

**Living with Schizophrenia: A Phenomenological Study
of People with Schizophrenia Living in the Family**

Registration no: H-3498

Exam Roll: 3810

Session: 2007-2008

Academic Year: 2011-2012

Institute of Social Welfare and Research

University of Dhaka

Acknowledgement

At the very beginning, I am brightly glad to have the greatest opportunity to disclose my heartiest gratitude and thanks to the academic committee to give me a chance to complete a thesis paper on certain topic among a few numbers of students of Masters of Social Sciences in Social Welfare on the basis of merit.

I would also like to convey my special gratitude and thanks to my honorable supervisor. Whose scholastic experience and valuable guidance, suggestion helped me at all stages of my thesis paper and to prepare this report properly. I am extremely grateful to his personality.

I acknowledge with gratitude that - professor Dr. Waziul Alam Chowdhury, Director cum professor of National Institute of Mental Health and Hospital (NIMH) to give me permission to collect data from the indoor and outdoor schizophrenic patients. I am particularly grateful to psychiatric social worker Jamal Hossain and Kawser Parvin Madam (Officer, Department of Social Service) to give me the opportunity to use their personal room for data recording purpose in National Institute of Mental Health and Hospital (NIMH). I am grateful to the many people who took part in this study, and to those who encouraged others to participate. In extent my cordial thanks to librarian and deputy librarian and all staff of the library of ISWR to help me to prepare my thesis paper.

Finally I would like to recall all of my teachers at the Institute of Social Welfare and Research, University of Dhaka with great honor for their advice and support during the study.

With thanks

Exam Roll no-3810

List of Acronym and Abbreviation

DSM	Diagnostic and Statistical Manual of Mental Disorders
GO	Government Organization
ICD	International Classification of Diseases
ISWR	Institute of Social Welfare and Research
MSE	Mental Status/State Examination
NGO	Non-government Organization
NIMH	National Institute of Mental Health and Hospital
WHO	World Health Organization (UN)

Abstract

Health includes physical, mental, social and spiritual wellbeing of individual. Normal mental health is the ability of an individual to function normally, adjust with his/her environment and contribute to the society satisfactorily. As it is important to recognize normal mental health of an individual, it is also important to recognize abnormal mental health. The purpose of this current thesis paper is to investigate and understand the psycho-social conditions of people living with schizophrenia in the family. Case Study based on interpretative phenomenological analysis of phenomenological qualitative research method is the basic method of this current study paper. Because this proposed study requires in-depth information of the psycho-social conditions of people living with schizophrenia in family. The National Institute of Mental Health and Hospital (NIMH) has considered as the study area. There are fifteen cases have taken to analysis the data. The result of this current study paper shows schizophrenia is not only a problem for individual but also it has a great negative effect on his or her family members' individual, group or social life. The greatest burden on patients and family members of patients is the financial cost to the family. This can include treatment costs, transport to appointments, the cost of hiring a carer and adapting their home environment. The schizophrenic patients create disruption in daily routine activities, in leisure time, in interaction or family relationships, education and work, and also affect the physical and mental health of other caregivers or family members. This study also shows that people with schizophrenia and their family face different types of stigma in their social life cycle. In concluding step it might be said that GO and NGO, national, international initiatives and strategies should be execute properly and community based awareness building program and mental health services should be ensure to treat the schizophrenic patients properly and ensure their proper status and social functioning in the society.

CONTENTS OF THE STUDY

CHAPTER ONE : INTRODUCTION TO THE STUDY PAPER

Serial no	Contents	Page no
1.1	Title of the Study-----	02
1.2	Overview of the Study-----	02
1.3	Introduction-----	05
1.4	Statement of the Problem-----	08
1.5	Rationale-----	10
1.6	Objectives of the Study-----	12
1.7	Operational Definition of Concepts-----	13
1.7.1	Family burden-----	13
1.7.2	Mental State Examination-----	13
1.7.3	Neurosis-----	13
1.7.4	Psychosis-----	13
1.7.5	Psycho-Social Condition-----	13
1.7.6	Schizophrenia-----	13

CHAPTER TWO : SCHIZOPHRENIA-AN OVERVIEW

Serial no	Contents	Page no
2.1	Schizophrenia: An Overview-----	15
2.1.1	What is Schizophrenia-----	15
2.1.2	When does Schizophrenia start and who gets it-----	15
2.1.3	Causes of Schizophrenia-----	16
2.1.4	Symptoms of Schizophrenia-----	17
2.1.5	Treatment and Management of Schizophrenia-----	20
2.1.6	Tips to Help Family Members and Friends-----	26
2.1.7	What is the Outlook for the Future-----	28

CHAPTER THREE : LITERATURE REVIEW

Serial no	Content	Page no
3.1	Literature Review-----	30

CHAPTER FOUR : THEORETICAL FRAMEWORKS

Serial no	Contents	Page no
4.1	Theoretical Frameworks-----	41
4.1.1	Stress Theory of Schizophrenia-----	41
4.1.2	Structural Strain Theory of Schizophrenia-----	42
4.1.3	Labeling Theory of Schizophrenia-----	43

CHAPTER FIVE : METHODOLOGY OF THE STUDY

Serial no	Contents	Page no
5.1	Methodology of the Study-----	47
5.1.1	Basic Method-----	47
5.1.2	Study Area-----	48
5.1.3	Population of the Study-----	48
5.1.4	Sampling-----	48
5.1.5	Data Collection Technique-----	48
5.1.5.1	Semi-Structure Interview-----	49
5.1.5.2	Use of Recording Device-----	49
5.1.5.3	Observation-----	49
5.1.6	Data Analysis and Interpretation-----	49
5.1.7	Ethical Consideration-----	50
5.1.8	Limitations of the Study-----	51

CHAPTER SIX : FINDINGS AND ANALYSIS

Serial no	Contents	Page no
6.1	Findings and Analysis-----	53
6.1.1	Analysis of the Study Result-----	53
6.1.2	Discussion-----	76
6.1.3	Case Study-----	85
6.1.4	Recommendation-----	108
6.1.5	Conclusion-----	109

REFERENC

Reference-----	112
----------------	-----

APPENDIX

Appendix-01	Semi-Structure Interview Schedule-----	115
Appendix-02	Domains of Mental State/Status Examination-----	120
Appendix-03	A Visual Exhibition of People with Schizophrenia Living in the Family -----	123
Appendix-04	Application for Seeking Permission to Visit and Collect Data--	124

Chapter-01

✍ *Title of the Study Paper*

✍ *Overview of the Study*

✍ *Introduction*

✍ *Statement of the Problem*

✍ *Rationale*

✍ *Objectives of the Study*

✍ *Operational Definition of Concepts*

- *Family burden*
- *Mental State Examination*
- *Neurosis*
- *Psychosis*
- *Psycho-Social Condition*
- *Schizophrenia*

1.1 Title of the Study Paper

Living with Schizophrenia: A Phenomenological Study of People with Schizophrenia Living in the Family

1.2 Overview of the Study

Most existing health-related quality-of-life research concerns the impact of schizophrenia on patients. However, in several mental disabilities, studies have been carried out investigating the impact of schizophrenia on the lives of patients and families of patients. The aim of this paper is to investigate and understand the psycho-social conditions of people living with schizophrenia in family. Ten papers were identified for review. This study shows that a wide variety of aspects of family members' lives can be affected, including emotional, financial, family relationships, education and work, leisure time, and social activities. Many of these themes are linked to one another, with themes including financial impact and social impact being linked to emotional impact. Some positive aspects were also identified from the literature, including family relationships growing stronger. Several instruments exist to measure the impact of schizophrenia on the family, and most are specialty specific (Golics et al., 2013). The impact of schizophrenia on patients and families of patients are often unrecognized and underestimated. Taking into account the quality of life of families as well as patients can offer the clinician a unique insight into issues such as family relationships and the effect of treatment decisions on the patient's close social group of partner and family. Most of the schizophrenic patients have similar effects on the patients and family members of the patients including psychological and emotional functioning, disruption of leisure activities, effect on interpersonal relationships and financial resources. Several common themes were identified from the studies reviewed. Financial, routine, leisure, social, emotional, educational, interactional impact were reported separately in much of the study, and hence are reported as separate themes (Golics et al., 2013). The community people can help the schizophrenic patients and their family very effectively but there are some obstacles also created by the community people. Unfortunately, many people have negative views on schizophrenia. Negative attitudes and a lack of understanding can cause people with mental health problems to be treated badly or labeled in a way that hurts their standing in the

community. People described the names others used to describe people living with schizophrenia, such as 'mad', 'crazy', 'cuckoo', or 'nuts'. Some care giver said that the community people are favorable to the patient's condition because they behave correctly with mental patients and help the family by providing loan facilities, financial assistance without interest, providing the treatment related information (Fadden, Bebbington and Kuipers, 1987). Families can play an important role in supporting a loved one with a mental health or addiction condition. Family members often deal with crises, assist with system navigation, serve as informal case managers, encourage and support treatment, secure housing, arrange for income assistance, monitor symptoms and maintain records of previous treatments, medications and hospitals. Some caregivers said that support from family is not sufficient relating to treatment and management of their patients because they have lack of knowledge about the behavior pattern or how to behave with a schizophrenic patient and they have no available information about the patient's conditions. Many caregivers said that their family support is sufficient relating to treatment and management of their patients. They are supporting the patients through gathering information, contact with psychiatrists, psychotherapists, take care in hospital and home and they are trying to behave appropriately with the patients and also providing support in family and society, awareness building among community people etc. Many caregivers said that the organizational support especially National Institute of Mental Health and Hospital is sufficient for the treatment and management of the psychiatric patients because we took different services from different mental health clinic and village doctors and Saint (e. g. Mawlana, Oza, Fokir) but their service very poor to treat and manage mental health patients. Doctors, nurses, psychotherapists and social workers are cordial to treat and manage the psychiatric patients in this hospital. Someone said that the organizational support is not sufficient for the treatment and management of the psychiatric patients because the doctors and nurses of this hospital are not attentive to patients at required level. Doctors are busy in private practice; at the emergency moment generally they are absence in hospital; lack of supply of medicine is another important aspect we have to buy medicine from outside pharmacies; The bathroom, toilet, and bed sheet is very dirty; Bug is another problem in this hospital for bug we are not sleeping easily in the bed at night. Many attendants of the patients said that to ensure effective family support/family participation in

treatment and management we should behave with patients properly, Contact with psychiatrists regularly, follow doctor's advice properly, and fulfill patient's needs, and provide financial and other assistance as much as possible from our family. Someone said that we should participate in family counseling program relating to patients conditions. Caregivers said that local gate keepers are important parts of the society. So to ensure the effective support from society we should include the local gate keepers in awareness building program so that the community people cannot misbehave with psychiatric patients because it increases abnormal behavior of the psychiatric patients. All of the respondents said that psychiatrists, nurses, and others professionals should be cordial with patients and care givers, a strong supervisory committee must be established in the hospital who supervise the situations of the patients to take the proper actions at the proper time, bathroom, toilet facilities should be developed, should be ensure fresh water supply, should be kept the every ward and bed neat and clean, and should be used medicine to reduce the bug problem etc. Many caregivers commented on doctors and nurses behavior that they are not enthusiastic to the patient's situations at expected level but psychotherapists and social workers are playing good role to develop the psycho-social conditions of the psychiatric patients. So, psychiatrists, psychotherapists, social workers and nurses should be more careful to their patients and clients.

1.3 Introduction

Schizophrenia is a major mental health issue in the world across the developed and developing countries. Today schizophrenia are key public health issues. A large number of people worldwide suffer from schizophrenia. According to World Health Organization (2009) at least 40 million people in the world suffer from mental disorders such as schizophrenia and dementia. The World Health Organization estimates that depression will become the second most important cause of disability after ischemic heart disease world-wide by 2020 (WHO, 2009). Being a developing country Bangladesh and its prevalence of psychiatric illness is not less than that of any other country in the world.

The National Health Policy 2009 of Bangladesh, health has been defined as a ‘state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (Ministry of Health and Family Welfare 2012). In this definition, mental wellbeing was equally prioritized as physical and social wellbeing. Due to stigma, prejudices, maltreatment, the issue of mental health is less addressed by the government and the private and NGO sectors as well as civil society organizations in Bangladesh.

It is such a country with an approximate geographical area of 1, 47, 570 square kilometers and a population of 150 million people. “In Bangladesh, socio-political situation is insecure and unstable with poverty and vulnerable to natural disaster which causes psychiatric morbidity” (UNDP, 2012). It is anticipated that mental disorders would be a big health related problem in Bangladesh. Very few studies were done previously based on schizophrenia in Bangladesh. In 1978, one study reported that 6.5% of people in a village (of all ages) suffered from mental illness. Twenty years later, another study in an urban area reported a prevalence of 28% psychiatric illness in adults. From 2003 to 2005, a national survey was conducted on mental health in Bangladesh. It showed that 16.1% of the adult people were suffering from various mental disorders and the prevalence was higher in women than men (19 percent vs. 12.9 percent) (Muhit, 2006).

According to World Health Organization (WHO, 2009), Prevalence of psychiatric disorders in adult population of Bangladesh is 18.6%, 12.9% males and 19% females in Bangladesh suffer from psychiatric disorders. Prevalence of mental health related problems in children of Bangladesh is about 25%, 18.4% children suffer from psychiatric disorders, 3.8% children suffer from mental retardation, 2% children suffer from epilepsy and 0.8% children suffer from substance abuse. Alongside these, “hyperactivity, conduct disorder, aggressiveness, delinquency, depression, schizoid anxiousness, social withdrawal, nervousness, inattentiveness, self-destructiveness, psycho-sexual problems etc are some of the common behavior problems in Bangladeshi society” (Anisuzzaman, 2011). Socially these mentally retarded people experienced rejection by family, friends, neighbors and community members. Their responses included avoidance, name calling and teasing, and occasionally extreme responses such as being disowned by families, divorced by partners and sacked from their job. This stigma constitutes social exclusion at home, in personal life and in the community, and is unacceptable. Every person has the right to be treated equally and should not be denied opportunities that would otherwise be open to them.

Mental illness is most neglected in Bangladesh, although a large number of people are suffering from different types of mental illnesses. The prevalence rate of schizophrenia in Bangladesh may be in the same magnitude as in developed countries. Based on global estimates, there are 14 million mentally ill people in Bangladesh. 0.5 Per cent of the population are mentally disabled (DSM IV, 2005). There are seventy qualified psychiatrists and one hospital bed for 200,000 people in the country (WHO, 2009). The total number of psychiatrist working for mental health service including private practice per 100000 is 0.073 (Thikanabd.com, accessed on-12.12.2012). The density of the psychiatrists in or around the largest city (eg: Dhaka) is five time greater than the density of psychiatrists in all over Bangladesh. Another source of information denoted that “*Bangladesh, for its present population of over 150 million, has only about 100 psychiatrists*” (Mohit, 2001). *Development of mental health policy, innovative community-based service related program, advocacy and awareness campaigns and support for research are essential*” (Anisuzzaman, 2011).

For all individuals, mental, physical and social health is vital and interwoven strands of life. As our understanding of this relationship grows, it becomes ever more apparent that mental health is crucial to the overall well-being of individuals, societies and countries. Indeed, mental health can be defined as a state of well-being enabling individuals to realize their abilities, cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities (WHO, 2003). Unfortunately, in most parts of the world, mental health, mental disorders and the social conditions of schizophrenic patients are not accorded anywhere near the same degree of importance as physical health. Rather, they have been largely ignored or neglected. This study aims to guide the discovery of the magnitude and psycho-social conditions of people living with schizophrenia and in understanding what can be done to manage psycho-social condition due to schizophrenia. Effective treatments and interventions that are also cost-effective are now readily available. It is therefore time to overcome barriers and work together in a joint effort to narrow the gap between what needs to be done and what is actually being done, between the psycho-social consequences of psychiatric patients and the resources being used to address this problem. Closing the gap is a clear obligation not only for the patients but also for government's aid and development agencies, foundations, research institutions and the business community. On the basis of present conditions of psychiatric patients, the proposed study "*Living with Schizophrenia: A Phenomenological Study of People with Schizophrenia Living in the Family.*" is taken to conduct as an effort for understanding and describing the psycho-social conditions of people living with schizophrenia in the family.

1.4 Statement of the problem

Health cannot be completed without mental health. As it is important to recognize normal mental health of an individual, it is also important to recognize abnormal mental health. The purpose of this current thesis paper is to investigate and understand the psycho-social conditions of people living with schizophrenia in family. Unfortunately, in most parts of the country (Bangladesh), mental health and the psycho-social conditions of people living with schizophrenia are not accorded anywhere near the same degree of importance as physical health. Rather, they have been largely ignored or neglected (WHO, 2003). Schizophrenia is not only a problem for individual but also it has a great negative effect on his or her family members' individual, group or social life. The greatest burden on patients and family members of patients is the financial cost to the family. This can include treatment costs, transport to appointments, the cost of hiring a carer and adapting their home environment. The schizophrenic patients create disruption in daily routine activities, in leisure time, in interaction or family relationships, education and work, and also affect the physical and mental health of other caregivers or family members. People with schizophrenia and their family face different types of stigma in their social life cycle by the community people. Although prevalence of schizophrenia is relatively high, schizophrenia remains a neglected area in our country with shortage of service facilities, manpower and logistic support to provide service to the people. Side by side prejudice, superstition and ignorance about mental illness continue to exist. So, physical torture of a mentally ill person is a common phenomenon in the society. Beating, hitting, chaining, dipping in pond, forced inhalation of pungent fumes dried red chilly, cutting of muscles, arteries and nerves, putting poisonous mustard oil into eyes, putting marks on shoulder and body with burning hot iron rod are practiced. Death is a result of these is not frequent in this country (Firoz, 2007). It is therefore time to overcome barriers and work together in a joint effort to narrow the gap between what needs to be done and what is actually being done, between the psycho-social conditions of schizophrenic patients and the resources being used to address this problem. Closing the gap is a clear obligation not only for the patients and their family but also for government's aid and development agencies, foundations, research institutions and the business community. GO and

NGO, national, international initiatives and strategies should be executed properly and community based awareness building program and mental health services should be ensured to treat the schizophrenic patients properly and ensure their proper status and social functioning in the society. Besides this understanding the psycho-social conditions of schizophrenic patients in family helps the clinical social workers to increase their empathy skill, to stabilize neurotic and psychotic symptoms of others family members, to reduce likelihood of relapse and re-hospitalization, to ensure appropriate treatment, to minimize problems in relationships and life disruption, to identify needs of rehabilitation, to provide proper patient and family education, to make collaborative decision, to provide assistance with obtaining services and resources, to provide training and assistance with activities of daily living, to give supportive therapy and to ensure peer support/self-help group for the purpose of reducing stress and burden on families and managing the psycho-social conditions of schizophrenic patients. In addition there is no qualitative research in this field in Bangladesh yet. So it may be said that the findings of this study helps the lawyers, policy makers, social workers, community leaders, community people, different GOs and NGOs on this issue in our country. The findings of this study also to be a relevant literature for researchers, information investigators and interested person on this field.

1.5 Rationale

Health cannot be completed without mental health. Health includes physical, mental, social and spiritual wellbeing of individual. Normal mental health is the ability of an individual to function normally, adjust with his/her environment and contribute to the society satisfactorily. As it is important to recognize normal mental health of an individual, it is also important to recognize abnormal mental health. Normal mind has a normal development process known as psychology whereas abnormal mind covers a wide range of behavior which most of the time is self-defeating and maladaptive in nature (Firoz, 2007).

Although prevalence of schizophrenia is relatively high, schizophrenia remains a neglected area in our country with shortage of service facilities, manpower and logistic support to provide service to the people. Side by side prejudice, superstition and ignorance about schizophrenia continue to exist. So, physical torture of a schizophrenic person is a common phenomenon in the society. Beating, hitting, chaining, dipping in pond, forced inhalation of pungent fumes dried red chilly, cutting of muscles, arteries and nerves, putting poisonous mustard oil into eyes, putting marks on shoulder and body with burning hot iron rod are practiced. Death is a result of these is not frequent in this country (Firoz, 2007).

A community based multi-centric service oriented research on mental illness conducted in 2003-2005 reported that 16% (19% women 135 men) suffer from mental disorders. Neurosis 8.4%, major depressive disorder 4.6%, and generalized anxiety disorder 2.9% are the commonest forms of mental illness in Bangladesh. Studies in IPGMR and general practice in Dhaka observed that about 30% of medical care seekers are mentally ill patients (Firoz, 2007).

Going by estimates in national survey in Bangladesh, we have about 14 lacs people suffering from major mental disorders, 64 lacs and 54 thousands people suffering from depressive disorder and one core 17 lacs and 46 thousands people suffering from neurotic disorders. Most of them are the patients found in general practice, out patient service at hospitals and primary health care centres (Firoz, 2007).

Schizophrenia is becoming a major problem in Bangladesh. The rising trends are evident in both urban and rural areas. Young people are the most common affected by schizophrenia. The prevalence of schizophrenia was found 0.63% in national survey on mental health. The likelihood of developing a mental disorders increases after the age of 65 years (Firoz, 2007).

Primary recognition and treatment of schizophrenia, doctor-patient relationship is important in mental health area. Majority of general physicians treat emotional disorder prescribing psychotropic drugs. That is why the medical practitioners, medical students, residents, nurses and clinical social workers should have experience with all forms of emotional disorders especially with those patients who are chronically ill. So, it is the expectation of time to conduct research on the psycho-social conditions of schizophrenic patients in family in the mental health field to provide effective treatment and proper management of schizophrenic patients.

Besides this understanding the psycho-social conditions of people living with schizophrenia in the family helps the clinical social workers to increase their empathy skill, to stabilize neurotic and psychotic symptoms of others family members, to reduce likelihood of relapse and re-hospitalization, to ensure appropriate treatment, to minimize problems in relationships and life disruption, to identify needs of rehabilitation, to provide proper patient and family education, to make collaborative decision, to provide assistance with obtaining services and resources, to provide training and assistance with activities of daily living, to give supportive therapy and to ensure peer support/self-help group for the purpose of reducing stress and burden on families and managing the psycho-social conditions of schizophrenic patients.

