The Lived Experience of Families with Schizophrenic loved Ones

Salem Ayele Debela

School of Social Work

Addis Ababa University

June 2015

The Lived Experience of Families with Schizophrenic loved Ones

Salem Ayele Debela

School of Social Work

Addis Ababa University

June 2015

The Lived Experience of Families with Schizophrenic Loved ones

A Case Study on Caregivers of Inpatients at Addisu Michael Higher Clinic

By

Salem Ayele Debela

A Thesis Submitted To the School of Social Work, Addis Ababa University

In Partial Fulfillments of the Requirements for the Degree of Master of Social Work

Advisor: Demelash Kassaye, PhD, Commander

June 2015

Addis Ababa

Approved by Examining Board

Dr. Comdr. Demelash Kassaye		9/JULY/2015
Advisor	Signature	Date
Dr. Tenagne Alemu		09/07/15
Examiner	Signature	Date
Dr.Mulat Asnake		09/07/2015
Examiner	Signature	Date

DECLARATION

I, the undersigned, declare that this is my original work, has not been presented for a degree in any other university and that all sources of materials used for the thesis have been duly acknowledged.

Name Salem Ayele

Signature

Advisor Demeiash Kassaye Dr. Comor

Signature

Place and Date of Submission: Addis Ababa University

June, 2015

Acknowledgement

My genuine gratitude goes to my advisor Commander Dr. Demelash Kassaye for all his professional support and guidance on the completion of this thesis work. I would like to express my deep appreciation to Dr. Yonas Baheretibeb for allowing me to conduct my research at Addisu Michael Higher Clinic.

A special thanks goes to hospital staffs for their willingness to be interviewed and for their cooperation and support for the study to be conducted at the hospital setting. I am very grateful to the people who participated in this study and devoted their precious time in sharing their very personal experience.

Dedicated to Ermu Niguss

…and every child living with schizophrenia

…and the brave caregivers like my Mom.

Abstract

This paper described the lived experience of families living with schizophrenic loved ones with the aim of understanding their awareness about schizophrenia and their day to day interaction with their schizophrenic loved ones. The coping mechanisms families use in time of relapse and the effect of schizophrenia on their everyday living was also covered. Methodologically, the research was informed by qualitative case study approach. The study was undertaken utilizing an in-depth interview. Ten participants were purposely selected and interviewed. The key findings of the research indicated that participants have different understanding about the cause of schizophrenia. They associated the illness with evil spirit, work related stress as well as substance use and addiction. The findings of this study also indicated that caregivers come across various forms of challenges in dealing and living with their schizophrenic loved ones. These challenges include personal, social, economical and emotional problems. As the study indicated the challenges participants encountered are multi dimensional and interrelated. As a result holistic interventions are needed at different levels such as individual, family, society and organizational levels. The interventions should be designed and implemented to ensure basic information and understanding about the nature of the illness, course and outcome of treatments as well as advocacy for work place legal protection, social services provision, and mental health treatment centers expansion.

Table of Contents

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CIA	Central Investigation Agency
CT	Computed Tomography
DA	Dopamine Receptor Antagonist
EPS	Extra Pyramidal Side effects
FBI	Federal Bureau of Investigation
FDA	Food and Drug Administration
FGD	Focus Group Discussion
HERV	Human Endogenous Retrovirus
HSV	Herpes Simplex Virus
MNT	Medical News Today
MRI	Magnetic Resonance Imaging
NIH	National Institution of Health
NIMH	National Institution of Mental Health
SGA	Second Generation Antipsychotics
SDA	Serotonin Dopamine Antagonists
WHO	World Health Organization

Chapter One

Introduction

Thesis Organization

This thesis report is organized in six parts. The first part incorporates background of the study, which highlights the focus of the research, statement of the problem, research questions, objectives and significance of the study. The second section consists of the reviewed literature about the overall definition, cause and treatment of schizophrenia as well as the effect of schizophrenia on the family. The third part presents the methods used for the study such as, the research design, description and selection criteria of participants of the study, description of data gathering tool, ethical considerations, and limitations and delimitation of the study. Then, the findings are presented in section four followed by discussion of the major findings in section five. The final section consists of the conclusion and social work implications.

