# Cognitive Illness Representation as Perceived by Persons With Schizophrenia in Bangladesh

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I hereby certify that this work has not already been accepted in substance for any degree, and is not being concurrently submitted in candidature for any degree.

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## ABSTRACT

This descriptive cross-sectional study aimed to examine cognitive illness representation as perceived by persons with schizophrenia. Using a convenience sampling method, 135 persons with schizophrenia who met the inclusion criteria were recruited from the outpatient department (OPD) of the National Institute of Mental Health (NIMH) Dhaka, Bangladesh. Data were collected by using a set of self-reported questionnaires consisting two parts: 1) the demographic and the clinical characteristics and 2) the Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ). The CIRSQ was validated for cultural relevancy by a psychiatric expert and the face validity was validated by three persons with schizophrenia. Reliability of the CIRSQ was examined using percentage of agreement and Cronbach's alpha coefficients. Of 58 symptom items, 36 items yielded agreement of 80% and more and 14 items were in between 61% and 79%. Cronbach's alpha coefficients of cause, timeline-acute/chronic, cyclical, consequences, personal and treatment control subscales were .91, .76, .54, .60, .11, and .66, respectively.

All subjects labeled their illness as schizophrenia. The two most frequently perceived symptoms were being violent to other and loss of interest in my personal care (99.3%), followed by difficulty sleeping(98.5%), being suspicious of others, and talking or laughing to myself (97.8%), being withdrawn (97.0%), hearing

voices (96.3%), feeling agitated (95.6%), not doing much (94.8%), and problems communicating with other people (93.3%).

Persons with schizophrenia strongly perceived psychological causes of the illness including money worries (95.6%), stress and lack of friends or people who cared about me (88.9%), followed by biological causes including chemical imbalance (77.0%). Chance or bad luck was also endorsed (83.7%). In addition, black magic, stress or worry, and hereditary came up from the ranking three most important factors believing causes of their illness.

For other dimensions of the cognitive illness representation, persons with schizophrenia had a high level of perception of timeline as chronic and cyclical, consequences, and personal and treatment control.

Nurses and health care providers may utilize these findings as baseline information to develop psycho-education program, cognitive illness representation based program for persons with schizophrenia in Bangladesh in order to change or modify their cognitive illness representation.

**Key words**: Schizophrenia, Cognitive Illness Representation, Common-Sense Model

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Kanis Fatema

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# CHAPTER 1

# INTRODUCTION

This chapter details the study's background and significance of the problem, objective, research question, conceptual framework, definition of term, and scope of the study and significance of the study.

## Background and Significance of the Problem

Schizophrenia is the most common and serious form of psychological disorder that can lead to person's disabling. Although schizophrenia is a psychological disorder, it stems from a physiological malfunctioning of the brain (Shives, 2012). Globally, 24 million people are affected by schizophrenia. The prevalence of persons with schizophrenia is 7 per 1,000 of the adult population, and the incidence of persons with schizophrenia is about 3 per 10,000 people each year (World Health Organization [WHO], 2012). The prevalence of schizophrenia in Bangladesh is about 1.1% of the adult population (Firoz as cited in Mazumder et al., 2011). In comparison with global statistics, the prevalence of schizophrenia in Bangladesh is considered quite high.

Worldwide, more than half of persons with schizophrenia cannot access appropriate care and 90% of them remain untreated in developed and developing countries (WHO, 2012). Evidence showed that in the year 2010, there were only 539 persons with schizophrenia who had received treatment at the National Institute of Mental Health (Government of the People's Republic of Bangladesh,

2011). Due to untrained health care personal, unavailable essential drug supply, lack of home care, appropriate referral support, lack of education regarding stigma and discrimination, many persons with schizophrenia are unaware about schizophrenia and its consequences (WHO, 2012). That is why many persons with schizophrenia may seek the help of religious healers (22%), traditional healers and magicians, which may not be appropriate for them (Giasuddin, Chowdhury, Hashimoto, Fujisawa, & Waheed, 2012).

Schizophrenia has several effects on a person, including physical, psychological, economical and spiritual aspects. Physically, persons with schizophrenia might be suffering primarily from distressing symptoms of illness. A person with schizophrenia also lack of self-esteem because they are unable to participate in work and leisure activities. Schizophrenia also has an impact on family members of persons with schizophrenia including the financial, emotional response to the patients, disruption of everyday household work, problems of coping with social withdrawal and decrease of social activities. For society, it also has an impact on manpower because chronic schizophrenia, contributes to cognitive impairment and a decrease in social/work functioning (WHO, 1998).

Schizophrenia is an episodic and chronic psychological health problem. Some persons with schizophrenia can be cured completely from their illness whereas some persons with schizophrenia may experience persistent residual symptoms. For the worst cases, persons with schizophrenia encounter recurrent episodes or a relapse (Ciompi as cited in Lobban, Barrowclough, & Jones, 2005). Across the developed and developing countries, the relapse rate varies from 50% to 92% (Suzuki, Yasumura, Fukao, & Otani, 2003). Relapse is a complex phenomenon

and a challenging issue in caring for persons with schizophrenia. There are a number of factors contributing to the relapse of persons with schizophrenia. Chabungbam, Avasthi, and Sharan (2007) found that relapse in schizophrenia was significantly associated with improper treatment adherence, side effects of medication, unemployment, stressful events, and psychological stress.

Whether a person with schizophrenia adheres to medication or not somewhat depends on how they perceive their illness. According to Leventhal, Meyer, and Nerenz (1980), how a person selects ways to handle with their illness is influenced by cognitive illness representation. Cognitive illness representation is a kind of individual cognitive structure or framework composed of perception regarding their illness. This cognitive illness representation is implicit which means, it is difficult to observe directly but can be recognized through the patients' perception of their illness. Cognitive illness representation contributes to how people perceive, interpret their illness experiences and influence their coping behaviors.

The individual's emotional response to the illness and coping behavior is directly influenced by the cognizance of the illness and in particular, coping behavior, such as adherence to medication (Leventhal et al., 1980; Petrie & Weinman, 2006). Evidence showed that cognitive illness representation influences medication adherence of persons with schizophrenia. Persons with schizophrenia may perceive the symptoms of their illness as having negative consequences in their life. Persons with schizophrenia also believed that the medical treatment could be used to control the symptoms of their illness. In order to obtain a desired outcome, persons with schizophrenia have to adhere to the medication (Lobban, Barrowclough, & Jones, 2003; Watson et al., 2006). Mccann, Boardman, and Clark (2008) explained that

medication adherence is the degree to which individuals follow directions for regularly taking prescribed medications. Medication adherence might be an important coping strategy to deal with the possible threat of illness.

Cognitive illness representation can vary from person to person according to their knowledge, norms and cultural beliefs. Kindderman, Setzu, Lobban, and Salmon (2006) stated that persons with schizophrenia might find it difficult to perceive their illness and to manage their treatment because of disturbance in their cognitive function. Persons with schizophrenia do not perceive their psychological health problems from the perspective of reality during their acute phase, but some persons with schizophrenia have awareness of this during the remission phase (during follow-up/outpatient). According to Sanseeha, Chontawan, Sethabouppha, Disayavanish, and Turale (2009), persons with schizophrenia believed that their illness is not curable by regular taking medication but it could be managed. However, they did not take medication regularly and relapsed. Changming, Sitthimongkol, Wattanapailin, and Ngamthipwattana (as cited in Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011) reported that more than half of schizophrenics patients believed that their condition had improved but still required treatment whereas, some believed that they had not improved.

Leventhal et al. (1980) developed the Common-Sense Model (CSM). The CSM comprised of three constructs: 1) illness representation, 2) coping and 3) outcome appraisal. Moreover, information about illness representation comes from three sources of stimuli, 1) an individual present experience with illness, 2) information from social environment (psychiatrist, nurse, family members and media) and 3) previous experience with illness. Leventhal and colleagues also stated that

illness representation has two levels. The cognitive illness representation is a part of illness representation. The cognitive illness representation of the CSM contains five dimensions: 1) identity, 2) timeline, 3) consequences, 4) controllability and 5) cause.

The three constructs of the CSM are very important for understanding persons with schizophrenia. Among them, illness representation is the first construct of the CSM and the cognitive illness representation is the central and main concept of illness representation. In this study, the researcher selected only cognitive illness representation due to its predictability of coping and outcome appraisal. There are few studies that have been conducted to examine the illness representation (Fortune, Barrowclough, & Lobban, 2004; Lobban et al., 2005; Rungruangsiripan et al., 2011). These studies were conducted on different populations, cultures, and in different countries. However, based on literature review these studies also did not include all components and dimensions of the illness representation. In Bangladesh, there has not been any research directly examining illness representation in persons with schizophrenia. Therefore, the researcher was interested in examining only cognitive illness representation of persons with schizophrenia.

The purpose of this study was to examine the cognitive illness representation of persons with schizophrenia. Knowing, the persons with schizophrenia is helpful to understand their situation and to facilitate better care. A well trained health care provider can deliver standard service to the patients and help to enhance the patient's awareness of regularity in taking medication and adhere with other self-care activities.

## Objective of the Study

To examine the cognitive illness representation as perceived by persons with schizophrenia

## Research Question of the Study

What is the cognitive illness representation as perceived by persons with schizophrenia?

## Conceptual Framework

This study was guided by the concept of the cognitive illness representation of the Common-Sense Mode (CSM). The CSM consists of three main constructs: 1) illness representation, 2) coping, and 3) outcome appraisal. Illness representation is a first and preliminary construct of the CSM. It has two parallel responses. When faced with stimuli, both internal and external, persons will generate both the cognitive illness representation (CIR) and the emotional illness representation (EIR) in response to possible threats. Both CIR and EIR can lead to coping strategies and outcome appraisal. Both CIR and EIR are shaped by stimuli as three major sources of information or stimuli including 1) Bodily experience with illness 2) information obtained from media and social environment such as, family, friends, and health care providers and 3) information from the past experience with

illness (Leventhal et al., 1980). However, in this study, the researcher was focused on only the CIR aspect.

The cognitive illness representation was a central and major concept of the illness representation of the CSM, proposed by Leventhal and colleagues (Leventhal et al., 1980; Leventhal et al., 1997)**.** The CIR is a structure of beliefs, ideas and information related to illness. The CIR is comprised of five dimensions: 1) identity, 2) timeline (acute/chronic and cyclical), 3) consequences, 4) curability/ controllability (personal control/treatment control) and 5) cause (Leventhal et al., 1980). These five dimensions can be explained as follows:

Identity is the person's recognition of symptoms or awareness that the symptoms relate to illness. There are three common symptoms in schizophrenia including positive (e. g., hallucinations, delusions, suspiciousness, violence), negative (e. g., loss of interest in personal care, lack of energy, not doing much, being withdrawn), and cognitive symptoms (e. g., lack of concentration, inattention toward study or work).

Timeline refers to a person's perception about the duration and course of the illness and symptoms of the schizophrenia. There is a variation of the perceived timeline, including acute for short duration, chronic for long duration/permanent, and episodic for cyclical.

Consequences refers to a person's perception about the possible minor or major effects on one's life, which result from schizophrenia, such as physical, psychological, social relationships, and economical consequences. In addition, consequences refer to a person's perception about severity of the illness, quality of life and daily life.

Curability/Controllability refers to a person's perception of schizophrenia whether it can be treated and controlled or untreated. The curability/controllability dimension has two parts: one is personal control and the other is treatment control. Personal control is the ability to manage themselves, their symptoms and their beliefs that there is nothing to do. Treatment control refers to the perception of efficacy of medication or other treatments to control the illness.

Cause of illness refers to the perception of the determinants of the illness mechanisms. Some causes of schizophrenia have been attributed to psychological factor like stress and biological factors such as chemical imbalance, and accidents to the brain. Genetics are another biological factor perceived to be a cause of the illness.

## Definition of Term

Person's cognitive illness representation refers to the patient's perception of his/her illness, "schizophrenia," which includes identity, a label of the experiencing symptoms (e. g., hearing voices, seeing things, losing touch with reality); timeline (duration and course of illness e.g., short and longtime, cyclical or episodic); consequences (impact of illness on physical e.g., inability to work, psychological, social cannot communicate with other, spiritual and economical e.g., money worries); curability/controllability- treatment control (able to be cured or kept illness under control e.g., prevented/avoided by treatment); personal control (to some extent what I can do to determine whether my mental health problems gets better or worse); and cause (determinants of the illness e. g., genetic, chance or bad luck,

chemical imbalance in the brain). Cognitive illness representation was measured by the Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ) modified by the researcher from illness perception questionnaire for schizophrenia (IPQS) (Lobban et al., 2005).

## Scope of the Study

This descriptive study provides information about cognitive illness representation of Bangladeshis persons with schizophrenia. The sample of the study involved persons with schizophrenia who were in either stabilization or maintenance phase. The subjects were recruited only from the outpatient department (OPD), at the National Institute of Mental Health (NIMH), Shar-e- Bangla Nagar, Dhaka-1207, Bangladesh. The data collections were performed during April to September 2013.

## Significance of the Study

The research findings could provide knowledge about the cognitive illness representation of persons with schizophrenia. These findings of the study can be used as information for future studies that are associated to cognitive illness representation. In addition, these findings can help the health care team to understand schizophrenics' patients better than ever before. Besides, they may utilize these findings as baseline information to develop psycho-education program, cognitive illness representation based program for persons with schizophrenia in Bangladesh in order to change or modify their cognitive illness representation.

# CHAPTER 2

# LITERATURE REVIEW

This research is a descriptive study of cognitive illness representation as perceived by persons with schizophrenia in Bangladesh. Related literature, textbooks and research were reviewed and presented in the following relevant topics:

1. Overview of Schizophrenia
    - 1.1 Types of Schizophrenia
    - 1.2 Symptoms of Schizophrenia
    - 1.3 Causes of Schizophrenia
    - 1.4 Course of Schizophrenia
    - 1.5 Impacts of Schizophrenia
    - 1.6 Treatment Modalities of Schizophrenia
    - 1.7 Side-Effects of Antipsychotic Medication
2. The Common-Sense Model (CSM) of the Illness Representation
    - 2.1 Definition of the Cognitive Illness Representation
    - 2.2 Components of the Cognitive Illness Representation
    - 2.3 Formation of the Cognitive Illness Representation
    - 2.4 The Measurement of the Cognitive Illness Representation
3. Cognitive Illness Representation of Persons with Schizophrenia
4. Treatment Facilities for Mental Health Illness in Bangladesh
5. Summary of the Literature Review

## Overview of Schizophrenia

The word “schizophrenia” came from the two Greek roots. One was *skhizo, which means a split,* and *other phren* that refers to mind (Townsend, 2006). According to World Health Organization [WHO], (2012), schizophrenia is a severe mental disorder, characterized by profound abnormal thought, emotion, perception, and behaviors. Schizophrenia often includes psychotic experiences, such as hearing voices or delusions and it can impair functioning through the loss of an acquired capability to earn a livelihood, or the disruption of the everyday work or studies. In this section, the following key knowledge of schizophrenia was described: types, symptoms, causes, course, impact, Treatment modalities, and side effects of schizophrenia.

### Types of Schizophrenia

Based on the Diagnostic Statistical Manual of Mental Disorders, 4th edition, Text Revision (DSM-IV-TR), there are five subtypes of schizophrenia according to the patient's predominant symptoms including paranoid schizophrenia, disorganized schizophrenia, catatonic schizophrenia, undifferentiated schizophrenia, and residual schizophrenia (Bostrom & Boyd, 2005; Shives, 2012; Townsend, 2006; Videbeck, 2011).

Paranoid schizophrenia is characterized by persecutory grandiose delusions, hallucinations, and occasionally, excessive religiosity. In most cases of, this type of illness the patient is suspicious, tense, reserved and may be argumentative, hostile and exhibit aggressive behavior (Bostrom & Boyd, 2005; Townsend, 2006;

Videbeck, 2011). Patients with paranoid schizophrenia can be preoccupied with one or more delusions or frequent auditory hallucinations (Bostrom & Boyd, 2005; Foley, 2010; Townsend, 2006).

The disorganized type is commonly characterized by grossly inappropriate, bizarre, strange mannerisms, poor grooming, poor contact with reality, and poor social skills. Communication is consistently incoherent, coupled with loose associations, and extremely disorganized behavior (Townsend, 2006; Videbeck, 2011).

The catatonic type is characterized by signing psychomotor disturbances. It consists of motor immobility that could be manifested by stupor, excessive motor activity that is apparently purposeless and not influenced by external stimuli, and extreme negativism or mutism (Bostrom & Boyd, 2005; Townsend, 2006). The other characteristics of catatonic schizophrenia involve the peculiarities of voluntary movement, echolalia, and echopraxia (Foley, 2010; Videbeck, 2011).

The undifferentiated type is characterized by mixed schizophrenic symptoms except the paranoid, catatonic, and disorganized type. Therefore, it means occurring disturbances of thought, affect, and behavior (Townsend, 2006; Videbeck, 2011).

The last, the residual type is continued demonstrations of negative symptoms. For example, withdrawal from others or social isolation, impaired personal hygiene and grooming, poor or overly elaborate speech, flat affect, or loose association (Foley, 2010). Based on Bostrom and Boyd (2005), patients might suffer from absence of prominent delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior.

**Symptoms of Schizophrenia**

The symptoms of schizophrenia are divided into three major categories: positive or hard symptoms, negative or soft symptoms, and cognitive symptoms (Bostrom & Boyd, 2005; Moller, 2005; Shives, 2012; Videbeck, 2011).

**Positive or hard symptoms.** Positive symptoms refer to alteration of the normal function. The positive symptoms are a hallucination or a sensory perception, delusions, disorganized speech and grossly disorganized or catatonic behavior. Hallucination or a sensory perception means perceptual experiences, which are not shared by others and occur without actual external stimuli. Hallucination may involve the five sensory organs including visual (seeing some things which are not there) and auditory (hearing the voice of God or close relatives which are not heard by others). Persons with schizophrenia also have tactile (touch), gustatory (taste), and olfactory (smell) hallucinations but these are rare. Auditory hallucination is more common than others (Bostrom & Boyd, 2005; Pearson, 2009; Shives, 2012; Videbeck, 2011).