In addition there is no research based on interpretative phenomenological analysis of qualitative research method on this current issue in Bangladesh yet. So it may be said that the findings of this current study paper helps the lawyers, policy makers, social workers, community leaders, community people, different GOs and NGOs on this issue in our country. The findings of this study also to be a relevant literature for researchers, information investigators and interested person on this field.

1.6 Objectives of the Study

General objective

Investigate and understand the psycho-social conditions of people living with schizophrenia in the family.

Specific objectives

To fulfill the general objectives there are some specific objectives.

1. To know the socio-demographic and economic profile of respondents;
2. To know the psychological conditions of schizophrenic patients;
3. To know the social status of schizophrenic patients in family and society;
4. To know the support from family, society and organization for the treatment and management of schizophrenic patients; and
5. To know the opinion of the respondents to manage the psycho-social conditions of people living with schizophrenia.

On the basis of these objectives the proposed study has conducted.

1.7 Operational Definition of Concepts

1.7.1 Family burden: Family burden refers to the care giving, psychosocial, and financial burden associated with a family member's medical condition. It may consider financial burden, effect on mental health of other family members, effect on physical health of other family members, effect on family interaction, family routine, and family leisure time etc.

1.7.2 Mental State Examination: The mental status examination or mental state examination (MSE) is a structured way of observing and describing a patient's current state of mind, under the domains of appearance, attitude, behavior, mood and affect, speech, thought process, thought content, perception, cognition, insight and judgment.

1.7.3 Neurosis: Neurosis is a class of functional mental disorders involving distress but neither delusions nor hallucinations, whereby behavior is not outside socially acceptable norms. It is also known as psychoneurosis or neurotic disorder, and thus those suffering from it are said to be neurotic. The term essentially describes an "invisible injury" and the resulting condition.

1.7.4 Psychosis: Psychosis refers to an abnormal condition of the mind, and is a generic psychiatric term for a mental state often described as involving a "loss of contact with reality". People suffering from psychosis are described as psychotic. Psychosis is given to the more severe forms of psychiatric disorder, during which hallucinations and delusions and impaired insight may occur.

1.7.5 Psycho-Social Condition: In this study psycho-social conditions refers to the effect that influences on emotion, social wellbeing, social functioning of the Schizophrenic patients and his/her family members in family as well as in society.

1.7.6 Schizophrenia: Schizophrenia is a serious brain disorder that distorts the way a person thinks, acts, expresses emotions, perceives reality, and relates to others. People with schizophrenia, the most chronic and disabling of the major mental illnesses often have problems functioning in society, at work and at school, and in relationships.

Chapter-02

- ✎ Schizophrenia: An Overview*
- ✎ What is Schizophrenia?*
- ✎ When does Schizophrenia start and who gets it?*
- ✎ Causes of Schizophrenia*
- ✎ Symptoms of Schizophrenia*
- ✎ Treatment and Management of Schizophrenia*
- ✎ Tips to Help Family Members and Friends*
- ✎ What is the Outlook for the Future?*

2.1 Schizophrenia: An Overview

The term schizophrenia was coined by **Eugen Bleuler**. Schizophrenia is a chronic, severe, and disabling brain disorder that has affected people throughout history (Regier et al., 1993). People with the disorder may hear voices other people don't hear. They may believe other people are reading their minds, controlling their thoughts, or plotting to harm them. This can terrify people with the illness and make them withdrawn or extremely agitated. People with schizophrenia may not make sense when they talk. They may sit for hours without moving or talking. Sometimes people with schizophrenia seem perfectly fine until they talk about what they are really thinking. Families and society are affected by schizophrenia too. Many people with schizophrenia have difficulty holding a job or caring for them, so they rely on others for help. Treatment helps relieve many symptoms of schizophrenia, but most people who have the disorder cope with symptoms throughout their lives. However, many people with schizophrenia can lead rewarding and meaningful lives in their communities. Researchers are developing more effective medications and using new research tools to understand the causes of schizophrenia. In the years to come, this work may help prevent and better treat the illness.

2.1.1 What is Schizophrenia?

Schizophrenia is a serious brain disorder that distorts the way a person thinks, acts, expresses emotions, perceives reality, and relates to others. People with schizophrenia -- the most chronic and disabling of the major mental illnesses -- often have problems functioning in society, at work and at school, and in relationships. Schizophrenia can leave its sufferer frightened and withdrawn. It is a lifelong disease that cannot be cured but usually can be controlled with proper treatment.

2.1.2 When does Schizophrenia start and who gets it?

Schizophrenia affects men and women equally. It occurs at similar rates in all ethnic groups around the world. Symptoms such as hallucinations and delusions usually start between ages 16 and 30. Men tend to experience symptoms a little earlier than women. Most of the time, people

do not get schizophrenia after age 45 (Masi et al., 2006). Schizophrenia rarely occurs in children, but awareness of childhood-onset schizophrenia is increasing (Nicolson et al., 2000).

It can be difficult to diagnose schizophrenia in teens. This is because the first signs can include a change of friends, a drop in grades, sleep problems, and irritability—behaviors that are common among teens. A combination of factors can predict schizophrenia in up to 80 percent of youth who are at high risk of developing the illness. These factors include isolating one and withdrawing from others, an increase in unusual thoughts and suspicions, and a family history of psychosis (Cannon et al., 2008). In young people who develop the disease, this stage of the disorder is called the "prodromal" period.

2.1.3 Causes of Schizophrenia

The causes of schizophrenia are not fully known. However, it appears that schizophrenia usually results from a complex interaction between genetic and environmental factors.

Genetic causes of schizophrenia: Schizophrenia has a strong hereditary component. Individuals with a first-degree relative (parent or sibling) who has schizophrenia have a 10 percent chance of developing the disorder, as opposed to the 1 percent chance of the general population.

But schizophrenia is only influenced by genetics, not determined by it. While schizophrenia runs in families, about 60% of schizophrenics have no family members with the disorder. Furthermore, individuals who are genetically predisposed to schizophrenia don't always develop the disease, which shows that biology is not destiny.

Environmental causes of schizophrenia: Twin and adoption studies suggest that inherited genes make a person vulnerable to schizophrenia and then environmental factors act on this vulnerability to trigger the disorder.

As for the environmental factors involved, more and more research is pointing to stress, either during pregnancy or at a later stage of development. High levels of stress are believed to trigger schizophrenia by increasing the body's production of the hormone cortisol.

Research points to several stress-inducing environmental factors that may be involved in schizophrenia, including:

- Prenatal exposure to a viral infection
- Low oxygen levels during birth (from prolonged labor or premature birth)
- Exposure to a virus during infancy
- Early parental loss or separation
- Physical or sexual abuse in childhood

Abnormal brain structure: In addition to abnormal brain chemistry, abnormalities in brain structure may also play a role in schizophrenia. Enlarged brain ventricles are seen in some schizophrenics, indicating a deficit in the volume of brain tissue. There is also evidence of abnormally low activity in the frontal lobe, the area of the brain responsible for planning, reasoning, and decision-making. Some studies also suggest that abnormalities in the temporal lobes, hippocampus, and amygdala are connected to schizophrenia's positive symptoms. But despite the evidence of brain abnormalities, it is highly unlikely that schizophrenia is the result of any one problem in any one region of the brain.

2.1.4 Symptoms of schizophrenia

The symptoms of schizophrenia fall into three broad categories: positive symptoms, negative symptoms, and cognitive symptoms.

Positive symptoms

Positive symptoms are psychotic behaviors not seen in healthy people. People with positive symptoms often "lose touch" with reality. These symptoms can come and go. Sometimes they are severe and at other times hardly noticeable, depending on whether the individual is receiving treatment. They include the following:

Hallucinations are things a person sees, hears, smells, or feels that no one else can see, hear, smell, or feel. "Voices" are the most common type of hallucination in schizophrenia. Many people with the disorder hear voices. The voices may talk to the person about his or her behavior, orders the person to do things, or warn the person of danger. Sometimes the voices talk to each other. People with schizophrenia may hear voices for a long time before family and friends notice the problem.

Other types of hallucinations include seeing people or objects that are not there, smelling odors that no one else detects, and feeling things like invisible fingers touching their bodies when no one is near. "Voices" are the most common type of hallucination in schizophrenia.

Delusions are false beliefs that are not part of the person's culture and do not change. The person believes delusions even after other people prove that the beliefs are not true or logical. People with schizophrenia can have delusions that seem bizarre, such as believing that neighbors can control their behavior with magnetic waves. They may also believe that people on television are directing special messages to them, or that radio stations are broadcasting their thoughts aloud to others. Sometimes they believe they are someone else, such as a famous historical figure. They may have paranoid delusions and believe that others are trying to harm them, such as by cheating, harassing, poisoning, spying on, or plotting against them or the people they care about. These beliefs are called "delusions of persecution."

Thought disorders are unusual or dysfunctional ways of thinking. One form of thought disorder is called "disorganized thinking." This is when a person has trouble organizing his or her thoughts or connecting them logically. They may talk in a garbled way that is hard to understand.

Another form is called "thought blocking." This is when a person stops speaking abruptly in the middle of a thought. When asked why he or she stopped talking, the person may say that it felt as if the thought had been taken out of his or her head. Finally, a person with a thought disorder might make up meaningless words, or "neologisms."

Movement disorders may appear as agitated body movements. A person with a movement disorder may repeat certain motions over and over. In the other extreme, a person may become catatonic. Catatonia is a state in which a person does not move and does not respond to others. Catatonia is rare today, but it was more common when treatment for schizophrenia was not available (WHO, 1992).

Negative symptoms

Negative symptoms are associated with disruptions to normal emotions and behaviors. These symptoms are harder to recognize as part of the disorder and can be mistaken for depression or other conditions. These symptoms include the following:

- "Flat affect" (a person's face does not move or he or she talks in a dull or monotonous voice)
- Lack of pleasure in everyday life
- Lack of ability to begin and sustain planned activities
- Speaking little, even when forced to interact.

People with negative symptoms need help with everyday tasks. They often neglect basic personal hygiene. This may make them seem lazy or unwilling to help themselves, but the problems are symptoms caused by the schizophrenia.

Cognitive symptoms

Cognitive symptoms are subtle. Like negative symptoms, cognitive symptoms may 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" (the ability to understand information and use it to make decisions)
- Trouble focusing or paying attention
- Problems with "working memory" (the ability to use information immediately after learning it).

Cognitive symptoms often make it hard to lead a normal life and earn a living. They can cause great emotional distress (WHO, 1992).

2.1.5 Treatment and Management of Schizophrenia

Because the causes of schizophrenia are still unknown, treatments focus on eliminating the symptoms of the disease. Treatments include antipsychotic medications and various psychosocial treatments.

Pharmacological Treatment and management

Antipsychotic medications have been available since the mid-1950's. The older types are called conventional or "typical" antipsychotics. Some of the more commonly used typical medications include:

- Chlorpromazine (Thorazine)
- Haloperidol (Haldol)
- Perphenazine (Etrafon, Trilafon)
- Fluphenazine (Prolixin).

In the 1990's, new antipsychotic medications were developed. These new medications are called second generation, or "atypical" antipsychotics.

One of these medications, clozapine (Clozaril) is an effective medication that treats psychotic

symptoms, hallucinations, and breaks with reality. But clozapine can sometimes cause a serious problem called agranulocytosis, which is a loss of the white blood cells that help a person fight infection. People who take clozapine must get their white blood cell counts checked every week or two. This problem and the cost of blood tests make treatment with clozapine difficult for many people. But clozapine is potentially helpful for people who do not respond to other antipsychotic medications (Gogtay et al., 2008).

Other atypical antipsychotics were also developed. None cause agranulocytosis. Examples include:

- Risperidone (Risperdal)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Ziprasidone (Geodon)
- Aripiprazole (Abilify)
- Paliperidone (Invega).

When a doctor says it is okay to stop taking a medication, it should be gradually tapered off, never stopped suddenly.

What are the side effects?

Some people have side effects when they start taking these medications. Most side effects go away after a few days and often can be managed successfully. People who are taking antipsychotics should not drive until they adjust to their new medication. Side effects of many antipsychotics include:

- Drowsiness
- Dizziness when changing positions
- Blurred vision
- Rapid heartbeat

- Sensitivity to the sun
- Skin rashes
- Menstrual problems for women.

Atypical antipsychotic medications can cause major weight gain and changes in a person's metabolism. This may increase a person's risk of getting diabetes and high cholesterol (Lieberman et al., 2005). A person's weight, glucose levels, and lipid levels should be monitored regularly by a doctor while taking an atypical antipsychotic medication.

Typical antipsychotic medications can cause side effects related to physical movement, such as:

- Rigidity
- Persistent muscle spasms
- Tremors
- Restlessness.

Long-term use of typical antipsychotic medications may lead to a condition called tardive dyskinesia (TD). TD causes muscle movements a person can't control. The movements commonly happen around the mouth. TD can range from mild to severe, and in some people the problem cannot be cured. Sometimes people with TD recover partially or fully after they stop taking the medication.

TD happens to fewer people who take the atypical antipsychotics, but some people may still get TD. People who think that they might have TD should check with their doctor before stopping their medication.

How are antipsychotics taken and how do people respond to them?

Antipsychotics are usually in pill or liquid form. Some anti-psychotics are shots that are given once or twice a month.

Symptoms of schizophrenia, such as feeling agitated and having hallucinations, usually go away within days. Symptoms like delusions usually go away within a few weeks. After about six weeks, many people will see a lot of improvement.

However, people respond in different ways to antipsychotic medications, and no one can tell beforehand how a person will respond. Sometimes a person needs to try several medications before finding the right one. Doctors and patients can work together to find the best medication or medication combination, as well as the right dose.

Some people may have a relapse-their symptoms come back or get worse. Usually, relapses happen when people stop taking their medication, or when they only take it sometimes. Some people stop taking the medication because they feel better or they may feel they don't need it anymore. But no one should stop taking an antipsychotic medication without talking to his or her doctor. When a doctor says it is okay to stop taking a medication, it should be gradually tapered off, never stopped suddenly.

How do antipsychotics interact with other medications?

Antipsychotics can produce unpleasant or dangerous side effects when taken with certain medications. For this reason, all doctors treating a patient need to be aware of all the medications that person is taking. Doctors need to know about prescription and over-the-counter medicine, vitamins, minerals, and herbal supplements. People also need to discuss any alcohol or other drug use with their doctor.

Psycho-social Treatment and Management

Psychosocial treatments can help people with schizophrenia that is already stabilized on antipsychotic medication. Psychosocial treatments help these patients deal with the everyday challenges of the illness, such as difficulty with communication, self-care, work, and forming and keeping relationships. Learning and using coping mechanisms to address these problems

allow people with schizophrenia to socialize and attend school and work.

Patients who receive regular psychosocial treatment also are more likely to keep taking their medication, and they are less likely to have relapses or be hospitalized. A therapist can help patients better understand and adjust to living with schizophrenia. The therapist can provide education about the disorder, common symptoms or problems patients may experience, and the importance of staying on medications.

Illness management skills: People with schizophrenia can take an active role in managing their own illness. Once patients learn basic facts about schizophrenia and its treatment, they can make informed decisions about their care. If they know how to watch for the early warning signs of relapse and make a plan to respond, patients can learn to prevent relapses. Patients can also use coping skills to deal with persistent symptoms.

Integrated treatment for co-occurring substance abuse: Substance abuse is the most common co-occurring disorder in people with schizophrenia. But ordinary substance abuse treatment programs usually do not address this population's special needs. When schizophrenia treatment programs and drug treatment programs are used together, patients get better results.

Rehabilitation: Rehabilitation emphasizes social and vocational training to help people with schizophrenia function better in their communities. Because schizophrenia usually develops in people during the critical career-forming years of life (ages 18 to 35), and because the disease makes normal thinking and functioning difficult, most patients do not receive training in the skills needed for a job. Rehabilitation programs can include job counseling and training, money management counseling, help in learning to use public transportation, and opportunities to practice communication skills. Rehabilitation programs work well when they include both job training and specific therapy designed to improve cognitive or thinking skills. Programs like this help patients hold jobs, remember important details, and improve their functioning (Greig, 2007, Bell, 2007 & Hogarty et al., 2004).

Family education: People with schizophrenia are often discharged from the hospital into the care of their families. So it is important that family members know as much as possible about the disease. With the help of a therapist, family members can learn coping strategies and problem-solving skills. In this way the family can help make sure their loved one sticks with treatment and stays on his or her medication. Families should learn where to find outpatient and family services.

Cognitive behavioral therapy: Cognitive behavioral therapy (CBT) is a type of psychotherapy that focuses on thinking and behavior. CBT helps patients with symptoms that do not go away even when they take medication. The therapist teaches people with schizophrenia how to test the reality of their thoughts and perceptions, how to "not listen" to their voices, and how to manage their symptoms overall. CBT can help reduce the severity of symptoms and reduce the risk of relapse.

Self-help groups: Self-help groups for people with schizophrenia and their families are becoming more common. Professional therapists usually are not involved, but group members support and comfort each other. People in self-help groups know that others are facing the same problems, which can help everyone feel less isolated. The networking that takes place in self-help groups can also prompt families to work together to advocate for research and more hospital and community treatment programs. Also, groups may be able to draw public attention to the discrimination many people with mental illnesses face (NIMH, 2009).

2.1.6 Tips to Help Family Members and Others

The closest family member or friend should speak-up and be an advocate for the person with schizophrenia: Sometimes only the family or others close to the person with schizophrenia will be aware of strange behavior or ideas that the person has expressed. Since patients may not volunteer such information during an examination, family members or friends should ask to speak with the person evaluating the patient so that all relevant information can be taken into account.

Ensure ongoing compliance with treatment, especially when released from inpatient care: Ensuring that a person with schizophrenia continues to get treatment after hospitalization is also important. A patient may discontinue medications or stop going for follow-up treatment, often leading to a return of psychotic symptoms.

Offer strong emotional encouragement and support for continuing treatment: Encouraging the person to continue treatment and assisting him or her in the treatment process can positively influence recovery. Without treatment, some people with schizophrenia become so psychotic and disorganized that they cannot care for their basic needs, such as food, clothing and shelter. All too often, people with severe mental illnesses such as schizophrenia end up on the streets or in jails, where they rarely receive the kinds of treatment they need.

Know how to respond to bizarre statements or beliefs: Those close to people with schizophrenia are often unsure of how to respond when patients make statements that seem strange or are clearly false. For the individual with schizophrenia, the bizarre beliefs or hallucinations seem quite real — they are not just “imaginary fantasies.” Instead of “going along with” a person’s delusions, family members or friends can tell the person that they do not see things the same way or do not agree with his or her conclusions, while acknowledging that things may appear otherwise to the patient.

It is very important not to challenge the person's beliefs or delusions. They are very "real" to the person who experiences them, and there's little point in arguing with them about the delusions or false beliefs. Instead, move the conversation along to areas or topics where you both agree upon.

Keep a record: It may also be useful for those who know the person with schizophrenia well to keep a record of what types of symptoms have appeared, what medications (including dosage) have been taken, and what effects various treatments have had. By knowing what symptoms have been present before, family members may know better what to look for in the future. Families may even be able to identify some "early warning signs" of potential relapses, such as increased withdrawal or changes in sleep patterns, even better and earlier than the patients themselves. Thus, return of psychosis may be detected early and treatment may prevent a full-blown relapse. Also, by knowing which medications have helped and which have caused troublesome side effects in the past, the family can help those treating the patient to find the best treatment more quickly.

Help the person set attainable, simple goals in his or her life: In addition to involvement in seeking help, family, friends and peer groups can provide support and encourage the person with schizophrenia to regain his or her abilities. It is important that goals be attainable, since a patient who feels pressured or repeatedly criticized by others will probably experience stress that may lead to a worsening of symptoms. Like anyone else, people with schizophrenia need to know when they are doing things right. A positive approach may be helpful and perhaps more effective in the long run than criticism. This advice applies to everyone who interacts with the person (Smith, 2009).

2.1.7 What is the outlook for the future?

The outlook for people with schizophrenia continues to improve. Although there is no cure, treatments that work well are available. Many people with schizophrenia improve enough to lead independent, satisfying lives. Continued research and understanding in genetics, neuroscience, and behavioral science will help scientists and health professionals understand the causes of the disorder and how it may be predicted and prevented. This work will help experts develop better treatments to help people with schizophrenia achieve their full potential. Families and individuals who are living with schizophrenia are encouraged to participate in clinical research.

Chapter-03

☞ Literature Review

3.1 Literature Review

The literature review is an exacting task, calling for a deep insight and clear perspective of the over all field (Mouly, 1963: 112). To present the proposed study as a meaningful and compatible with modern era I want to mention some literature review as example.

Stigma and expressed emotion: a study of people with schizophrenia and their family members in China

This study is completed by M. R. Phillips, V. Pearson, Fefei Li, M. Xu and L. Yang in 2002. The aim of this study is to explore the factors that mediate patients 'emotional and cognitive responses to stigma. Based on responses to 10 open-ended questions about stigma appended to the Chinese version of the Camber well Family Interview, trained coders rated the effect of stigma on both patients and family members in 1491 interviews conducted with 952 family members of 608 patients with schizophrenia at 5 sites around China from 1990 to 2000.

The findings of this study are family members reported that stigma had a moderate to severe effect on the lives of patients over the previous 3 months in 60% of the interviews, and on the lives of other family members in 26% of the interviews. The effect of stigma on patients and family members was significantly greater if the respondent had a high level of expressed emotion, if the patient had more severe positive symptoms, if the respondent was highly educated and if the family lived in a highly urbanized area (Phillips et al, 2002).

Improving quality of life for people with dementia in care homes: making psychosocial interventions work

This study is completed by V. Lawrence, J. Fossey, C. Ballard, E. Moniz-Cook and J. Murray in 2012. The aim of this study is to understand what underlies the successful implementation of psychosocial interventions in care homes. Systematic review and meta-synthesis of qualitative research is followed in this study.