Background

Schizophrenia is a chronic, severe, and disabling brain disorder that generally appears in late adolescence or early adulthood, however it can emerge at anytime in life. It is also a psychotic disorder characterized by severely impaired thinking, emotions and behavior that may include delusions, loss of personality (flat affect), confusion, agitation, social withdrawal, psychosis, and bizarre behavior. The English term schizophrenia comes from the two Greek words to mean 'Split Mind' to describe the splitting apart of mental functions that are considered as the core characteristics of schizophrenia (MNT, 2014).

The Lived Experience of Families

According to Nemade & Dombeck (2009),the prevalence of schizophrenia is thought to be about 1 % of the total population around the world.1.2% or 3. 2 million Americans have the disorder. 25 % of hospital beds in Canada and United States of America are filled with patients with schizophrenia. The disorder is considered to be one of the top ten causes of long term disability worldwide.

According to WHO (2015), Schizophrenia has affected 21,000,000 people worldwide. And in the Ethiopian context, studies show that mental disorders take 11% of the total burden of disease in Ethiopia (Abdullah, et al., 2001). A research carried out by Fekadu et. Al, (2007) shows that, from the total cases of mental illness admitted to the only Psychiatric Hospital in Ethiopia, found in Addis Ababa named Amanuel Psychiatric hospital, 56 % is of schizophrenia.

People with schizophrenia may hear voices other people do not hear. They may believe other people are reading their minds, controlling their thoughts, or plotting to harm them. They may not make sense when they talk, they may sit for hours without moving or talking which can terrify themselves and make them withdrawn or extremely agitated (NIH, 2014).

Moreover, people with schizophrenia have difficulty distinguishing what is real from what is not. Controlling their emotions and thinking logically is difficult for them. They experience delusions and false beliefs. They feel paranoid and confused regarding family members. The characteristics of the disorder make them hear voices or see things that do not really exist. Therefore relating with people around them is very difficult (Levine and Levine, 2009)

Families and society are affected by schizophrenia. Many people with schizophrenia have difficulty holding a job, or caring for themselves, so they rely on others for help (NIH, 2014). Family members especially parents are the primary caregivers of people with schizophrenia

(Cohen, 2003). Family members of people with schizophrenia are under a great deal of stress every day. Care giving for a schizophrenic loved one might be a very tough task. The delusion experienced by the schizophrenic person can create conflicts that might be confusing and frightening for the family members (Veague, 2007).

Even though it is impossible for people with schizophrenia to lead their lives without depending on their family, the nature of the disorder would make them lack a smooth and healthy communication with their care givers. This at the end creates frustration and disappointments both on the family and on the schizophrenic loved ones which at the end may contribute on the exacerbation of schizophrenia. It is clear that both the patient and the family will be negatively affected if the relationship between the two parties is not smooth and health (Veague, 2007). Therefore this study will focus on the lived- in experience, interaction and the understanding between families and people with schizophrenia, the type of support the families give and the kind of coping mechanism the families use in their day to day life with their schizophrenic loved ones.

Statement of the problem

Countless researches had been done all over the world on the issue of schizophrenia. Bimerew (2007) wrote about substance abuse and the risk of readmission of people with schizophrenia at Amanuel Hospital in Addis Ababa, Ethiopia. The study suggested that alcohol and khat abuse were contributing factors for the rate of readmission of people with schizophrenia in the mentioned hospital.

Regarding people with schizophrenia and their care givers, Gallagher and Mechanic (1996) argued that being a care giver to a schizophrenic loved one or living with a person with schizophrenia could be really stressful that could affect health and activities of the care giver.

The Lived Experience of Families

Shibre et al, (2002) studied the impact of schizophrenia on family members in a traditional society. The study focused on the magnitude of burden related to social, financial and economical factors that family of people with schizophrenia experiencing. On another study, the same author focused on perception of stigma among family members of individuals with schizophrenia. The study focused on how families are affected by the stigma experienced because of the relationship they have with individuals with schizophrenia.