Delusion means permanent false beliefs, which usually involve misinterpretation of experiences. There are different types of delusional disorder such as persecutory, somatic, grandiose, nihilistic, referential and religious (Moller, 2005; Townsend, 2006; Varcarolis, 2006; Videbeck, 2011). Persecutory delusion refers to the schizophrenic's belief that he/she is being mistreated or someone is spy on them or planning to harmed, poisoned, and ridiculed by other people. Somatic delusion refers to the belief concerning individual health or bodily abnormalities, functions or structures. Grandiose delusion refers to the person's belief that individual has exceptional powers, wealth, and skill, influence and a destiny that makes the

individual more significant than others. Nihilistic delusion refers to the belief that the individual is dead or a calamity is impending. Referential delusion refers to the ideas that television broadcasts, music or newspaper articles has special meaning for the individual. Religious delusion refers to the belief that God communicates directly to schizophrenic, giving the patients special religious power (Moller, 2005; Pearson, 2009; Videbeck, 2011).

Disorganized speech is associated with language and thought disorder. Disorganized speech that is related to thought process, and language, might impair effective communications. These symptoms include confusing speech, difficulty of speech, and derailment (speech goes from one topic to another topic). Tangentiality means that the topic of conversation is changed to an entirely different topic (Bostrom & Boyd, 2005; Pearson, 2009).

Grossly disorganized or catatonic behavior is an inappropriate behavior related to external environment. Grossly disorganized behavior may include agitation, aggression, sexual dysfunction, silliness, unable to complete daily activities; patients cannot use clothes or cannot keep themselves cleaned. Moreover, catatonic behavior involves decreasing in reactivity to the environment, catatonic stupor, rigidity, negativism, posturing, and excitement (Moller, 2005; Pearson, 2009). Catatonic stupor is illuminated by immobility, and a lack of responsive to questions (Bostrom & Boyd, 2005; Townsend, 2006). In rigidity, persons may allow others to move their body, for that matter any part of the body, this is called waxy flexibility (Moller, 2005; Varcarolis, 2006). For excitement, an individual may exhibit uncontrolled, aimless motor activity and engage in repetitive stereotypic movements without

purpose, such as rocking back and forth for hours. Persons with schizophrenia may manifest mannerisms out of context, such as grimacing and posturing (Moller, 2005).

**Negative or soft symptoms.** Negative symptoms of schizophrenia include reducing normal activities and feeling weakness or lacking in energy (anergia). Negative effects are disturbances which include affective flattening or blunting which means failure to change their facial expression, poor eye contact and anhedonia (lack of interest in friends, family and hobbies). Alogia is a tendency to speak very little or to convey little substance of meaning. Avolition manifests when the persons with schizophrenia cannot perform their social work or self-care and continue an occupational function (Pearson, 2009; Shives, 2012; Videbeck, 2011).

**Cognitive symptoms.** Cognitive symptoms have a devastating effect on the function of the brain and the ability to function in daily life, for example, the brain cannot process, storage, and retrieve information. These cognitive symptoms are related to processing information, including making decisions, solving problems, interpreting the environment, and learning new information (Moller, 2005; Shives, 2012).

In summary, symptoms of schizophrenia are divided into three major categories: positive, negative and cognitive symptoms. These symptoms are in the identity component of cognitive illness representation.

## Causes of Schizophrenia

Causes of schizophrenia: genetic predisposition; biochemical and nuerostructural changes in the brain; organic or path physiologic changes of the brain;

environmental or cultural influences; perinatal influences and psychological stress (Shives, 2012).

**Genetic predisposition factors.** Many studies mentioned that a genetic contribute to the development of schizophrenia. Based on genes, a higher incidence of the illness occurs in the relatives of persons with schizophrenia than that found in the general population. There are two degrees of relatives. These are first degree (such as parents, siblings, and children or offspring) and second degree (such as grandparents, grandchildren, aunts, uncles, and half siblings). It was found that the first-degree relatives are at greater risk than second degree relatives (Moller, 2005; National Institute of Mental Health [NIMH], 2006).

Several studies showed that there are three groups of persons to be at ‘‘very-high risk’’ for development of schizophrenia.

1) the first group is one parent, in these filed risks of developing schizophrenia 10% to 20% in children (Cornblatt et al., 2003; Shives, 2012).

2) the second group is both parents, in these filed risks of developing schizophrenia, is about 40% to 46% in their children (NIMH, 2006; Shives, 2012).

and 3) the third group is no close relatives, in these filed risks of developing schizophrenia approximately 60% of persons with schizophrenia had no close relatives (Narasimhan & Buckley, 2005).

**Biochemical and neurostructural changes in the brain.** Dopamine hypothesis is a combination of both biochemical and neurostructural. An excessive amount of neurotransmitter dopamine permits nerve impulses to bombard the mesolimbic pathway. Normally, the mesolimbic pathway is involved in arousal and motivation. Communication is disrupted in the brain as a result developed

hallucinations and delusions, which are called positive symptoms of schizophrenia (Shives, 2012).

The cause of high levels of dopamine release has not yet been found, but the blockage of the excessive release, due to administration of neuroleptic medication, can affect psychotic symptoms. Other neurotransmitters or chemicals in the brain include glutamate, the amino acids glycine and proteins called SNAP-25. Glutamate is the most prevalent excitatory neurotransmitter in the brain. Many neurologic and psychotic disorders could happen in the brain due to the dysfunction of glutamate receptors (Spollen, 2005).

Many neurons are presented in the brain, which work as a neuro circuitry. A neuronal circuit filters by transferring the relevant information from one part and another in the brain for determining action. A defect circuit might not filter information correctly; as a result positive and a negative symptom occur. Abnormal circuitry in the frontal cortex relates to cognitive deficit, memory loss and impairment of attention and the executive function (Moore as cited in Shives, 2012).

**Organic or pathophysiologic changes of the brain.** Schizophrenia is a functional deficit which is occurring in the brain due to stressors such as viral infection, toxins, trauma, or abnormal substance. In addition, schizophrenia is a metabolic disorder (Well-Connected as cited in Shives, 2012).

**Environmental and socio-cultural influences.** The environmental and socio-cultural theory states that the person who elevates schizophrenia has a bad reaction to the environment, incapable to respond to several social functions. Schizophrenia is caused by low socio-economic areas or single parent homes. In

addition, schizophrenia is associated with poverty or life style (Kolb as cited in Shives, 2012).

**Psychological stress.** Schizophrenia probably occurs from poor mother-child relationships, disturbance of family interpersonal relationships, impaired body image and sexual identity, rigid concept of reality and repeated exposure to double-bind situations which are related to stressors (Kolb as cited in Shives, 2012). Moreover, schizophrenia can be caused by marital conflict, families that stayed together for the children were blamed and schizophrenia was proposed to manifest in a person at an early stage of psychosocial development (Moller, 2005). In addition, regarding the risk factors (stressors) in the stress-vulnerability model, schizophrenia may include poverty, substance abuse, social support, family problems, and a stable living environment (Browne, 2005)

In conclusion, there are some causes that might be related to schizophrenia, such as the combination of genetic predisposition, biochemical and neurostructural changes in the brain, organic or path physiologic changes in the brain, environmental or cultural influences, perinatal influences, and psychological stress. These change an individual's capability in both the cognitive and emotional aspect, to manage life events and societal condition.

## Course of Schizophrenia

A symptom of schizophrenia is a plateau of natural progression described as deteriorating with time, with an event. Actually, no one really knows what the course of schizophrenia would be if persons are able to adhere to a prescribed medication during their illness. The clinical feature fluctuates from one to

another and the practice for a particular individual may be different from phase to phase. There are four phases of schizophrenia 1) acute phase, 2) stabilization phase, 3) maintenance phase and recovery phase and 4) relapse phase (Bostrom & Boyd, 2005).

**Acute phase.** In this phase, the person's knowledge and skill to support changes of thought and behavior become disruptive or bizarre (e.g., aggressive acts against the self and others). These behaviors may be confusing and frightening to both the patients and family. When the symptoms increase, persons with schizophrenia have abnormal self-care ability and less ability to care for basic needs such as cleaning, eating, and sleeping, cooking, schooling, or working. After the symptoms increase, they become dependent on their family members, friends. Furthermore, they become unemployed. In the acute phase, persons with schizophrenia have a high risk for suicide and should be hospitalized to save themselves and other family members from any serious harm. During this period, persons with schizophrenia may have deficits their function. In this situation the health care provider, can provide education to the persons with schizophrenia and to family members regarding total intervention to cope with them. Treatment depends on their symptoms (Bostrom & Boyd, 2005).

**Stabilization phase.** In this period, acute symptoms are reduced but they still continue, so persons with schizophrenia need continuous medication management. In this period, the patients and family members are prepared for a long-term adjustment in daily activity and socialization to achieve rehabilitation (Bostrom & Boyd, 2005).

**Maintenance and recovery phase.** In this period, schizophrenics focus on functioning and improving their usual of life or quality of life. Medication

adherence is required in order to decrease disability and to reduce symptoms of illness. Moreover, medication adherence is also required to decrease the severity of the symptoms and to diminish the extremes an individual experiences. In addition, chronic illness, stress events and major crises contribute to the exacerbation of symptoms. At that time, family help and participation are important for the patients. After diagnosis, the health care provider can intervene and explain to the family members and patients about expected relapses and how to cope (Bostrom & Boyd, 2005).

**Relapse phase.** During the treatment and recovery phase, persons with schizophrenia could be relapse at anytime. Every relapse may be need a longer time to recover. The main factor of a relapse is associated with irregular taking the medication and breaking the follow-up. Moreover, other factors can lead to relapses, including stressors, accessibility of community resources (e. g. transportation, housing, level of entry, and employment and social services) and stigmatization, lack of support from their caregivers, friends, family or health care providers (Bostrom & Boyd, 2005). Based on van Meijel, van der Gaag, Kahn, and Grypdonck (2003) combining antipsychotics medication and psychosocial treatment greatly diminishes the severity and frequency of recurrent relapses. In addition, the successful treatment might reduce re-hospitalization and provide quality of life for them.

In summary, the course of schizophrenia is fluctuated between acute, stable, recovery and relapse. Due to these fluctuations, the course of schizophrenia can impact differently on the patients.

**Impacts of Schizophrenia**

The diagnosis of schizophrenia impacts on persons with a schizophrenic's life in several ways, which can be divided into physical, psychological, economical and spiritual.

**Physiological impact.** A case study of physical deformity associated of psychotic symptoms in two patients with schizophrenia conducted by Hacioglu, Yildirim, Ugurlu, Erek, and Saatcioglu (2011) found that, they suffered from, cervical kyposis, due to constant neck flexion posture, peroneal nurve injury, and a dropped foot, related to a constant crossing of the legs, and inactivity-hypokinesia, a fixed body posture, and postural disorders, common in diagnosed as chronic with disorganized and paranoid schizophrenia.

Few studies reported that, weight gain and obesity is a kind of side effect of schizophrenia, which was associated with a high intake of antipsychotic medication. Moreover, weight gain and obesity were also linked with reduced quality of life and a decrease general health (Allison, Mackell, & McDonnell, 2003; Kolotkin et al., 2008). In the researcher's experience, persons with schizophrenia might be physically injured due to beatings and restraints by others and or their relatives.

**Psychological impact.** Persons with schizophrenia may feel psychological distress such as shame. These persons feel that, they cannot seek proper medical help, because they feel ashamed of themselves. Moreover, schizophrenia relapse has a substantial impact on persons with schizophrenias' quality of life (Briggs et al., 2008). In addition, schizophrenics could not keep relationships with family members; a person with schizophrenia cannot perform everyday tasks at home or any kind of leisure activities (Thornicroft et al., 2003). In society, most people

think that schizophrenia is a shameful disease and they suspect that they have lost of manpower due to suicide.

**Economical impact.** Illness may impact on their job and economic situation. Thornicroft et al. (2003) found that, 79% of people with schizophrenia were unemployed. According to WHO (1998), long period care, treatment, and re-hospitalization can affect social cost.

**Spiritual impact.** Schizophrenia persons may be in fear of death, fear of the consequences of 'sins' or religiously 'bad' behavior and/or an inability to focus on 'God' or to meditate.

## Treatment Modalities of Schizophrenia

There are two types of treatment modalities of persons with schizophrenia: 1) pharmacological/physical treatment modalities of schizophrenia, and 2) psychosocial treatment modalities of schizophrenia (Addington & Lecomte, 2012; Tandon, Nasrallah, & Keshavan, 2010).

### Pharmacological Treatment Modalities of Schizophrenia

Typical and atypical antipsychotic drugs. In this review, only typical and atypical antipsychotic medication was described as follows:

**The typical medication.** The typical antipsychotic medication is the previous generation of medication. The first generation, which is conventional, is also typical of antipsychotic medication. The conventional antipsychotic, or typical medication, works upon the positive signs of schizophrenia but has no effect on the negative signs.

The typical medications are dopamine antagonists. Antipsychotic medications work by blocking dopamine receptors and reducing dopamine activity. So they have a strong effect on reducing positive symptoms and but are less effective in treating the negative symptoms (Videbeck, 2011).

Major symptoms (hallucination, delusion, disorganized speech and behavior, flat or inappropriate affect and catatonia) are controlled by these drugs (Moller, 2009). Now some typical antipsychotic medications are available in the market, for example, Haloperidol (Haldol) 2 mg to 20 mg, chlorpromazine (Thorazine) 25 mg to 50 mg, fluphenazine (Prolixin) 2.5 mg to 20 mg, thioridazine (Mellaril) 50 mg to 100 mg, trifluoperazine (Stelazine) 5 mg, Loxapine (Loxitan) 60 mg to 100 mg, Molindone (Moban) 50 mg to 100 mg, Perphenazine (Trilafon) 16 mg to 32 mg, and Thiothixene (Navane) 6 mg to 30 mg (Ahmed et al, 2011; Moller, 2009; Videbeck, 2011).

**The atypical medication.** The atypical medications are newer generation. The atypical antipsychotic medications work on both neurotransmitters, including dopamine, and serotonin receptors. The atypical antipsychotic medications not only minimize the positive signs of schizophrenia, such as delusions, hallucinations, disturbed thinking and other psychotic's symptoms but also reduce the negative signs of schizophrenia, such as lack of volition and motivation, social withdrawal and anhedonia (Videbeck, 2011). Dopamine and serotonin receptor are worked especially at post synaptic D2 and serotonin (Videbeck, 2011). The atypical medications have an effect on reducing both positive and negative symptoms and have fewer side effects than typical drugs (Shives, 2012). According to Geddes, Freemantle, Harrison, and Bebbintion (2000) atypical antipsychotics are slightly more

effective and better tolerated in persons with schizophrenia. Moreover, atypical antipsychotics also have a significantly lower risk of causing extrapyramidal side-effects. Furthermore, atypical antipsychotics are more expensive than the conventional drugs. Atypical drugs in the market are risperidone (Risperdon) 2 mg to 8 mg Olanzapine (zyprexa) 5 mg to 10 mg (Ahmed et al, 2011) clozapine (clozaril) 25 mg, aripiprazole (abilify) 10 mg to 30 mg, ziprasidone (Geodon) 20 mg to 160 mg, and quetiapine (seroquel) 300 mg to 800 mg, Iloperidone (fanapt), Paliperidone (Invega) 3 mg to12 mg (Shives, 2012).

### Psychosocial Treatment Modalities of Schizophrenia

Psychosocial treatments of persons with schizophrenia include psycho-education, cognitive behavioral therapy (CBT), social skills training, and assertive community treatment (ACT) (Bustillo, Lauriello, Horan, & Keith, 2001; Mueser, Deavers, Penn, & Cassisi, 2013)**.**

**Psycho-education**. Psycho-education is one of many systematic therapies which is designed to provide information related to mental health problems (e.g. symptoms, the duration of illness, consequences, treatment, coping and management strategies), and to educate the persons with schizophrenia and their relatives (Wiedemann, Klingberg, Piyschel-Walz, & Psycoedukation, 2003). Based on Xia, Merinder, and Belgamwar (2013) psycho-education has a positive effect on persons with schizophrenia's well being and promotes better their social function and it also has a significant reduction of relapse or readmission rate. Xia et al. (2013) suggested that psycho-education may enhance compliance with medication but, the spread of enhancement is not clear.

**Cognitive behavioral therapy** (CBT). CBT is one of the psychosocial treatment modalities that have received much attention (Addington & Lecomte, 2012). It is the most widely used and effective treatment of psychiatric problems. Over the last twenty years, CBT is gaining recognition as a potentially effective treatment in schizophrenia at all stages of the illness, including the pre-psychotic phase (Addington & Lecomte, 2012)**.** In the context of a collaborative working alliance, the aims of CBT is to improve the person's non adaptive thoughts and beliefs by teaching the link between perceptions, beliefs and emotional or behavioral reactions, and teaching effective coping strategies for dealing with distressing symptoms, questioning the apparent evidence supporting abnormal beliefs, and encouraging self-monitoring of thoughts (Addington & Lecomte, 2012). A study found that the CBT can be effectiveness for the appearance of early signs of relapse in schizophrenia (Gumley et al., 2003).

**Social skills training (SST).** SST is a specific type of training which is derived from psychosocial treatment modality for teaching persons with schizophrenia to communicate their emotions and requests (Kopelowicz, Liberman, & Zarate, 2006). It is needed because persons with schizophrenia who have a lack of social skills. It uses learning theory to improve social functioning by working with persons with schizophrenia to remediate problems in activities of daily living, employment, recreation, and relationships (Bustillo et al., 2001; Tandon et al., 2010).

**Assertive community treatment (ACT).** ACT is an approach to provide clinical services to the persons with schizophrenia in the community by a multidisciplinary team and a high frequency of patients contact, fewer patients to health care provider ratios, and outreach to patients in the community (Tandon et al.,

2010). ACT team could be interdisciplinary that includes a psychiatrists, nurses, and specialists which are includes vocational rehabilitation and co-occurring substances abuses). The ACT can provide a wide range of services including practical supports (e.g., improving housing stability, social functioning), reducing re-hospitalization (Bustillo et al., 2001).