The findings are the synthesis of 39 qualitative papers revealed that beneficial psychosocial

interventions met the needs of people with dementia to connect with others, make a meaningful contribution and reminisce. Successful implementation rested on the active engagement of staff and family and the continuing provision of tailored interventions and support. This necessitated staff time, and raised issues around priorities and risk, but ultimately helped redefine staff attitudes towards residents and the care giving role. The findings from the meta-synthesis can help to inform the development and evaluation of psychosocial interventions in care homes and support their widespread implementation in clinical settings (Lawrence et al, 2012).

Homelessness, Housing and Mental Illness by R. K. Schutt (2011), Harvard University Press.

In *Homelessness, Housing, and Mental Illness*, sociologist Russell Schutt has written what must surely be the most thorough multi-method study yet to appear of efforts to help homeless people with serious mental illness reenter mainstream community living. The book is based on an 18-month randomized trial of two approaches conducted in the early 1990s by principal investigator Stephen Goldfinger, M.D., and a multidisciplinary team that included Schutt. The trial was modest in size, with just under 60 patients in each of two groups. All participants were guaranteed a housing subsidy that would support their exit from homelessness and give them a chance to move out of emergency shelter. One-half were assigned to live in independent living apartments. The other half moved to innovative evolving consumer households, in which a trained facilitator was instructed to guide on-site staff in promoting a sense of empowerment that would help residents create cohesive, mutually supportive communities that would eventually become self-sustaining without staff support after project funding ended. The bottom line of the experiment—as understood by this reviewer from the book and related publications—is that by traditional intention-to-treat analysis, there were few, if any, group differences, although the evolving consumer household group had fewer days of homelessness and substantially higher costs during the 18-month intervention (1, 2), while the independent living group had more days of independent housing after the intervention ended. However, Schutt takes his presentation far beyond traditional experimental analysis and offers his readers extensive sub-analyses that address patient housing preferences and the ways in which such preferences change over time,

along with provider judgments about what kind of housing would be “best” for each client, and the interaction between client and provider perspectives. Schutt is so imaginative in his intricate and numerous subgroup and subscale analyses that he seems to forget the hazard of multiple comparisons in the analysis of experimental data. He finds, for example, that individuals who did not abuse substances showed specific benefits in the evolving consumer household model in the area of executive neurocognitive functioning, contrasted with several other neurocognitive dimensions that showed no differences; however, he concludes, too generally in my reading, that the evolving consumer household model distinctively benefits executive functioning (p. 266). He rightly places the evolving consumer household concept in the tradition of utopian thinking about supportive communities in a world of cold impersonality. It is a mark of his honesty that he acknowledges that the evolving consumer household attempt failed to achieve its utopian objectives in this case. Schutt demonstrates his commitment to rigorous multi-method investigation, once again, when he presents extensive qualitative data obtained through anthropological field methods. Numerous vignettes highlight the successes, paradoxes, and disappointments of the evolving consumer household endeavor. On the one hand, some clients value the supportive social environment, while others find it oppressive and intrusive. And although the investigators are deeply committed to principles of consumer choice, front-line staff find that this undermines their professional roles and it is only when active substance users are forced to leave the evolving consumer household that these communities achieve their desired unity. These often painful descriptions of the experiential texture of the programs ring true, even as they complicate the empirical findings. One wishes that there were similar qualitative descriptions of the clients in the independent living condition. It is hard to extract a simple conclusion from this demanding gold mine of objective data and lived experience. In the end, we are left with a humble sense of how much more difficult it is to reintegrate homeless people with mental illness into social communities than it is to put roofs over their heads. We should not minimize the importance of the latter goal to a just society, but we should likewise not minimize the incompleteness of this goal and the challenge of going beyond it (Schutt, 2011; 204).

Barriers to Family Care in Psychiatric Settings

This research paper is completed by Linda E. Rose, R. Kevin Mallinson, and Benita Walton-Moss in 2004. The main objectives of this research paper to identify barriers to family care in psychiatric settings and to describe family and provider perspectives about what constitutes effective family care. A qualitative exploratory approach with focus groups, Seventy-eight people participated in 11 focus groups conducted with families, patients, and health professionals. The summary of this research papers - Families identified poor quality care, conflict with health professionals about treatment, and lack of a role for families in the treatment. African American families also identified isolation of their communities from the mental health care system. Adolescents emphasized their role as caregivers and their needs for support. Health professionals conveyed concerns about system-based barriers, professional practice-based barriers, and family based barriers to care. Patients stated the need for their families to be better educated about mental illness (Rose et al, 2004).

The Effects that Patients Have on their Families in a Community Care and a Control Psychiatric Service - A Two Year Follow-up

This research paper is completed by Grad and Sainsbury in 1968. The main objectives of this research paper to explore the family burden due to due to community care and control psychiatric service. The case study method is used in this study. There are 823 cases from the Chichester service and 585 cases from the Salisbury mental health centre are selected for data collection. Grad and Sainsbury mention in this paper that a comparison of the situation of families one month later with that at referral showed that contact with either psychiatric service had had an immediate effect in relieving family burden. At this time both services were equally effective in relieving burden when it was severe but not when it was less marked: more families in Salisbury who had been rated as having some (but not severe) burden was relieved. This apparently greater relief to Salisbury families observed one month after referral was not statistically significant, but it was a trend that was consistently maintained in all social and clinical groups (Sainsbury and Grad, 1968).

The general conclusion to be drawn from these findings is that it is possible to reduce the number of psychiatric beds without necessarily affecting the community adversely according to our measures. This was achieved in Chichester, notably for patients over 65 years by the ready availability of psychiatrists in the community to visit patients at home and by their close collaboration with general practitioners. Since the biggest demand is beds for geriatric patients, and since these patients presented the most severe problems to their families at referral, the success of the Chichester service in reducing this demand without increasing family burden is noteworthy. The series of patients we studied covered the whole spectrum of psychiatric patients and the effects they had on their families, geriatric patients apart, was not so gross or disrupting as that found for schizophrenics by Brown et al. (1966) and for sub normal by Tizard and Grad (1961). However, we did find the social cost to the family of having a psychiatric patient to be high in both psychiatric services. Even after two years, at least 20 per cent of the families were still affected. While this burden that families have to carry is partly the inevitable consequence of illness, it would be unwise to conclude that little more can be done to diminish it. The fact that 61 per cent of families had been suffering from the problems they reported for more than two years before the patient was first referred suggests that tardiness and reluctance to instigate referral of psychiatric patients also plays some part in adding to families' problems (Grad and Sainsbury, 1968).

A cohort of patients treated in two psychiatric services with differing admission policies was followed-up for two years and the effects of the patients on their families was measured and compared at the beginning and end of the period. All the measures used showed that the community service which favored extra-mural care left the patient's families more heavily burdened. However, this did not apply when those families whose patients had been the most severe burden at referral were considered separately. These families were helped equally in both services even though significantly fewer patients were admitted in the community one. Similarly, the families of all patients over 65 years and of all patients who were never admitted to hospital were not adversely affected to a significantly greater extent in the community care service after two years, although there was an unmistakable trend in that direction. When the differences between the services in family burden was examined in more detail, the higher ratings obtained

in the community service were found to be due to the effects on the family of a discrete group of patients. These were the younger, mainly psychoneurotic, patients who had had at least one admission and who had never been a severe burden, but who continued to cause their families problems after two years. The community service was not providing as much social support to the families of this group as was the control service (Grad and Sainsbury, 1968).

The burden of care: the impact of functional psychiatric illness on the patient's family.

This research paper is completed by G. Fadden, P. Bebbington and L. Kuipers in 1987. The main objectives of this research paper to mention different literature due to understand the family burden. The document study method is used in this study. The summary of this research papers are in the following-

Biegel & Milligan (1992) have suggested that there is little empirically convincing evidence available to support the relationship between family burden, and socio-demographic characteristics of patients, such as age, education, gender, ethnicity or social class. However, this conclusion has been challenged by recent trends which do support the relationship of socio-cultural variables to family burden. Ethnicity and social class have received sparse attention in the literature in relation to family burden (Guarnaccia & Parra, 1996).

In relation to family burden, Jenkins (1988) suggests that Hispanic families may conceptualize mental illness on a continuum, and that their ideas permit both acceptances of current disability and hope for the future; these cultural orientations may mediate the subjective dimensions of family burden.

Mors et al (1992) report that if the patient is male, family stress levels are likely to be significantly higher. Chaves et al (1993) found that male patients fare worse than female patients on a family disability assessment scale.

George Brown *et al* (1962) long ago observed that the type of household in which patients reside was important to re-hospitalization: patients who had been hospitalized for schizophrenia who were discharged to live with kin fared worse than did their counterparts who settled into lodgings outside their family setting. The living situation or social ecology of the home environment may be expected to mediate the clinical course of illness and the type of family burden.

Mandelbrote & Folkard (1961) in a study of schizophrenic patients reported the degree to which families were restricted or disturbed by the patient's presence in the home, though it is not clear how they rated these factors. Fifty-five per cent of families were rated as disturbed in some way, though only 2% of relatives reported severe stress. The authors are vague about what they regards stress on the family, describing typical stress situations as those in which the behavior of the patient upset his family or prevented them from doing certain things'. Another shortcoming of the study is that at follow up they did not interview the families of those patients (18% of sample) whom it had not been possible to maintain in the community, and who presumably had the most severe effects on their families. The authors found that there were more disturbed families in rural than in urban areas.

One of the most damaging consequences of living with a relative with a persistent mental illness is the detriment to social and leisure activities. This was noted in the first study of the problem (Yarrow *et al* 1955) wives consistently believed that mental illness was regarded by others as a stigma and expressed fears regarding social discrimination. In consequence, one-third adopted a pattern of 'aggressive concealment', making drastic changes in order to avoid or cut off former friends, with some going so far as to move to a different part of town. Another third had told only members of the family, or close friends who either understood the problem or had been in a similar situation themselves (Yarrow *et al*, 1955).

These have been emphasized in a number of studies (Yarrow *et al*, 1955; Mandelbrote & Folkard, 1961; Mills, 1962; Hoenig & Hamilton, 1966, 1969; Stevens, 1972). To some extent, difficulties may arise because caring for a patient with a persistent psychiatric disorder limits opportunities for an adequate income. The most severe problems, however, occur when the patient was formerly the breadwinner, particularly if circumstances prevent the relative from taking over this role. The extent to which the families of psychiatric patients are impoverished should not be underestimated.

Waters & Northover (1965) also remarked that relatives showed surprising tolerance of disturbed behavior. Brown and his colleagues (1966) felt strongly that too much was sometimes being asked of relatives who, however, did not complain, either because they were too ashamed to talk about their problems or because they had concluded that no effective help would be offered. It

was evident that relatives needed expert aid, which they received only when their difficulties had reached a crisis. Brown and his colleagues (1966) warn against those involved in service provision assuming patients are better off at home because the majority of relatives do not complain “the fact that there is this lack of complaint cannot be interpreted as a justification of - community care”.

The burden of schizophrenia on the family: A study from Nigeria

This research paper is completed by I. S. M. Yellowe in 1992. The main objectives of this research paper to understand the burden of schizophrenia on the family. The socio-demographic and clinical characteristics of the subjects were recorded, and their key relatives (usually spouse, otherwise closets careers) were interviewed using the modified Pai & Kapur instrument the GHQ-28. The modified Pai & Kapur instrument used in this study consisted of 20 questions relating to objective burden, arranged in four subgroups (effects on family finances, effects on family routine, effects on family interactions, effects on family leisure) and a 21st question relating to subjective burden. Scoring was on a three-point scale (no burden, 0; moderate burden, 1; severe burden, 2). The standard format of the GHQ-28 was used, and the scoring was on a four-point Linkert scale (normal, 0; mild, 1; moderate, 2; severe, 3).

Yellowe (1992) mentions in this paper that forty-four subjects were required 24 of whom (55%) were from rural families. Thirty-six subjects (82%) were men, 36 (82%) were single, and 30 (68%) had attained at least a post-primary level of education. Thirty-four subjects (77%) were on their first admission at the hospital, while the rest were in out-patient follow-up care. All 44 subjects had been ill for at least 6 months (range 8 months to about 10 years). The mean and standard deviation were difficult to obtain as exact date could not be obtained for most subjects. However, it was possible to establish that 32 subjects (73%) had been ill for less then 3 years. All 44 subjects had some treatment elsewhere before presenting at the hospital. Results of such treatment varied from little or no change to full recovery, but all the subjects were ill enough to be admitted at the time of inclusion. Four subjects (9%) had been treated at another psychiatric hospital, 9 (20%) had received spiritual treatment, 15 (34%) had received traditional treatment, and 16 (36%) had received both spiritual and traditional treatment.

The greatest burden was scored for effect on family routine, followed by effect on family

interaction. Overall, rural families had higher 'burden' scores than urban families. The care for the schizophrenic at home constitutes an appreciable burden on the family even in Nigeria, economically and are therefore more likely to feel the expense of treatment, and of transportation for follow-up treatment, as a burden. Furthermore, an age range of 21-45 years and male sex constitute the most productive segment of the society, when lack of productivity due to schizophrenic illness is likely to be felt as a (financial) burden by the family ((Yellowe, 1992).)

Family burden of schizophrenia and depressive illness: Specifying the effects of ethnicity, gender and social ecology.

This research paper is completed by J. H. Jenkins and J. G. Schumacher in 1999. Aim of this study to investigate the relationship between family burden and socio-cultural context. The study design called for a two-by-two comparative sample of 80 subjects divided into four groups of 20 by ethnicity (Latino and Euro-American) and diagnosis (schizophrenia and depression). An explicitly comparative design for the study of these questions can help to ascertain whether socio-behavioral features of family response are (a) non-specific to particular disorders, and/or (b) variable across cultural settings.

Jenkins & Schumacher (1999) indicate that regardless of diagnosis or ethnicity, patient misery was found most burdensome and distressing. However, considerable difference in shades of meaning and nuance across groups appears in relation to what is classed similarly as 'misery'. Only gender was significantly associated with social performance (males reported to have greater deficits). A complex cultural - ecological effect was observed among the Latino-schizophrenia group.

Burden on caregivers of people with schizophrenia: comparison between Germany and Britain

This Study is completed by C. Roick, D. Heider, P. E. Bebbington, M. C. Angermeyer, J. M. Azorin, T. S. Brugha, R. Kilian, S. Johnson, M. Toumi and A. Kornfeld on behalf of the Euro SC Research Group. Aim of This study to analyze whether family burden is affected by national differences in the provision of mental health Services.

The method of this study refers to the patients with schizophrenia and their key relatives were examined in Germany (N=333) and Britain (N=170). Differences in family burden in both countries were analyzed with regression models controlling for patient and caregiver characteristics.

Results of this study is family burden is associated with patients 'symptoms, male gender, unemployment and marital status, as well as caregivers 'coping abilities, patient contact and being a patient's parent. However, even when these attributes were controlled for, British caregivers reported more burden than German caregivers. National differences in family burden may be related to different healthcare systems in Germany and Britain. Support for patients with schizophrenia may be shifted from the professional to the informal healthcare sector more in Britain than in Germany (Roick et al, 2007).

Family-Based Intervention for Schizophrenic Patients in China: A Randomized Controlled Trial

This study is completed by W. Xiong, M. A. Phillips, X. Hu, R. Wang, Q. Dai, J. Kleinman and A. Kleinman in 1994. The objective of this study is to understand the family-based intervention for schizophrenic patients. Sixty-three DSM-III-R schizophrenic patients living with family members were enrolled when admitted to hospital and randomly assigned to receive standard care or a family-based intervention that included monthly 45-minute counseling sessions focused on the management of social and occupational problems, medication management, family education, family group meetings, and crisis intervention.

The findings of the is at 6, 12, and 18-month follow-ups by blind evaluators, the proportion of subjects re-hospitalized was lower, the duration of re-hospitalization was shorter, and the duration of employment was longer in the experimental group than in the control group; these differences were statistically significant at the 12 and 18-month follow-ups and were not explained by differences in drug compliance. Family intervention was associated with significantly lower levels of family burden. This intervention is less costly than standard treatment, is suitable for urban families of schizophrenic patients in China and feasible given the constraints of the Chinese mental health system (Xiong et al, 1994).

Chapter-04

✎ Theoretical Frameworks

4.1 Theoretical Frameworks

Chemist (2012) said there are many approaches to describe Schizophrenia. Although fact is still unknown but researches were been made to describe it. There are two main approaches to describe Schizophrenia are (a) Bio-determinable approach also known as Biological theories and (b) Social Based Approach also known as sociological theories.

I want to mention some sociological theories of schizophrenia. In these theories determinants of mental illness are external (in environment or person's social situation). These theories don't explain fully all causes of mental illness. However, demonstrate that mental illness is not randomly distributed among the population but tends to occur more in disadvantaged groups. Three main theories are mentioned here:

4.1.1 Stress Theory of Schizophrenia

Stress has both physiological and psychological components. We respond to external events or even imagined events with a generalized set of responses called General Adaptation Syndrome or the stress response, but our responses are to some degree tailored to the nature of the event. Selye (2000) studied animals exposed to negative stimuli and found 3 stages of response:

Flight or fight

The Alarm Phase- The body mobilizes the sympathetic nervous system to meet the immediate threat, the release of adrenal hormones, epineprine and norepinephrine, occurs with any intense emotion and produces a boost in energy and tense muscles reduced sensitivity to pain, the shutting down of digestion, along with a rise in blood pressure. Decades earlier a psychologist Walter Cannon (1929) called this reaction "fight or flight", which is still used today.

Resistance

The Resistance Phase- Your body attempts to resist or cope with a persistent stressor that cannot be avoided. In this phase the physiological responses of the alarm phase continue. However, these very responses make the body more vulnerable to other stressors. For Example, when your body has mobilized to fight off the flu, you may find you are more easily annoyed by minor frustrations. Eventually the body will adapt to the stressor and return to normal.

Exhaustion

The Exhaustion Phase- Persistent stress lowers the body of energy, and increases vulnerability to physical problems and eventually illness. The same reactions that allow the body to respond effectively in the alarm and resistance phases are unhealthy as long-range responses. Tense muscles can cause side effects such as headaches and neck pain along with increased blood pressure and digestive disorders. Hans Selye (2000) believed there was no such thing as a stress free life. Some stress can be positive and productive, even if it requires the body to produce short-term energy. Selye (2000) also believes that some negative stress is unavoidable.

Treatment/prevention implications of stress theory

Changing environment, eliminate/reduce stressors

Give a stronger sense of control

Increase social support

4.1.2 Structural Strain Theory of Schizophrenia

Society's organization puts some groups at an economic disadvantage and Economic disadvantage is a strain that leads to higher rates of psychological breakdown (Donald & Murray, 2000).

According to Webster's dictionary strain (in the form of a verb) means to be subjected to tension or stress.

Donald & Murray (2000) said strain may be either:

- **Structural:** This refers to the processes at the societal level which filter down and affect how the individual perceives his or her needs, i.e. if particular social structures are inherently inadequate or there is inadequate regulation, this may change the individual's perceptions as to means and opportunities.
- **Individual:** This refers to the frictions and pains experienced by an individual as he or she looks for ways to satisfy his or her needs, i.e. if the goals of a society become significant to an individual, actually achieving them may become more important than the means adopted.

In criminology, the strain theory states that social structures within society may pressure citizens to commit crime

Treatment/prevention implications of Structural Strain Theory

Farnworth & Leiber (2003) identified the following prevention implications of Structural Strain Theory:-

To prevent psychological breakdown, need large scale interventions—e.g., guaranteed income.

However, Seattle and Denver Income Maintenance Experiments showed minimal benefit from income guarantee in preventing symptoms of psychological distress

4.1.3 Labeling Theory of Schizophrenia

Labeling theory had its origins in *Suicide*, a book by French sociologist Émile Durkheim. He found that crime is not so much a violation of a penal code as it is an act that outrages society. He was the first to suggest that deviant labeling satisfies that function and satisfies society's need to control the behavior (Durkheim, 1987).

Howard Becker (1989) who first began describing the process of how a person adopts a deviant role in a study of dance musicians. He later studied the identity formation of marijuana smokers. This study was the basis of his *Outsiders* published in 1996. This work became the manifesto of the labeling theory movement among sociologists. In his opening, Becker (1989) writes: “*Social groups create deviance by making rules whose infraction creates deviance*”

And by applying those roles to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act the person commits, but rather a consequence of the application by other of rules and sanctions to an 'offender.' The deviant is one to whom that label has been successfully applied; deviant behavior is behavior that people so label.

While society uses the stigmatic label to justify its condemnation, the deviant actor uses it to justify his actions. He wrote: "To put a complex argument in a few words: instead of the deviant motives leading to the deviant behavior, it is the other way around, the deviant behavior in time produces the deviant motivation

Modified labeling theory

Bruce Link and colleagues have conducted several studies which point to the influence that labeling can have on mental patients. Through these studies, which took place in 1987, 1989, and 1997, Link advanced a "modified labeling theory" indicating that expectations of labeling can have a large negative effect, that these expectations often cause patients to withdraw from society, and that those labeled as having a mental disorder are constantly being rejected from society in seemingly minor ways but that, when taken as a whole, all of these small slights can drastically alter their self concepts. They come to both anticipate and perceive negative societal reactions to them, and this potentially damages their quality of life.

Modified Labeling theory has been described as a "sophisticated social-psychological model of 'why labels matter' ". In 2000 results from a prospective two-year study of patients discharged from a mental hospital (in the context of deinstitutionalization) showed that stigma was a powerful and persistent force in their lives, and that experiences of social rejection were a persistent source of social stress.

Bruce Link (1997) also said efforts to cope with labels, such as not telling anyone, educating people about mental distress/disorder, withdrawing from stigmatizing situations, could result in further social isolation and reinforce negative self-concepts. Sometimes an identity as a low self-esteem minority in society would be accepted. The stigma was associated with diminished motivation and ability to "make it in mainstream society" and with "a state of social and psychological vulnerability to prolonged and recurrent problems".