Pilling (2001) worked on psychological treatments in schizophrenia meta analysis of family intervention and cognitive behavioral therapy. The study concluded that family intervention should be offered to people with schizophrenia who are in contact with care givers. Another research conducted by Pharoan et al, (2012) studied about the family intervention for schizophrenia. According to the research people with schizophrenia from families that express high level of criticism and hostility have more frequent relapse than people with similar problem from families that tend to be less expressive of emotions.

Michael et al, (2003) conducted a research on burden in schizophrenia caregivers, impact of family psycho education. On the other hand, Grandon et al, (2008) studied about primary care givers of schizophrenia out patients burden and predictor variables. The article explored on family burden in relation to relatives coping strategies and social networks as well as in relation to patients' severity of positive and negative symptoms. Hultman, et al, (1997) had also worked on relationships between social support, social coping and life events in the relapse of schizophrenic patients.

In a country like Ethiopia, where mental health facilities are not sufficiently available, the burden and stress will be at the shoulder of the patient's family (kebede et.al, 2005). Studies show that the family members may have difficulty on effective communication with their

schizophrenic loved ones. Seeing the patient talking to himself or herself or responding to unseen or nonexistent objects can be frightening and confusing (Levine and Levine, 2009).

On the other hand, families may become socially isolated. They may also feel embarrassed about their loved ones unpredictable and bizarre behavior. The stigma associated with mental illness is also another factor they will have to encounter with (Veague, 2007).Being over burn with worry about loved one and ignoring oneself and one's own need also another factor caregivers of people with schizophrenia experience in their day to day living. The experience would make them extremely anxious and worried resulting on 'burnout' that really needs prevention (Veague, 2007).

The above mentioned and many other researchers contributed on the issue of schizophrenia in relation to the burden and impact on the families and care givers. But I did not find a study conducted in Ethiopia, that focused particularly on the lived-in experience of families or caregivers with their schizophrenic loved ones.

Therefore my research aims to focus on how family members understand their schizophrenic loved ones and communicate with them, how the family members manage to keep the communication healthy and smooth, what the family members do when their loved one becomes delusional and confused and what they do when their schizophrenic loved one experience relapse, how the families cope with stressful situation resulted from schizophrenia. In general, the main focus of my study would be on the lived-in experience of families or caregivers of people with schizophrenia.

Operational Definition

In this research a couple of terms that are linked to the lived experience of caregivers are used. In order to have a common understanding, these terms are defined as follows:

The Lived Experience of Families

Caregivers: People that live with and provide support for their schizophrenic loved ones.

Family: a fundamental social unit consisting of a group of two or more individuals related by marriage or blood. In this research the term caregiver is equivalently used to refer family.

Schizophrenic loved one: a person who is diagnosed with schizophrenia. The term 'People living with schizophrenia' has a similar meaning to "schizophrenic loved one'.

Objectives of the study

General Objective

The overall objective of this study was to understand the lived-in experience of families with their schizophrenic loved ones.

Specific objectives

The following specific objectives are what the study tried to attain at the end

1. To explore how families understand their schizophrenic loved ones.
2. To describe how families interact with their schizophrenic loved ones.
3. To explore the type of support families provide to their schizophrenic loved ones
4. To identify the coping mechanisms that family members of schizophrenic loved ones use in their day to day lives.

Research questions

The following research questions are what this study addresses at the end.

1. Are the care givers well acquainted to the essence of schizophrenia?
2. How do families interact with their schizophrenic loved ones?
3. What kind of support will families provide to their schizophrenic loved ones?

4. How do caregivers cope with the stress that results from the effect of schizophrenia?

Significance Of the study

This research aimed to contribute on the study of the lived experience of families or caregivers with their schizophrenic loved ones. By looking at the contributing factors that negatively affect the family relationship, this research contributed on recommending the possible solution for the healthier and smoother communication and family relationship between family members and schizophrenic loved ones. After the study is conducted, this research clearly understood the interaction and communication between families or caregivers of people with schizophrenia, described the level of understanding families have concerning the mental illness of their schizophrenic loved ones, explored the support that the families or care givers provide to their schizophrenic loved ones and explained the coping mechanisms the families or care givers use when their schizophrenic loved ones relapse. At the end of the study, the research recommended on the healthier and smoother communication as well as on creating better understanding between families or caregivers and their schizophrenic loved ones that at the end will be a possible solution for the problems that hinder a better life and healthy family relationship between caregivers and their schizophrenic loved ones.