**Side Effects of Antipsychotic Medication**

The side effects of antipsychotic medications can make difficulties for persons to adjust to the illness, because the medication has terrible side effects. There are also some side effects that can create medication adherence problems (Gray, Wykes, & Gournay, 2002; Kem, Bruce, & Bill, 2005; Videbeck, 2011). Extra pyramidal symptoms (EPS) are common side effects of antipsychotic medications, which include, acute dystonic reactions, which are severe muscle spasms; akathisia which means inner restlessness and continual muscle activity and an inability to sit still; parkinsonism (tremor, rigidity, and unsteadiness), tardive dyskinnesia which means involuntary body movements that may be slow; seizures, neuroleptic malignant syndrome, agranulocytosis, anticholinergic manifestations, blurred vision, dry mouth, constipation, urinary retention, feeling sedated, nausea, vomiting, orthostatic hypotension, weight gain, decreased libido, and photosensitivity (Townsend, 2006; Videbeck, 2011).

## The Common-Sense Model (CSM) of the Illness Representation

The CSM was developed by Leventhal et al. (1980). The CSM consists of three main constructs: 1) illness representation, 2) coping, and 3) outcome appraisal. These three constructs are described as follows:

**Illness Representation.** According to Leventhal et al. (1980), the illness representations are an individual's perceptions about their illness. There are two types of illness representation. One is the cognitive illness representation (CIR) and other is the emotional illness representation (EIR). There is a reciprocal relationship between the CIR and the EIR. Moreover, these two also have feedback on the representation (Leventhal et al., 1980).

**Coping.** Based on Leventhal et al. (1980) the CSM has two control processes: danger control process and fear control process. The danger control process is correlated with cognitive perception, it means how individuals treat their illness and what persons should do to improve their condition (e.g. taking pills, going to the doctor, resting, talking to friends about emotions). The fear control process is correlated with emotion, which means how people identify the reason that makes them feel fear, and what people do in order to face their fear (e.g. denial, wishful thinking) (Leventhal et al., 1980).

**Outcome Appraisal.** Appraisal is the final construct in the CSM. At this point people evaluate their coping strategy as either effective or ineffective. If it is appraised as effective then people will continue with the same set of coping strategies and if the coping strategies are appraised as ineffective then there is motivation to think of alternatives (Leventhal et al., 1980).

To sum up, these three constructs is very important for persons with schizophrenia. But the researcher only selected the illness representation because the illness representation is the primary construct leading to the following two constructs. Understanding illness representation is therefore giving a foundation to explore the rest. Moreover, in the context of Bangladesh there may be contextual matters contributed to illness representation of persons with schizophrenia. Besides, the cognitive illness representation (CIR) was specifically chosen in order to deeply understand this group of population on their thinking. It was hoped that understanding the CIR of persons with schizophrenia in the context of Bangladesh would be a good foundation to further design effective intervention for them.

**Definition of the Cognitive Illness Representation** (CIR)

According to Leventhal et al. (1980), the CIR is an organized system of perceptions, ideas, knowledge and information related to the illness. The CIR is constructed to make sense of the illness. Moreover, the CIR is conceptualized as a generic and organized which is derived from prior experiences from medical domain, including personal experiences with the illness, information obtained from media and social environment such as, family, friends, and health care providers and health and illness information in the culture.

**Components of the Cognitive Illness Representation**

A number of attempts have been made to describe the structure of the cognitive illness representation. The cognitive illness representation has five components comprising identity, timeline, consequences, curability/controllability

and causes (Leventhal et al., 1980). They focused on how people think and perceive schizophrenia regarding these five components. The components are described as follows:

1. Identity is the symptoms that patients perceive when there is awareness that the symptoms tie in with the illness. There are three common symptoms in schizophrenia, which are positive (e. g. hallucinations, delusions, violent, suspiciousness), negative (e. g. lack of interest in my personal care, lack of energy, being withdrawal), and cognitive (e.g. lack of concentration, inattention to studies and work).

2. Timeline refers to a person's perception about the duration and course of schizophrenia. There is a variation of the perceived timeline including acute for short, chronic for long, and episodic for cyclical.

3. Consequences refer to the person's perception of the possible minor or major effects on one's life which result from schizophrenia, such as physical, psychological, social, and economical consequences.

4. Curability/Controllability refers to a person's perception about schizophrenia. It can be treated, or controlled. The curability/controllability dimension has two parts, personal control and treatment control. Personal control is ability to manage themselves, their symptoms and their beliefs that there is nothing to do. Treatment control refers to perception about efficacy of medication or other treatments to control the illness.

5. Causes of the illness refers to the perception about the determinants of the illness mechanism. Some causes related to schizophrenia include black magic,

supernatural powers, and biological factors, such as accidents to the brain. Genetic is another biological factor perceived to be a cause of illness.

**Formation of the Cognitive Illness Representation**

People construct their cognitive illness representation or their perceptions about the illness by organizing, analyzing and interpreting information derived from a variety of sources including 1) inherited culture, 2) social environments, and 3) personal illness experience.

**Inherited culture.** The influence of cultural beliefs on an individual's illness representations has been widely discussed and studied. Leventhal et al. (1997) mentioned that cultural beliefs and language have an influence on every aspect of illness representation as well as illness related problems solving. For instance, religious and spiritual beliefs can have direct influence on the causal representation. For example, from the in-depth interview among Thai Buddhists diagnosed with schizophrenia who received government mental health-care services (Sanseeha et al., 2009), bad karma from the past and supernatural power were emerged as the causal representation of schizophrenia. The law of karma or the law of cause and effect is the foundation of Buddhist morality. A study conducted by Kurihara, Kato, Reverger, and Tirta (2006) revealed that the relatives of individuals in Bali, Indonesia who screened positive for schizophrenia had firm traditional beliefs that mental illness is not medical disease. The relatives gave the causal representation of schizophrenia to supernatural causes including God's will or fate, witchcraft, and disturbance by spirits. Besides, the researchers found that all of the individuals with schizophrenia had undergone traditional healing. This finding may indicate the influence of culture

on the individual's coping indirectly through the individual's cognitive illness representation. Similarly, within Bangladesh culture, the belief in possession of black magic and evil spirits as the causal attributions regarding mental illness is evident. From informal conversations, interviews, and focus group of people in a suburban community, Selim and Satalkar (2008) revealed the participants believed that mental illness was caused by "jinns" or the evil spirits.

**Social environment.** Social environment such as health care providers, media, friends, and family are the important sources of information. The contents of an individual's illness representations could be influenced by information obtained from the interaction with people within the individual's social network (e.g., family members and friends), through contact with health care providers, and via the media (Leventhal et al., 1980). The family plays important role as it provides the earliest and closest context for the acquisition of memories and skills for the exploration, labeling and management of symptoms. Information from the health care providers can have a great influence to shape the contents of an individual's illness representation of to be congruent to medical model.

**Personal illness experience.** Both past and present illness experience is considered to have influence on formation of cognitive illness representation (Leventhal et al., 1980). This personal illness experience can be either the suffering from the illness oneself or knowing an individual who has the illness. The influence of personal experience on the formation of cognitive illness representation was explained by a number of researchers and theorists (Bishop, Briede, Cavazos, Grotzinger, & McMahon, 1987; Lau & Hartman, 1983; Scisney-Matlockm, 1997). Concluded from a series of studies, past experience with illness plays important role

because it provides existing illness schema (Lau & Hartman, 1983) or illness prototypes (Bishop et al., 1987) for the individual to understand his/her current illness experience. When individuals encounter symptoms, they seek to match their symptom experiences to illness prototypes or illness schema. They are likely to interpret their symptoms as being indicative of a particular disease when a matching occurs whereby the closer the symptoms individuals experience congruence with the symptoms shaping their prototype or schema for that disease. However, when the individuals cannot match their current symptom experiences to the existing illness schema or prototypes, then they initiate new illness schema or prototypes.

Scisney-Matlockm (1997) had explained the influence of past experience on formation of cognitive illness representation through Posner's learning approach. Individuals are viewed as active learners and cognitive illness representation represents a continuous learning process. Knowledge regarding illness or the content of illness representation is built through mental configuration of past perceptual experiences into retrievable prototypes.

In sum, through the use of illness schema or prototype, individuals' past experience of illness can guide their illness representation for current and future illness. The formation of cognitive illness representation is a learning process which is strengthened by repeated experience of the illness.

**The Measurement of the Cognitive Illness Representation**

The Illness Perception Questionnaire (IPQ) is a measure of illness representation, developed by Weinman, Petrie, Moss-Morris, and Horne (1996). The IPQ was originally developed based on the Common-Sense Model to assess the

cognitive representations of illness. This model was derived from in depth, semi-structured interviews for physical health problems. This measure is a theoretically derived scale that provides information on five cognitive representation of illness. The IPQ was used in patients with heart disease, cancer, diabetes, rheumatoid arthritis, chronic fatigue syndrome, and chronic pain. It has five subscales with 38 items. The identity subscale consists of 12 items of identity component rated by a four-point Likert scale, ranging from "all of the time'' to "never.'' The range of identity scores was 12-48. Causes were structured in 10 items and rated by a five-point Likert scale, ranging from "strongly disagree'' to "strongly agree.'' Timeline was 3 items to assess duration of illness, consequences 7 items to assess effects and outcome of illness, and cure/control was 6 items to assess how controls or recover from illness. The range scores were 26-130. The IPQ was tested for internal consistency (Cronbach's alpha). The Cronbach's alpha of each subscale of identity .82, timeline .73, consequences .82, and control/cure .73, respectively. The IPQ was tested for stability. The control/cure and consequences scales have higher levels of test-retest reliability than the identity and timeline. The IPQ was also tested for concurrent, discriminate and predictive validity in MI, patients with insulin dependent diabetes, rheumatoid arthritis, chronic fatigue syndrome and chronic pain, MI sample in hospital with a subsequence follow-up assessment.

Later, the IPQ was revised by the Moss-Morris et al. (2002) which was the Illness Perception Questionnaire-Revised (IPQ-R). It has nine subscales with 70 items. The IPQ-R consists of three parts. Part one is the identity scale containing 14 items common physical illness symptoms (12 items from the original and 2 items added). The symptom scale asks for a "Yes-No" response to each symptom. Subjects

were asked to tick according to the options. A tick for “Yes” indicates that the subjects’ have common experience or the subjects are aware about their identity (symptom) and “No” indicates the subjects do not have experience or the subjects no have awareness about their symptoms.

Part two is the timeline (acute/chronic), timeline (cyclical), consequences, personal control, treatment control, illness coherence, emotional representation with 38 items. The revised part was timeline (cyclical). To improve the measurement properties, three items were added to the list of timeline (cyclical). Personal control, the items that were added generated from feedback from studies using the IPQ. Illness coherence, this was newly added five items were generated by the investigators to represent an overriding dimension of how much patients understanding or comprehend their illness and emotional representation. Items for the emotional representation subscale were developed to tap into a set of six affective responses, which were found in prior research to be sensitive to differences in illness perceptions and predict health related responses such as seeking medical care.

Part three is the causal scale, which consists of 18 items common causes of different physical illness. The IPQ-R is rated on a five-point Likert scale: “strongly disagree’’ to “strongly agree.” The IPQ-R had been used in various populations such as asthma, diabetes, rheumatoid arthritis, acute pain, chronic pain, myocardial infarction, multiple sclerosis and HIV. The Cronbach’s alpha of each subscale of timeline acute/chronic .89 and cyclical .79, consequences .84, personal control .81, treatment control .80, illness coherence .87, and emotional representation .88, respectively. The all subscales of the IPQ-R showed good test-

retest reliability (.67- .89). The IPQ-R was tested for structural, discriminate, predictive validity. The IPQ-R is not disease specific related.

The Illness Perception Questionnaire for Schizophrenia (IPQS) was a modified version from the IPQ-R (Moss-Morris et al., 2002) by the Lobban et al. (2005). The IPQS is a disease specific questionnaire. The modified area of the IPQS was personal blame to assess perception of self-blame. It has 10 subscales with 131 items. The identity component composed of 58 items, cause 26 items, timeline, acute/chronic 6 items and cyclic 4 items, consequences 11 items, personal control 4 items, personal blame 3 items, treatment control 5 items, illness coherence 5 items and emotional illness representation 9 items.

The identity (symptom) subscale was composed of 58 items. The symptom scale asks for a "Yes-No" response to each symptom. Subjects were asked to tick according to the options. A tick for "Yes" indicates that the subjects have common experience or the subjects are aware about their identity (symptom) and "No" indicates the subjects do not have experience or the subjects no have awareness about their symptoms. The other scales were used on a 5-point Likert scale (strongly disagree to strongly agree respectively similar to the original IPQ-R).

Concerning the interpretation of the subscales, for identity, high scores indicated high awareness of symptom experience. For timeline, acute/chronic, a high score denotes a chronic timeline, and cyclic, a high score on this subscale denotes a cyclical timeline. For consequences, a high score on this subscale denotes a perception of a high level of negative consequences as a result of mental health problems. For personal control, a high score on the personal control subscale denotes a perception of having a high degree of personal control. A high score on the blame

subscale denotes a high degree of self-blame. For treatment, a high score on this subscale denotes a belief that treatment will be helpful in managing mental health problems. For illness coherence, a high score on this subscale denotes a sense of not having a coherent understanding of the mental health problems. For emotional representation, a high score on this subscale denotes a strong negative emotional response as a result of mental health problems. All subscales of the IPQS had reliability ranging from .68 to .87, except for the personal blame subscale, which was .47 (Lobban et al., 2005).

**Cognitive Illness Representation to Persons with Schizophrenia**

Bangladesh is a developing Asian country situated in south Asia. The population of Bangladesh, according to the Bangladesh Bureau of Statistics [BBS] (2014), was 156, 583, 279 million. Half of the populations are reside in rural area and ninety nine percent of people are engaged in agriculture production sector in Bangladesh but there is still a shortage of food and Bangladesh is still dependent upon imported food. In both developed and developing countries the help-seeking behavior is influenced by socio-economic, cultural and other factors (Giasuddin et al., 2012).

Many persons with schizophrenia do not have the insight to think about their illness. According to the American Psychiatric Association [APA] (2000), insight refers to an ability of persons with schizophrenia to acknowledge the illness, accept the need for medication and ask for help. Moreover, in psychiatry, the term insight refers to a particular state of mind (usually concerning the self), thinking evidenced by speech content and behavior (Markova & Berrios as cited in Schwartz, 1998). In addition, insight is a complex and multidimensional concept that includes

awareness of mental illness, awareness of specific signs and symptoms of mental illness, understanding of the social consequences of mental illness, awareness of the need for treatment and the attribution of symptoms to mental illness (Amador & David, 1998; Mintz, Dobson, & Romney, 2003).

A lack of insight or poor insight is widespread and very common in many persons with schizophrenia (Schwartz, 1998). Persons with schizophrenia are unaware of their illness and symptoms and have severely impaired insight (Schwartz, 1998). Furthermore, poor insight or denial in schizophrenia is the most important barrier between the patients and health care providers and between the patients and family members (Amador & David, 1998). Baier (2010), stated that 30% to 50% of people with schizophrenia lack insight, and their mental health providers are unsuccessful in helping to them increase an awareness of their illness. There are some causes of poor insight, such as neuropsychological deficits due to frontal lobe dysfunction (Amador & Kronengold as cited in Baier, 2010) and anosognosia or unawareness of a neurological disorder (Rickelman as cited in Baier, 2010). Amador and Gorman (as cited in Mintz et al., 2003) estimated that between 50% and 80% of persons with schizophrenia do not believe they have a mental illness. However, some persons with schizophrenia may have insight of their symptoms but not a label of illness. Persons with schizophrenia may think that they are pressured from their family and friends. In this situation, when the health care providers apply their own perception to the persons with schizophrenia, schizophrenics' patients may makes difficulties for health care providers to help them. Therefore, the researcher is interested in exploring how they think about their illness by using the conceptual idea of Leventhal et al.'s work, namely cognitive illness representation.

Based on Sanseeha et al. (2009) the patients with schizophrenia believed that the causes of their illness comes from biological factors or supernatural powers, black magic and bad karma from the past. Moreover, the patients with schizophrenia believed that the cause of their illness also comes from cultural and spiritual beliefs and attitudes unique according to Thai tradition. On the other hand, according to Sanders, Kydd, Morunga, and Broadbent (2011), only five Maori patients with schizophrenia believed that their mental illness occurred as a chance or spiritual factors. In addition, Maori and New Zealand Caucasian patients with schizophrenia believed that the most common cause of their illness were drugs/alcohol, family relationships, abuse and biological factors. Moreover, Maori patients with schizophrenia believed that their illnesses would continue significantly less in timeline than New Zealand Caucasian patients with schizophrenia.

## Treatment Facilities for Mental Health in Bangladesh

In Bangladesh, the persons with mental health problems are receiving mental health services from both government and private service facilities. There are two major tertiary level hospitals. The first one is the Pabna Mental Health Hospital, and the second one is the National Institute of Mental Health and Hospital (NIMH).

Pabna Mental Health Hospital is situated in the Pabna district. Pabna Mental Health Hospital is the first and only mental hospital in Bangladesh. It was established in 1957 by the Civil Surgeon of Pabna District in a local landlord's house. After two years, it was shifted to Hemayetpur, 8 km from the District town, on an area of 111.25 acres of land. Initially, there were only 60 beds which subsequently

increased by 120 more beds. Two hundred beds were added in 1966. There are 18 wards, 13 for male, of which 11 non-paying and 2 paying wards. There are 5 female wards with 4 non-paying and 1 paying wards. There are separate departments for indoor (inpatient) and outdoor (outpatient) patients. It has total 500 beds includes paying beds. Also free medicines are provided from this hospital.

The NIMH is located in the capital city, Dhaka. The NIMH is the second one and also a specialized tertiary level government hospital in Dhaka city, Bangladesh. It was established in 2000. There are different departments for indoor (inpatient) having residential facilities for 150 psychiatric beds for the patients in mental health units and also having outdoor (outpatient) and emergency services for all persons with mental problems. Free medicines are provided only for inpatients.

The NIMH also serves for medical education (Ahmed et al., 2011). The NIMH also has been training general physicians, health workers, religious leaders (imams) and community leaders for more last 20 years to provide mental health services at the community level of the country. Until now, the institute has trained about 4000 physicians, 5000 health workers, 200 imams and 50 civil surgeons on mental health. They are now providing mental health services to community people in the rural areas. Physicians, workers, and imams are working at the Thana level to cover almost all health care. Bangladesh has been trying its best to improve its mental health service.