Bruce Link and his colleagues (1997) said there was an up and down pattern in self-esteem, however, and it was suggested that, rather than simply gradual erosion of self-worth and increasing self-deprecating tendencies, people were sometimes managing, but struggling, to maintain consistent feelings of self-worth. Ultimately, "a cadre of patients had developed an entrenched, negative view of themselves, and their experiences of rejection appear to be a key element in the construction of these self-related feelings" and "hostile neighborhoods may not only affect their self-concept but may also ultimately impact the patient's mental health status and how successful they are".

Drawbacks of labeling theory

Chemist (2012) said this theory doesn't explain initial causes of deviant behavior so theory has limited usefulness.

Chapter-05

✎ *Methodology of the Study*

✎ *Basic Method*

✎ *Study Area*

✎ *Population of the Study*

✎ *Sampling*

✎ *Data Collection Technique*

- *Semi-Structure Interview*

- *Use of Recording Device*

- *Observation*

✎ *Data Analysis and Interpretation*

✎ *Ethical Consideration*

✎ *Limitation and Strength of the Study*

5.1 Methodology of the Study

The proposed study is conducted on the basis of phenomenological qualitative research method. Especially the interpretative phenomenological analysis of phenomenological research method is followed in this study. Interpretative Phenomenological Analysis (IPA) is an approach to psychological qualitative research with an idiographic focus, which means that it aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon. Usually these phenomena relate to experiences of some personal significance - such as a major life event, or the development of an important relationship (Smith, 2007). The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants. The phenomenological approach involves detailed examination of the participant's life world; it attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself. At the same time, IPA also emphasizes that the research exercise is a dynamic process with an active role for the researcher in that process. One is trying to get close to the participant's personal world, to take, in Conrad's (1987) words, an 'insider's perspective', but one cannot do this directly or completely. Access depends on, and is complicated by, the researcher's own conceptions; indeed, these are required in order to make sense of that other personal world through a process of interpretative activity. Thus, a two-stage interpretation process, or a double hermeneutic, is involved. The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Eatough, 2006). The methodology of the study considers the following basic aspects.

5.1.1 Basic Method: Case Study based on interpretative phenomenological analysis of phenomenological qualitative research method is the basic method of this study. Because this proposed study requires in-depth information of the psycho-social conditions of people living with schizophrenia in the family.

5.1.2 Study Area: The National Institute of Mental Health and Hospital (NIMH) is considered as the study area.

5.1.3 Population of the Study: Population refers to a group of individuals or items that share one or more characteristics from which data can be gathered and analyzed. The schizophrenic patients and any family member (adult and capable to provide information) of home and out-schizophrenic patients under the treatment of National Institute of Mental Health and Hospital (NIMH) is considered as population in this study.

5.1.4 Sampling: Sampling is the process of selecting units (e.g., people, organizations) from a population of interest so that by studying the sample I may fairly generalize our results back to the population from which they were chosen. The schizophrenic patients and his/her family members are selected through purposive sampling technique. There are 15 cases (schizophrenic patients and his/her family) are selected for data collection. Because purposive sampling technique is an acceptable method for data collection regard to the special situation and in phenomenological qualitative research method. In this regard Neuman & Krueger said that “Purposive sampling is appropriate in three situations. First, a researcher uses it to select unique cases that are especially informative. Second, a researcher may use purposive sampling to select members of a difficult-to-reach specialized population. Third, another situation for purposive sampling occurs when a researcher wants to identify particular types of cases in-depth investigation” (Neuman & Krueger, 2003: 211).

5.1.5 Data Collection Technique

In Interpretative Phenomenological Analysis (IPA) researchers wish to analyze in detail how participants perceive and make sense of things which are happening to them. It therefore requires a flexible data collection instrument. While it is possible to obtain data suitable for IPA analysis in a number of ways – such as personal accounts, and diaries – probably the best way to collect data for an IPA study and the way most IPA studies have been conducted is through the semi-structured interview. This form of interviewing allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of the participants’ responses and

the investigator is able to probe interesting and important areas which arise (Smith & Eatough, 2006). In IPA, researchers gather qualitative data from research participants using techniques such as interview, use of diaries, recording device or focus group etc (Smith, 2007). In this proposed study, I have followed the following data collection technique:-

5.1.5.1 Semi-Structure Interview: In this study, data is collected from the primary sources of data. Data is collected through direct interview. Because of it is a qualitative study so the semi-structure interview schedule is written by bangla is used for the purpose of data collection. In semi-structure interview schedule, the questions are pre-determined but the answers are not indicated. The purpose of using this semi-structure interview schedule to understand the feelings, thinking, lived experience of the respondent and to explore the unknown things on the basis of respondent' answers about psycho-social conditions of people living with schizophrenia in the family.

5.1.5.2 Use of Recording Device: Recording device is used to record data as MP3 or Audio format for the purpose of gathering reliable data from the respondents.

5.1.5.3 Observation: Mental State Examination (MSE)/MSE Observational Scale is used to identify the psychological condition of the schizophrenic patients. In addition structured and unstructured observation is performed.

5.1.6 Data Analysis and Interpretation

A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or the phenomenon. Phenomenological data analysis proceeds through the methodology of reduction, the analysis of specific statements and themes, and a search for all possible meanings. The researcher also sets aside all prejudgments, bracketing his or her experiences and relying on intuition, imagination, and universal structures to obtain a picture of the experience. The researcher needs to understand the philosophical perspectives behind the approach, especially the concept of studying how people experience a phenomenon. The investigator writes research questions that explore the meaning of that experience for individuals

and asks individuals to describe their everyday lived experiences. The phenomenological data analysis steps are generally similar for all psychological phenomenologists who discuss the methods. The original protocols are divided into statements. Then, the units are transformed into clusters of meanings expressed in psychological and phenomenological concepts. Finally, these transformations are tied together to make a general description of the experience, the textural description of what was experienced and the structural description of how it was experienced. The phenomenological report ends with the reader understanding better the essential, invariant structure (or essence) of the experience, recognizing that a single unifying meaning of the experience exists (Creswell, 1998; 51).

In this proposed study the collected data from the fields is edited properly and then data is analyzed through using the interpretative phenomenological qualitative analysis strategy. The main characteristic of the interpretative phenomenological qualitative analysis is the subjective reflection of thinking and lived experience. In this study the data analysis process emphasize on individuals experiences in their every steps of personal and social life cycle. The collected data is analyzed on the basis of phenomena or characteristics and made meaningfulness by considering the objectives of the study.

5.1.7 Ethical Consideration

Ethics is a vital issue in social research. Researcher followed some ethical principle to conduct the current study. For example, to inform the respondents about research objectives, expected results and other possible aspects is one of them. In addition to make understand the respondents that, collected data will be used for the research and education purpose and to ensure confidentiality of personal information of the respondents. Finally, researcher was very careful that the values of respondents, social values and the personal values of researcher that generally influence the study.

5.1.8 Limitations of the Study

Research is a complex, complicated, and scrutinizing activity based on scientific knowledge and competence. The current study paper investigates and understands the psycho-social conditions of people living with schizophrenia in family. There is no remarkable previous study paper in this concern issue based on interpretative phenomenological analysis of phenomenological qualitative research method. Some problems and limitations are therefore, in the way of preparing such a complex and complicated task. The problems and limitations, which have been perceived during the every steps of preparing my current study paper are mention in below:

- ✎ As a new researcher based on interpretative phenomenological analysis of phenomenological qualitative research method, I think I have little knowledge about this method as result I had to face problem in preparing the current study paper properly.
- ✎ I had to face problem to convert the Bangla language of patient's caregivers about their experience, feelings of their personal and social life to English language
- ✎ A very few research paper is found based on interpretative phenomenological analysis of phenomenological qualitative research method as a result it is difficult to me to prepare the study paper properly based on this qualitative research method
- ✎ Some of the respondents believe that mental disorder is a social stigma. So they weren't cooperative, they felt shy. Most of the time they avoided giving the right answers
- ✎ Some of the caregivers have aggressive outlook and subconscious mood. So sometimes they gave irrelevant information
- ✎ This study has some financial problem too because the institute didn't bear the cost of the study

After all, the study has carried out in a new field of knowledge. Besides the limitations it can be a first hand data for the researchers, information investigators and interested person on this field. The findings of this study also helps the lawyers, policy makers, social workers, community leaders, community people, different GOs and NGOs on this issue to take corrective measures at the mental health treatment and services in our country.

Chapter-06

✍ Findings and Analysis

- *Analysis of the Study Result*
- *Discussion*
- *Case Study*
- *Recommendation*

6.1 Findings and Analysis

The study title is “*Living with Schizophrenia: A Phenomenological Study of People with Schizophrenia living in the Family*”. In this conducted study, the collected data through semi-structure interview schedule from the family members of people living with schizophrenia is analyzed and presented on the basis of the concept of studying how people experience a phenomenon or how a given person, in a given context, makes sense of a given phenomenon (Larkin, et al., 2006).

6.1.1 Analysis of the Study Result

1. Socio-Demographic Profile of Respondents and Schizophrenic Patients

The family is the foundational and basic social unit that fosters the stability, wellbeing and sustainability of society. The quality of family relationships shapes and influences the social, psychological, and biological development and functioning of its members. This may be especially relevant to individuals with schizophrenia. Families are much more than groups of individuals. They have their own goals and aspirations. They also are places where every child and adult should feel that he or she is special and be encouraged to pursue his or her own dreams; a place where everyone's individuality is permitted to flourish (Yellowe, 1992). Although every family has conflicts, all the family members should feel as though they can express themselves openly, share their feelings, and have their opinions listened to with understanding. In fact, conflicts and disagreements are a normal part of family life and are important insofar as they permit people to communicate their differences and ventilate their feelings. Generally there are two types family are small family and extended family in our society. The entire patient has come to hospital from a small family except **Case-k** is from joint family and their family is headed by their father. In some cases due to absence of father (e. g. death, abroad or others) family is headed by elder brother or sister. For example *I asked to Case-K who is the head of your family? She said that “As an elder sister I am the head of the family because my father is dead”*.

The relationship pattern in family with children, husband-wife and other family members are not good at all. In terms of relationship with relatives is very bad. *I asked Case-J what is the relationship pattern in your family with children, husband-wife and with your relatives? He said “The relationship pattern in my family is good but with my relatives and neighbor is not good at all because you know my nephew is schizophrenic patients and sometimes my nephew is physically and mentally tortured by neighbor”. I asked the same question to Case-M. She said “You know my husband is mental patient so that the relationship with my husband is very bad as well as with my children because he always disturbs us in our daily activities such as disturb in cooking, study of the children and so on”.*

In addition, the patient’s socio-demographic profile shows that their educational level is horn’s or less than horn’s and someone has no educational level. Male and female patients are equal but the vulnerability of the female patients is more than male patients. Most of the patients are unmarried and someone is married. In accordance with occupation most of the patient is student and others are housewife, job holder, and day labor etc.

2. Economic Profile of Respondents and Schizophrenic Patients

There’s a famous saying that “money is the barrier against all the possible evils”. However, there is another saying that “money is the root of all evil”. What does this ambiguity tell us? That money is just the vehicle; the individual is the pilot; it can help or hurt, assist or hinder. Yes, it is intent and soul of a person that matters here. However you look at it, without coin one cannot survive in this world. Just as the worth of currency is changing daily, so even the importance is also a variable to be considered; it’s always in flux. For education, business, entertainment, food, shelter, treatment and what not, everything is dependent on cash (Lawrence et al., 2012). Nowadays you need money for your whole life; for clothes, for food, for a shelter and even water costs. You may know the proverb ‘Money doesn’t bring happiness’. It’s very controversial. Half says it is wrong, the other says it is true. But would you be happy without any coin? Since money is a large part of our life, you need at least little money to be happy.

Schizophrenia imposes a huge burden on individuals, families and society. The cost of illness incurred by individuals, employers and governments is enormous and includes: Direct healthcare costs (services and materials used in prevention, diagnosis and treatment), indirect healthcare costs (other resources), Indirect costs (value of the output lost because of inability to work due to illness), and Intangible costs (can be valued as quality-adjusted life years). The economic costs associated with mental illness fall into two main categories. These include the direct costs related to health services and indirect costs linked to loss of productivity and quality of life. Acute-care inpatient costs for mental and behavioral disorders are highest for people aged 15 to 44. They are second-highest for people from 45 to 64. It is important to note that most of the costs are from the two age groups that are most active economically (Roick et al., 2007). A patient who has a mental or behavior disorder is not only put in the hospital more often, they also stay in the hospital twice as long as other patients. Some of the specific economic and social costs include: lost production from premature deaths caused by; lost production from people with mental illness who are unable to work, in the short, medium or long term; lost productivity from family members caring for the mentally-ill person; reduced productivity from people being ill while at work; cost of accidents by people who have psychiatric disabilities; supporting dependents of the mentally ill person; direct and indirect financial costs for families caring for the mentally-ill person; unemployment. The costs of mental health conditions to the individuals and the state are considerable (Rose, Mallinson and Walton, 2004). While individuals has to bear the economic costs of lost income in addition to the burden of the conditions itself, the impact on the state is loss of productivity from reduced workforce participation, lost income taxation revenue, and increased government support payments - in addition to direct health care costs.

Generally there are three types of people regarding to the economic status in our society are (a) high class (b) middle class and (c) lower class. Most of the patients have come from middle class families and someone has come from high class and lower class family.

It is the common feature of economic profile of the Schizophrenic patients is that he or she may lost his or her job, stop doing the work that he was doing before. But this type of loss of patient's income a family faces a lot of problem. *I asked to Case-D. He said "my uncle was a job holder*

*in abroad but he is not able to perform any work to do at present due to his mental illness". I also asked to **Case-H**. He said "my brother was a day labor and he was trying to rescue the victimized people relating to saver tragedy but after three days of his rescuing activities he became as mental patient and know he is not able to perform any work and his family at stake now because he is the only earning person of his family". I also asked to **Case-G**. He said "my brother was a bus driver of ASIALINE Dhaka to Camilla but due to use excessive drug with his peer group in hotel Nurjahan he became affected by drug as a metal patient and now he has no positive sense to do any job but he has wife and a child, they are facing a great financial burden to manage the patients".*

The family members also face economic problem due to the schizophrenic patients. Any family member can stop working in order to stay at home, for care, lost pay, lost a job. This type of financial complexity brings out an unbearable financial burden to the society. Family members revealed that they often had to stop work in order to care for their relative with mental illness. *I asked to **Case-G**. He said "I am a garments worker as an operator. Due to my husband illness I had to lose my job and now we are facing unbearable economic problem". I also asked to **Case-L**. He said "I am working at Boshundhora City market in an cloth store as worker of the shop but now I am in a position for brother, I am not able to participate in the cloth shop".* In addition most of the care givers comment that they have no chance to continue their job for the caring of schizophrenic patients.

Schizophrenia has been deemed the most expensive behavioral health care diagnosis, costing more than twice as much as depression per affected individual. Total costs largely arise from indirect costs and are attributable to lost productivity, in turn arising from absenteeism and presenteeism. The inpatient hospitalization rate of schizophrenic patients was greater than the characterizing all other patients with behavioral health care diagnoses. *I asked to **case -F**. She said "I had to spend two lucks taka for my child and I don't know how much money will be needed to treat the illness of my child with a frustrated mind".*

There are some schizophrenic patients spent or lost money irrationally due to his or her illness. *I asked to case-K. She said “my sister is a mental patient and she spends money irrationally, she provides important household materials to other irrationally”. Suppose she provides the Jug, Mug, Spoon etc”.*

The greatest burdens on family members of patients are the financial cost to the family. This can include treatment costs, transport to appointments, the cost of hiring a carer and adapting their home environment. Families spent on average twenty thousand taka per month on care or support for the patient with schizophrenia. *I asked to case-G. He said “We have to spend twenty to fifty thousand taka per month for the treatment, transport to appointments and others”*

Many described not having any money left at the end of the month. The financial strains felt by family members of patients often lead to stress and worry. Family members of mental patients increase their working hours in order to support their family financially, and many need state benefits to cover the extra costs which may lead to compromises for other family members. When caring for a child with cerebral palsy, providing even the basic necessities put financial pressure on the parents, and accessing funding was also challenging, which again increased stress and emotional effects (Schene, 1990).

Another financial burden is loan that is taken for the treatment purpose of member with schizophrenia. This loan has great impact on the family for example family member must have to pay the ‘KISTY’ in a due time otherwise they have financial punishment. This situation often leads to stress and worry. *I asked to Case-B. He said “I am a rickshaw puller. I have already taken twenty thousand taka as loan and I have no scope to return the amount of loan with out selling my property”.*

There are some planned activities of the family put off because of the financial pressure of the patient's illness for instance, postponing marriage, a journey or a religious rite etc. *I asked to Case-O. She said "Due to my husband illness we are participating in our yearly puja (worship) program". I also asked to Case-N. He said "my brother's illness has postponed my younger sister's marriage ceremony".*

People living with schizophrenia face stigma and discrimination in a variety of settings which can have an economic impact. Mental illness stigma/discrimination was found to impact negatively on employment, income, public views about resource allocation and healthcare costs. People with mental health problems are at a disadvantage when it comes to employment. It is therefore expected that this will manifest itself in reduced income. The income differential between those with schizophrenia and those with no mental health problems has been shown to be especially wide. What is interesting is that schizophrenic status has been shown to have a negative effect on employment and income even after controlling for illness severity. Furthermore, the extent to which patients felt stigmatized or discriminated against appears to adversely affect income. It is demonstrated that individuals with mental health problems but who did not feel stigmatized against had similar income levels to those without mental health problems (Schutt, 2011). These studies each report associations and establishing cause and effect is problematic. Low income may well generate feelings of stigma or discrimination and expected stigma may lead to individuals seeking less well-paid jobs. *I asked to Case-C. He said "My brother is a schizophrenic patient for this reason he always faces stigma and discrimination in working environment for instance his salary is six thousand that is of the other workers in the sugar mills factory".*

The economic cost of mental health conditions to individuals is also large. Due to low rates of labor force participation in their working years, people who suffer from mental health conditions may be more prone to poverty in retirement, due to lack of accumulated savings. As such, mental illness can lead to a lifetime of social and economic marginalization.

I asked to Case-E. He said “due to treatment purpose we had to pay three lucks taka and lose job but now we have nothing to pay for treatment and this mental illness leads to us as poor people”.

Individuals with schizophrenia are at greater risk for decreased quality of life, educational difficulties, lowered productivity and poverty, social problems, vulnerability to abuse, and additional health problems. Education is often compromised when early-onset mental disorders prevent individuals from completing their education or successfully pursuing a career. In addition, schizophrenia results in lowered individual productivity due to unemployment, missed work, and reduced productivity at work. Workers aged 16 to 54 years “lose, fail to seek, or cannot find employment” due to mental illness (Scazufca & Kuipers, 1996). Of mentally ill individuals who were employed, mental illness was estimated to reduce their annual income. Reduced earnings and decreased employment potential put mentally ill individuals at an increased risk of poverty. Mental illness and poverty “interact in a negative cycle”, in which poverty acts as a risk factor for mental illness, and mental illness increases the risk that individuals will “drift into or remain in poverty” This negative cycle may also contribute to high rates of homelessness among individuals with mental illness. Mentally ill individuals are vulnerable to low-quality care, abuse, and human rights violations, particularly in low-income areas with limited mental health care resources (Scazufca & Kuipers, 1996).

3. Psychological Conditions of Schizophrenic Patients

The mental status examination or mental state examination, abbreviated MSE, is an important part of the clinical assessment process in psychiatric practice. It is a structured way of observing and describing a patient's current state of mind, under the domains of appearance, attitude, behavior, mood and affect, speech, thought process, thought content, perception, cognition, insight and judgment. There are some minor variations in the subdivision of the MSE and the sequence and names of MSE domains. The purpose of the MSE is to obtain a comprehensive cross-sectional description of the patient's mental state, which, when combined with the biographical and historical information of the psychiatric history, allows the clinician to make an

accurate diagnosis and formulation, which are required for coherent treatment planning. The data are collected through a combination of direct and indirect means: unstructured observation while obtaining the biographical and social information, focused questions about current symptoms, and formalized psychological tests (Trzepacz & Baker, 1993; 202).

Psychological Conditions of Schizophrenic Patients

Appearance: Most of the schizophrenic patients have come with dirty clothes might suggest schizophrenia and their posture and movement is not normal.

Attitudes: Most of the schizophrenic patient's attitudes are uncooperative, hostile, and suspicious.

Behavior: Most of the schizophrenic patients have Stereotypes (repetitive purposeless movements such as rocking or head banging) or mannerisms (repetitive quasi-purposeful abnormal movements such as a gesture or abnormal gait) are the feature of schizophrenia.

Affect: Most of the schizophrenic patients have a flat or blunted affect.

Mood: Most of the schizophrenic patients have dysphoric, Alexithymic, apathetic.

Speech: Most of the schizophrenic patients have Echolalia (repetition of another person's words) and palilalia (repetition of the subject's own words) can be heard with patients with schizophrenia.

Thought: Formal thought disorder is a common feature of schizophrenia. Poverty of thought is one of the negative symptoms of schizophrenia.

Perception: Most of the schizophrenic patients have auditory and visual, hallucinations.

Cognition: All of the schizophrenic patients have difficulties in attention and concentration, consciousness, and orientation.

Insight: Most of the schizophrenic (positive symptoms) patient's insight not intact but in some cases those who have negative symptoms of schizophrenia their insight is intact.

Judgment: Most of the schizophrenic (positive symptoms) patient's judgment is not intact but in

some cases those who have negative symptoms of schizophrenia their judgment is intact.

4. Social Status of Schizophrenic Patients in Family and Society

Family members caring for a person with mental disorder and also the psychiatric patients have a drastic effect on their social lives. Mothers caring for disabled children felt that their lives were so different from their friends and felt that they could only contribute to depressing conversations, and therefore lost friends as a result. Other family members described friends “drifting away”, as they do not understand the family situation. A large number of individuals with a relative suffering from a mental disorder complained of social disruption. Conditions which result in visible signs of disease (for example, Different types of psychotic and neurotic patients have need different types of therapy) may have a greater effect on the social lives of patients and their relatives, for fear of strangers, reactions to their visible condition. Mothers of adolescent patients suffering from severe chronic pain reported more restrictions in their social life than mothers of children with less severe chronic pain and it may be said that this could be directly related to the illness (Golics et al., 2013).