Chapter Two

Literature Review

Conceptualizing schizophrenia as a problem to family relationship

"Schizophrenia is a psychotic disorder (or a group of disorders) marked by severely impaired thinking, emotions, and behaviors. Schizophrenic patients are typically unable to filter sensory stimuli and may have enhanced perceptions of sounds, colors, and other features of their environment. Most schizophrenics, if untreated, gradually withdraw from interactions with other people, and lose their ability to take care of personal needs and grooming"(WHO, 2001).

Description

The course of schizophrenia in adults can be divided into three phases or stages called acute, stabilization and maintenance. In the acute phase, the patient has an overt loss of contact with reality that requires intervention and treatment. In the second or stabilization phase, the initial psychotic symptoms have been brought under control but the patient is at risk for relapse if treatment is interrupted. In the third or maintenance phase, the patient is relatively stable and can be kept indefinitely on antipsychotic medications. Even in the maintenance phase, however, relapses are not unusual and patients do not always return to full functioning.(The free dictionary, 2007)

The English term schizophrenia comes from two Greek words that mean "split mind." It was observed around 1908, by a Swiss doctor named Eugen Bleuler, to describe the splitting apart of mental functions that he regarded as the central characteristic of schizophrenia. Recently, some psychotherapists have begun to use a classification of schizophrenia based on two main types. People with Type I, or positive schizophrenia, have a rapid (acute) onset of

symptoms and tend to respond well to drugs. They also tend to suffer more from the "positive" symptoms, such as delusions and hallucinations. People with Type II, or negative schizophrenia, are usually described as poorly adjusted before their schizophrenia slowly overtakes them. They have predominantly "negative" symptoms, such as withdrawal from others and a slowing of mental and physical reactions or psychomotor retardation (NIMH, 2009).

Economically, schizophrenia costs the United States over $60 billion per year in direct treatment costs, including direct healthcare costs, non-healthcare losses, and indirect costs (Wu et al., 2005). Men and women are equally affected by schizophrenia (Mueser & McGurk, 2004).

The illness occurs at similar rates in various ethnic groups worldwide, regardless of culture, race, and religion (Mueser & McGurk, 2004). Schizophrenia is quite common. Approximately 1 of every 100 people in the United States has this disorder. Approximately 2.5 million Americans are living with schizophrenia today, and over 100,000 new cases are diagnosed each year (NIMH, 1990). Psychotic symptoms usually emerge in the teens or twenties in men and the twenties or early thirties in women. Symptoms may become better or worse at different times in a person's life (NIMH). Schizophrenia does run in families. Having a close relative with this disorder increases the risk for developing it. Ten percent of people with a first-degree relative (parent or sibling) who has the illness will develop it. If one identical twin has schizophrenia, there is a 40% to 65% chance that the other twin will as well (Cardno & Gottesman, 2000).

Types of Schizophrenia

Paranoid

The key feature of this subtype of schizophrenia is the combination of false beliefs (delusions) and hearing voices (auditory hallucinations), with more nearly normal emotions and cognitive functioning (cognitive functions include reasoning, judgment, and memory). The delusions of paranoid schizophrenics usually involve thoughts of being persecuted or harmed by others or exaggerated opinions of their own importance, but may also reflect feelings of jealousy or excessive religiosity. The delusions are typically organized into a coherent framework. Paranoid schizophrenics function at a higher level than other subtypes, but are at risk for suicidal or violent behavior under the influence of their delusions (The free dictionary, 2007).