Beside these two hospitals, persons received mental health services from the psychiatric department of Bangabandhu Sheikh Mujib Medical University. There are 30 beds. In addition, the medical college hospitals in the country have nine small psychiatric units each of them with 30 beds. In the private sector, some of the

medical colleges and several large private hospitals have indoor (inpatient) facilities and outdoor (outpatient) services for mentally ill persons. In addition, psychiatrists treat mentally ill persons in their private chambers according to their existing regulation (Ahmed et al., 2011).

For this study, the researcher chose the NIMH to be a study setting because of its located in Dhaka, Bangladesh. Patients are referred from primary level hospitals and the surrounding rural areas of Bangladesh.

## Summary of the Literature Review

Schizophrenia is a mental disorder which is characterized by positive or hard symptoms, negative or soft symptoms, and cognitive symptoms. It is evident that schizophrenia may be caused by genetics predisposing, biochemical and neurostructural change, environmental and socio-cultural factors (e.g. home environment), or psychological factors (e.g. poor relationships). Schizophrenia has four phases of the illness trajectory: acute, stabilization, maintenance and recovery phase, and relapse phase. Once occurs, their lives change such as physiological, psychological, economic and spiritual aspects. The treatment modalities of schizophrenia can be divided into pharmacological and psychological modalities.

Cognitive illness representation or illness perception is central to the Common-Sense Model as it guides people how to cope with health threat information and also evaluate and adjust their coping strategies. Individuals may have different perceptions of their illness since they build up their cognitive illness representation from variety of sources including inherited culture, social environments, and personal

experience. From the literature review, it is evident that people with schizophrenia somewhat perceive their illness differently, leading to various coping and health outcomes particularly adherence with medication and other self-care activities. In Bangladesh, cognitive illness representation in person with schizophrenia has not been directly examined. Therefore, this study was conducted to explicate cognitive illness representation as perceived by persons with schizophrenia in Bangladesh. Hopefully, the findings would be helpful for the Bangladeshi health care providers to understand their schizophrenia clients and to facilitate better care.

# CHAPTER 3

# RESEARCH METHODOLOGY

This is a descriptive cross-sectional study, aimed to examine the cognitive illness representation of persons with schizophrenia. This chapter presents the methodology of this study, including research design, setting, population and sample, sampling procedure, instrumentations, translation of the instruments, validity and reliability of the instruments, ethical considerations, data collection methods, and data analysis, respectively.

## Research Design

A descriptive, cross-sectional study was conducted to examine the cognitive illness representation as perceived by persons with schizophrenia.

## Research Setting

This study was conducted at a tertiary level hospital operated by the National Institute of Mental Health (NIMH) located in capital city of Bangladesh. It was founded in 1981 by the World Health Organization (WHO) and started activities in 2000. The NIMH has 150 beds. People come from rural and urban areas to get mental health services here. The hospital provides mental health care services to the patients and is also used as learning centre for medical students. The hospital provides a variety of services to the outpatient and inpatient including electro-convulsive

therapy (ECT), cognitive behavioral therapy (CBT) by psychiatrist, and individual and group counseling and psychotherapy, which are provides to the patients twice in a week (Sunday and Wednesday) by a counselor and the psychologist. There is a free ambulance service and free treatment facilities for every patient, except medications. Social welfare services are only provided for inpatients who cannot bear the extra medication cost. When doctors examine the patients at the outpatient department (OPD), they also advise each patient individually. In addition, nurses provide information to the patients according to their needs.

## Population and Sample

### Population

In this study, the target population was 1,320 persons with schizophrenia, who came to the OPD at the hospital operated by the NIMH, in Bangladesh, in the year of 2012.

### Sample

In this study, the inclusion criteria of the samples were (1) patients who had a discharge plan certificate or OPD ticket with diagnosed schizophrenia showing that they were diagnosed with schizophrenia (2) more than 18 years old (3) willing and agreed to participate in this study, (4) who were in either stabilization or maintenance phase 5) able to communicate with the researcher either verbally or in written in Bengali, and 6) having a score on the Brief Psychiatric Rating Scale (BPRS) (Leucht, Kane, Kissling, Hamann, Etschel, & Engel, 2005) of not more than 40.

**Sample Size Estimation**

For this study, the researcher used a proportion from the known population to determine the sample size. The sample size was calculated from 10% of the total population to represent the population for the descriptive studies (Singchangchai, Khampalikit, & Na-Sae, 1996). The samples were as per the population, listed above. The sample size was calculated per every 10% of the target population.

Table 1

*A proportion of population to determine the sample size*

| **Total population** | **Sample size** |
|---|---|
| 100-999 | 25% of N |
| 1,000-9,999 | 10% of N |
| >10,000 | 5% of N |

According to medical records, there were 1,320 persons with schizophrenia (male and female) who received treatment in the OPD from this hospital in the year 2012. The sample size was calculated by using a proportional estimation from 1,320 persons with schizophrenia. A sample of 10% of the population size ranging from 1,000- 9,999 is considered suitable for a descriptive study (Singchangchai et al., 1996). The sample size in this study was estimated by taking 10% of the total 1,320 persons with schizophrenia. Therefore, the numbers of samples in this study were132 persons with schizophrenia. The researcher rounded up the

sample size to avoid any missing data. Thus, for this study 135 persons with schizophrenia were included as the sample.

**Sampling Procedure**

Convenience sampling was used to recruit eligible samples in this study. With the co-operation of the nurse in-charge, the researcher recruited persons with schizophrenia whenever they came to the OPD of the target hospital.

## Instrumentation

In this study the instruments include 1) the Brief Psychiatric Rating Scale (BPRS) 2) the Demographic and Clinical Characteristics Questionnaire (DCCQ) 3) the Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ). The details of each questionnaire are described as follows.

**1. The Brief Psychiatric Rating Scale (BPRS)**

The BPRS was developed by (Overall and Gorham as cited in Leucht et al., 2005), which has 18 items. The BPRS is used to measure the patients' condition according to their psychotic symptoms. This questionnaire was used to identify the subjects who met the inclusion criteria BPRS score of less than 40. The response ranged from 1-7 (1= not present, 2= very mild, 3= mild, 4= moderate, 5= moderately severe, 6= severe, and 7= extremely severe). The total score is the sum of the score from the 18 items, which equal 126. The higher scores indicate that the subjects have more severe psychotic symptoms, who were inappropriate in this study. Exploring the subjects' cognitive illness representation, require subjects who were able to think

about themselves. The researcher used a BPRS score with not more than 40, which is these categories: mildly ill (score 31-40), borderline ill (score 19-30), and normal (score 18) (Leucht et al., 2005) (Appendix B). The researcher got mildly ill (72.6%), borderline ill (26.7%), and normal (0.7%), respectively which shown in Table 6.

**2. The Instruments for Data Collection**

**2.1 The Demographic and Clinical Characteristics Questionnaire (DCCQ)**

This questionnaire was developed by the researcher to assess the demographic and clinical characteristics of persons with schizophrenia. This questionnaire comprises 13 items of age, sex, marital status, religion, educational level, occupation, income, and residential area of persons with schizophrenia and clinical characteristics, which includes the duration of illness, hospitalization experience, sources of learning about schizophrenia, and family history of schizophrenia, and treatment of persons with schizophrenia (Appendix C).

2.2 **The Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ)**

In this study, the CIRSQ was a modified version of the original Illness Perception Questionnaire for Schizophrenia (IPQS) developed by Lobban, Barrowclough and Jones (2005) in Western country. The IPQS was the modified version from IPQ-R to measure both the cognitive and the emotional illness representation of persons with schizophrenia. Permission from the original authors to use and modify the IPQS was obtained (Appendix C). In this study, the researcher assessed only cognitive illness representation. Therefore, 17 items of the IPQS that were not relevant to cognitive illness presentation were excluded. In addition, according to an evaluation of the psychometric properties of the CIRSQ, the

reliability was quite low of some subscales. To improve the reliability the researcher further deleted 8 items. The details of the CIRSQ are described as follows.

The CIRSQ consists of five subscales that are:

1) Identity (symptoms), 58 items, (no. 1 to 58), to assess individual experience of symptoms related to schizophrenia.

2) Timeline,

a) acute/chronic timeline, 6 items, (no. 1, 2, 3, 4, 5, and 6) to assess whether perception of patterns of the illness was acute or chronic

b) cyclical timeline, 2 items, (no. 7, and 8) to assess perception of patterns of the illness was cyclical.

3) Consequences, 9 items, (no. 9, 10, 11, 12, 13, 14, 15, 16, and 17) to assess perception of impacts of the illness on persons with schizophrenia physically, psychologically, socially and economically.

4) Controllability,

a) personal control, 2 items, (no. 18 and 19) to assess if persons with schizophrenia perceived whether the illness was under their control

b) treatment control, 3 items, (no. 20, 21, and 22) to assess if persons with schizophrenia perceived whether their treatments were helpful in managing the illness.

5. Causes, 26 items, (no. 1 to 26) to assess perception of causes of the illness.

The format of the CIRSQ is a combination of a dichotomous and a Likert scale. For the identity, there are two sub-dimensions including label and symptoms. The label has five item statements including one positive statement (no.

4), three negative statements (no. 1, no 2 and no. 3) and one fill in the gap (no. 5) with a five Likert scale. Symptoms subscale was responded in the dichotomous format. The item symptoms are scored 0 for not having the specific symptom and 1for having the specific symptom.

The other subscales used on a 5-point Likert format. The positive statements were scored from 1 to 5 and are listed as follows: strongly disagree = 1, disagree = 2, neither agree nor disagree = 3, agree = 4, strongly agree = 5. For negative statements, they are reversed scored. There is a mix of negative and positive statements. Scoring and interpretation are described as follows.

The acute/chronic of timeline dimension consists of three positive statements, (no. 2, 3, and 5), and three negative statements, (no. 1, 4, and 6). The mean score of acute/chronic items were calculated for the total scores of the subscale and the level as follows:

| Scoring level | Perceived level |
|---|---|
| 6.00 to 14.00 | Low |
| 14.01 to 21.99 | Moderate |
| 22.00 to 30.00 | High |

The cyclical of the timeline dimension consists of two positive statements (no. 7 and 8). The mean score of cyclical items were calculated for the total scores of the subscale and the level as follows:

| Scoring level | Perceived level |
|---|---|
| 2.00 to 4.66 | Low |
| 4.67 to 7.33 | Moderate |
| 7.34 to 10.00 | High |

The consequences dimension consists of nine positive statements, (no. 9, 10, 11, 12, 13, 14, 15, 16 and 17). The mean score of consequences items were calculated for the total scores of the subscale and the level as follows:

| Scoring level | Perceived level |
|---|---|
| 9.00 to 21.00 | Low |
| 21.01 to 32.99 | Moderate |
| 33.00 to 45.00 | High |

The personal control of the controllability dimension consists of two positive statements, (no. 18 and 19). The mean score of personal control items were calculated for the total scores of the subscale and the level as follows:

| Scoring level | Perceived level |
|---|---|
| 2.00 to 4.66 | Low |
| 4.67 to 7.33 | Moderate |
| 7.34 to 10.00 | High |

The treatment control of the controllability dimension consists of three positive statements, (no. 20, 21 and 22). The mean score of treatment control items were calculated for the total scores of the subscale and the level as follows:

| Scoring level | Perceived level |
|---|---|
| 3.00 to 7.00 | Low |
| 7.01to 10.99 | Moderate |
| 11.00 to 15.00 | High |

**Translation of the Instrument**

The questionnaire was originally developed in English. To achieve a conceptual equivalence across the languages, back translation technique was needed (Sperder, Devellis, & Boehlecke, 1994). The researcher contacted three Bangladeshi bilingual translators. The English version questionnaires translated into the Bengali version by the first translator. The second translator translated the Bengali version into the English version. The third translator checked the conceptual equivalence in all items between the original English version and the English back translated version. Then the researcher and third translator made final adjustments and revised the questionnaires to set-up the same meaning based on the third translators' suggestions. Finally, the Bengali version of the questionnaire was used for data collection.

**Validity and Reliability of the Instrument**

The CIRSQ was modified from the IPQS which had been assessed for validity and reliability (Lobban et al., 2005) to use in different cultures, however, validity and reliability for the questionnaire was still needed.

**Validity of the Instrument**. Since the CIRSQ was modified from the IPQS which is a standard tool, only cultural relevancy and face validity were assessed in this study. Prior to the translation process, cultural relevancy was examined by a psychiatrist expert who worked at the target hospital. Two items, which were cultural discrepancy and change, were suggested to change: the items "frittering money away" changed to "over spending money away" and the item "panic attacks" changed to "anxiety attacks".

For face validity, The researcher asked three persons with schizophrenia how understandable the instrument in the Bengali version were to them, who had similar criteria as the subjects to completed the face validity test the feasibility of the instruments in the Bengali version.

**Reliability of the Instrument.** The reliability of the CIRSQ was examined by calculating the percentage of agreement, Cronbach's alpha coefficient, and the Intraclass Correlation Coefficient (ICC). This instrument was tested with 20 persons with schizophrenia who meet the same inclusion criteria of the study. The re-test data were collected twice within 3 days.

For the symptom subscale of the identity dimension, the percentage of agreement ranged from 40% to 100%. Of total 58 items, there were 36 items that had percentage of agreement 80% and more, 14 items between 61% and 79% and a few items between 40% and 60% (Appendix I, Table 16).

For the causes, the timeline (acute/chronic and cyclical), the consequences, the controllability personal control and treatment control, Cronbach's alpha Coefficient and the Intraclass Correlation Coefficient (ICC) were computed to examine the internal consistency reliability and the results are shown in Table 2.

Table 2

*The Reliability of the Cognitive Illness Representation of Schizophrenia Questionnaire Subscales Scores of Cronbach's alpha Coefficients and Intraclass Correlation Coefficients*

| Subscales | Cronbach's alpha Coefficient (α) | Intraclass Correlation Coefficient |
|---|---|---|
| Cause | .91 | |
| Timeline | | |
| Acute/Chronic | .76 | .77 |
| Cyclic | .54 | .36 |
| Consequences | .60 | .86 |
| Controllability | | |
| Personal control | .11 | .65 |
| Treatment control | .66 | .74 |

## Ethical Considerations

Ethics approval was obtained from the Research Ethics Committee of Faculty of Nursing, Prince of Songkla University, Thailand. The hospital director of the study setting was asked for official permission by the researcher to conduct the study. The researcher separately and clearly explained about the purpose of the study, the procedure, and the possible benefits to every persons with schizophrenia. The participants were free to ask any questions about the study. The researcher informed them that they had freedom, and the right to choose whether to participate in the study, or not and the researcher explained in Bengali language. The subjects who were willing to participate in the study were asked to sign a consent form before collecting data. During their response to the questionnaires, if they felt discomfort or

demonstrated any signs of psychological discomfort, the researcher stopped asking questions and let them express their feelings. The researcher listened to them attentively and provided psychological support. If the researcher failed to provide any help, the participant was referred for further interventions with their permission.

## Data Collection Methods

The data were collected after obtaining permission from the Director of NIMH, Dhaka, Bangladesh during April to September 2013. The data collection procedures were divided into two phases: preparation phase and implementation phase.

### Preparation phase

1. The research proposal was approved by the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand.

2. The researcher took a letter of request from the dean of the Faculty of Nursing, Prince of Songkla University, Thailand to the director of the National Institute of Mental Health, Shar-e- Bangla Nagar, Dhaka, Bangladesh.

3. The researcher explained the study's objective and the data collection procedures to the director of the National Institute of Mental Health in Dhaka.

4. The researcher obtained permission for data collection from the Director of the National Institute of Mental Health.

5. The researcher met the nurse in-charge, resident physician, and three medical officers, and the researcher explained the study's objective, benefits and method of data collection in order to get their help.

6. After preparation of all materials and instruments, the researcher started to collect the data. During introducing time, the researcher performed BPRS test for screening. The researcher found three categories of subjects who had the BPRS scores mildly ill (score 31- 40) 72.6%, borderline ill (score 19- 30) 26.7% and normal (score 18) 0.7%, respectively.

**Implementation phase**

1. The nurse in-charge assisted the researcher in identifying persons with schizophrenia who were score in score ≤ 40. Then the researcher approached the subjects and gave a brief description of the study objective and obtained verbal and written consent.

2. The researcher administered the questionnaires to the participants with an explanation a as how to respond the questionnaires.

3. The participants were asked if they had any questions. The researcher gave clarification which part they did not understand the questionnaires. In this study, majority of the persons with schizophrenias' were helped by the researcher in reading the questionnaires due to incapability of reading, and many items of questionnaires and ticking the answers, according to their responses.

4. During response to the questionnaires, the researcher found five participants; showing discomfort/signs of psychological distress, the researcher stopped asking questions and let them express their feelings. The researcher listened

to them attentively and provided psychological support. When the researcher had not provided any help, the participant was referred for further intervention to the nurse in-charge and residential physician.

6. Lastly, the researcher checked the completeness of the questionnaires and asked the subjects who did not fill in the questionnaires completely to complete. It was finished with the help of the researcher.

## Data Analysis

Data were entered into a computer software program. Before data analysis, the researcher performed all data management process including data entry, screening, cleaning, and recoding of the questionnaire to ensure accuracy of the data entries into the computer software program. Descriptive statistics were used to analyze and describe the demographic and clinical characteristics using frequencies, percentage. In addition, cognitive illness representation of symptoms and cause were analyzed by using frequencies, and percentage. Cognitive illness representation of timeline acute/chronic, cyclical, consequences, personal control and treatment were analyzed by using maximum, minimum, mean, and standard deviation, median and interquartile range.