Actually I want to explain the social status of psychiatric patients in family and society from the following point of views are (a) Disruption in routine activities (b) Disruption in leisure (c) Disruption in interaction (d) Effect on physical health of others (e) Effect on mental health of others and (f) The community people appearance and behavior towards psychiatric patients.

Disruption in Routine Activities

Daily routine is an important issue in our life. Without a daily schedule, family life can become quite chaotic. Family Routines also let your children know what is important to you as parents. It helps you teach values and beliefs and when everyone is involved it also teaches belonging and teamwork. Routines and family schedules help you keep some normality and sense of security when changes occur in your family. A family is not precious one with a member with mental disorder that means routine is also important in the family members of a psychiatric patient and also his or her life.

Many caregivers said “the patient are not going to work, school, college, Patient not helping in the household work. Patients disturb in the activities of other members of the family: (for instance spend time to look after the patients abandoning another routine activity)”. **Case-D** said that “his patient's behavior disrupting the activities of my wife such as patient insisting on someone being with him, not allowing that person to go out, etc”. **Case-O** comments that “patients become violent, breaking things, not sleeping and not allowing other members to sleep. Neglect of the rest of the family due to patient's illness”. **Case-N** said that “family members miss school, meals, etc. These conditions seriously affect the family”.

Disruption in routines may arise as a result of mental disorders. Normal activities and chores may have to be set aside and left to be attended to on a later date when the episode subsides. Family roles can also be affected by bipolar disorder. Children may be forced to take on an adult role when their parent becomes ill; spouses may feel they can no longer rely on their partner to fulfill their share of household and family responsibilities (Golics et al., 2013).

Case-B said that “my patients can make daily life very difficult and stressful for kids and teens. In the morning, he feels he must do his rituals right, or the rest of the day will not go well. In the evenings, he must finish all of his compulsive rituals before they go to bed. Some kids and teens even stay up late because of their father illness, and are often exhausted the following day”. Schizophrenic patients can affect homework, attention in class, and school attendance. The stress of hiding their rituals from peers, time spent with obsessions and compulsions, and how their friends react to their illness related behaviors can all affect friendships.

Schizophrenic patients come with uncomfortable feelings, such as fear, disgust, doubt, or a feeling that things have to be done in a way that is "just right." They take a lot of time and get in the way of important activities the person values (socializing, working, going to school, etc.).

Household routines are often disrupted and special plans or allowances are often made for the sufferer. A partner often must take on family responsibilities such as bills, shopping, and driving children to activities. **Case-C** said “I feel overwhelmed and burned out”.

Disruption of family routine was another area in which burden was experienced in schizophrenia.

Most families found the patient's inability to work distressing and inconvenient. As a consequence of the patient's illness, family members tended to be tense and irritable, and had frequent misunderstandings among themselves about caring for the patient. A significant number of caregivers of schizophrenic patients reported reduced interaction with friends and neighbors. Families of schizophrenics experienced a great deal of internal distress and physical, financial and emotional burden. *Case-B* said "*schizophrenic patients always disrupt the family's social life and leisure for instance he disturb my mother cooking, disturb at the time of eating etc*".

Disruption in Leisure Time

Leisure is defined as freedom from the demands of work or duty. Everybody needs leisure in their lives, to balance the stress of work and life. Leisure helps re-energize and relax people, so they can perform activities well in their lives. People use their free time (leisure time) in a variety of different ways; engaging in outdoor activities, entertainment like watching movies or television, or just having time to themselves. Another activity people enjoy doing is just socializing with family and friends. Leisure is an essential part of our lives, and the only problem with leisure is when can we enjoy it? In our society we have a hard time finding time to relax and take a break from our stressful lives.

Leisure is an important aspect in human life because we cannot be happy without leisure in our life but a family which has a member with mental disorder is not happy due to hampering their recreational time. Mental patients stop their normal recreational activities completely, partially, and not at all. *Case F* Said "*my patients stop his normal recreational activities completely*". Patient's illness also use up another person's holiday and leisure time. Patients are not attentive to other members of the family such as children, and its effect on them seriously. *Case-H* said "*my wife has no attention to other members of the family even her children*". Different leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering. It creates a boring and angry oriented mentality of family members of the patients.

Case-O said “Due to my husband illness I was not able to participate to the KALI PUJA (worship)”. A schizophrenic patient in the family affects almost all aspects of family life. This leads to problems, difficulties or adverse events which impact the lives of family members and causes enormous burden on family caregivers.

Family burden was moderate or severe in cases in all groups and more for disruption of family leisure’. Family burden was associated with low income and rural location. It was associated neither with age, education or duration of dependence of the patients, nor with family size, type of caregiver or caregiver’s education and occupation. Almost all caregivers reported a moderate or severe burden, which indicates the gravity of the situation and the need for further work in this area. The rural population to be more burdened for financial domain, and disruption of family leisure was reported more in married, elderly and female caregivers (Phillips et al., 2002).

Family members being able to participate in the hobbies they enjoy. The barriers that prevent families from taking advantage of leisure opportunities link into other domains of family, including lack of time due to the responsibilities of care, limited finance and lack of support available. However, encouragingly, it has been shown that when family members do take the initiative to plan leisure activities, they usually work out positively, despite the restrictions due to the relative’s illness, and families show high satisfaction with this achievement. Family members also find difficulty in taking family holidays, often depending on the disease state of their relative. Problems with finding suitable accommodation can make holiday planning ‘awkward’.

Case K said “I am a student I have to play cricket with team as the best and first batch man but for the care purpose of my brother I am not able to participate with my team”.

Disruption in Interaction

In every person's life, communicating and interacting with others is very vital. It helps spread awareness, knowledge and helps build understanding among all the people around the world. Communicating and interacting helps a person to easily express his/her feelings, ideas, thoughts; it also helps to create a special bond with loved ones in a family, in a friend circle; it helps a teacher understand his/her students and what not. I have seen people who prefer to be silent all the time and I do not find that amazing about any person who is like that. Communication and interaction in a family is very necessary for everyone to gain family support for anything.

Interaction is a vital issue in family life but when it is hampered due to the schizophrenic patients that create an unbearable situation among family members and also with the schizophrenic patient. It has an ill effect on the general atmosphere in the house may be dull, quiet. A lot of misunderstandings are found in the family. Family members get into arguments to over this (for instance over how the patient should be treated, who should do the work, who is to blame, etc. *Case-I* said “we always blame my father and elder brother because they destroy the life of my brother through their barbarian decision”.

Relatives and neighbors stop visiting the family or reduce the frequency of their visits because of the patient's behavior or the stigma attached to his illness. *Case-J* said “due to the mental illness all of the relatives of husband group and some neighbors stop visiting us”. The family becomes secluded. It avoids mixing with others because of shame or fear of being misunderstood. *Case-L* said “We have a great respect in the society but our head is on the land due to my child is a mental patient and nobody allow my child to be married even the marriage decision was determined”.

The schizophrenic patients have effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc. Theses conditions affect the

family seriously. *Case-K* said “*due to the illness of my sister his husband already has divorced my sister*”.

Family members of patients experience a negative effect on their family relationships, both between the relative and the patient, and between other members of the family as a result of the patient’s illness. Poor family relationships do not bode well for chronic disease management regardless of the disease and often family members find relationships difficult as they do not know how to emotionally support each other (Phillips et al., 2002). Family members of patients with schizophrenia reported negative effects on their relationships with each other, resulting in arguments, tension and a lack of understanding of each other’s feelings.

In particular, relatives struggle to deal with patients whose beliefs, outlook and behavior have altered as a consequence of their disease. There was little time for relationships between other members of the family. For example, people with mental conditions felt that their family relationships had been affected as a result of their condition. Partners of patients experience a negative effect on their sex lives as a result of the patient’s disease, often as a result of the patient’s symptoms or not having time to spend together as a couple due to another family member’s illness. It can lead to friction between couples, and in some cases can lead to the break down of relationships or partners seeking sexual encounters outside the relationship.

However, in some families relationships can grow stronger, as the family members work together to help each other and become more closely knit. In families with a child with an intellectual disability, the majorities were taking the initiative to maintain good family relations, and engaging in family activities to encourage this. An increase in family closeness was also found in families of mental illness survivors; one husband of a survivor (*Case-F*) said “*I look at life differently after that. I feel much closer to her.*”

Effect on Physical Health of Others

The schizophrenic patients affect the physical health of others. Others members of the family suffered physical ill health, injuries, etc due to the patient's behavior. It has also an adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated). *Case-A said "My wife is going to losing weight and giving up the eating gradually about tension of her beloved son"*.

Feelings of distress and depression associated with care giving also negatively affect the caregiver's physical health. High rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities of daily living, such as bathing, grooming and other personal care activities, put many caregivers at serious risk for poor physical health outcomes. *Case-M said "I cannot perform activities of daily living, such as bathing, grooming and other personal care activities in the hospital properly"*. Indeed, the impact of providing care can lead to increased health care needs for the caregiver.

About one in ten caregivers report that care giving has caused their physical health to get worse. Caregivers have lower levels of subjective well-being and physical health than non-caregivers. Caregivers reported fair or poor health status, one or more chronic conditions, or a disability, compared with one-third of non-caregivers. Care givers also reported chronic conditions (including heart attack/heart disease, diabetes and arthritis) at nearly twice the rate of non-caregivers. Caregivers suffer from increased rates of physical ailments (including acid reflux, headaches, and pain/aching), increased tendency to develop serious illness, and have high levels of obesity and bodily pain.

The physical stress of care giving can affect the physical health of the caregiver, especially when providing care for someone who cannot transfer him/herself out of bed, walk or bathe without assistance. Ten members of primary caregivers report that they are physically strained. *Case-D said "The health of family carers may affect not only their own lives but also the lives of the*

people for whom they provide care". The caring role can affect the health and well-being of a carer of a person who has a mental or physical disorder.

Women providing care to an ill/disabled spouse are more likely to report a personal history of high blood pressure, diabetes and higher levels of cholesterol. *A woman (Case-F) who spend nine or more hours a week caring for an ill or disabled spouse increase their risk of heart disease two-fold.* It is believed that their health was adversely affected by their caring role. Physical health problems included back injury and hypertension. Back injury was associated with caring for individuals with physical disabilities.

From my study it is proved that the physical health of carers has been shown to be adversely affected, with increased rates of hypertension, lower immune response, altered response to influenza vaccination and slowing of response to wound healing. The presence of depressive symptoms was not a significant predictor of poor physical health in carers but led to increased use of services.

Physical health problems of caregivers increase for those providing the highest levels of care. Similarly, there is a link between caregiver burden and symptoms of infectious illnesses (primarily upper respiratory illness) experienced by caregivers. The more severe the loved one's symptoms, the greater the number of infectious illnesses contracted by the caregiver.

Additionally, Worried, Tired and Alone found that many caregivers of individuals with mental illness reported feeling very tired, drained, emotionally stressed and sick from their care giving responsibilities; some of them had also developed physical illness. Family members living with a person with bipolar disorder reported poorer physical health, more limited activity, and greater health service utilization than non-caregivers. People with severe mental illness are more likely to become victims of violent crime; violence is a stressor that affects family caregivers both emotionally and physically.

Effect on Mental Health of Others

The schizophrenic patients affect the mental health of others. Other family member sought help for psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future). Other member of the family lost sleep, become depressed or weepy, expressed suicidal wishes, become excessively irritable, etc.

Case-M said “I am the only one who has to job and care my husband but sometimes I become depressed or weepy, sometimes I express suicidal wishes, become excessively irritable, etc”.

Caregivers feel isolated, restricted from pursuing their own activities, and may be overwhelmed by a lack of support from friends, family and treatment providers. Frustration in ensuring medication adherence; coping with disturbed or awkward interpersonal behavior and fatigue from continuous supervision of a family member have also been reported to add to caregiver burden. In addition, caregivers have reported great anxiety due to fear that their relative may attempt suicide. *Case-B* said “we are felling guilt, loss, helplessness, fear, Anxiety etc. relating to the patients behavior”. Guilt, loss, helplessness, fear, vulnerability, and cumulative feelings of defeat, anxiety, resentment, and anger are commonly reported by caregivers.

Worried, Tired and Alone found that many caregivers feel a deep and pervasive sense of fear and uncertainty as well as powerlessness and helplessness, often exacerbated by the unpredictable behaviors of the individual with mental illness experiencing a relapse. Most commonly reported behaviors were the reactions of violence, volatile mood swings, alienation, abusive language and the capacity of the individual to appear normal one minute and on the edge the next.

The Community People towards Schizophrenic patients

The community people can help the schizophrenic patients and their family very effectively but there are some obstacles also created by the community people. Unfortunately, many people have negative views of mental health problems. Negative attitudes and a lack of understanding can cause people living with schizophrenia to be treated badly or labeled in a way that hurts their standing in the community. This is sometimes called 'stigma', and can affect those with mental or emotional problems and their carers and families.

Many caregivers said that the patients living with schizophrenia are not treated well by the community people. Schizophrenic patients and their family face different types of stigma or discrimination. *Case-G* said “the community people are not favorable to the patient’s condition because they create and ask the mental patients by different types of bad name and blame the patient’s family and also try to postpone marriage ceremony of the family member of patients”.

Some care giver said that the community people are favorable to the patient’s condition because they behave correctly with mental patients and help the family by providing loan facilities, financial assistance without interest, providing the treatment related information. *Case-H* said “My neighbors help me providing the right information of treatment and also help me to come to this hospital through financial assistance”.

The public’s attitude toward mental illnesses such as schizophrenia is important if the community based treatment of mental illness is to succeed. Patients with mental illness achieve better integration in neighborhoods where people accept them as neighbors and believe that mental illness is best treated in the community as opposed to institutions. *Patients with schizophrenia and their families have suffered greatly from the stigmatizing effects and the educational, vocational, and interpersonal barriers resulting from negative social attitudes toward their conditions narrated by Case-N.* Patients with schizophrenia have tremendous difficulties finding employment and acquiring living quarters, and they suffer from falsely pressed charges for violent crimes by these kinds of stigmatizing effects.

In analyzing personal experience, stigmatizing attitudes toward schizophrenia appeared to be significantly lower among residents who had a family member with a schizophrenic illness; however, this did not hold true for residents who had a friend with a schizophrenic illness. Stigma can be defined as a sign of disgrace or discredit, which sets a person apart from others. The experience of stigma is characterized by shame, blame, secrecy, being the “black sheep of the family”, isolation, social exclusion and discrimination. It is a major barrier to treatment and the prevention of suicide. Stigma is also a major reason why sufferers of mental illness fail to acknowledge their illness and it has been described as the underlying factor mitigating against

the social re-integration of those recovering from mental illness. **Case-E** said *“Community people believe that individuals living with schizophrenia are not friendly, they are crazy, they are dangerous, we are afraid of being close to such individuals, they are unpredictable and can result harm, individuals living with schizophrenia are moody, they are not kind, they have disturbed/negative thoughts, its better to avoid them”*.

Stigma has been described as a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses. When stigma leads to social exclusion or discrimination, it results in unequal access to resources that all people need to function well: educational opportunities, employment, a supportive community, including friends and family, and access to quality health care. These types of disparities in education, employment, and access to care can have cumulative long-term negative consequences. For example, a young adult with untreated mental illness who is unable to graduate from high school is less likely to find a good paying job that can support his or her basic needs, including access to health care. These disadvantages can cause a person to experience more negative outcomes. Being unemployed, living at or below the poverty line, being socially isolated, and living with other social disadvantages can further deflate self-esteem, compounding mental illness symptoms, and add to the burden of stigma. **Case-L** said *“People described the names others used to describe people living with schizophrenia, such as 'mad', 'crazy', 'cuckoo', or 'nuts’*”. They said people living with schizophrenia can be excluded from the community or made fun of.

Some said their whole family was treated with suspicion or as 'untouchables'. This was shown in body language, by staying away, by staring, making fun of them or ignoring them on the street. **Case-N** said that *“Such behavior hurts people and affects social and family life and in some cases even opportunities for getting married and starting a family”*.

Some carers believed that people living with schizophrenia can have spiritual causes. Others felt beliefs that explain schizophrenia by curses, or part of one's destiny or Karma, don't help and are

misleading. *Case-C* said that such beliefs 'do not serve us any more' because they focus on blame and not on helping people who are ill. *Case-E* said that her ex-husband had decided their son should not go to a psychiatric hospital because he was worried it could affect his future career. Another mentioned that her son did not want to socialize with other people with mental health problems to avoid being labeled.

Stigma may affect relationships both within and outside the family. Relationships may break down as partners find it difficult to cope with changes in behavior, energy levels, moods, and contribution to household chores and activities. The result is that a large number of parents experiencing mental illness are reliant on a pension for their income – either because of being a single parent or because of inability to maintain employment as a result of their illness. Many (but importantly, not all) of these single parents are women, and thus may experience the double stigma of both mental illness and single motherhood.

5. Support from Family, Society and Organization for the Treatment and Management of Schizophrenic patients

Families can play an important role in supporting a loved one with a mental health or addiction condition. Family members often deal with crises, assist with system navigation, serve as informal case managers, encourage and support treatment, secure housing, arrange for income assistance, monitor symptoms and maintain records of previous treatments, medications and hospitals. Family members may experience anxiety, stress, shame, self-blame, depression, fear and anger. Mental health and addiction problems can also have an impact on a family's employment and financial situation. This is the result of the additional stresses and time demands of care giving, as well as the actual costs of supporting an individual who may not be financially independent. Caregivers of people with schizophrenia indicated they rarely or never get social support from family and friends. Without sufficient supports themselves, family members are at-risk of poor health themselves. People dealing with schizophrenia in their family can initially not have adequate information regarding the problem, treatment or available resources. Over time, they may feel that they are not adequately regarded for their knowledge of their family member

and contribution to the mental health and addictions system. This situation is beginning to change as more family-to-family support becomes available and service providers more actively involve families in planning to improve the navigation and quality of the mental health and addictions system.

Many caregivers said that their family support is sufficient relating to treatment and management of their patients. They are supporting the patients through gathering information, contact with psychiatrists, psychotherapists, take care in hospital and home and they are trying to behave appropriately with the patients and also providing support in family and society, awareness building among community people etc. *Case-G* said “*I think support from family to treat the patient is appropriate because we are helping my brother financially with no risk, contacting with doctor regularly and trying to follow doctor’s advice in every moment*”. Some caregivers said that support from family is not sufficient relating to treatment and management of their patients because they have lack of knowledge about the behavior pattern or how to behave with a psychiatric patient and they have no available information about the patient’s conditions. *Case-F* said “*My husband is a mental patients but my support is not so well to treat my husband properly because I have financial complexity and have to work in the office as a result I am not able to take care my husband properly*”

Many caregivers said that the patients living with schizophrenia are not treated well by the community people. Mental patients and their family face different types of stigma or discrimination. *Case-G* said “*the community people are not favorable to the patient’s condition because they create and ask the mental patients by different types of bad name and blame the patient’s family and also try to postpone marriage ceremony of the family member of patients*”. Some caregiver said that the community people are favorable to the patient’s condition because they behave correctly with schizophrenic patients and help the family by providing loan facilities, financial assistance without interest, providing the treatment related information etc. *Case-H* said “*my neighbors help me providing the right information of treatment and also help me to come to this hospital through financial assistance*”.

Many caregivers said that the organizational support especially National Institute of Mental

Health and Hospital is sufficient for the treatment and management of the psychiatric patients because we took different services from different mental health clinic and village doctors and Saint (e. g. Mawlana, Oza, Fokir) but their service very poor to treat and manage mental health patients. Doctors, nurses, psychotherapists and social workers are cordial to treat and manage the psychiatric patients in this hospital. *Case-F* said “*To be free and cure from mental disorder of my child I went many places but my child was not cured at last I have come to National Institute of Mental Health and Hospital and after taking treatment from this hospital my child is free from mental disorder*”. Someone said that the organizational support is not sufficient for the treatment and management of the schizophrenic patients because the doctors and nurses of this hospital are not attentive to patients at required level. Doctors are busy in private practice; at the emergency moment generally they are absence in hospital; lack of supply of medicine is another important aspect we have to buy medicine from outside pharmacies; The bathroom, toilet, and bed sheet is very dirty; Bug is another problem in this hospital for bug we are not sleeping easily in the bed at night. *Case-I* said “*I think the support from hospital is not sufficient because we faces different problem such as beaten by bug insects, dirty toilet and bathroom, absence of doctors at emergency moment, misbehavior of nurses etc*”.

6. Respondent’s Opinion to Manage the Psycho-social Conditions of Schizophrenic patients

Many attendants of the patients said that to ensure effective family support/family participation in treatment and management we should behave with patients properly, Contact with psychiatrists regularly, follow doctor’s advice properly, and fulfill patient’s needs, and provide financial and other assistance as much as possible from our family. Someone said that we should participate in family counseling program relating to patients conditions.

Caregivers said that local gate keepers are important parts of the society. So to ensure the effective support from society we should include the local gate keepers in awareness building program so that the community people cannot misbehave with psychiatric patients because it increases abnormal behavior of the psychiatric patients. *Case-D* said “*we can establish village*

organization to protect the mental patients and to provide effective support from society”.

All of the respondents said that psychiatrists, nurses, and others professionals should be cordial with patients and care givers, a strong supervisory committee must be established in the hospital who supervise the situations of the patients to take the proper actions at the proper time, bathroom, toilet facilities should be developed, should be ensure fresh water supply, should be kept the every ward and bed neat and clean, and should be used medicine to reduce the bug problem etc.