Disorganized

Disorganized schizophrenia (formerly called hebephrenic schizophrenia) is marked by disorganized speech, thinking, and behavior on the patient's part, coupled with flat or inappropriate emotional responses to a situation (affect). The patient may act silly or withdraw socially to an extreme extent. Most patients in this category have weak personality structures prior to their initial acute psychotic episode(The free dictionary , 2007).

Catatonic

Catatonic schizophrenia is characterized by disturbances of movement that may include rigidity, stupor, agitation, bizarre posturing, and repetitive imitations of the movements or speech of other people. These patients are at risk for malnutrition, exhaustion, or self-injury.
This subtype is presently uncommon in Europe and the United States. Catatonia as a symptom is most commonly associated with mood disorders(The free dictionary, 2007)

Undifferentiated

Patients in this category have the characteristic positive and negative symptoms of schizophrenia but do not meet the specific criteria for the paranoid, disorganized, or catatonic subtypes(The free dictionary, 2007).

Residual

This category is used for patients who have had at least one acute schizophrenic episode but do not presently have strong positive psychotic symptoms, such as delusions and hallucinations. They may have negative symptoms, such as withdrawal from others, or mild forms of positive symptoms, which indicate that the disorder has not completely resolved. The risk of schizophrenia among first-degree biological relatives is ten times greater than that observed in the general population. Furthermore the presence of the same disorder is higher in monozygotic twins (identical twins) than in dizygotic twins (nonidentical twins). The research concerning adoption studies and identical twins also supports the notion that environmental factors are important, because not all relatives who have the disorder express it.

Most patients are diagnosed in their late teens or early twenties, but the symptoms of schizophrenia can emerge at any age in the life cycle. The male/female ratio in adults is about 1.2:1. Male patients typically have their first acute episode in their early twenties, while female patients are usually closer to age 30 when they are recognized with active symptoms.

Schizophrenia is rarely diagnosed in preadolescent children, although patients as young as five or six have been reported. Childhood schizophrenia is at the upper end of the spectrum of severity and shows a greater gender disparity. It affects one or two children in every 10,000; the male/female ratio is 2:1(The free dictionary, 2007).

Causes of Schizophrenia

One of the reasons for the ongoing difficulty in classifying schizophrenic disorders is incomplete understanding of their causes. It is thought that these disorders are the end result of a combination of genetic, neurobiological, and environmental causes. A leading neurobiological hypothesis looks at the connection between the disease and excessive levels of dopamine, a chemical that transmits signals in the brain (neurotransmitter). The genetic factor in schizophrenia has been underscored by recent findings that first-degree biological relatives of schizophrenics are ten times as likely to develop the disorder as are members of the general population(NIMH, 2009).

Prior to recent findings of abnormalities in the brain structure of schizophrenic patients, several generations of psychotherapists advanced a number of psychoanalytic and sociological theories about the origins of schizophrenia. These theories ranged from hypotheses about the patient's problems with anxiety or aggression to theories about stress reactions or interactions with disturbed parents. Psychosocial factors are now thought to influence the expression or severity of schizophrenia rather than cause it directly(NIMH, 2009).

As of 2004, migration is a social factor that is known to influence people's susceptibility to psychosis. Psychiatrists in Europe have noted the increasing rate of schizophrenia and other psychotic disorders among immigrants to almost all Western European countries. Black immigrants from Africa or the Caribbean appear to be especially vulnerable. The stresses involved in migration include family breakup, the need to adjust to living in large urban areas, and social inequalities in the new country(MIMH,, 2009).

Another hypothesis suggests that schizophrenia may be caused by a virus that attacks the hippocampus, a part of the brain that processes sense perceptions. Damage to the hippocampus would account for schizophrenic patients' vulnerability to sensory overload. As of 2004, researchers are focusing on the possible role of the herpes simplex virus (HSV) in schizophrenia, as well as human endogenous retroviruses (HERVs). The possibility that HERVs may be associated with schizophrenia has to do with the fact that antibodies to these retroviruses are found more frequently in the blood serum of patients with schizophrenia than in serum from control subjects. According to the vulnerability-stress model of the causes of schizophrenia, the severity and course of the disorder are determined by biological vulnerability (due to an imbalance in brain chemistry caused by genetic factors or early biological risks), stress and coping skills (John M., 2013)

Symptoms of schizophrenia

Patients with a possible diagnosis of schizophrenia are evaluated on the basis of a set or constellation of symptoms; there is no single symptom that is unique to schizophrenia. In 1959, the German psychiatrist Kurt Schneider proposed a list of so-called first-rank symptoms, which he regarded as diagnostic of the disorder. These symptoms include delusions, somatic, hallucinations, hearing voices commenting on the patient's behavior, thought insertion or thought withdrawal(The free dictionary, 2007).