# CHAPTER 4

# RESULTS AND DISCUSSION

The purpose of this chapter was to present the results and discussion of the study's findings. This descriptive study was designed to examine cognitive illness representation as perceived by persons with schizophrenia in Bangladesh. The findings were derived from 135 persons with schizophrenia who attended the OPD at the National Institute of Mental Health and met the inclusion criteria. The results and discussion of the study are presented under the following headings:

1. Demographic and Clinical characteristics of the persons with schizophrenia
2. Cognitive illness representation of schizophrenia

## Results

### Demographic Characteristics of the Persons with Schizophrenia

**Demographic Characteristics.** The study subjects**'** demographic characteristics are presented in Table 3. The age of persons with schizophrenia ranged from 18 to 55 years with the mean age of 30.7 years (SD = 9.82). The majority of persons with schizophrenia were male (54.8%) and were married (48.9%). Most of the persons with schizophrenia were Muslim (94.8%). A small portion of the subjects (8.1%) was illiterate. For the literate, their education levels were primary school (23.0%), secondary school (38.5%), higher secondary school (17.8%), diploma training (4.4%) and university (8.1%). For occupation, about one-third were employed (32.6%) while the rest of them were unemployed (27.4%), were housewives (23.7%)

and were students (16.3%). About two-thirds of them (67.4 %) had no income. Nearly half of them (47.4%) lived in an urban area.

Table 3

*Frequency and Percentage of Demographic Characteristics (N = 135)*

| Characteristics | Frequency (n) | Percentage (%) |
|---|---|---|
| Age (years old) *M* (*SD)* = 30.7 (9.82) | | |
| Range 18-55Years | | |
| 18- 20 | 27 | 20.0 |
| 21- 40 | 86 | 63.7 |
| 41-55 | 22 | 16.3 |
| Sex | | |
| Male | 74 | 54.8 |
| Female | 61 | 45.2 |
| Marital status | | |
| Single | 56 | 41.5 |
| Married | 66 | 48.9 |
| Separated | 13 | 9.6 |
| Religious status | | |
| Islam | 128 | 95.0 |
| Hindu | 6 | 4.4 |
| Christian | 1 | 0.7 |
| Education level | | |
| Illiterate | 11 | 8.1 |
| Primary school | 31 | 23.0 |
| Secondary School | 52 | 38.5 |
| Higher secondary school | 24 | 17. 8 |
| Diploma | 6 | 4.4 |
| University | 11 | 8.1 |
| Occupational status | | |
| Unemployment | 37 | 27.4 |
| Housewife | 32 | 23.7 |
| Student | 22 | 16.3 |
| Private employee | 15 | 11.1 |

Table 3 (continued)

| | | | |
|---|---|---|---|
| Occupational status | | | |
| | Personal Business | 10 | 7.4 |
| | Labor | 10 | 7.4 |
| | Government employee | 5 | 3.7 |
| | Farmer | 4 | 3.0 |
| Income per month | | | |
| | No income | 91 | 67. 4 |
| | <5000 | 8 | 5.9 |
| | 5,000-10,000 | 20 | 14.8 |
| | > 10,000 - 15,000 | 10 | 7.4 |
| | > 15,000 - 20,000 | 5 | 3.7 |
| | >20,000 | 1 | 0.7 |
| Residential area | | | |
| | Urban/City | 64 | 47.4 |
| | Village | 43 | 31. 9 |
| | Sub-urban | 28 | 20.7 |

**Clinical Characteristics of the Persons with Schizophrenia**

**Clinical Characteristics.** The subjects' clinical characteristics are shown in Table 4. Approximately 40.7% of the subjects had suffered for 5 to 10 years. About 28.1% were admitted in the hospital more than 10 times. More than half of the subjects (54.1%) learned about their illness from their relatives, whereas a small number of them learned from health care providers, including psychiatrists (12.6%) and nurses (8.9%). The family history of schizophrenia reported as follows; relatives (15.6%), siblings (14.8%), grandparents (12.6%), parents (8.9%), and no relatives (47.4%), respectively. In terms of current treatment with medication, all persons with schizophrenia were treated with antipsychotics; typical antipsychotics (50.4%) and atypical (64.4%). In addition, antiparkinonism (99.3%) and antianxiety (28.9%) were used as well.

Table 4

*Frequency and Percentage of Clinical Characteristics (N = 135)*

| Clinical characteristics | *n* | *%* |
|---|---|---|
| Duration of illness | | |
| < 6 months | 3 | 2.2 |
| 6 months- 1 years | 20 | 14.8 |
| >1 Years-3 years | 28 | 20.7 |
| >3 years- 5 years | 29 | 21.5 |
| >5 years- 10 years | 55 | 40.7 |
| Hospitalizations | | |
| Never | 15 | 11.1 |
| 1 times- 2 times | 33 | 24.4 |
| 3 times- 5 times | 33 | 24.4 |
| 6 times- 10 times | 16 | 11.9 |
| >10 times | 38 | 28.1 |
| Sources of learning about schizophrenia | | |
| Relatives | 73 | 54.1 |
| Psychiatrists | 17 | 12.6 |
| Nurse | 12 | 8.9 |
| Media | 6 | 4.4 |
| No sources | 27 | 20.0 |
| Family history of schizophrenia | | |
| Relatives (Aunt, uncle, cousins) | 21 | 15.6 |
| Siblings | 20 | 14.8 |
| Grand Parents | 17 | 12.6 |
| Parents | 12 | 8.9 |
| Children | 1 | 0.7 |
| No relatives | 64 | 47.4 |
| Medicine | | |
| Antipsychotics | | |
| Typical. Tablet (haloperidol and chlorpromazine), Injection (Fluphenazine) | 68 | 50.4 |
| Atypical.(olanzipine/clozapine/risperidon) | 87 | 64.4 |
| Antiparkinonism (procyclide/kedrine/perkinil) | 134 | 99.3 |
| Antianxiety (clonazepam/temazepam/benzodiazepine) | 39 | 28.9 |
| Antidepressant (escitalopram/Amitriptyline/aripiprazole/sertraline | 5 | 3.7 |
| Anticonvulsants (epilim 300mg/valex 300mg) | 5 | 3.7 |
| Antiulcerative (ranitidine 150mg/omeprazole 20 mg) | 3 | 2.2 |
| Antibacterial (montelukast) | 1 | 0.7 |
| Antihypertensive (propanolol) | 6 | 4.4 |
| Others | | |
| Vitamin | 11 | 8.1 |
| Doxicycline | 1 | 0.7 |
| Calcium | 1 | 0.7 |

**Scores of the Persons with Schizophrenia According to the Brief Psychiatric Rating Scale (BPRS)**

Table 5 shows the subjects BPRS scores who was not more than 40. The most of the subjects mildly ill (72.6%), followed by borderline ill (26.7%) and normal (0.7%), respectively.

Table 5

*Frequency and Percentage of Subjects of the Brief Psychiatric Rating Scale Scores (N = 135)*

| Category of BPRS Score | Score | n | % |
|---|---|---|---|
| Normal | 18 | 1 | 0.7 |
| Borderline ill | 19 – 30 | 36 | 26.7 |
| Mildly ill | 31 – 40 | 98 | 72.6 |

**Cognitive Illness Representation**

**Identity Dimension of the Cognitive Illness Representation**

The identity dimension of cognitive illness representation is composed of two aspects: "label" and "symptoms". The findings are described as follows:

**Label**. The researcher found that all subjects strongly labeled their mental health problem as schizophrenia.

**Symptoms.** Table 6 presents the frequency and percentage of top ten-symptoms of cognitive illness representation. The two most frequently perceived symptoms were being violent to others and loss of interest in their personal care (99.3%). Whereas the rest of them were frequently perceived between (93.3%-98.5%) as follows: difficulty in sleeping (98.5%) and being suspicious of other people (97.8%), talking or laughing to myself (97.8%), being withdrawn (97.0%), hearing

voices (96.3%), feeling agitated (95.6%), not doing much (94.8%), problems communicating with other people (93.3%), respectively.

Table 6

*Frequency and Percentage of Top Ten Identity (Symptoms) of the Cognitive Illness Representation (N = 135)*

| Symptoms of the Cognitive illness representation | Yes *n (%)* | No *n (%)* |
|---|---|---|
| Being violent to other | 134 (99.3) | 1 (0.7) |
| Loss of interest in my personal care, | 134 (99.3) | 1 (0.7) |
| Difficulty sleeping | 133 (98.5) | 2 (1.5) |
| Being suspicious of other people | 132 (97.8) | 3 (2.2) |
| Talking or laughing to myself | 132 (97.8) | 3 (2.2) |
| Being withdrawn | 131 (97.0) | 4 (3.0) |
| Hearing voices | 130 (96.3) | 5 (3.7) |
| Feeling agitated | 129 (95.6) | 6 (4.4) |
| Not doing much | 128 (94.8) | 7 (5.2) |
| Problems communicating with other people | 126 (93.3) | 9 (6.7) |

**Timeline, Consequences, Controllability Dimensions of Cognitive Illness Representation**

Table 7 shows the level of cognitive illness representation based on experiences by persons with schizophrenia of each dimension. Regarding the timeline dimension of the CIR, the mean of chronic sub-dimension was 22.17, with scores ranging from 15 to 29 (possible scores range from 6 to 30), indicate that persons with schizophrenia highly perceived their illness chronic. The mean of the cyclical sub-dimension was 9.47, with scores ranging from 8 to 10 (possible scores range from 2 to 10), indicating that persons with schizophrenia highly perceived their illness cyclical. For the consequence, the mean score was 43.51, with scores ranging from 36 to 45 (possible scores range from 9 to 45), indicating that the persons with schizophrenia perceived high consequences as a result of their mental illness. With respect to

controllability, the mean of the personal control was 8.13, with scores ranging from 4 to 10 (possible scores range from 2 to 10), indicating that perception of the persons with schizophrenia on their abilities to control the illness was at a high level. The mean of the treatment control was 12.23, with scores ranging from 9 to 15 (possible scores range from 3 to 15), indicating that perception of the persons with schizophrenia on treatment effectiveness was at a high level.

Table 7

*Minimum, Maximum, Mean, Standard Deviation, Median, Interquartile Range, Level of the Cognitive Illness Representation (N = 135)*

| Cognitive Illness Representation | Min | Max | M (SD) | Mdn (IQR) | Level |
|---|---|---|---|---|---|
| Timeline | | | | | |
| Chronic | 15 | 29 | 22.17 (2.93) | 22.00 (4.00) | High |
| Cyclical | 8 | 10 | 9.47 (.62) | 10.00 (2.00) | High |
| Consequences | 36 | 45 | 43.51 (1.86) | 44.00 (2.00) | High |
| Controllability | | | | | |
| Personal control | 4 | 10 | 8.13 (1.44) | 8.00 (2.00) | High |
| Treatment control | 9 | 15 | 12.23 (1.62) | 12.00 (2.00) | High |

**Top Ten Causes of the Cognitive Illness Representation**

Table 8 shows the top ten causes of cognitive illness representation. The majority of the subjects strongly perceived “money worries” (95.6%) as a cause of their illness, followed by stress or worry (88.9%), lack of friends or people who cared about me (88.9%), overwork (88.1%), thinking about things too much (86.7%), a trauma (85.1%), chance or bad luck (83.7%), lack of sleep (83.0%). Moreover, the subjects also strongly perceived a number of small cause items like brain damage or abnormality (81.5%), and chemical imbalance in the brain (77.0%), respectively.

Table 8

*Frequency and Percentage of Top Ten Cause of the Cognitive Illness Representation (N = 135)*

| Causes | Strongly disagree *n (%)* | Disagree *n (%)* | Neither agree nor disagree *n (%)* | Agree *n (%)* | Strongly agree *n (%)* |
|---|---|---|---|---|---|
| Money worries | | | | 6 (4.4) | 129 (95.6) |
| Stress or worry | | | | 15 (11.1) | 120 (88.9) |
| Lack of friends or people who cared about me | | | | 15 (11.1) | 120 (88.9) |
| Overwork | | | | 16 (11.9) | 119 (88.1) |
| Thinking about things too much | | | 2 (1.5) | 16 (11.9) | 117 (86.7) |
| A trauma; something disturbing or shocking that happened in my life | | 1(.7) | | 19 (14.1) | 115 (85.1) |
| Chance or bad luck | | | | 22 (16.3) | 113 (83.7) |
| Lack of sleep | | | | 23 (17.0) | 112 (83.0) |
| Brain damage or abnormality | | | 3(2.2) | 22 (16.3) | 110 (81.5) |
| Chemical imbalance in the brain | | 2 (1.5) | 2 (1.5) | 27 (20.0) | 104 (77.0) |

**Three Most Important Factors that Persons with Schizophrenia Believing to be Causes**

Table 9 shows the three most important factors which were identified as causes of their illness.

Table 9

*Frequency and Percentage of Three Most Important Factors that Persons with Schizophrenia Believing to be Causes (N = 135*)

| Most Important Three Causes | First rank n (%) | Second rank n (%) | Third rank n (%) |
|---|---|---|---|
| Black Magic/Pishogue | 20 (14.8) | 14 (10.4) | 5 (3.7) |
| Stress or Worry | 17 (12.5) | 22 (16.3) | 33 (24.4) |
| Hereditary | 12 (8.9) | 1 (0.7) | 6 (4.4) |
| Bad bullied at school/family members/others | 11 (8.1) | 5 (3.7) | 4 (3.0) |

**Table 9 (continued)**

| Most Important Three Causes | First rank n (%) | Second rank n (%) | Third rank n (%) |
|---|---|---|---|
| Death of loved one | 9 (6.7) | 5 (3.7) | 4 (3.0) |
| Trauma | 8 (5.9) | 7 (5.2) | 1 (0.7) |
| Family's problems | 7 (5.2) | 12 (8.9) | 12 (8.9) |
| Possession by demons/ghost/ jinnee/evil spirit | 7 (5.2) | 15 (11.1) | 7 (5.2) |
| Less sleep/lack of sleep/difficulty sleeping | 7 (5.2) | 19 (14.1) | 10 (7.4) |
| Lack of friends/broken friendship | 6 (4.4) | 6 (4.4) | 8 (5.9) |
| Money worries | 6 (4.4) | 4 (3.0) | 3 (2.2) |
| Over study/Overwork | 5 (3.7) | 5 (3.7) | 6 (4.4) |
| Someone spiked with my drink | 4 (3.0) | 1 (0.7) | - |
| Loneliness | 3 (2.2) | 1 (0.7) | 6 (4.4) |
| Thinking too much | 3 (2.2) | 9 (6.7) | 7 (5.2) |
| Bad luck | 2 (1.5) | 1 (0.7) | 6 (4.4) |
| My upbringing | 2 (1.5) | - | 3 (2.2) |
| Second marriage of my husband | 1 (0.7) | - | 1 (0.7) |
| Poor medical care in my past life | 1 (0.7) | 4 (3.0) | 6 (4.4) |
| Lack of people or friends who cared about me | 1 (0.7) | 2 (1.5) | 3 (2.2) |
| Because of drinking alcohol | 1 (0.7) | - | - |
| Failed of HSC final exam | 1 (0.7) | - | - |
| Fear about anything | 1 (0.7) | - | - |
| Worry events | - | 2 (1.5) | - |
| Problems with delivery | - | - | 1 (0.7) |
| Divorce | | | 1 (0.7) |
| Infertility | - | - | 1 (0.7) |
| Environment | - | - | 1 (0.7) |

## Discussion

Discussion of the study consists of demographic characteristics, clinical characteristics, and cognitive illness representation. The discussions are presented as follows:

### Demographic Characteristics of the Persons with Schizophrenia

One hundred and thirty five persons with schizophrenia who take treatment during follow-up visit in the National Institute of Mental Health hospital, Sher-e- Bangla Nagar, Dhaka, participated in this study. The mean age of persons

with schizophrenia was 30.7 years old, ranging from 18 - 55 years old. Schizophrenia can affect people when they were as young as 15 years old (World Health Organization [WHO], 2012). Schizophrenia is a chronic illness so that it can be found in both adult and elderly age group.

More than half of the persons with schizophrenia were male in this study (55%). Aleman, Kahn, and Selten (2003) stated that there is no significance sex difference in developing countries. This means that prevalence of schizophrenia is similar in male and female. On the other hand, in Bangladesh, in a study carried out on fifty patients with schizophrenia (Ahammad, Rahman, Islam, Rahman, & Rabbani, 2009), the percentages of male and female were 54% and 46% which are comparable to this study.

In developed countries, society plays a very important role in marriage (Naheed, Akter, Tabassum, Mawla, & Rahman, 2012). Marriage is considered as a social identity for a person in these countries. Approximately half of the persons with schizophrenia in this study were married (48.9%) which was relatively equal distribution to those who were single (41.5%) and separated (9.6%). This result is comparable with the result of study done by Ahammad et al. (2009) where the patients were unmarried (46.0%) and married (46.0%) and other (08.0%). However, in Europe, Thornicroft et al. (2003) found that 65.0% of persons with schizophrenia were single. Furthermore, persons with schizophrenia may be single related to their illness (Harrison et al as cited in Naheed et al., 2012).

Most of the persons with schizophrenia of the study were Muslim (95.0%) and the small portions were Hindu (4.4%) and Christian (0.7%). Bangladesh is the most populous Muslim-majority country; consequently, Muslim persons with

schizophrenia were high in this study. According to Government of the People's Republic of Bangladesh (2011), nearly 90.0% population are Muslims and with small populations (10.0%) of Hindu, Christian, and Buddhist. This result is also comparable with the study result done by Ahammad et al. (2009) where most of the patients were Muslim (90.0%).

Most of the subjects (91.8%) were literate and their education level ranged from primary school (23.0%), secondary school (38.5%), higher secondary school (17.8%), diploma (4.4%) and university (8.1%). In Bangladesh, the compulsory educational level is primary and free education level for girls is up to secondary. For Bangladeshi boys, families prefer and support for their education. However, higher education of the subjects may be interrupted once they developed schizophrenia.

Most of the subjects had no income (67.4%). This may because only 30% of the subjects were employed and the others were unemployed (27.4%), housewives (23.4%) and students (16.3%). From a review of Naheed et al. (2012), people with schizophrenia in low-and middle- income countries were employed more than their Western counterparts. They also noted that in India, employment rate was up to 75% and in China, about half was able to work after 5 years of follow–up. The employment rate of the patients reported from most Western studies was between 10 – 20 % (Marwaha as cited in Naheed et al., 2012). Apparently, in comparison to other developing countries, the employment rate of the subjects in this current study appears less. In Bangladesh, 5% of population had been unemployment (Central Intelligence Agency [CIA], 2013. The higher portion of the unemployed among

people with schizophrenia compared to general population may contribute to the perception of impact of schizophrenia on their lives.