Many caregivers commented on doctors and nurses behavior that they are not enthusiastic to the patient’s situations at expected level but psychotherapists and social workers are playing good role to develop the psycho-social conditions of the psychiatric patients. So, psychiatrists, psychotherapists, social workers and nurses should be more careful to their patients and clients.

6.1.2 Discussion

Most existing health-related quality-of-life research concerns the impact of schizophrenia on patients. However, in several mental disabilities, studies have been carried out investigating the impact of schizophrenia on the lives of patients and families of patients. The aim of this paper is to investigate and understand the psycho-social conditions of people living with schizophrenia in family. Ten papers were identified for review. This study shows that a wide variety of aspects of family members' lives can be affected, including emotional, financial, family relationships, education and work, leisure time, and social activities. Many of these themes are linked to one another, with themes including financial impact and social impact being linked to emotional impact. Some positive aspects were also identified from the literature, including family relationships growing stronger. Several instruments exist to measure the impact of schizophrenia on the family, and most are specialty specific (Golics et al., 2013). The impact of schizophrenia on patients and families of patients are often unrecognized and underestimated. Taking into account the quality of life of families as well as patients can offer the clinician a unique insight into issues such as family relationships and the effect of treatment decisions on the patient's close social group of partner and family.

Most of the schizophrenic patients have similar effects on the patients and family members of the patients including psychological and emotional functioning, disruption of leisure activities, effect on interpersonal relationships and financial resources. Several common themes were identified from the studies reviewed. Financial, routine, leisure, social, emotional, educational, interactional impact were reported separately in much of the study, and hence are reported as separate themes (Roick et al., 2007).

The family is the foundational and basic social unit that fosters the stability, wellbeing and sustainability of society. The quality of family relationships shapes and influences the social, psychological, and biological development and functioning of its members. This may be especially relevant to individuals with mental health problems. Generally there are two types family are small family and extended family in our society relating to mental and their caregivers' answers. The entire patient has come to hospital from a small family except someone

is from joint family and their family is headed by their father. In some cases due to absence of father (e. g. death, abroad or others) family is headed by elder brother or sister. The relationship pattern in family with children, husband-wife and other family members are not good at all. In terms of relationship with relatives is very bad.

Generally there are three types of people regarding to the economic status in our society are (a) high class (b) middle class and (c) lower class. Most of the patients have come from middle class families and someone has come from high class and lower class family. It is the common feature of economic profile of the schizophrenic patients is that he or she may lost his or her job, stop doing the work that he was doing before. But this type of loss of patient's income a family faces a lot of problem. The family members also face economic problem due to the member with mental disorder. Any family member can stop working in order to stay at home, for care, lost pay, lost a job. This type of financial complexity brings out an unbearable financial burden to the society. Family members revealed that they often had to stop work in order to care for their relative with mental illness. There are some mental patients (especially the bipolar mood disorder affected patients) spent or lost money irrationally due to his or her illness. There are some planned activities of the family put off because of the financial pressure of the patient's illness for instance, postponing marriage, a journey or a religious rite etc.

The greatest burden on schizophrenic patients and family members of patients is the financial cost to the family. This can include treatment costs, transport to appointments, the cost of hiring a carer and adapting their home environment. Families spent on average twenty thousand per month on care or support for the patient with an intellectual disability; many described not having any money left at the end of the month. The financial impact on families caring for patients with schizophrenia varied from twenty thousand to fifty thousand depending on the severity of the patient's situations. The financial strains felt by family members of patients often lead to stress and worry. Family members of schizophrenic patients increase their working hours in order to support their family financially, and many need state benefits to cover the extra costs which may lead to compromises for other family members (Pasamanick, Scarpetti & Dinitz, 1967). When caring for a child with cerebral palsy, providing even the basic necessities put financial pressure on the parents, and accessing funding was also challenging, which again

increased stress and emotional effects. The difficulties involved in accessing funding are greater in low-income families, who often receive minimal support and face greater problems with social functioning and relationships.

The mental status examination (MSE) is an important part of the clinical assessment process in psychiatric practice. It is a structured way of observing and describing a patient's current state of mind, under the domains of appearance, attitude, behavior, mood and affect, speech, thought process, thought content, perception, cognition, insight and judgment (Wikipedia, 2013). But in regarding psychotic patients their mental status is abnormal type such as schizophrenic patients. On the other hands in regarding neurotic patients their mental status is normal (e. g. social phobia) but in regarding some neurotic patients may develop abnormal mental status (e. g. depression, obsessive-compulsive disorder etc.).

Family members caring for a person living with schizophrenia and also the schizophrenic patients have a drastic effect on their social lives. Mothers caring for schizophrenia affected children felt that their lives were so different from their friends and felt that they could only contribute to depressing conversations, and therefore lost friends as a result. Other family members described friends “drifting away”, as they do not understand the family situation. A large number of individuals with a relative suffering from a mental disorder complained of social disruption. Conditions which result in visible signs of disease (for example, Different types of schizophrenic patients have need different types of therapy) may have a greater effect on the social lives of patients and their relatives, for fear of strangers, reactions to their visible condition (Golics et al., 2013). Mothers of adolescent patients suffering from severe chronic pain reported more restrictions in their social life than mothers of children with less severe chronic pain and it may be said that this could be directly related to the illness.

Daily routine is an important issue in our life. Without a daily schedule, family life can become quite chaotic. It helps to teach values and beliefs and when everyone is involved it also teaches belonging and teamwork. Routines and family schedules help to keep some normality and sense of security when changes occur in your family. A family is not precious one with a member with

mental disorder that means routine is also important in the family members of a schizophrenic patient and also his or her life. Many caregivers said “the patient are not going to work, school, college, Patient not helping in the household work. Patients disturb in the activities of other members of the family: (for instance spend time to look after the patients abandoning another routine activity).

An important part of family is family members being able to participate in the hobbies they enjoy. The barriers that prevent families from taking advantage of leisure opportunities link into other domains of family, including lack of time due to the responsibilities of care, limited finance and lack of support available. However, encouragingly, it has been shown that when family members do take the initiative to plan leisure activities, they usually work out positively, despite the restrictions due to the relative’s illness, and families show high satisfaction with this achievement (Grad and Sainsbury, 1968). Family members also find difficulty in taking family holidays, often depending on the mental illness state of their relative. Problems with finding suitable accommodation can make holiday planning ‘awkward’. Relatives of patients living with schizophrenia described limitations of holiday planning, for example, not wanting to travel together at the park or their relative having to wear certain types of clothes.

Interaction is a vital issue in family life but when it is hampered due to the schizophrenic patients that create an unbearable situation among family members and also with the psychiatric patient. It has an ill effect on the general atmosphere in the house may be dull, quiet. A lot of misunderstandings are found in the family. Family members get into arguments to over this (for instance over how the patient should be treated, who should do the work, who is to blame, etc. Relatives and neighbors stop visiting the family or reduce the frequency of their visits because of the patient's behavior or the stigma attached to his/her illness. The schizophrenic patient's illness has effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc. Theses conditions affect the family seriously (Falloon, Boyd & McGill, 1984).

Family members suffer greatly from the emotional effects of living with and caring for, a relative with a disease, with the impact of some diseases being felt by every member of the family. Emotional impact was the most common topic discussed in the study. The psychological distress felt by family members often results from their feelings of helplessness and lack of control. Many different emotions are mentioned by family members: guilt, anger, worry, upset, frustration, embarrassment, despair, loss and relief. Each emotion affects family members in different ways and to different extents, often depending on the disease severity of the patient, and the period of time that has passed since the diagnosis. Female partners of mental patients had higher psychological distress than male partners (Anisuzzaman, 2011). However, no significant difference was seen between genders when measuring overall quality of life of relatives. There may be gender differences in responses to care giving, based on the gender of the patient. It is not just the parents and partners who are affected emotionally by a relative's disease. For example, siblings of children with schizophrenia suffered from significant adjustment problems.

Family members of patients experience a negative effect on their family relationships, both between the relative and the patient, and between other members of the family as a result of the patient's illness. Poor family relationships do not bode well for chronic disease management regardless of the disease and often family members find relationships difficult as they do not know how to emotionally support each other. Family members of patients living with schizophrenia reported negative effects on their relationships with each other, resulting in arguments, tension and a lack of understanding of each other's feelings. In particular, relatives struggle to deal with patients whose beliefs, outlook and behavior have altered as a consequence of their disease. There was little time for relationships between other members of the family. For example, adolescents with bipolar mood disorder conditions felt that their family relationships had been affected as a result of their conditions (Jenkins and Schumacher, 1999). Partners of patients experience a negative effect on their sex lives as a result of schizophrenia, often as a result of the patient's symptoms or not having time to spend together as a couple due to another family member's illness. It can lead to friction between couples, and in some cases can lead to the break down of relationships or partners seeking sexual encounters outside the relationship.

However, in some families relationships can grow stronger, as the family members work together to help each other and become more closely knit. In families with a child with an intellectual disability, the majority was taking the initiative to maintain good family relations, and engaging in family activities to encourage this.

Living with, or caring for, a relative with schizophrenia can have a large impact on the education and careers of family members. This could include disruption of school work in siblings or children of the patients or the employment of adults being affected and the burden of care placed upon them. Some families of children with disabilities felt that some of their family members would not be able to attend work or school in the near future. The unpredictable nature of children's health and lives does not often fit with a typical, progressive work profile. One or both parents had given up an education or career to care for their child with schizophrenia. Family members of schizophrenic patients felt that their employment was affected by their family member's condition. Reasons included needing to look after the patient, attending hospital appointments and emotional effects affecting work. Looking after a patient with mental disorder can also have a huge impact on a family member's work on a day-to-day basis. Family member carers were reporting late for work, missing work, spending time at work talking on the telephone to their relative and some left work due to their carer responsibilities (Kuipers & Bebbington, 1988).

The schizophrenic patients affect the physical health of others. Others members of the family suffered physical ill health, injuries, etc due to the patient's behavior. It has also an adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated) Feelings of distress and depression associated with care giving also negatively affect the caregiver's physical health. High rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities of daily living, such as bathing, grooming and other personal care activities, put many caregivers at serious risk for poor physical health outcomes. Physical health problems of caregivers increase for those providing the highest levels of care. Similarly, there is a link between caregiver burden and symptoms of schizophrenia experienced by caregivers. The more severe the loved one's symptoms, the greater the number of schizophrenia contracted by the caregiver. Additionally,

Worried, Tired and Alone found that many caregivers of individuals living with schizophrenia reported feeling very tired, drained, emotionally stressed and sick from their care giving responsibilities; some of them had also developed physical illness. Family members living with schizophrenia reported poorer physical health, more limited activity, and greater health service utilization than non-caregivers (Pasamanick, Scarpetti & Dinitz, 1967). People living with schizophrenia are more likely to become victims of violent crime; violence is a stressor that affects family caregivers both emotionally and physically.

The schizophrenic patients affect the mental health of others. Other family member sought help for psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future). Other member of the family lost sleep, become depressed or weepy, expressed suicidal wishes, become excessively irritable, etc. Caregivers feel isolated, restricted from pursuing their own activities, and may be overwhelmed by a lack of support from friends, family and treatment providers. Frustration in ensuring medication adherence; coping with disturbed or awkward interpersonal behavior and fatigue from continuous supervision of a family member have also been reported to add to caregiver burden. In addition, caregivers have reported great anxiety due to fear that their relative may attempt suicide. Guilt, loss, helplessness, fear, vulnerability, and cumulative feelings of defeat, anxiety, resentment, and anger are commonly reported by caregivers (Pasamanick, Scarpetti & Dinitz, 1967). Worried, Tired and Alone found that many caregivers feel a deep and pervasive sense of fear and uncertainty as well as powerlessness and helplessness, often exacerbated by the unpredictable behaviors of the individual living with schizophrenia experiencing a relapse. Most commonly reported behaviors were the reactions of violence, volatile mood swings, alienation, abusive language and the capacity of the individual to appear normal one minute and on the edge the next.

The community people can help the schizophrenic patients and their family very effectively but there are some obstacles also created by the community people. Unfortunately, many people have negative views on schizophrenia. Negative attitudes and a lack of understanding can cause people living with schizophrenia to be treated badly or labeled in a way that hurts their standing

in the community. The community people are not favorable to the patient's condition because they create and ask the schizophrenic by different types of bad name and blame the patient's family and also try to postpone marriage ceremony of the family member of patients. In analyzing personal experience, stigmatizing attitudes toward schizophrenia appeared to be significantly lower among residents who had a family member with schizophrenia; however, this did not hold true for residents who had a friend with schizophrenic patient. Community people believe that individuals with mental disorders are not friendly, they are crazy, they are dangerous, we are afraid of being close to such individuals, they are unpredictable and can result harm, individuals living schizophrenia are moody, they are not kind, they have disturbed/negative thoughts, its better to avoid them. People described the names others used to describe people living with schizophrenia, such as 'mad', 'crazy', 'cuckoo', or 'nuts'. Some care giver said that the community people are favorable to the patient's condition because they behave correctly with mental patients and help the family by providing loan facilities, financial assistance without interest, providing the treatment related information (Phillips et al., 2002).

Families can play an important role in supporting a loved one with a mental health or addiction condition. Family members often deal with crises, assist with system navigation, serve as informal case managers, encourage and support treatment, secure housing, arrange for income assistance, monitor symptoms and maintain records of previous treatments, medications and hospitals. Some caregivers said that support from family is not sufficient relating to treatment and management of their patients because they have lack of knowledge about the behavior pattern or how to behave with a schizophrenic patient and they have no available information about the patient's conditions (Roick et al., 2007). Many caregivers said that their family support is sufficient relating to treatment and management of their patients. They are supporting the patients through gathering information, contact with psychiatrists, psychotherapists, take care in hospital and home and they are trying to behave appropriately with the patients and also providing support in family and society, awareness building among community people etc. Many caregivers said that the organizational support especially National Institute of Mental Health and Hospital is sufficient for the treatment and management of the psychiatric patients

because we took different services from different mental health clinic and village doctors and Saint (e. g. Mawlana, Oza, Fokir) but their service very poor to treat and manage mental health patients. Doctors, nurses, psychotherapists and social workers are cordial to treat and manage the psychiatric patients in this hospital. Someone said that the organizational support is not sufficient for the treatment and management of the schizophrenic patients because the doctors and nurses of this hospital are not attentive to patients at required level. Doctors are busy in private practice; at the emergency moment generally they are absence in hospital; lack of supply of medicine is another important aspect we have to buy medicine from outside pharmacies; The bathroom, toilet, and bed sheet is very dirty; Bug is another problem in this hospital for bug we are not sleeping easily in the bed at night.

Many attendants of the patients said that to ensure effective family support/family participation in treatment and management we should behave with patients properly, Contact with psychiatrists regularly, follow doctor's advice properly, and fulfill patient's needs, and provide financial and other assistance as much as possible from our family. Someone said that we should participate in family counseling program relating to patients conditions. Caregivers said that local gate keepers are important parts of the society. So to ensure the effective support from society we should include the local gate keepers in awareness building program so that the community people cannot misbehave with schizophrenic patients because it increases abnormal behavior of the schizophrenic patients. All of the respondents said that psychiatrists, nurses, and others professionals should be cordial with patients and care givers, a strong supervisory committee must be established in the hospital who supervise the situations of the patients to take the proper actions at the proper time, bathroom, toilet facilities should be developed, should be ensure fresh water supply, should be kept the every ward and bed neat and clean, and should be used medicine to reduce the bug problem etc. Many caregivers commented on doctors and nurses behavior that they are not enthusiastic to the patient's situations at expected level but psychotherapists and social workers are playing good role to develop the psycho-social conditions of the schizophrenic patients. So, psychiatrists, psychotherapists, social workers and nurses should be more careful to their patients and clients.

6.1.3 Case study

Case Study 01

Raihan is a 15 years old boy diagnosed with schizophrenia. He has been referred to National Institute of Mental Health and Hospital (NIMH) for treatment purpose. He is not able to provide information about his illness and other aspects for this reason I took an interview from his father.

Socio-Demographic and Economic Profile

- Name: Raihan
- Age: 15
- Sex: Male
- Address: Jessore
- Education: Class 9
- Siblings: 2 Brothers
- Position: First
- Marital status: Unmarried
- Occupation: Student
- Religion: Islam
- Economic status: Lower Class

I asked to the father of Raihan what the pattern of your family is and how many family members in your family? He said “We live in a single family and there are four members in my family.” I also asked to him what is the relationship pattern in your family with parents and children, among family members, and with relatives ? He said “The relationship with relative is not good and sometimes I face quarrel to my wife about my son’s disease. I also asked to him who and what is the occupation or profession of the head of your family? How much money earned by the head of the family in a month? He said “I am the head of the family and I am a rickshaw puller. My monthly income is tk 5,000 BDT.

I asked to the father of Raihan has anybody stopped working in order to stay at home, lost pay, lost a job ? To what extent does it affect the patient in family? He said “you know I am a rickshaw puller but to stay at the hospital I had to give up my occupation and this situation has an unbearable financial scarcity in my family.”

I asked to the father of Raihan how much has been spent on treatment, medicines, transport, and accommodation away from home and so on and how has this affected family finances? He said “I had to spend tk 70,000 BDT for treatment, medicines, transport, and accommodation purpose.”

I asked to the father of Raihan how large a loan? How do you plan to pay it back? He said “I had to take tk 20,000 BDT as loan and my plan to pay the loan back is to sell my on village property.” I also asked to him did you spend from savings and how much is the family affected? He said “I have no savings for this reason I will have to face financial trouble in future.”

Psychological Conditions of Schizophrenic Patient

This part is completed by the help of psychiatrists’ mental state examination on the schizophrenic patients.

Appearance and behavior: All category of appearance and behavior are not normal.

Affect: Dysphoric

Mood: Dysphoric

Speech: Not normal level

Thought: Thought blocking

Perception: No hallucination is found

Cognition: Disorientation and Stupor

Insight: Impaired

Judgment: Impaired

Social Status of Schizophrenic Patients in Family and Society

Disruption in routine activities

I asked to the father of Raihan has someone to spend time looking after the patient, thus abandoning another routine activity and how inconvenient is this? He said “My wife and I have to spend time to look after my child due to his illness for this reason we are not able to maintain our daily routine activities relating to household chores and occupation.” He also said “My child not sleeping and not allowing ours to sleep. In Addition that due to his illness my younger child has to miss his class and it’s really harmful for my younger child for his future but we have nothing to do.”

Disruption in leisure

I asked to the father of Raihan do you find any disruption of your child recreational activities? Raihan’s father said “My child usually play cricket in the playground but now he has stopped playing cricket completely.” I also asked to the father of Raihan is your child disrupt your leisure time? He said “Yeah he is disrupting our holiday and leisure time for this we feel boring about his abnormal behavior.” He also said Raihan has lack of attention to other members of the family, such as his mother and younger brother. I asked to the father of Raihan has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering and how do the family members feel about it? He said “Exactly due to his illness we have no scope to go for a pleasure trip or family gathering, it’s hampering our life seriously.”

Disruption in interaction

I asked to the father of Raihan do you find and explain any disruption in interaction due to your child illness? He said “Her mother says it is curse of our seen but I think it is misunderstanding. Sometimes we blame to each other on the basis of child illness. I say to his mother it’s your responsibility to get rid of your child illness this situation creates quarrel between us. He also

said my relatives and neighbors stopped visiting the family or reduced the frequency of their visits because of the patient's behavior or the stigma attached to his illness for this reason my family become a secluded family from the society.” I also asked to the father of Raihan does it avoid mixing with others because of shame or fear of being misunderstood and how do the members feel about this? He said “Yes we feel shame to mix with others”

Effect on physical health of others

I asked to the father of Raihan has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated) and how severe is it? He said “I feel tension and it creates weight loss. In addition lack of sleep and diarrhea are common for me.”

Effect on mental health of others

I asked to the father of Raihan has any other family member sought help for - psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future) and how severe is this? He said “I feel worry about his future and its make me frustrated day by day.” I also asked to the father of Raihan Has any other member of the family lost sleep, be come depressed or weepy, expressed suicidal wishes, become excessively irritable, etc and how severely? He said “I and my wife feel lack of sleep depressed or weepy and sometimes we become excessively irritable.”

The community people towards schizophrenic patient

I asked to the father of Raihan how the patients and your family are treated by the community people? He said “the community people are favorable to the patient’s condition.” I also asked to the father of Raihan how the community people help the patient and your family? He said “The community people are helping us by providing appropriate information about treatment, providing loan facilities etc.” What are the problems are created by community people relating to

patient's conditions asked by myself to Raihan's father. He said "Social stigma is the problem created by community people."

Support from Family, Society and Organization for the Treatment and Management of Schizophrenic Patient

I asked to the father of Raihan do you think your family support is sufficient for the treatment and management of your patient and how you are supporting the patient ? He said "Support from family is not sufficient because I am facing the financial complexity to provide appropriate treatment to my child. Now we are supporting my child through hospitalization, taking care etc."

I asked to the father of Raihan in what extent have you get support from your society ? He said "The society people are helping us by providing appropriate information about treatment, providing loan facilities etc." I also asked to the father of Raihan do you think the organizational support is sufficient for the treatment and management of your patient and how you are supported by the different relevant organizations ? He said "The organizational support is not sufficient for the treatment and management of mental illness. In my second question's answer he said we had taken treatment service from jessore mental health clinic before hospitalized of my child here."

Respondent's Opinion to manage the Psycho-social Conditions of Schizophrenic patient

I asked to the father of Raihan what are your suggestions to ensure effective family support/family participation in treatment and management procedure by considering your patient's conditions? He said "The family education on metal health is required." I also asked to the father of Raihan what are the effective measures can be taken for the effective support from society? He said "Community awareness building program on mental health, involve community leader to reduce social stigma, community welfare trust for mental health patient etc can be taken for the effective support from society." I asked to the father of Raihan have you share anything to develop the organizational support at expected level ? He said "The organizational support should increase from the administrative authority." I also asked to the father of Raihan

how different professionals relating to your patient's should play role to develop the psychosocial conditions of your patient ? He said "Psychiatrists, psychotherapists, social workers and nurses should be more careful to their patients."

