিবারের অন্যান্য সদস্য অথবা বন্ধুদের সাথে সম্পর্কের অবনতি হচ্ছে ?

৭। আপনি কি আপনার আত্মীয়ের ভবিষ্যৎ নিয়ে ভীত ?

৮। আপনি কি মনে করেন আপনার আত্মীয় আপনার উপর নির্ভরশীল ?

৯। আপনি যখন আপনার আত্মীয়ের সাথে থাকেন তখন কি চাপ অনুভব করেন ?

১০। আপনি কি মনে করেন আপনার আত্মীয়ের সেবা করার কারনে আপনার স্বাস্থ্যের অবনতি হচ্ছে ?

১১। আপনি কি মনে করেন আপনার আত্মীয়ের কারনে আপনি আপনার গোপনীয়তা রক্ষা করতে পারছেন না ?

১২। আপনি কি মনে করেন আপনার আত্মীয়ের প্রতি যত্নশীল হওয়ার কারনে আপনার সামাজিক জীবন ব্যহত হচ্ছে ?

১৩। আপনি কি মনে করেন আপনার আত্মীয়ের কারনে আপনার বন্ধুত্ব নষ্ট হচ্ছে ?

১৪। আপনি কি মনে করেন আপনার আত্মীয় আপনার কাছ থেকে সেবাযত্ন প্রত্যাশা করেন এবং আপনি আপনার আত্মীয়ের একমাত্র অবলম্বন যার উপর সে নির্ভর করতে পারে ?

১৫। আপনি কি মনে করেন আপনার আর্থিক স্বল্পতার কারনে আপনি আপনার আত্মীয়ের প্রতি যত্নশীল হতে পারছেন না ?

১৬। আপনি কি মনে করেন আপনি আপনার আত্মীয়ের যত্ন আর বেশি দিন নিতে পারবেন না ?

১৭। আপনি কি মনে করেন আপনার আত্মীয়ের অসুস্থতার কারনে আপনার জীবন ক্ষতিগ্রস্থ হচ্ছে ?

১৮। আপনি কি আপনার আত্মীয়ের যত্ন নেবার কাজ অন্য কোনও ব্যক্তির উপর ছেড়ে দিতে চান ?

১৯। আপনি কি মনে করেন আপনি আপনার আত্মীয়কে নিয়ে অনিশ্চয়তার মধ্যে আছেন ?

২০। আপনি কি মনে করেন আপনার আত্মীয়ের জন্য আপনার আরও বেশি কিছু করা উচিত ?

২১। আপনি কি মনে করেন আপনি আরও ভালোভাবে আপনার আত্মীয়ের যত্ন নিতে পারেন ?

২২। মোটকথা , আপনার আত্মীয়ের যত্ন নেওয়া আপনার কাছে কতটুকু বোঝা মনে হয় ?

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