In this study, nearly half of the persons with schizophrenia (48%) lived in urban areas. This finding is similar to the study of Ahammad et al. (2009). City living may be an additional risk factor for developing schizophrenia. Fahmida, Wahab, and Rahman (2009) reported that psychiatric disorders are common in both rural and urban areas of Bangladesh. On the other hand, the risk of schizophrenia may be greater amongst those born or brought up in poor urban areas (Faris & Dunham as cited in Ahammad et al., 2009) because it is created hazards in personal, occupational or social level.

**Clinical Characteristics of the Persons with Schizophrenia**

In the present study, 40.7% of the subjects have had schizophrenia for more than 5 years to 10 years and have been admitted 6 times or more (40%) in the hospital. Comparing to the findings from the Khan et al.'s study (2011), the average years of treatment were 19.2 years in their study with Bangladeshi patients. The range of duration of illness was 1 to 20 years. These findings may confirm that schizophrenia is a chronic, episodic and severe illness (Bostrom & Boyd, 2005; Videback, 2011). Persons with chronic schizophrenia need continuation of treatment.

Persons with schizophrenia reported that they learned about illness from their relatives (54.1%). This may be because caring is a duty of a family member and is an expected and accepted norm of a family member, especially in Bangladesh. So, family members become the major source of information.

Persons with schizophrenia reported that their family members suffered with the same problems of their relatives, siblings, grandparents, parents, and children 15.6%, 14.8%, 12.6%, 8.9%, and 0.7%, respectively. Genetics plays an important role in the etiology of schizophrenia. The incidence rate of schizophrenia of people in the affected families is higher than in the general population. However, a variation of incidence occurs. According to Moller (2009), incidence rate of schizophrenia is 50% among individuals who have monozygotic twin affected and among having dizygotic twin affected, both parent affected, one parent affected, and second degree relatives affected are 15%, 35%, 10% and 2-3%, respectively. In addition, the National Institute of Mental Health stated that relatives of persons with schizophrenia (first degree relatives) have a higher incidence than second degree relatives.

The findings also revealed that most of persons with schizophrenia (64.4%) were treated by atypical antipsychotics (for example olanzipine, clozapine and risperidone). Naheed et al. (2012) stated that antipsychotics are the cornerstones of acute and maintenance treatment of schizophrenia and are effective in the treatment of positive and negative symptoms. In particular, clozapine may have specific benefits for controlling positive symptoms, as well as violent, hostile, or suicidal behaviors (Meltzer, 2012). Moreover, according to Freedman (2005), clozapine might be significantly more effective than the other antipsychotic drugs and clozapine had more efficacy than first-generation drugs. Apparently, the subjects had received treatments that would be effective to control their illness. This may contribute to the subjects' perceptions of treatment control.

## Cognitive Illness Representation

### Identity Dimension

The identity dimension of cognitive illness representation is comprised of two aspects. "label" and "symptoms". Regarding the label aspect, this study found that all subjects strongly labeled their mental health problems as "schizophrenia". Obviously, in describing or labeling the illness the subjects used similar term as used by psychiatrists or mental health professionals. In Bangladesh, "*pagal*" was the language used by lay persons to describe or label someone who had mental illness (Selim & Satalkar, 2008). In Selim and Satalkar's study, the informants were recruited from a village where no psychiatrist or mental health professional offered services. However, in this current study, the subjects had contact with psychiatrist and mental health professional during their treatment and hospitalization. This is why all subjects were able to label their mental health problems as "schizophrenia". The finding could suggest that the influence of information inherited within culture on formation of cognitive illness representation may be faded off by information persons received though interactions with health care providers.

Top ten symptoms that the majority of the subjects experienced were being violent to other (99.3%), lost interest in personal care (99.3%), difficulty sleeping (98.5%), being suspicious of other people (97.8%), talking or laughing to myself (97.8%), being withdrawn (97.0%), hearing voices (96.3%), feeling agitated (95.6%), not doing much (94.8%), and problems communicating with other people (93.3%), respectively. These symptoms are tied with schizophrenia (Shives, 2012; Videbeck, 2011). Apparently, the subjects were able to identify their symptoms

associated with schizophrenia. About half of them had been admitted in the hospitals 1-5 times (Table 4). The repeated experience may help the subjects to recognize these symptoms. Repeated experience makes people become experts that are likely to recognize numerous and more complex of elements representing past mental experience (Scisney-Matlock, 1997). The nature of cognitive processing (i.e., attention and working memory) has influence on persons' capacity to formulate their cognitive illness representation. In this current study, all of the subjects were in the stabilization phase as indicated by the scores on the BPRS less than 40 so that the subjects could be able to pay attention and retrieve the stored information of previous symptom experience.

**Cause dimension**

The most common cause of the illness about which the persons with schizophrenia strongly endorsed were money worries (95.6%), stress or worry (88.9%), lack of friends or persons who cared about patients (88.9%), overwork (88.1%), thinking too much (86.7%), traumatic experience (85.1%), bad luck (83.7%) and lack of sleep (83.0%). In addition, a large portion of the subjects also contributed the cause of their illness to brain abnormality (81.5%), and chemical imbalance (77.0%) (Table 8).

When further asked them to rank "in order'' the three most important factors that they believed were causes of their mental health problem, the finding is somewhat spreading where the first, second, and third rank causes were variable. Among them the following three causes came up: black magic, stress or worry, and hereditary (Table 9).

Within Bangladesh culture, there is a belief about supernatural causes of mental illness. From the group discussion of patients, caregivers and villagers, Selim and Satalkar (2008) found that not only stress but also a belief about evil spirits were mentioned as the cause of mental illness. Thus, it is not surprising for the finding that the persons with schizophrenia in this current study mentioned possession of black magic and evil spirits as the most important cause of their illness.

Stress is a common trigger of symptoms relapsing (Shives, 2012; Videbeck, 2011). Information derived from the experience when the subjects encounter relapsing episode could contribute to their perception in that stress is the cause of their illness. Besides, the subjects also had family history of schizophrenia (Table 4). This may make the subjects perceive that the cause of their illness is heredity. Moreover, most of the subjects reported they have learned about their illness from various sources including relatives, psychiatrists, nurses, and media (Table 4). This also could be a reason why most of the subjects highly endorsed many factors to cause their illness.

**Timeline dimension**

In this study, the timeline refers to the perception of the persons with schizophrenia about duration and characteristic course of their illness. The persons with schizophrenia had strong perceptions that their illness was chronic and cyclical in nature (Table 7). Information from the subjects' personal illness experiences, involving the suffering from the illness oneself and knowing an individual who had the illness, might have influence on the development of these perceptions. Nearly half of the subjects (40.7%) had suffered from their illness more than five years and 65% of them were re-hospitalized more than 3 times and above. Also, more than half

of the subjects (53%) had family history of schizophrenia. The affected were their grandparents, parents, siblings, relatives and even their own child. Through observation of their relatives' experiences integrated with their own illness experiences, it might lead the subjects to strongly perceive that their mental illness or schizophrenia was likely to be permanent rather than temporary and might expect that the illness would last for the rest of their life (Appendix E, Table 11). They also stated that they had times when they were well and times when they were not well. This infers to the episodic or cyclical character of schizophrenia.

The subjects' perceptions regarding the timeline of schizophrenia are consistent with the medical viewpoint in which schizophrenia is an episodic and chronic illness. The findings are also in line with previous findings. From a systemic review of literatures, Baines and Wittkowski (2013) concluded that in general adults with psychosis including schizophrenia viewed their mental illness as both chronic and cyclical in nature.

**Consequences dimension**

The consequences refers to the perception of persons with schizophrenia of the possible minor and major effects, as a result of the illness, on their lives encompassing physical, psychological, financial, and social consequences. This present study revealed that the persons with schizophrenia perceived negative consequences from their mental illness at a high level (Table 7).

Negative psychological consequence appears to be the biggest problem. The subjects perceived that having mental health problem highly meant they were valued less by other people ($M$ = 4.93, $SD$ = 0.26) (Appendix E, Table 12).

Stigmatization may contribute to this perception. Societal stigma (e.g., social avoidance and rejection, low expectations, prejudice, discrimination) is a common phenomenon experienced by people with schizophrenia, worldwide. Evidence of societal stigma in Bangladesh is illustrated in Selim and Satalkar's study (2008). The participants revealed to the researchers that both men and women with mental illness had difficulty getting married because people were afraid of them. In this current study, experience with stigma was not directly assessed. However, 41.5% of the subjects were single. Taken together, this may infer that the persons with schizophrenia in this current study, to some extent, might have experienced societal stigma.

Another major consequence of mental illness as perceived by the subjects involves interpersonal relationship. The subjects perceived that due to their mental health problem, they highly lost important relationship ($M$ = 4.89, $SD$ = 0.31) and did not get along well with family ($M$ = 4.80, $SD$ = 0.50) (Appendix E, Table 12). The finding suggests that the subjects experienced difficulties to initiate and maintain relationship with others. The relationship problem is frequently found among people with schizophrenia and its cause is contributed to their cognitive, emotional, and behavioral symptoms (such as violence and aggression, paranoid, poor communication, being withdrawn, and agitation) (Shives, 2012; Videbeck, 2011). Likewise, cognitive, emotional, and behavioral symptoms the subjects in this present study experienced could jeopardize their relationship with family and others.

The subjects also reported high financial problem as the consequence of their mental illness ($M$ = 4.87, $SD$ = 0.33) (Appendix E, Table 12). High cost of long-term treatment appears to be the biggest concern of most persons with

schizophrenia (Rossler, Salize, & Knapp, 1998). The subjects in this current study were recruited from the National Institute of Mental Health (NIMH) where except medications, other treatments such as CBT, psycho-education, and counseling are provided free of charge. The subjects were mainly treated with atypical antipsychotics such as risperidon and clozapine which are more expensive than typical antipsychotics such as haloperidol and chlorpromazine. In addition to medication expense, the persons with schizophrenia also needed money for transportations which may be quite burdensome since about half of them lived in village (31.9%) and sub-urban area (20.7%). Apparently, taken together with the facts that they were ill for more than 5 years (40.7%), had no job (27.4%) and had no income (67.4%), the subjects had experienced immense financial problems. leading to the perception of the negative consequence caused by their mental illness.

**Controllability dimension**

In terms of the illness controllability, personal control and treatment control were referred in this study. Regarding personal control, this study reveals that perception of persons with schizophrenia on their personal ability to control their illness was at a high level ($M$ = 8.13, $SD$ = 1.44). Human is an active problem solver. It is also true for persons with schizophrenia. From a study of Sanseeha et al. (2009), the participants who believed they were chronically ill sought ways to manage the illness by adjusting their self-care activities and social behaviors and practicing mindfulness to handle their stress. Thus, it is likely that throughout long-term experience with the illness, the subjects may have tried to find ways to manage their

symptoms and have learnt that they have capacities to make their illness better or worse.

With respect to treatment control, perception of the subjects on the effectiveness of their treatment in managing their illness was also at a high level (*M* = 12.23, *SD* = 1. 62). It is likely that the subjects may formulate this perception based on their personal experience in which their symptoms were reduced or cured when they took medication. According to the BPRS scores, the subjects were in the remission phase of the illness suggesting their symptoms were reduced or cured. The subjects in this current study received both atypical antipsychotics (e.g., risperidon and clozapine) and typical antipsychotics (e.g., haloperidol and chlorpromazine). These medications are approved for their effectiveness to treat both positive (e.g., hallucination, paranoid) and negative symptoms (e.g., blunt affect, being withdrawn) (Shives, 2012; Videbeck, 2011). According to Islam and Howard (1993), Bangladeshi persons with schizophrenia appear to have remarkably good response to antipsychotic medication.

# CHAPTER 5

# CONCLUSION AND RECOMMENDATIONS

This chapter describes conclusion of the study. The main topics in this chapter include a conclusion of the study, limitations of the study, and implications and recommendations.

## Conclusion of the Study

A descriptive, cross-sectional study was conducted in 135 Bangladeshi persons with schizophrenia, at the Outpatient Department (OPD), the National Institute of Mental Health (NIMH) Dhaka. This descriptive study aimed to examine the cognitive illness representation as perceived by persons with schizophrenia. The subjects were recruited by using the convenience sampling method from those who met the inclusion criteria. Data were collected by using a set of self-reported questionnaire which consisted of two parts: 1) the demographic and the clinical characteristics and 2) the Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ). The cultural relevancy was validated by a psychiatric expert. The CIRSQ was back translated to the Bengali language and was administered to three persons with schizophrenia in order to check the clarity of the response.

The reliability of the CIRSQ was examined. For the identity subscale, the percentage of agreement of 58 symptom items, 36 items yielded 80.0% and more and 14 items were in between 61.0% and 79.0% and a few items were in between 40.0% and 60.0%. The Cronbach's alpha coefficients of cause, timeline

(acute/chronic), cyclical, consequences, personal control and treatment control subscales were in acceptable to satisfactory levels, except in some subscales (e.g. cyclical timeline and personal control). Data were analyzed by using descriptive statistics.

The age of the persons with schizophrenia was between 18 and 55 years with a mean age of 30.7 years (*SD* = 9.82). The majority of them were Muslim (95.0%), and about half were male (54.8%), and married (48.9%). For education more than half of the subjects were educated at a primary and secondary school level (61.5%). About one-fourth of persons with schizophrenia were unemployed (27.4%).

The majority of them had no income (67.4%) and about half lived in urban areas (47.4%). Nearly half of the persons with schizophrenia have been suffered from this illness more than 5 to 10 years (40.7%) and about one- forth (28.1%) had number of hospitalizations more than 10 times. More than half of the subjects learned about the illness from their relatives. Persons with schizophrenias reported that their family members suffered with the same problems.

The findings revealed that all subjects labeled their illness as schizophrenia. With respect to the symptom aspect of the identity, the two most frequently perceived symptoms were being violent to other and loss of interest in my personal care (99.3%), followed by difficulty sleeping (98.5%), being suspicious of other people (97.8% ), and talking or laughing to myself (97.8%), being withdrawn (97.0%), hearing voices (96.3%), feeling agitated (95.6%), not doing much (94.8%), problems communicating with other people (93.3%), respectively.

Regarding perceived causes of the illness, the most frequently and strongly agreed cause was money worries (95.6%), equally followed by stress and

lack of friends or people who cared about (88.9%). Other causes included overwork (88.1%), thinking about things too much (86.7%), a trauma (85.1%), chance or bad luck (83.7%), brain damage (81.5%), chemical imbalance (77.0%). In addition, from the order ranking of the three most important factors believing to be causes of their illness, the following three causes came up: black magic, stress or worry, and hereditary.

For other dimensions of the cognitive illness representation, perception of the persons with schizophrenia was at a high level, concerning these dimensions: acute/chronic timeline ($M$ = 22.17, $SD$ = 2.93), cyclical timeline ($M$ = 9.47, $SD$ = 0.62), consequences ($M$ = 43.5, $SD$ = 1.86), personal control ($M$ = 8.13, $SD$ = 1.44), and treatment control ($M$ = 12.23, $SD$ = 1.62).

## Limitations of the Study

Generalizability of the findings may be limited due to use of convenience sampling method. The findings of the study may not represent cognitive illness perception of persons with schizophrenia in Bangladesh as a whole. However, these findings can be used to explain the perceptions regarding schizophrenia of those who only come to get treatment at the OPD of the NIMH in Bangladesh.

Another major limitation of this study may be attributed to measurement error. There were some subscales of the CIRSQ with low reliability. Cronbach's alpha values of some subscales of the CIRSQ were relatively lower than the accepted value (.80), particularly, the ones of cyclical timeline and personal control. Besides, the measurement is considered lengthy. This may contribute to the

subjects' tiredness and that may make them pay less attention during responding to the questionnaires, specifically to the CIRSQ.

## Implications and Recommendations

The findings of this study do offer practical implications and recommendations as the followings.

### Nursing practice

The results of this study provide information of how persons with schizophrenia perceived about their cognitive illness representation regarding the most common experienced symptom, cause, timeline (acute/chronic and cyclical), consequences, and controllability (personal control and treatment control). Nurses and health care providers who work at the National Institute of Mental Health and Hospital can use these findings as baseline information to develop psycho-education programs and cognitive illness representation-based program aimed to help their patients to cope with schizophrenia and enhance other health behaviors including medication adherence. Moreover, they need to pay attention particularly to the negative consequences in persons with schizophrenia. They should also be alert to any signs of distress of their patients and promptly provide psychological support whenever needed. Furthermore, the nurses and health care providers can investigate carefully on what makes persons with schizophrenia perceived negative consequences of their illness. They also can further assess about health related behaviors such as medication adherence and be alert to the risk.

**Nursing research**

For further replication study, it is recommended to collect data by using other strategies, such as interview because it can help the researcher to get more detail leading to more understanding. Moreover, there is a need to modify the CIRSQ and test of its psychometric properties for use in the context of Bangladeshi culture. For example, the cause subscale may need to include these items: black magic, demon, evil spirit, caught jinnee, saddle and super natural power in order to capture Bangladeshi beliefs about causes of mental illnesses.

In addition, the researcher hopes that this thesis will help to increase interest and further research regarding cognitive illness representation in schizophrenia population and their relatives. A comparative study to explore the difference in patients' and relatives' cognitive illness representation of persons with schizophrenia is also suggested. Finally, the researcher suggests that further research on cognitive illness representation in different settings in Bangladesh (the government and private sectors) to generalize the whole population may be worth investigated.

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# APPENDICES

# APPENDIX A

## Invitation Letter and Informed Consent Form

Dear participants,

I am Mrs. Kanis Fatema, a master's student of Mental Health and Psychiatric Nursing Program at the Faculty of Nursing, Prince of Songkla University, Thailand. I am also a senior staff nurse at the Dhaka Medical College Hospital, Dhaka. I am conducting a nursing study to see how you think about your illness. I am inviting you to participate in this study because you are the person who has experienced with schizophrenia for a year. Your response will help the health care team understand you better than ever before so that they can provide better care to you and other people like you in the future.