Somatic hallucinations refer to sensations or perceptions concerning body organs that have no known medical cause or reason, such as the notion that one's brain is radioactive. Thought insertion and/or withdrawal refer to delusions that an outside force (for example, the FBI, the CIA, Martians, etc.) has the power to put thoughts into one's mind or remove them

Positive Symptoms

The positive symptoms of schizophrenia are those that represent an excessive or distorted version of normal functions. Positive symptoms include Schneider's first-rank symptoms as well as disorganized thought processes (reflected mainly in speech) and disorganized or catatonic behavior. Disorganized thought processes are marked by such characteristics as looseness of associations, in which the patient rambles from topic to topic in a disconnected way; tangentially, which mean that the patient gives unrelated answers to questions; and "word salad," in which the patient's speech is so incoherent that it makes no grammatical or linguistic sense. Disorganized behavior means that the patient has difficulty with any type of purposeful or goal-oriented behavior, including personal self-care or preparing meals(NIMH, 2009).

Negative Symptoms

Schizophrenia includes three so-called negative symptoms. They are called negative because they represent the lack or absence of behaviors. The negative symptoms that are considered diagnostic of schizophrenia are a lack of emotional response (affective flattening), poverty of speech, and absence of volition or will. In general, the negative symptoms are more difficult for doctors to evaluate than the positive symptoms(NIMH,2009).

Diagnosis

A doctor must make a diagnosis of schizophrenia on the basis of a standardized list of outwardly observable symptoms, not on the basis of internal psychological processes. There are no specific laboratory tests that can be used to diagnose schizophrenia. Researchers have, however, discovered that patients with schizophrenia have certain abnormalities in the structure

and functioning of the brain compared to normal test subjects. These discoveries have been made with the help of imaging techniques such as computed tomography scans (CT scans).

When a psychiatrist assesses a patient for schizophrenia, he or she will begin by excluding physical conditions that can cause abnormal thinking and some other behaviors associated with schizophrenia. These conditions include organic brain disorders (including traumatic injuries of the brain), temporal lobe epilepsy, Wilson's disease, prion diseases, Huntington's chorea, and encephalitis. The doctor will also need to rule out heavy metal poisoning and substance abuse disorders, especially amphetamine use (The free dictionary, 2007).

After ruling out organic disorders, the clinician will consider other psychiatric conditions that may include psychotic symptoms or symptoms resembling psychosis. These disorders include mood disorders with psychotic features; delusional disorder; dissociative disorder not otherwise specified or multiple personality disorder; schizotypal, schizoid, or paranoid personality disorders; and atypical reactive disorders. In the past, many individuals were incorrectly diagnosed as schizophrenic. Some patients who were diagnosed prior to the changes in categorization should have their diagnoses, and treatment, reevaluated. In children, the doctor must distinguish between psychotic symptoms and a vivid fantasy life, and also identify learning problems or disorders. After other conditions have been ruled out, the patient must meet a set of criteria specified. The patient must have two (or more) of the following symptoms during a one-month period: delusions; hallucinations; disorganized speech; disorganized or catatonic behavior; negative symptoms. The patient should decline in social, interpersonal, or occupational functioning, including self-care. And also the disturbed behavior must last for at least six months

And mood disorders, substance abuse disorders, medical conditions, and developmental disorders have been ruled out (NIMH, 2009).