Case Study 02

Samim Al Mamun is a 40 years old man diagnosed with schizophrenia. He has been referred to National Institute of Mental Health and Hospital (NIMH) for treatment purpose. He is not able to provide information about his illness and other aspects for this reason I took an interview from his nephew.

Socio-Demographic and Economic Profile

- Name: Samim Al Mamun
- Age: 40
- Sex: Male
- Address: Tangail
- Education: HSC
- Siblings: 4 Brothers and 3 sisters
- Position: Second
- Marital status: Unmarried
- Occupation: Unemployed
- Religion: Islam
- Economic status: Middle Class

I asked to the nephew of Samim Al Mamun what the pattern of patient's family is and how many family members in patient's family? He said "He lives with his elder brother in a single family and there are six members in his family." I also asked to him what is the relationship pattern in patient's family among family members, and with relatives? He said "The relationship with relative is not good and sometimes family members not take care properly and show disrupts behavior with patient. I also asked to him who and what is the occupation or profession of the

head of your family? How much money earned by the head of the family in a month? He said “His elder brother is the head of the family and he is a government service holder. His monthly income is tk 25,000 BDT.

I asked to the nephew of Samim Al Mamun has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent does it affect the patient in family? He said “You know I am a man who has a little business but to stay at the hospital I had to give up my business and this situation has a financial complexity in my family.”

I asked to the nephew of Samim Al Mamun how much has been spent on treatment, medicines, transport, and accommodation away from home and so on and how has this affected family finances? He said “We had to spend tk 4, 50, 000 BDT for treatment, medicines, transport, and accommodation purpose and to collect this amount of money we had to sell the property of patient.”

I asked to the nephew of Samim Al Mamun do you have any cost relating to extra arrangement of patient? He said “Sometimes patient go away from home so for commig back home we had to spend money as mobile and transport cost and we had to spend money to go any place according to patient’s will for instance to in the bank of river, to go to the mazar etc.”

Psychological Conditions of Schizophrenic Patient

This part is completed by the help of psychiatrists’ mental state examination on the schizophrenic patients.

Appearance and behavior: All category of appearance and behavior are abnormal.

Affect: Dysphoric

Mood: Dysphoric

Speech: Not normal level

Thought: Though broadcasting

Perception: Auditory hallucination is found

Cognition: Disorientation and Stupor

Insight: Impaired

Judgment: Impaired

Social Status of Schizophrenic Patients in Family and Society

Disruption in routine activities

I asked to the nephew of Samim Al Mamun has someone to spend time looking after the patient, thus abandoning another routine activity and how inconvenient is this? He said “I have to spend time to look after patient due to his illness for this reason I am not able to maintain daily routine activities relating to household chores and business. In addition before affecting disease he helped the family through marketing of daily necessary commodities but now patient is not helping in the household work.” I also asked him does patient disrupt the activities of other members of the family? He said “Patient’s behavior is disrupting activities of family members (e. g. patient insisting on family member being with him, not allowing family member to go out, not allowing to cook, to watch TV, to study and patient becoming violent, breaking things, not sleeping and not allowing others to sleep. It has a tremendous effect on family.”

Disruption in leisure

I asked to the nephew of Samim Al Mamun do you find any disruption in recreational activities of patient? Nephew of Samim Al Mamun said “He usually watches TV, listen song but now he has stopped everything partially.” I also asked to the nephew of Samim Al Mamun do patient disrupt your leisure time ? He said “Yeah he is disrupting our holiday and leisure time for this we feel boring about his abnormal behavior.” He also said Samim Al Mamun has lack of attention to other members of the family, such as his younger brother and sister. I asked to the nephew of Samim Al Mamun has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering and how do the family members feel about it? He said “Exactly due to his illness we have no scope to go for a pleasure trip or family gathering, it’s hampering our life seriously for example in previous month we arranged a marriage ceremony of my sister but due to his illness his younger sister didn’t participate in the marriage ceremony.”

Disruption in interaction

I asked to the nephew of Samim Al Mamun do other members get into arguments to over this for instance over how the patient should be treated, who should do the work, who is to blame ? How are they affected? He said “Family member say it is his elder brother responsibility to get rid of his illness this situation creates quarrel between us. He also said his relatives stopped visiting the family or reduced the frequency of their visits because of the patient's behavior or the stigma attached to his illness (e. g. his three sisters and the smallest brother stopped visiting and bearing cost relating to treatment of his illness).” I also asked to the nephew of Samim Al Mamun has the patient's illness had any other effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it? He said “Sometime quarrel is found among brothers relating to treatment and take care cost of the patient.”

Effect on physical health of others

I asked to the nephew of Samim Al Mamun has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated) and how severe is it? He said “His mother feels tension and it creates weight loss. In addition lack of sleep and diarrhea are common for his mother.”

Effect on mental health of others

I asked to the nephew of Samim Al Mamun has any other family member sought help for - psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future) and how severe is this? He said “We feel worry about his future and its make us frustrated day by day.” I also asked to the nephew of Samim Al Mamun has any other member of the family lost sleep, be come depressed or weepy,

expressed suicidal wishes, become excessively irritable, etc and how severely? He said “His mother feels lack of sleep depressed or weepy and sometimes we become excessively irritable to his behavior.”

The community people towards schizophrenic patient

I asked to the nephew of Samim Al Mamun how the patients and your family are treated by the community people ? He said “Most of the community people are favorable to the patient’s condition but someone creates problem such as pushing into the pond, calling as judo, nado, mental etc.” I also asked to the nephew of Samim Al Mamun how the community people help the patient and your family? He said “The community people are helping us by providing appropriate information about treatment.” What are the problems are created by community people relating to patient’s conditions asked by myself to the nephew of Samim Al Mamun. He said “Social stigma is the problem created by community people such as postponing marriage offer due to social stigma as narrated by the community people.”

Support from Family, Society and Organization for the Treatment and Management of Schizophrenic Patient

I asked to the nephew of Samim Al Mamun do you think your family support is sufficient for the treatment and management of your patient and how you are supporting the patient? He said “Support from family is sufficient. Now we are supporting the patient through hospitalization, taking care etc.” I asked to the nephew of Samim Al Mamun in what extent have you get support from your society ? He said “The society people are helping us by providing appropriate information about treatment.” I also asked to the nephew of Samim Al Mamun do you think the organizational support is sufficient for the treatment and management of your patient and how you are supported by the different relevant organizations? He said “The organizational support is not sufficient for the treatment and management of mental illness. In my second question’s answer he said we had taken treatment service from different Oza, Fokir, Mawlana and tangail mental health clinic before hospitalized the patient here.”

Respondent's Opinion to manage the Psycho-social Conditions of Schizophrenic patient

I asked to the nephew of Samim Al Mamun what are your suggestions to ensure effective family support/family participation in treatment and management procedure by considering your patient's conditions? He said "The family education on metal health is required." I also asked to the nephew of Samim Al Mamun what are the effective measures can be taken for the effective support from society? He said "Community awareness building program on mental health can be taken for the effective support from society." I asked to the nephew of Samim Al Mamun have you share anything to develop the organizational support at expected level ? He said "The organizational support should increase from the administrative authority. They should provide individual treatment related facility for example to provide all time electric facility, supply of water, and every room should contain four beds but in here, there are eight beds that is gathering and harmful for patients." I also asked to the nephew of Samim Al Mamun how different professionals relating to your patient's should play role to develop the psycho-social conditions of your patient ? He said "Doctors don't give much time to the patient, nurses become irritable to patient, and sometimes word boys torture the patient so psychiatrists, psychotherapists, social workers and nurses, word boy should be more careful to their patients."

Case Study 03

Atiqur Rahman is a 50 years old man diagnosed with schizophrenia. He has been referred to National Institute of Mental Health and Hospital (NIMH) for treatment purpose. He is not able to provide information about his illness and other aspects for this reason I took an interview from his wife.

Socio-Demographic and Economic Profile

- Name: Atiqur Rahman
- Age: 50
- Sex: Male
- Address: Sirajgonge

- Education: HSC
- Siblings: 2 brothers and 2 sisters
- Position: Second
- Marital status: Married
- Occupation: Private service holder
- Religion: Islam
- Economic status: Middle Class

I asked to the wife of Atiqur Rahman what the pattern of your family is and how many family members in your family? She said “We live with in a single family and there are four members in my family.” I also asked to her what is the relationship pattern in patient’s family among family members, and with relatives? She said “The relationship with relative is not good and sometimes we feel boring to take care properly and show disrupts behavior with patient. I also asked to her who and what is the occupation or profession of the head of your family? How much money earned by the head of the family in a month? He said “My elder daughter is the head of the family and she is working in reception desk of City Company. Her monthly income is tk 7,000 BDT.

I asked to the wife of Atiqur Rahman has he lost his job? Stopped doing the work which he was doing before? To what extent does it affect the patient in family? She said “ My husband worked in a private company but due to his illness he is not able to continue his job and for this reason we are not able to take proper food, to continue my child study to put on good dress on the occasion of Eid and other festivals.”

I asked to the wife of Atiqur Rahman has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent does it affect the patient in family? She said “I am a tailor and it is my first and last occupation but to stay at the hospital I had to give up my occupation and this situation has a great financial complexity in my family.”

I asked to the wife of Atiqur Rahman how much has been spent on treatment, medicines, transport, and accommodation away from home and so on and how has this affected family

finances? He said “We had to spend tk 15,000 BDT for treatment, medicines, transport, and accommodation purpose.”

I asked to the wife of Atiqur Rahman do you have any cost relating to extra arrangement of patient? He said “Sometimes patient go away from home so for coming back home we had to spend money as mobile and transport cost.”

I asked to the wife of Atiqur Rahman any other planned activity put off because of the financial pressure of the patient's illness for instance, postponing a marriage, a journey or a religious rite. How far is the family affected? She said “Lack of money we had to cancel the participation in marriage ceremony of our relative, due to financial pressure we are not able to go in relatives’ house and to go in a beautiful place.”

Psychological Conditions of Schizophrenic Patient

This part is completed by the help of psychiatrists’ mental state examination on the schizophrenic patients.

Appearance and behavior: All category of appearance and behavior are abnormal.

Affect: depressed

Mood: depressed

Speech: Not normal level

Thought: Thought broadcasting

Perception: Visual hallucination is found

Cognition: Disorientation and Stupor

Insight: Impaired

Judgment: Impaired

Social Status of Schizophrenic Patients in Family and Society

Disruption in routine activities

I asked to the wife of Atiqur Rahman has someone to spend time looking after the patient, thus abandoning another routine activity and how inconvenient is this? She said “I have to spend time to look after patient due to his illness for this reason I am not able to maintain daily routine activities relating to household chores and occupation. In addition before affecting disease he helped the family through marketing of daily necessary commodities but now patient is not helping in the household work.” I also asked her does patient disrupt the activities of other members of the family? She said “Patient’s behavior is disrupting activities of family members (e. g. patient insisting on family member being with him, not allowing family member to go out, not allowing to cook, to watch TV, to study and patient becoming violent, breaking things, not sleeping and not allowing others to sleep. In addition that patient creates disorder through dancing and singing without dress in front of family members. It has a tremendous effect on family.” I also asked to the wife of Atiqur Rahman is any other member missing school, meals, etc? How serious is this? She said “My elder daughter is a student of Degree College but she is not able to go to college regularly due to involve in job to support our family.”

Disruption in leisure

I asked to the wife of Atiqur Rahman do you find any disruption in recreational activities of patient? Wife of Atiqur Rahman said “He usually watches TV, listen song but now he has stopped everything partially.” I also asked to the wife of Atiqur do patient disrupt your leisure time? She said “Yeah he is disrupting our holiday and leisure time for this we feel boring about his abnormal behavior.” She also said patient has lack of attention to other members of the family, such as his wife, daughter and son. I asked to the wife of Atiqur Rahman has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering and how do the family members feel about it? He said “Exactly due to his illness we have no scope to go for a pleasure trip or family gathering, it’s hampering our life seriously.”

Disruption in interaction

I asked to the wife of Atiqur Rahman are there a lot of misunderstandings, etc? How do the family members view this? She said “I say this is curse and result of our sin and patient will never get rid of this mental disease.” I asked to the wife of Atiqur Rahman do other members get into arguments to over this for instance over how the patient should be treated, who should do the work, who is to blame ? How are they affected? She said “We say it is our responsibility to get rid of his illness and sometimes responsibility related situation creates quarrel between us. She said again we are blaming the rural saint for going away of husband due to his motivation to spiritual life illegally. She also said his relatives stopped visiting the family or reduced the frequency of their visits because of the patient's behavior or the stigma attached to his illness (e. g. his sisters and brothers stopped visiting him and his family).” I asked to the wife of Atiqur Rahman has the patient's illness had any other effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it? She said “Sometimes quarrel is found among family members relating to treatment and taking care of the patient.” I asked to the wife of Atiqur Rahman has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this? She said “I think we are secluding from the society day by day because of shame or fear of being misunderstood.”

Effect on physical health of others

I asked to the wife of Atiqur Rahman has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated) and how severe is it? She said “I feel tension and it creates weight loss.”

Effect on mental health of others

I asked to the wife of Atiqur Rahman has any other family member sought help for - psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future) and how severe is this? She said "We feel worry about his future and its make us frustrated day by day and sometimes I feel I want to die." I asked to the wife of Atiqur Rahman has any other member of the family lost sleep, be come depressed or weepy, expressed suicidal wishes, become excessively irritable, etc and how severely? She said "I feel lack of sleep, depressed or weepy and sometimes we become excessively irritable to his behavior."

The community people towards schizophrenic patient

I asked to the wife of Atiqur Rahman how the patients and your family are treated by the community people? She said "Community people are not favorable to the patient's condition and creates problem such as calling as judo, nado, mental etc." I asked to the wife of Atiqur Rahman how the community people help the patient and your family ? She said "The community people may help us by providing appropriate information about treatment, advice my husband to be good man in his life." What are the problems are created by community people relating to patient's conditions asked by myself to the wife of Atiqur Rahman. She said "Social stigma is the main problem created by community people."

Support from Family, Society and Organization for the Treatment and Management of Schizophrenic Patient

I asked to the wife of Atiqur Rahman do you think your family support is sufficient for the treatment and management of your patient and how you are supporting the patient? She said "Support from family is not sufficient due to financial complexity. Now we are supporting the patient through hospitalization, taking care etc." I asked to the wife of Atiqur Rahman in what

extent have you get support from your society? She said “The society people are helping us.” I also asked to the wife of Atiqur Rahman do you think the organizational support is sufficient for the treatment and management of your patient and how you are supported by the different relevant organizations ? She said “The organizational support is not sufficient for the treatment and management of mental illness because in here I found lack of proper attention of doctors, nurses and others to the patient.”

Respondent’s Opinion to manage the Psycho-social Conditions of Schizophrenic patient

I asked to the wife of Atiqur Rahman what are your suggestions to ensure effective family support/family participation in treatment and management procedure by considering your patient’s conditions? She said “We should provide nutritious food to the patient, to behave gently with patient, to take care properly etc.” I also asked to the wife of Atiqur Rahman what are the effective measures can be taken for the effective support from society? She said “Community awareness building program on mental health can be taken for the effective support from society.” I asked to the wife of Atiqur Rahman how different professionals relating to your patient’s should play role to develop the psycho-social conditions of your patient? She said “Doctors don’t give much time to the patient, nurses become irritable to patient, and sometimes word boys torture the patient so psychiatrists, psychotherapists, social workers and nurses, word boys should be more careful to their patients.”

Case Study 04

Abdul Alim is a 25 years old man diagnosed with schizophrenia. He has been referred to National Institute of Mental Health and Hospital (NIMH) for treatment purpose. He is not able to provide information about his illness and other aspects for this reason I took an interview from his uncle.

Socio-Demographic and Economic Profile

- Name: Abdul Alim
- Age: 25
- Sex: Male
- Address: Manikgonge
- Education: HSC
- Siblings: Only a brother and sister
- Position: Second
- Marital status: Married
- Occupation: Business man
- Religion: Islam
- Economic status: Middle Class

I asked to the uncle of Abdul Alim what the pattern of patient's family is and how many family members in patient's family? He said "He lives in a single family and there are three members in his family." I also asked to him what is the relationship pattern in patient's family among family members, and with relatives? He said "The relationship in family is not good because patient disturbs everyone family and society." I also asked to him who and what is the occupation or profession of the head of your family? How much money earned by the head of the family in a month? He said "Now I am the head of his family and I am a teacher of madrasah. My monthly income is tk 8,000 BDT. I asked to the uncle of Abdul Alim has he lost his job? Stopped doing the work which he was doing before? To what extent does it affect the patient in family? He said "He stopped the business due to his illness which he was doing before and it has a financial effect not only his family but also in family because I have to bare the cost of treatment and others."

I asked to the uncle of Abdul Alim has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent does it affect the patient in family? He said "you know I am a teacher but to stay at the hospital I am not able to teach the student and this situation has a

tremendous effect in my personal and family life.” I asked to the uncle of Abdul Alim how much has been spent on treatment, medicines, transport, and accommodation away from home and so on and how has this affected family finances? He said “We had to spend tk 2, 00, 000 BDT for treatment, medicines, transport, and accommodation purpose and to collect this amount of money we had to stock the property of patient.” I asked to the uncle of Abdul Alim do you have any cost relating to extra arrangement of patient? He said “As extra arrangement we had to spend money to take the different traditional treatment from Mowlana, Oza, Fokir etc it might me tk 5,000 BDT.” I asked to the uncle of Abdul Alim has any other planned activity put off because of the financial pressure of the patient's illness for instance, postponing a marriage, a journey or a religious rite. How far is the family affected? He said “Exactly we were not able to participate in my cousin, nephew and neighbor marriage ceremony due to his mental illness but we had to send the present on the occasion of marriage ceremony.”

Psychological Conditions of Schizophrenic Patient

This part is completed by the help of psychiatrists’ mental state examination on the schizophrenic patients.

Appearance and behavior: All category of appearance and behavior are abnormal.

Affect: Elated

Mood: Elated

Speech: Not normal level

Thought: Thought broadcasting

Perception: Auditory hallucination is found

Cognition: Disorientation and Stupor

Insight: Partial Impaired

Judgment: Partial Impaired

Social Status of Schizophrenic Patients in Family and Society

Disruption in routine activities

I asked to the uncle of Abdul Alim has someone to spend time looking after the patient, thus abandoning another routine activity and how inconvenient is this? He said “I have to spend time to look after patient due to his illness for this reason I am not able to maintain daily routine activities relating to household chores and teaching profession. In addition before affecting disease he helped the family through marketing of daily necessary commodities but now patient is not helping in the household work.” I also asked to him does patient disrupts the activities of other members of the family? He said “Patient’s behavior is disrupting activities of family members (e. g. patient insisting on family member being with him, not allowing family member to go out, not allowing to cook, to watch TV, to study and patient becoming violent, breaking things, not sleeping and not allowing others to sleep in family and also disturb other community people through breaking their household materials, disturbing their sleep at mid night etc. It has a tremendous effect on family and society.” He again said sometimes patient tortures night guard of the singhail market with iron stick and kicks the door of neighbor house at mid night and it is really unbearable to the society people.

Disruption in leisure

I asked to the uncle of Abdul Alim do you find any disruption in recreational activities of patient? Uncle of Abdul Alim said “He usually passes time through roaming in the street but now he has stopped everything.” I also asked to uncle of Abdul Alim do patient disrupt your leisure time? He said “yeah he is disrupting our holiday and leisure time for this we feel boring about his abnormal behavior.” He also said Abdul Alim has no attention to other members of the family even his 2.5 years child. I asked to the uncle of Abdul Alim has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering and how do the family members feel about it? He said “Exactly due to his illness we have no scope

to go for a pleasure trip or family gathering, it's hampering our life seriously for example in previous month we arranged a marriage ceremony of my cousin but due to his illness we didn't participate in the marriage ceremony."

Disruption in interaction

I asked to the uncle of Abdul Alim do other members get into arguments to over this for instance over how the patient should be treated, who should do the work, who is to blame ? How are they affected? He said "His father has no intention to the illness of his son for this reason it is my responsibility to get rid of patient from this situation. He also said his relatives stopped visiting the family or reduced the frequency of their visits because of the patient's behavior or the stigma attached to his illness (e. g. his father stopped visiting and bearing cost relating to treatment of his illness)." I also asked to the uncle of Abdul Alim has the patient's illness had any other effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it? He said "The relationship pattern with relatives and neighbors is decreasing day by day due to patient behavior and the alarming assumption is that separation between husband and wife may be happened." I also asked to the uncle of Abdul Alim has the family become secluded ? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this? He said "His mental illness makes his family vulnerable and secluded from society and it has a multi-dimensional problem to mix with others because of shame or fear of being misunderstood."

Effect on physical health of others

I asked to the uncle of Abdul Alim has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated) and how severe is it? He said "His grandpa (my mother) and his wife feel tension and it creates weight loss. In addition lack of sleep is common for his wife."

Effect on mental health of others

I asked to the uncle of Abdul Alim has any other family member sought help for - psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future) and how severe is this? He said "We feel worry about his future and its make us frustrated day by day." I also asked to the uncle of Abdul Alim has any other member of the family lost sleep, be come depressed or weepy, expressed suicidal wishes, become excessively irritable, etc and how severely? He said "His wife feels lack of sleep, depressed or weepy and sometimes we become excessively irritable to his behavior."

The community people towards schizophrenic patient

I asked to the uncle of Abdul Alim how the patients and your family are treated by the community people? He said "Most of the community people are favorable to the patient's condition but someone creates problem indirectly such as calling as mental." I also asked to the uncle of Abdul Alim how the community people help the patient and your family? He said "The community people are helping us by providing appropriate information about treatment, appropriate behavior to patient etc." What are the problems are created by community people relating to patient's conditions asked by myself to the uncle of Abdul Alim. He said "Community people are involving themselves in social stigma relating to the patient condition such as calling to each to other Abdul Alim is mental patient."