If you decide to participate in the study, you are asked to respond to a set of questionnaires. It will take approximately 45-60 minutes to complete the questionnaires. If you do not want to do it by yourself, because you cannot read. I will read the questionnaires for you item by item and you will give me the answers. There is no monetary incentive in doing this.

There is no known risk in participating in the study. However, it is possible that during reading and answering to some items you will feel discomfort or uneasiness. If you experience that feeling, please feel free to stop or take some rest. Or if you don't want to answer to some statements, you are allowed to skip. You can also express your feeling with me. I will listen to you attentively and help you as much as I can.

You have right to leave the study at any time. Your participation or not participation will have no consequences to the care you receive from this hospital.

Your data will keep confidential, the data will be only use for research purpose, and it will be destroyed after the research report is completed.

If you agree to participate in this study, please sign your name under the given space below.

..... ……. …….

Name of researcher Signature of researcher Date

I agree to participate in this study. I have full understanding about the information mentioned above.

…… …… ……

Name of participant Signature of participant Date

If you have any inquiries, please contact me at 88-01716399150

## APPENDIX B

### *The Brief Psychiatric Rating Scale (BPRS)*

| No | Statement | Not present (1) | Very mild (2) | Mild (3) | Moderate (4) | Moderately severe (5) | Severe (6) | Extremely severe (7) |
|---|---|---|---|---|---|---|---|---|
| 1. | Somatic Concern<br>Degree of concern over present bodily health:<br>✓ Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have a realistic basis or not. | | | | | | | |
| 2. | Anxiety<br>Worry, fear, or over-concern for present or future.<br>✓ Rate solely based on verbal report of patient's own subjective experiences. Do not infer anxiety from physical signs or from neurotic defense mechanisms. | | | | | | | |
| 3. | Emotional Withdrawal<br>Deficiency in relating to the interviewer and to the interview situation.<br>✓ Rate only the degree to which the patient gives the impression of failing to be in emotional contact with other people in the interview situation. | | | | | | | |
| 4. | Conceptual Disorganization<br>Degree to which the thought processes are confused, disconnected, or disorganized.<br>✓ Rate based on integration of the verbal products of the patient; do not rate on the basis of patient's subjective impression of his own level of functioning. | | | | | | | |

| No | Statement | Not present (1) | Very mild (2) | Mild (3) | Moderate (4) | Moderately severe (5) | Severe (6) | Extremely severe (7) |
|---|---|---|---|---|---|---|---|---|
| 5. | Guilt Feelings<br>Over-concern or remorse for past behavior.<br>✓ Rate on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not infer guilt feelings from depression, anxiety, or neurotic defenses. | | | | | | | |
| 6. | Tension<br>Physical and motor manifestations of tension "nervousness", and heightened activation level.<br>✓ Tension should be rated solely on the basis of physical signs and motor behavior and not on the basis of subjective experiences of tension reported by the patient. | | | | | | | |
| 7 | Mannerisms and Posturing<br>Unusual and unnatural motor behavior, the type of motor behavior which causes certain mental patients to stand out in a crowd of normal people.<br>✓ Rate only abnormality of movements; do not rate simple heightened motor activity here. | | | | | | | |
| 8. | Grandiosity<br>Exaggerated self-opinion, conviction of unusual ability or powers.<br>✓ Rate only on the basis of patient's statements about himself or self-in-relation-to-others, not on the basis of his demeanor in the interview situation. | | | | | | | |
| 9. | Depressive Mood<br>Despondency in mood, sadness.<br>✓ Rate only degree of despondency; do not rate on the basis of interferences concerning depression based upon general retardation and somatic complaints | | | | | | | |

| No | Statement | Not present (1) | Very mild (2) | Mild (3) | Moderate (4) | Moderately severe (5) | Severe (6) | Extremely severe (7) |
|---|---|---|---|---|---|---|---|---|
| 10. | Hostility<br>Animosity, contempt, belligerence, disdain for other people outside the interview situation.<br>✓ Rate solely on the basis of the verbal report of feelings and actions of the patient toward others; do not infer hostility from neurotic defenses, anxiety, nor somatic complaints.<br>✓ Rate attitude toward interviewer under "uncooperativeness". | | | | | | | |
| 11. | Suspiciousness<br>Belief (delusional or otherwise) that others have now, or have had in the past, malicious or discriminatory intent toward the patient.<br>✓ On the basis of verbal report, rate only those suspicions which are currently held whether they concern past or present circumstances. | | | | | | | |
| 12. | Hallucinatory Behavior<br>Perceptions without normal external stimulus correspondence.<br>✓ Rate only those experiences which are reported to have occurred within the last week and which are described as distinctly different from the thought and imagery processes of normal people. | | | | | | | |
| 13. | Motor Retardation.<br>Reduction in energy level evidenced in slowed moments.<br>✓ Rate on the basis of observed behavior of the patient only; do not rate on the basis of patient's subjective impression of own energy level. | | | | | | | |
| 14. | Uncooperativeness<br>Evidence of resistance, unfriendliness, resentment, and lack of readiness to cooperate with the interviewer.<br>✓ Rate only on the basis of the patient's attitude and responses to | | | | | | | |

| No | Statement | Not present (1) | Very mild (2) | Mild (3) | Moderate (4) | Moderately severe (5) | Severe (6) | Extremely severe (7) |
|---|---|---|---|---|---|---|---|---|
| | the interviewer and the interview situation; do not rate on basis of reported resentment or uncooperativeness outside the interview situation. | | | | | | | |
| 15. | Unusual Thought Content<br>Unusual, odd, strange, or bizarre thought content.<br>✓ Rate here the degree of unusualness, not the degree of disorganization of thought processes. | | | | | | | |
| 16. | Blunted Affect<br>Reduced emotional tone, apparent lack of normal feeling or involvement. | | | | | | | |
| 17. | Excitement<br>Heightened emotional tone, agitation, increased, reactivity | | | | | | | |
| 18. | Disorientation<br>Confusion or lack of proper association for person, place, or time. | | | | | | | |

Note: The BPRS is used to measure subject's condition based on subject's psychosis symptoms. If the score BPRS less than 40, the subject can join in this study. It is because the BPRS score of 31 – 40 is mildly ill category (Leucht, Kane, Kissling, Hamann, Etschel, & Engel, 2005). The BPRS will be measured by researcher.

**APPENDIX C**

Code No

OPD _____

Date _____

Direction: - This questionnaire is divided into two parts: I. Demographic data and clinical characteristics Part: II. The Cognitive Illness Representation of Schizophrenia Questionnaire. Put "y" the one box that best describes the level of your perceptions.

A: Demographic Data Questionnaires

1.1 Age : Years old

1.2 Sex : ☐ 1. Male ☐ 2. Female

1.3 Marital status : ☐ 1. Single ☐ 2. Married

☐ 3. Separated

1.4 Religion : ☐ 1. Islam ☐ 2. Hindu

☐ 3. Christian

1.5 Educational level ☐ 1. Illiterate ☐ 2. Primary school

☐ 3. Secondary School ☐ 4. Higher Secondary School

☐ 5. Diploma ☐ 6. University

1.6 Occupational : ☐ 1. Unemployment

☐ 2. House wife

☐ 3. Government employee ☐ 4. Private employee

☐ 5. Farmer ☐ 6. Personal business

☐ 7. Labor ☐ 8. Other (student)

1.7 Income (Average per month): Taka

☐ 1. No Income ☐ 2. <5,000

☐ 3. 5,000-10,000 ☐ 4. >10,000-15,000

☐ 5. >15,000-20,000 ☐ 6. >20,000

1.8 Residential area:

☐ 1. Rural/Village ☐ 2. Urban/City

☐ 3. Sub urban

Clinical characteristics:

1 .9. How long you have suffered from this illness

☐ 1. <6 months ☐ 2. 6 months-1 year

☐ 3. >1- 3 years ☐ 4. 3- 5 years

☐ 5. > 5- 10 years

1.10. Hospitalization experience

☐ 1. Never ☐ 2. 1-2 times

☐ 3. 3-5 times ☐ 4. 6-10 times

☐ 5. > 10 times

1. 11. From whom you have learned about this illness

☐ 1. Media ☐ 2. Relatives

☐ 3. Psychiatrists ☐ 4. Nurses

☐ 5. No sources

1.12. Do other in your family have schizophrenia?

☐ 1. Yes ☐ 2. No

If yes, who are they…….

1. 13 Current use of medication _____

☐ Check by the researcher

☐ Respond from patients. Please specify…….

**YOUR VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS**

Please tick any of the following terms that have been used to describe your mental health problems, and add any other terms that may have been used. For each term, please indicate the extent to which you would agree that this label describes the experiences you have had.

| Label/term | Tick if been used | Strongly disagree | Disagree | Neither agree nor disagree | agree | Strongly agree |
|---|---|---|---|---|---|---|
| **Psychosis** | | | | | | |
| **Depression** | | | | | | |
| **Anxiety** | | | | | | |
| **Schizophrenia** | | | | | | |
| **Other** _____ | | | | | | |

**Please write the term/label that you feel best describes your mental health problems:**

_____

Listed below are a number of experiences that you may or may not have had since your mental health problems began. Please indicate by circling Yes or No whether or not you have had each of these experiences SINCE YOUR MENTAL HEALTH PROBLEMS BEGAN.

| | | **I have had this experience since my mental health problems** | |
|---|---|---|---|
| Number | Items | | |
| 1 | Being irritable | Yes | No |
| 2 | Pacing | Yes | No |
| 3 | Worrying | Yes | No |
| 4 | Believing people can read my mind | Yes | No |
| 5 | Receiving messages from the TV or media | Yes | No |
| 6 | Loss of motivation | Yes | No |
| 7 | Poor appetite | Yes | No |
| 8 | Mood swings | Yes | No |
| 9 | Being violent | Yes | No |
| 10 | Being withdrawn | Yes | No |
| 11 | Being secretive | Yes | No |
| 12 | Sleeping a lot | Yes | No |
| 13 | Not doing much | Yes | No |
| 14 | Lack of energy | Yes | No |
| 15 | Imagining things | Yes | No |
| 16 | Paranoia | Yes | No |
| 17 | Hearing voices | Yes | No |
| 18 | Feeling restless | Yes | No |
| 19 | Having thoughts I would rather not have | Yes | No |
| 20 | Difficulty concentrating | Yes | No |
| 21 | Being suspicious of other people | Yes | No |
| 22 | Feeling I am possessed | Yes | No |
| 23 | Memory problems | Yes | No |
| 24 | Believing that my thoughts are being broadcast to others | Yes | No |
| 25 | Feeling I am being watched | Yes | No |
| 26 | Thinking people are laughing at me | Yes | No |
| 27 | Believing I am a different person | Yes | No |

| | | **I have had this experience since my mental health problems** | |
|---|---|---|---|
| Number | Items | | |
| 28 | Gaining weight | Yes | No |
| 29 | Feeling agitated | Yes | No |
| 30 | Being argumentative | Yes | No |
| 31 | Feeling suicidal | Yes | No |
| 32 | Loss of interest in my personal care | Yes | No |
| 33 | Being self-absorbed | Yes | No |
| 34 | Difficulty sleeping | Yes | No |
| 35 | Not helping around the house | Yes | No |
| 36 | Becoming bored easily | Yes | No |
| 37 | Difficulty doing everyday tasks | Yes | No |
| 38 | Problems communicating with other people | Yes | No |
| 39 | Being aggressive | Yes | No |
| 40 | Anxiety attacks | Yes | No |
| 41 | Loss of self confidence | Yes | No |
| 41 | Feeling worthless | Yes | No |
| 43 | Seeing things that are not really there | Yes | No |
| 44 | Experiencing strange smells | Yes | No |
| 45 | Clouded thoughts | Yes | No |
| 46 | Feeling low | Yes | No |
| 47 | Shakiness | Yes | No |
| 48 | Talking or laughing to myself | Yes | No |
| 49 | Losing touch with reality | Yes | No |
| 50 | Believing I am special | Yes | No |
| 51 | Anxiety | Yes | No |
| 52 | Hyperactive | Yes | No |
| 53 | Having bizarre thoughts | Yes | No |
| 54 | Not being able to understanding other people | Yes | No |
| 55 | Over spending money away | Yes | No |
| 56 | Senses seem heightened so that noises and colours seem more intense | Yes | No |
| 57 | Excessive smoking | Yes | No |
| 58 | Feeling nervous | Yes | No |

The researcher is interested in your own personal views of how you NOW see your mental health problems. The researcher understands that your views are likely to have changed considerably over time, but please indicate how you NOW view things. Please indicate how much you agree or disagree with the following statements about your mental health problems by ticking the appropriate box.

| | VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS | Strongly disagree | Disagree | Neither agree nor disagree | agree | Strongly agree |
|---|---|---|---|---|---|---|
| **Timeline (acute/chronic)** | | | | | | |
| TL1 | My mental health problems will last a short time | 1 | 2 | 3 | 4 | 5 |
| TL2 | My mental health problem is likely to be permanent rather than temporary | 1 | 2 | 3 | 4 | 5 |
| TL3 | My mental health problems will last for a long time | 1 | 2 | 3 | 4 | 5 |
| TL4 | My mental health problems will pass quickly | 1 | 2 | 3 | 4 | 5 |
| TL5 | I expect to have this mental health problem for the rest of my life | | | | | |
| TL6 | My mental health problems will improve in time | 1 | 2 | 3 | 4 | 5 |
| **Timeline (cyclical)** | | | | | | |
| TC7 | I have times when I am well and times when I am not so well | 1 | 2 | 3 | 4 | 5 |
| TC8 | Some of my symptoms will be there all the time but others will come and go | 1 | 2 | 3 | 4 | 5 |
| **Consequences** | | | | | | |
| Cons 9 | My mental health problem is a serious condition | 1 | 2 | 3 | 4 | 5 |
| Cons 10 | My mental health problems have financial consequences | 1 | 2 | 3 | 4 | 5 |
| Cons 11 | My mental health problems make it more difficult for me to do day to day things | 1 | 2 | 3 | 4 | 5 |
| Cons 12 | My mental health problems cause difficulties for those who are close to me | 1 | 2 | 3 | 4 | 5 |
| Cons 13 | I don't get on as well with my family since my mental health problems | 1 | 2 | 3 | 4 | 5 |
| Cons 14 | My mental health problems have messed up my social life | 1 | 2 | 3 | 4 | |

| | VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS | Strongly disagree | Disagree | Neither agree nor disagree | agree | Strongly agree |
|---|---|---|---|---|---|---|
| **Consequences** | | | | | | |
| Cons 15 | My mental health problems mean that I am valued less by other people | 1 | 2 | 3 | 4 | 5 |
| Cons 16 | My mental health problems make working very difficult | 1 | 2 | 3 | 4 | 5 |
| Cons 17 | I have lost important relationship as a result of my mental health problems | 1 | 2 | 3 | 4 | 5 |
| **Controllability (personal control)** | | | | | | |
| PC 18 | There are some things which I can do to control my symptoms | 1 | 2 | 3 | 4 | 5 |
| PC 19 | To some extent what I do can determine whether my mental health problems get better or worse | 1 | 2 | 3 | 4 | 5 |
| **Controllability (treatment control)** | | | | | | |
| TR 20 | My treatment will be effective in managing my mental health problems | 1 | 2 | 3 | 4 | 5 |
| TR 21 | The negative effects of my mental health problems can be prevented (avoided) by my treatment | 1 | 2 | 3 | 4 | 5 |
| TR 22 | My treatment can control my mental health problems | 1 | 2 | 3 | 4 | 5 |

**CAUSES OF MY MENTAL HEALTH PROBLEMS**

The researcher is interested in what you consider may have been the causes of your mental health problems. As people are very different, there is no correct answer for this question. The researcher is most interested in your own views rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your mental health problems. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

| | **Possible causes** | Strongly disagree | Disagree | Neither agree nor disagree | agree | Strongly agree |
|---|---|---|---|---|---|---|
| C1 | Stress or worry | 1 | 2 | 3 | 4 | 5 |
| C2 | Hereditary; it runs in my family | 1 | 2 | 3 | 4 | 5 |
| C3 | A germ or virus | 1 | 2 | 3 | 4 | 5 |
| C4 | Diet or eating habits | 1 | 2 | 3 | 4 | 5 |
| C5 | Chance or bad luck | 1 | 2 | 3 | 4 | 5 |
| C6 | Poor medical care in my past life | 1 | 2 | 3 | 4 | 5 |
| C7 | Pollution in the environment | 1 | 2 | 3 | 4 | 5 |
| C8 | My own behavior | 1 | 2 | 3 | 4 | 5 |
| C9 | My family's behavior | 1 | 2 | 3 | 4 | 5 |
| C10 | My mental attitude e.g.; thinking about life negatively | 1 | 2 | 3 | 4 | 5 |
| C11 | Family problems | 1 | 2 | 3 | 4 | 5 |
| C12 | Overwork | 1 | 2 | 3 | 4 | 5 |
| C13 | Alcohol | 1 | 2 | 3 | 4 | 5 |
| C14 | Taking illicit drugs | 1 | 2 | 3 | 4 | 5 |
| C15 | My personality | 1 | 2 | 3 | 4 | 5 |
| C16 | Brain damage or abnormality | 1 | 2 | 3 | 4 | 5 |
| C17 | Lack of friends or people who cared about me | 1 | 2 | 3 | 4 | 5 |
| C18 | Chemical imbalance in the brain | 1 | 2 | 3 | 4 | 5 |
| C19 | A trauma; something disturbing or shocking that happened in my life | 1 | 2 | 3 | 4 | 5 |
| C20 | Death of a loved one | 1 | 2 | 3 | 4 | 5 |
| C21 | Money worries | 1 | 2 | 3 | 4 | 5 |
| C22 | Someone spiked my drink with illicit drugs | 1 | 2 | 3 | 4 | 5 |
| C23 | Lack of sleep | 1 | 2 | 3 | 4 | 5 |

| | Possible causes | Strongly disagree | Disagree | Neither agree nor disagree | agree | Strongly agree |
|---|---|---|---|---|---|---|
| C24 | Thinking about things too much | 1 | 2 | 3 | 4 | 5 |
| C25 | My upbringing | 1 | 2 | 3 | 4 | 5 |
| C26 | Being bullied at school | 1 | 2 | 3 | 4 | 5 |

Below, please list in rank order the three most important factors that you now believed caused YOUR mental health problems. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

| | |
|---|---|
| 1 | _____ |
| 2 | _____ |
| 3 | |

Thank you very much for completing this questionnaire.