Support from Family, Society and Organization for the Treatment and Management of Schizophrenic Patient

I asked to the uncle of Abdul Alim do you think your family support is sufficient for the treatment and management of your patient and how you are supporting the patient ? He said "Support from family is sufficient. Now we are supporting the patient through hospitalization, taking care etc." I asked to the uncle of Abdul Alim in what extent have you get support from your society ? He said

“The society people are helping us by providing appropriate information about treatment, making awareness building organization about mental health etc.” I also asked to the uncle of Abdul Alim do you think the organizational support is sufficient for the treatment and management of your patient and how you are supported by the different relevant organizations ? He said “The organizational support is not expected level for the treatment and management of mental illness because when patient becomes excited then the doctor is absent and nurses say we have nothing to do without doctor permission. In my second question’s answer he said we had taken treatment service from different Fokir, Mawlana and manikgonge mental health clinic before hospitalized the patient here.”

Respondent’s Opinion to manage the Psycho-social Conditions of Schizophrenic patient

I asked to the uncle of Abdul Alim what are your suggestions to ensure effective family support/family participation in treatment and management procedure by considering your patient’s conditions? He said “The family education on metal health is required.” I also asked to the uncle of Abdul Alim what are the effective measures can be taken for the effective support from society? He said “Community awareness building program on mental health can be taken for the effective support from society.” I asked to the uncle of Abdul Alim have you share anything to develop the organizational support at expected level ? He said “The organizational support should increase from the administrative authority they should observe the condition of health facilities and services are provided by hospital because I have found the bed cloth is not neat and clean, Bug is another problem and major problem is lack of fresh water to bath and drink.” I also asked to the uncle of Abdul Alim how different professionals relating to your patient’s should play role to develop the psycho-social conditions of your patient? He said “Doctors don’t give much time to the patient, nurses become irritable to patient, and sometimes word boys torture the patient so psychiatrists, nurses and word boys should be more careful to their patients and doctor should give much time to the patient.”

6.1.4 Recommendation

In Bangladesh, mental health service is generally concentrated on specialized psychiatric hospitals and clinical psychology service centers or clinics, which is grossly inadequate. There is an increasing awareness of the need to shift the emphasis from institution-based to community-based mental health services. Along with this, from very much professional point of view being a researcher, I recommend following issues to handle:

- ✓ Countrywide advertisement to increase people's awareness, co-operation of the Government and efficiency and commitment of service providers will be needed
- ✓ Development of mental health policy or metal health policy should be up to date
- ✓ To develop innovative community-based service related program
- ✓ It is highly required to identify the specific need to address the issue of mental health in Bangladesh
- ✓ Collaborative effort is needed to meet the requirement of the people living with schizophrenia
- ✓ The number of schizophrenic patients seeking treatment should increase
- ✓ To meet the need of the people the number of mental health professionals and facilities for mental health services are needed to be increased in government level as well as private sector.
- ✓ Much more emphasize should be given in education, research, and development of mental health services.
- ✓ Different professionals relating to mental health services must be co-operative and cordial to the schizophrenic patients and their caregivers

6.1.5 Conclusion

In my concluding remark I want to say some participants with schizophrenia reported perceiving their visions and voices positively; while for others it was a distressing experience. Participants with schizophrenia believed that others perceived them as failed, incompetent and sick people. Most participants with schizophrenia accepted the diagnosis, indicating a common shared knowledge of schizophrenia and some degree of compliance and complicity, despite reports of coercion in mental health care. The findings showed evidence of the social construction of schizophrenia and labeling, with resulting disempowerment of people with schizophrenia.

There was no shared understanding of care between participants with schizophrenia and nurses, or between participants with schizophrenia and their carers. A greater understanding of the meaning of schizophrenia to participants with schizophrenia and carers has been explored in the current study. It has been possible to identify the different perceptions of care and of schizophrenia in the study. Participants with schizophrenia had a perception of what care should be, which was emotional support, practical help on a daily basis and not being alone. Care meant people understanding their point of view and being valued, having some privacy and being treated as an equal and an adult. The care they received was control, coercion and medication, which they criticized. However carers believed that medication and coercion were necessary.

The participants with schizophrenia wanted full involvement in decision making and better communication with health professionals. The findings suggested that participants with schizophrenia's perceptions of care and nurses negatively affected their interactions with nurses and influenced their choice of strategy (e.g. compliance or avoidance). The findings suggested that the carers' perceptions of care and of schizophrenia influenced their choice of strategies in their interactions with their relatives with schizophrenia (e.g. controlling them) and in their interactions with nurses (e.g. seeking support and blaming them).

Many needs were unmet by the nursing services, and stress was prevalent in participants with schizophrenia and carers. The most common and severe problems reported were emotional, psychological and social. Negative identity led to participants with schizophrenia living a restricted life and acceptance of the negative identity led to negative psychological consequences, one of which was being stopped in life. Some participants felt that the behaviors of others had prevented them from moving on in life. Not moving on in life could have been a consequence of serious mental illness or of socialization into the sick role, caused by frequent admissions, disempowering care, and lack of resilience due to being older. Older people with schizophrenia may have accepted the objective reality of their illness because they belonged to a generation that did not question this and believed that one could not recover from schizophrenia. Living with a family that believed that schizophrenia was an illness one could not recover from might have prevented a participant with schizophrenia from moving on. Only a few, who had lived with schizophrenia for less than two years, had the best outcomes and the least loss, and were able to return to their old life with some success. Moving on appeared to involve the following: having a positive self-concept, disagreeing with the diagnosis, choosing isolation, being angry (as opposed to sad) and being employed. The feeling of moving on in life may have led to reduced contact with health professionals, while those who felt stopped in life maintained the contact. Reduced socialization into mental patienthood or effective and timely treatment may have led to the feeling of having moved on.

Only a few, who had lived with schizophrenia for less than two years, had the best outcomes and the least loss, and were able to return to their old life with some success. Moving on appeared to involve the following: having a positive self-concept, disagreeing with the diagnosis, choosing isolation, being angry (as opposed to sad) and being employed. The feeling of moving on in life may have led to reduced contact with health professionals, while those who felt stopped in life maintained the contact. Reduced socialization into mental patienthood, or effective and timely treatment may have led to the feeling of having moved on. The exact process is not clear.

Most participants felt disempowered and only some participants with schizophrenia appeared to engage in self-empowerment. The harm done by hospitals and mental health nurses was highlighted, yet participants with schizophrenia continued to seek support from mental health nurses, suggesting a degree of ambivalence.

Male participants with schizophrenia were more likely than female participants to be perceived as violent, rejected by the family, and live alone and unsupported. Living alone and the avoidance strategy appeared to bring some benefits to some people with schizophrenia.

Actions by families and events in society appeared to cause more problems for people with schizophrenia (e.g. intrusive family care, stigma and exclusion) than hearing voices or having delusions. All carers felt they were not supported by health professionals and were concerned about the lack of support for their relatives with schizophrenia. Adult male carers appeared to be blamed by their extended family and received less sympathy than adult female carers. Younger carers appeared to be less committed to continuing the care giving than older carers, indicating a lack of adaptation or a different attitude to care giving in this group. Support groups for carers appeared to be ineffective, but this finding must be treated some caution due to the small number of carers in this study.

References

1. American Psychiatric Association, 2005. *Diagnostic criteria from DSM IV-TR*. Washington DC: American Psychiatric Association.
2. Anisuzzaman, M., 2011. Mental Health and Bangladesh. *Daily New age*, 3 Sep. P. 4b.
3. Chemist, A., 2012. *Biological & Sociological Theories of Schizophrenia*. [Online] Available at: <<http://wethechemist.blogspot.com/2012/01/biological-theories-of-schizophrenia.html>> [Accessed 21 June 2013].
4. Creswell, J. W., 1998. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publication.
5. Fadden, G., Bebbington, P. and Kuipers, L., 1987. The burden of care: the impact of functional psychiatric illness on the patient's family. *British journal of Psychiatry*, Vol-150, pp. 285-292.
6. Falloon, I., Boyd, J. & McGill, C., 1984. *Family care of schizophrenia*. New York: Guilford Press.
7. Firoz, A. H. M., 2007. *Manual on mental health for primary health care physician*. Dhaka: National Institute of Mental Health.
8. Golics, C. J., Basra, M. K. A. & Finlay, A. Y. et al., 2013. The impact of disease on family members: a critical aspect of medical care, *Journal of the Royal Society of Medicine*, [online] Available at: <<http://jrs.sagepub.com/content/early/2013/04/26/0141076812472616>> [Accessed 22 August 2013].
9. Grad, J. and Sainsbury, P., 1968. The Effects that Patients Have on their Families in a Community Care and a Control Psychiatric Service--A Two Year Follow-up. *British journal of Psychiatry*, Vol-114, pp. 265-278.
10. Hatfield, A. & Lefley, H., 1987. *Families of the mentally ill: coping and adaptation*. New York: Guilford Press.

11. Jenkins, J. H. and Schumacher, J. G., 1999. Family burden of schizophrenia and depressive illness: Specifying the effects of ethnicity, gender and social ecology. *British journal of Psychiatry*, Vol-174, pp. 31-38.
12. Kuipers, L. & Bebbington, P., 1988. Expressed emotion research in schizophrenia: Theoretical and clinical implications. *Psychological Medicine*, Vol-18, pp. 893-909.
13. Lawrence, V., Fossey, J., Ballard, C. et al., 2012. Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *British journal of Psychiatry*, Vol-201, pp. 344-351.
14. Ministry of Health and Family Welfare, 2009. *National Health Policy*. Dhaka: Ministry of Health and Family Welfare, Government of Peoples Republic of Bangladesh.
15. Ministry of Health and Family Welfare, 2012. *National Health Policy*. [online] Ministry of Health and Family Welfare. Available at: <mohfw.gov.bd/healthpolicy-2012> [Accessed on: 11 April, 2013].
16. Mohit, M. A., 2001. *Diagnosis of Patients Attending Out Patient Department (OPD) of NIMH*. London: Bang J Psychiatry.
17. Mouly, G. J., 1963. *The science of educational research*. New Delhi: Eurasia Publishing House Pvt. Ltd.
18. Pasamanick, B., Scarpetti, F. & Dinitz, S., 1967. *Schizophrenias in the community: an experimental study in the prevention of re-hospitalization*. New York: Appleton-Century-Crofts.
19. Phillips, M. R., Pearson, V., YANG, L. et al., 2002. Stigma and expressed emotion: a study of people with schizophrenia and their family members in China. *British journal of Psychiatry*, Vol-181, pp. 488-493.
20. Roick, C., Heider, D., Bebbington, P. E. et al., 2007. Burden on caregivers of people with schizophrenia: comparison between Germany and Britain. *British journal of Psychiatry*, Vol-190, pp. 333-338.
21. Rose, L. E., Mallinson, R. K., Walton-Moss, B., 2004. Barriers to Family Care in Psychiatric Settings. *Journal of Nursing Scholarship*, 36 (1), pp. 39-47.

22. Scazufca, M. & Kuipers, E., 1996. Links between Expressed Emotion and Burden of Care in Relatives of Patients with Schizophrenia. *British journal of Psychiatry*, Vol- 168, pp. 580-587.
23. Schene, A. H., 1990. Objective and subjective dimensions of family burden toward an integrative framework. *Social Psychiatry and Psychiatric Epidemiology*, Vol-25, pp. 289-297.
24. Schutt, R. K., 2011. *Homelessness, Housing and Mental Illness*. USA: Harvard University Press.
25. Smith, J. A. 2007. Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*, Vol- 2, pp. 3-11.
26. Smith, J. A. and Eatough, V., 2006. Interpretative phenomenological analysis, in G. Breakwell, C. Fife-Schaw, S. Hammond and J. A. Smith (eds) *Research Methods in Psychology (3rd ed)*. London: Sage Publication.
27. Trzepacz, P.T. & Baker, R. W. 1993. *The Psychiatric Mental Status Examination*. UK: Oxford University Press.
28. U.S. Department of Health and Human Services, 2009. Schizophrenia. [pdf] USA: National Institute of Mental Health. Available at: <http://www.nimh.nih.gov/health/publications/schizophrenia/index.shtml> [Accessed 20 August 2013].
29. World Health Organization, 2003. *Investing in mental health*. [Online] Available at: www.who.int/mental_health [Accessed 21 March 2013].
30. World Health Organization, 2009. *Country Profile-Bangladesh*. Dhaka: World Health Organization.
31. Xiong, W., Phillips, M. R., Hu, X. et al., 1994. Family-Based Intervention for Schizophrenic Patients in China: A Randomized Controlled Trial. *British journal of Psychiatry*, Vol-165, pp. 239-247.
32. Yellowe, I. S. M., 1992. The burden of schizophrenia on the family: A study from Nigeria. *British journal of Psychiatry*, Vol-161, pp. 779-782.

Appendix-01: Semi-Structure Interview Schedule

The Semi-Structure Interview Schedule Institute of Social Welfare and Research University of Dhaka

Research Title: “Living with Schizophrenia: A Phenomenological Study of People with Schizophrenia Living in the Family.”

[This study is conducted as a course ‘Thesis’ of MSS 2nd semester (2011-2012) of Institute of Social Welfare and Research. Respondent’s information will be used only for research purpose and confidentiality of the informer will be maintained properly. I am trying to assess the various difficulties felt by the patient and family relating to schizophrenic patients and will ask you a few questions about these. Please do not hesitate to express your true feelings.]

Socio-Demographic and Economic profile of Respondents and Patients

<ul style="list-style-type: none"> • Name: • Age: • Sex: • Address: • Education: 	<ul style="list-style-type: none"> • Siblings: • Position: • Marital status: • Occupation: • Religion: • Economic status:
---	---

1. The familial aspect: (What is the pattern of your family and how many family members in your family? What is the relationship pattern in your family with parents and children, among family members, and with relatives? Who and what is the occupation or profession of the head of your family? How much money earned by the head of the family in a month?)
2. Loss of patient's income: (Has he/she lost his/her job? Stopped doing the work which he was doing before? To what extent does it affect the patient in family?)
3. Loss of income of any other member of the family due to patient's illness: (Has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent does it affect the patient in family?)

4. Expenditure incurred due to patient's illness and treatment: (Has he/she spent or lost money irrationally due to his/her illness? How much has this affected the family finances? How much has been spent on treatment, medicines, transport, and accommodation away from home and so on? How much has been spent on other treatments such as temples and native healers? How has this affected family finances?)
5. Expenditure incurred due to extra arrangements: (For instance, any other relative coming to stay with the patient; appointing a nurse or servant; boarding out children. How have these affected the family finances?)
6. Loans taken or savings spent: (How large a loan? How do they plan to pay it back? How much does it affect the family? Did they spend from savings? Were these used up? How much is the family affected?)
7. Any other planned activity put off because of the financial pressure of the patient's illness: (For instance, postponing a marriage, a journey or a religious rite. How far is the family affected?)

Psychological Conditions of Schizophrenic Patients

Appearance and behavior:

Affect:

Mood:

Speech:

Thought:

Perception:

Cognition:

Insight:

Judgment:

Social Status of Schizophrenic Patients in Family and Society

Disruption in routine activities

1. Patient not going to work, school, college, etc: How inconvenient is this for the family?
1. Patient not helping in the household work: How much does this affect the family?
2. Disruption of activities of other members of the family: (Has someone to spend time looking

after the patient, thus abandoning another routine activity? How inconvenient is this?)

3. Patient's behavior disrupting activities (Patient insisting on someone being with him, not allowing that person to go out, etc? Patient becoming violent, breaking things, not sleeping and not allowing others to sleep? How much does it affect the family?)
4. Neglect of the rest of the family due to patient's illness: (Is any other member missing school, meals, etc? How serious is this?)

Disruption in leisure

1. Stopping of normal recreational activities: (Completely, partially, and not at all? How do the members of family react?)
2. Patient's illness using up another person's holiday and leisure time: (How is this person affected by it?)
3. Patient's lack of attention to other members of the family, such as children, and its effect on them.
4. Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering? How do the family members feel about it?

Disruption in interaction

1. Any ill effect on the general atmosphere in the house (Has it become dull, quiet? Are there a lot of misunderstandings, etc? How do the family members view this?)
2. Do other members get into arguments to over this (for instance over how the patient should be treated, who should do the work, who is to blame, etc)? How are they affected?
3. Have relatives and neighbors stopped visiting the family or reduced the frequency of their visits because of the patient's behavior or the stigma attached to his illness? How does the family feel about this?
4. Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this?

5. Has the patient's illness had any other effect on relationships within the family or between the family and neighbors or relatives-e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it?

Effect on physical health of others

1. Have any other members of the family suffered physical ill health, injuries, etc due to the patient's behavior? How has this affected them?
2. Has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated)? How severe is it?

Effect on mental health of others

1. Has any other family member sought help for - psychological illness brought on by the patient's behavior (for instance by the patient's suicide bid, or his disobedience, or worry about his future)? How severe is this?
2. Has any other member of the family lost sleep, be come depressed or weepy, expressed suicidal wishes, become excessively irritable, etc? How severely?

The community people towards schizophrenic patients

1. How the patients and your family are treated by the community people?
2. Do you feel that the community people are favorable to the patient's condition?
3. How the community people help the patient and your family?
4. What are the problems are created by community people relating to patient's conditions?

Support from Family, Society and Organization for the Treatment and Management of Schizophrenic Patients

1. Do you think your family support is sufficient for the treatment and management of your patient? And how you are supporting the patient?
2. In what extent have you get support from your society?
3. Do you think the organizational support is sufficient for the treatment and management of

your patient? And how you are supported by the different relevant organizations?

Respondent's Opinion to manage the Psycho-social Conditions of Schizophrenic patients

1. What are your suggestions to ensure effective family support/family participation in treatment and management procedure by considering your patient's conditions?
2. What are the effective measures can be taken for the effective support from society?
3. Have you share anything to develop the organizational support at expected level?
4. How different professionals relating to your patient's should play role to develop the psycho-social conditions of your patient?

Finally, is there any other which we have not asked you? If so, what is it? How badly does it affect you? What is your opinion to reduce this? And what are the roles of others?

Appendix-02: Domains of Mental State/Status Examination

The mental status examination or mental state examination, abbreviated MSE, is an important part of the clinical assessment process in psychiatric practice. It is a structured way of observing and describing a patient's current state of mind, under the domains of appearance, attitude, behavior, mood and affect, speech, thought process, thought content, perception, cognition, insight and judgment. The purpose of the MSE is to obtain a comprehensive cross-sectional description of the patient's mental state, which, when combined with the biographical and historical information of the psychiatric history, allows the clinician to make an accurate diagnosis and formulation, which are required for coherent treatment planning (Wikipedia, 2013).

Appearance and Behavior

1. General appearance
2. Facial appearance
3. Rapport
4. Posture and movement
5. Social behavior
6. Motor behavior
7. Oddity of behavior

Attitudes

Attitudes may be uncooperative, hostile, and suspicious etc.

Affect

Trzepacz and Baker (1993) describe affect as "the external and dynamic manifestations of a person's internal emotional state" for example dysphoric, Alexithymic , apathetic etc.

Mood

Trzepacz and Baker (1993) describe mood as "a person's predominant internal state at any one time". For example Echolalia (repetition of another person's words) and palilalia (repetition of the subject's own words) etc.

Speech

- a. rate
- b. rhythm
- c. volume
- d. content

Thought

- a. From
 - Flight of ideas
 - Circumstantialities
 - Derailment
 - Loosening of association
 - Thought block
 - Punning/ rhyming
 - Thought inclusion
- b. Stream
- c. Content- obsession, delusion, suicidal and homicidal ideation
- d. Possession : thought broadcasting, thought insertion and thought withdrawal

Perception

- a. Normal
- b. Hallucination: auditory, visual, gastrointestinal, tactual and olfactory
- c. Illusion
- d. Others if any

Cognition

- a. Consciousness:
- b. Orientation:
Time: day or night? What time it is? Month, year, day?

Place: where he/she at the time?

Person: who with him/her? Who take his/her interview?

- c. Attention and concentration: serial 7 test(at list times)/ subtraction/ count in opposite direction from 20/ ask to mention name of months in opposite direction
- d. Memory:
 - Immediate: mention names of three objects and ask to repeat them immediately
 - Recent: ask what the client taken at breakfast or dinner
 - Remote: ask some historical event; date of birth etc
- e. Intelligence: apply standard IQ test or judge it clinically (understanding, response or fund of information)

Insight: ask question regarding his/her awareness about sickness. It may be Intact/Partially impaired/ impaired.

Judgment: ask meaning of proverb/ ask some question like what will you do if you see fire in neighbor house. It may be Intact/Partially impaired/ impaired.

Appendix-03: A Visual Exhibition of People with Schizophrenia Living in the Family

Source: Golics, C. J. et al., 2013. Journal of the Royal Society of Medicine.

Appendix-04: Application for Seeking Permission to Visit and Collect Data

Date: 27/05/2013

To

Director

National Institute of Mental Health and Hospital (NIMH)

Sheer-e-Bangla Nagar, Dhaka-1207, Bangladesh

Through

Director,

Institute of Social Welfare and Research

University of Dhaka, Dhaka-1205

Subject: Prayer for seeking permission to visit and collect data.

Sir,

With due respect, I would like to state that I am a student of Institute of Social Welfare and Research (ISWR), University of Dhaka. In our M.S.S. 2nd semester, thesis is an obligatory aspect for those students who are selected by the academic examination committee of ISWR through formal disciplinary procedure according to our academic syllabus. I have defined the title of my thesis paper as "*Living with Schizophrenia: A Phenomenological Study of People with Schizophrenia Living in the Family*" with the consultation of selected institute supervisor. In this circumstance, I have needed some important information from the patients under the treatment of your institute about this selected topic. So I am seeking permission to visit your institute, communicate with the patients and their family members and collect data.

So, I therefore pray and hope that, you would be grand my application for giving permission to visit and collect data from the patients and their family under the treatment of your institute. I will be obliged to you for cordial help.

Sincerely yours

X

M.S.S. 2nd semester, Roll no: 509, Session: 2011-2012

Signature_____