## APPENDIX D

Table 10

*Frequency and Percentage of Identity (Symptoms) Dimension (N = 135)*

| Identity (Symptoms) | Yes<br>*n (%)* | No<br>*n (%)* |
|---|---|---|
| Being irritable | 130 (96.3) | 5 (3.7) |
| Pacing | 125 (92.6) | 10 (7.4) |
| Worrying | 134 (99.3) | 1 (0.7) |
| Believing people can read my thought | 124 (91.9) | 11 (8.1) |
| People are getting messages about me from the TV or media | 16 (11.9) | 119 (88.1) |
| Loss of motivation | 122 (90.4) | 13 (9.6) |
| Poor appetite | 125 (92.6) | 10 (7.4) |
| Mood swings | 124 (91.9) | 11 (8.1) |
| Being violent to other | 134 (99.3) | 1 (0.7) |
| Being withdrawn | 131 (97.0) | 4 (3.0) |
| Being secretive | 131 (97.0) | 4 (3.0) |
| Sleeping a lot | 33 (24.4) | 122 (75.6) |
| Not doing much | 128 (94.8) | 7 (5.2) |
| Lack of energy and motivation | 131 (97.0) | 4 (3.0) |
| Imagining things | 126 (93.3) | 9 (6.7) |
| Paranoia | 132 (97.8) | 3 (2.2) |
| Hearing voices | 130 (96.3) | 5 (3.7) |
| Feeling restless | 132 (97.8) | 3 (2.2) |
| Having thoughts I would rather not have | 104 (77.0) | 31 (23) |
| Difficulty concentrating | 133 (98.5) | 2 (1.5) |
| Being suspicious of other people | 132 (97.8) | 3 (2.2) |
| Feeling I am possessed | 103 (76.3) | 32 (23.07) |
| Memory problems | 133 (98.5) | 2 (1.5) |
| Believing that my thoughts are being broadcast to others | 76 (56.3) | 59 (43.7) |
| Feeling I am being watched | 130 (96.3) | 5 (3.7) |
| Thinking people are laughing at me | 124 (91.9) | 11 (9.81) |
| Believing I am a different person | 120 (88.9) | 15 (11.1) |
| Gaining weight | 20 (14.8) | 115 (85.2) |
| Feeling agitated | 129 (95.6) | 6 (4.4) |
| Being argumentative | 130 (96.7) | 5 (3.7) |
| Feeling suicidal | 127 (94.1) | 8 (5.9) |

Table 10 (continued)

| Identity (Symptoms) | Yes<br>*n (%)* | No<br>*n (%)* |
|---|---|---|
| Loss of interest in my personal care | 134 (99.3) | 1 (0.7) |
| Being self-absorbed | 133 (98.5) | 2 (1.5) |
| Difficulty sleeping | 133 (98.5) | 2 (1.5) |
| Not helping around the house | 132 (97.8) | 3 (2.2) |
| Becoming bored easily | 133 (98.5) | 2 (1.5) |
| Difficulty doing everyday tasks | 134 (99.3) | 1 (0.7) |
| Problems communicating with other people | 126 (93.3) | 9 (6.7) |
| Being aggressive | 112 (83.0) | 23 (17.0) |
| Anxiety attacks | 112 (83.0) | 23 (17.0) |
| Loss of self confidence | 127 (94.1) | 8 (5.9) |
| Feeling worthless | 132 (97.8) | 3 (2.2) |
| Seeing things that are not really there | 96 (71.1) | 39 (28.9) |
| Experiencing strange smells | 52 (38.5) | 83 (60.5) |
| Clouded thought | 88 (56.2) | 47 (34.8) |
| Feeling low | 132 (97.8) | 3 (2.2) |
| Shakiness | 130 (96.5) | 5 (3.7) |
| Talking or laughing to myself | 132 (97.0) | 3 (2.2) |
| Losing touch with reality | 80 (59.0) | 55 (40.7) |
| Believing I am special | 53 (39.0) | 82 (60.7) |
| Anxiety | 133 (98.5) | 2 (1.5) |
| Hyperactive | 101 (34.8) | 34 (25.2) |
| Having bizarre thoughts | 132 (91.1) | 12 (8.9) |
| Not being able to understanding other people | 130 (96.3) | 5 (3.7) |
| Over spending money away | 19 (21.5) | 106 (28.5) |
| Senses seem heightened so that noises and colours seem more intense | 119 (88.1) | 16 (11.9) |
| Excessive smoking | 47 (34.0) | 88 (65.2) |
| Feeling nervous | 127 (94.1) | 8 (5.9) |

## APPENDIX E

Table 11

*Possible Scores, Minimum, Maximum, Mean, Standard Deviation, Median, and Interquartile Range about Dimension of Timeline (Acute /Chronic and Cyclical) of the Cognitive Illness Representation (N = 135)*

| Timeline | Possible Score | Minimum | Maximum | *M (SD)* | *Mdn (IQR)* |
|---|---|---|---|---|---|
| My mental health problems will last a short time | 1-5 | 1 | 5 | 2.97 (1.36) | 2.00 (2) |
| My mental health problem is likely to be permanent rather than temporary | 1-5 | 2 | 5 | 4.72 (.60) | 5 (0) |
| My mental health problems will last for long time | 1-5 | 1 | 5 | 4.62 (.65) | 5 (1) |
| My mental health problems will pass quickly | 1-5 | 1 | 5 | 2.90 (1.38) | 2 (2) |
| I expect to have this mental health problem for the rest of my life | 1-5 | 3 | 5 | 4.79 (.47) | 5 (0) |
| My mental health problems will improve in time | 1-5 | 1 | 5 | 4.10 (1.15) | 4 (1) |
| TOTAL TimeLine-Acute/Chronic | 6-30 | 15 | 29 | 22.17 (2.93) | |
| Cyclical | | | | | |
| I have times when I am well and times when I am not well | 1-5 | 4 | 5 | 4.74 (.44) | 5 (1) |
| Sometimes of symptoms will be there all the time but others will come and go | 1-5 | 4 | 5 | 4.73 (.44) | 5 (1) |
| TOTAL_Timeline_Cyclical | 2-10 | 8 | 10 | 9.47 (.62) | |

Table 12

*Possible Scores, Minimum, Maximum, Mean, Standard Deviation, Median, and Interquartile Range about Dimension of Consequences of the Cognitive Illness Representation (N = 135)*

| Consequences | Possible Score | Minimum | Maximum | *M (SD)* | *Mdn (IQR)* |
|---|---|---|---|---|---|
| My mental health problems is a serious condition | 1-5 | 4 | 5 | 4.90 (.29) | 5 (0) |
| My mental health problems have financial consequences | 1-5 | 4 | 5 | 4.87 (.33) | 5 (0) |
| My mental health problems make it more difficult for me to do day to day | 1-5 | 3 | 5 | 4.77 (.43) | 5 (0) |
| My mental health problems cause difficulties for those who are close to me | 1-5 | 3 | 5 | 4.83 (.39) | 5 (0) |
| I do not get as well with family since my mental health problems | 1-5 | 1 | 5 | 4.80 (.50) | 5 (0) |
| My mental health problems have messed up my social life | 1-5 | 2 | 5 | 4.61 (.88) | 5 (0) |
| My mental health problems mean that I am valued less by other people | 1-5 | 4 | 5 | 4.93 (.26) | 5 (0) |
| My mental health problems make working very difficult | 1-5 | 4 | 5 | 4.90 (.29) | 5 (0) |
| I have lost important relationship as a result of my mental health problems | 1-5 | 4 | 5 | 4.89 (.31) | 5 (0) |
| Total Consequences | 9-45 | 36 | 45 | 43.5 (1.86) | |

Table 13

*Possible Scores, Minimum, Maximum, Mean, Standard Deviation, Median, and Interquartile Range about Dimension of Personal Control of the Cognitive Illness Representation (N = 135)*

| Personal control | Possible Score | Minimum | Maximum | *M* (*SD*) | *Mdn* (*IQR*) |
|---|---|---|---|---|---|
| There are some things which I can do to control my symptoms | 1-5 | 1 | 5 | 3.64 (1.23) | 4 (2) |
| To some extent what I do can determine whether my mental health problems get better or worse | 1-5 | 2 | 5 | 4.49 (.64) | 5 (1) |
| Total_Personal_control | 2-10 | 4 | 10 | 8.13 (1.44) | |

Table 14

*Possible Scores, Minimum, Maximum, Mean, Standard Deviation, Median, and Interquartile Range about Dimension of Treatment Control of the Cognitive Illness Representation (N=135)*

| Treatment control | Possible Score | Minimum | Maximum | *M (SD)* | *Mdn (IQR)* |
|---|---|---|---|---|---|
| My treatment will be effective in my managing my mental health problems | 1-5 | 4 | 5 | 4.71 (.45) | 5 (1) |
| The negative effects of my mental health problems can be prevented (avoided) by my treatment | 1-5 | 1 | 5 | 2.89 (1.43) | 2 (2) |
| My treatment can control my mental health problems | 1-5 | 3 | 5 | 4.63 (.50) | 5 (1) |
| Total Controllability | 3-15 | 9 | 15 | 12.23 (1.62) | |

## APPENDIX F

Table 15

*Frequency and Percentage of Cause Dimension of the Cognitive Illness Representation (N = 135)*

| Causes | Strongly disagree *n (%)* | Disagree *n (%)* | Neither agree nor disagree *n (%)* | Agree *n (%)* | Strongly agree *n (%)* |
|---|---|---|---|---|---|
| Stress or worry | | | | 15 (11.1) | 120 (88.9) |
| Hereditary; it runs in my family | | | | 35 (25.9) | 100 (74.1) |
| A germ or virus | 6 (4.4) | 12 (8.9) | 26 (19.3) | 23 (17.0) | 68 (50.4) |
| Diet or eating habits | | | | 41 (30.4) | 93 (68.9) |
| Chance or bad luck | | | | 22 (16.3) | 113 (83.7) |
| Poor medical care in my past life | | | 1 (.7) | 22 (16.3) | 112 (83) |
| Pollution in the environment | | 1 (.7) | | 37 (27.4) | 97 (71.9) |
| My own behavior | | | 1 (.7) | 30 (22.2) | 104 (77) |
| My family's behavior | | 1 (.7) | | 26 (19.3) | 108 (80.0) |
| My mental attitude e.g.; thinking about life negatively | | | 1 (.7) | 28 (20.7) | 106 (78.5) |
| Family problems | | | | 22 (16.3) | 113 (83.7) |
| Overwork | | | | 16 (11.9) | 119 (88.1) |
| Alcohol | | | 1 (.7) | 31 (23.0) | 103 (76.3) |
| Taking illicit drugs | | | 1 (.7) | 25 (18.5) | 109 (80.7) |
| My personality | | | | 20 (14.8) | 115 (85.2) |
| Brain damage or abnormality | | | 3 (2.2) | 22 (16.3) | 110 (81.5) |
| Lack of friends or people who cared about me | | | | 15 (11.1) | 120 (88.9) |
| Chemical imbalance in the brain | | 2 (1.5) | 2 (1.5) | 27 (20.0) | 104 (77.0) |
| A trauma; something disturbing or shocking that happened in my life | | 1 (.7) | | 19 (14.1) | 115 (85.2) |

Table 15 (continued)

| Causes | Strongly disagree *n (%)* | Disagree *n (%)* | Neither agree nor disagree *n (%)* | Agree *n (%)* | Strongly agree *n (%)* |
|---|---|---|---|---|---|
| Death of a loved one | | | | 29 (21.5 | 106 (78.5) |
| Money worries | | | | 6 (4.4) | 129 (95.6) |
| Someone spiked my drink with illicit drugs | | 1(.7) | | 45 (33.3) | 89 (65.9) |
| Lack of sleep | | | | 23 (17.0) | 112 (83) |
| Thinking about things too much | | | 2(1.5) | 16 (11.9) | 117 (86.7) |
| My upbringing | 1(.7) | | | 31 (23.0) | 103 (76.3) |
| Being bullied at school | | | 1(.7) | 31 (23.0) | 103 (76.3) |

## APPENDIX I

Table 16

*Percentage of Agreement Scores of Identity (Symptoms) Dimension of the Cognitive Illness Representation (N = 20)*

| Subscale | Percentage of Agreement |
|---|---|
| Worrying | 100 |
| Loss of motivation | 100 |
| Memory problems | 100 |
| Gaining weight | 100 |
| Feeling suicidal | 100 |
| Difficulty doing everyday tasks | 100 |
| Difficulty concentrating | 95 |
| Feeling I am being watched | 95 |
| Loss of interest in my personal care | 95 |
| Feeling worthless | 95 |
| Feeling low | 95 |
| Believing people can read my mind | 90 |
| Being secretive | 90 |
| Lack of energy | 90 |
| Paranoia | 90 |
| Becoming bored easily | 90 |
| Anxiety attacks | 90 |
| Loss of self confidence | 90 |
| Shakiness | 90 |
| Anxiety | 90 |
| Feeling nervous | 90 |
| Being irritable | 85 |
| Receiving messages from TV or media | 85 |
| Hearing voices | 85 |
| Being suspicious of other people | 85 |
| Thinking people are laughing at me | 85 |
| Not helping around the house | 85 |
| Problems communicating with other people | 85 |
| Excessive smoking | 85 |
| Poor appetite | 80 |
| Feeling restless | 80 |
| Feeling agitated | 80 |
| Being self-absorbed | 80 |
| Difficulty sleeping | 80 |
| Not being able to understand other people | 80 |
| Senses seem heightened so that noises and colours seem more intense | 80 |

Table 16 (continued)

| Subscale | Percentage of Agreement |
|---|---|
| Pacing | 75 |
| Being violent | 75 |
| Being withdrawn | 75 |
| Being argumentative | 75 |
| Talking or laughing to myself | 75 |
| Having bizarre thoughts | 75 |
| Imagining things | 70 |
| Having thoughts I would rather not have | 70 |
| Believing I am a different person | 70 |
| Experiencing strange smells | 70 |
| Hyperactive | 70 |
| Sleeping a lot | 65 |
| Not doing much | 65 |
| Believing I am special | 65 |
| Mood swings | 60 |
| Feeling I am possessed | 60 |
| Being aggressive | 55 |
| Seeing things that are not really there | 55 |
| Clouded thoughts | 50 |
| Losing touch with reality | 50 |
| Over spending money away | 50 |
| Believing that their thoughts are being broadcast to others | 40 |

## APPENDIX J

### List of the Psychiatric Expert of Cultural Relevancy

One expert worked on the validation of the instrument. Especially the expert checked cultural relevancy on Cognitive Illness Representation of Schizophrenia Questionnaire (CIRSQ). The particulars of the expert are given below:

Dr. M. A. Mohit Kamal, M. Phil,
Associate Professor of Psychotherapy,
Department of Psychotherapy,
Clinical Psychology and Psychiatric Social Work,
National Institute of Mental Health,
Sher-E- Bangla Nagar, Dhaka

### List of the Language Experts

Three language experts worked on the translation of the instruments. These experts were:

**Rafik Uddin Ripon,** Mizan Translation Centre, 29/1 Toyenbee Circular Road Motijheel C/A**,** Dhaka 1000 **t**ranslated instrument Original English version to Bengali.

**Afroza Sultana,** Lecturer (English) Dept. of Graduate Nursing, Bangahbandhu Sheik Mujib Medical University translated instrument Bengali version to English.

**Dr. Abul Kasham K Zaman,** Neuro psychiatrist, National Institute of Mental Health, Sher-e- Bangla Nagar, Dhaka compared between two English versions and verified discrepancy

# APENDIX K

## Permission Letter for Illness Perception Questionnaire for Schizophrenia Asking Permission for Modification and Using

Dear Fatema

You are welcome to modify the questionnaire as you wish as long you are clear in citing the modifications in your paper so it does not get confused with the original version. Please find attached as requested. Good luck with your research

Best wishes

Fi

Dr Fiona Lobban [f.lobban@lancaster.ac.uk]

Senior Lecturer in Clinical Psychology

Spectrum Centre for Mental Health Research

School of Health and Medicine

Division of Health Research

Lancaster University

Sent: 10 December 2012 10:08

Dear Mrs Fiona Lobban

Good morning, firstly, I would like to introduce myself. My name is Kanis Fatema. I am a student of master degree at Faculty of Nursing, Prince of Songkla University, Hat Yai, Thailand. My major of Mental Health and Psychiatric Nursing. I am doing my thesis with the title: "Cognitive Illness Representation as Perceived by Persons with Schizophrenia in Bangladesh." Now I am in process

developing my thesis article with a descriptive study. I need your Questionnaire. Illness Perceptions Questionnaire for Schizophrenia (IPQS) version-patient. Could you please allow me for modify (part is emotional representation, illness coherence, and personal blame) because I want to focus only cognitive illness representation and use your questionnaire in this study.

Finally, I would like to give very much thank you for your permission.

Regards

Kanis Fatema [kanis.fatema17@gmail.com]

Student of Master Degree of Psychiatric Nursing

Prince of Songkla University

Thailand

# VITAE

**Name** Kanis Fatema

**Student ID** 5410420049

**Educational Attainment**

| Degree | Name of Institution | Year of Graduation |
|---|---|---|
| Bachelor of Nursing Science | College of Nursing University of Dhaka, Bangladesh | 2007 |

**Scholarship Awards during Enrolment**

**Project**

- The Expansion and Quality Improvement of Nursing Education, 2011-2013

**Granting agency**

- Director of Nursing Services (DNS) Bangladesh, Ministry of Health and Family Welfare (MOHFW), Government of the People's Republic of Bangladesh, 2011-2013

**Work-Position and Address**

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**List of Publication and Proceeding**

Fatema, K., Chanchong, W., & Suttharangsee, W. (2014). Cognitive Illness Representation as Perceived by Persons with Schizophrenia in Bangladesh. *The 4th Bangladesh Clinical Psychology Conference on Mental Health Gap in Bangladesh*: Resources and Response, Nobab Nowab Ali Chowdhury Senate Bhaban, Dhaka, Bangladesh, August 19-22, 2014. BCPC414-08.