Treatment

The treatment of schizophrenia depends in part on the patient's stage or phase. Psychotic symptoms and behaviors are considered psychiatric emergencies, and persons showing signs of psychosis are frequently taken by family, friends, or the police to a hospital emergency room. A person diagnosed as psychotic can be legally hospitalized against his or her will, particularly if he or she is violent, threatening to commit suicide, or threatening to harm another person. A psychotic person may also be hospitalized if he or she has become malnourished or ill as a result of failure to feed, dress appropriately for the climate, or otherwise take care of him- or herself. A patient having a first psychotic episode should be given a CT or MRI (magnetic resonance imaging) scan to rule out structural brain disease(NIMH, 2009).

Antipsychotic medications

The primary form of treatment of schizophrenia is antipsychotic medication. Antipsychotic drugs help to control almost all the positive symptoms of the disorder. They have minimal effects on disorganized behavior and negative symptoms. Between 60-70% of schizophrenics will respond to antipsychotics. In the acute phase of the illness, patients are usually given medications by mouth or by intramuscular injection. After the patient has been stabilized, the antipsychotic drug may be given in a long-acting form called a depot dose. Depot medications last for two to four weeks; they have the advantage of protecting the patient against the consequences of forgetting or skipping daily doses. In addition, some patients who do not

respond to oral narcoleptics have better results with depot form. Patients whose long-term treatment includes depot medications are introduced to the depot form gradually during their stabilization period. Most people with schizophrenia are kept indefinitely on antipsychotic medications during the maintenance phase of their disorder to minimize the possibility of relapse(NIMH, 2009).

As of the early 2000s, the most frequently used antipsychotics fall into two classes: the older dopamine receptor antagonists, or DAs, and the newer serotonin dopamine antagonists, or SDAs. (Antagonists block the action of some other substance; for example, dopamine antagonists counteract the action of dopamine.) The exact mechanisms of action of these medications are not known, but it is thought that they lower the patient's sensitivity to sensory stimuli and so indirectly improve the patient's ability to interact with others(NIMH, 2009). Dopamine receptor antagonist. The dopamine antagonists include the older antipsychotic (also called narcoleptic) drugs, such as haloperidol (Haldol), chlorpromazine (Thorazine), and fluphenazine (Prolixin). These drugs have two major drawbacks: it is often difficult to find the best dosage level for the individual patient, and a dosage level high enough to control psychotic symptoms frequently produces extrapyramidal side effects, or EPS. EPSs include parkinsonism, in which the patient cannot walk normally and usually develops a tremor; dystonia, or painful muscle spasms of the head, tongue, or neck; and akathisia, or restlessness. A type of long-term EPS is called tardive dyskinesia, which features slow, rhythmic, automatic movements. Schizophrenics with AIDS are especially vulnerable to developing EPS(NIMH,2009).
The serotonin dopamine antagonists, also called atypical antipsychotics, are newer medications that include clozapine (Clozaril), risperidone (Risperdal), and olanzapine (Zyprexa). The SDAs

have a better effect on the negative symptoms of schizophrenia than do the older drugs and are less likely to produce EPS than the older compounds(The free dictionary, 2007).

The newer drugs are significantly more expensive in the short term, although the SDAs may reduce long-term costs by reducing the need for hospitalization. They are also presently unavailable in injectable forms. The SDAs are commonly used to treat patients who respond poorly to the DAs. However, many psychotherapists now regard the use of these atypical antipsychotics as the treatment of first choice; in particular, clozapine appears to be more effective than other antipsychotics in controlling persistent aggression in some patients. Newer Drugs. Some newer antipsychotic drugs have been approved by the Food and Drug administration (FDA) in the early 2000s. These drugs are sometimes called second-generation antipsychotics or SGAs. Aripiprazole (Abilify), which is classified as a partial dopaminergic agonist, received FDA approval in August 2003. Two drugs that are still under investigation, a neurokinin antagonist and a serotonin 2A/2C antagonist respectively, show promise in the treatment of schizophrenia and schizoaffective disorder (NIMH, 2009).

Psychotherapy

Most schizophrenics can benefit from psychotherapy once their acute symptoms have been brought under control by antipsychotic medication. Psychoanalytic approaches are not recommended. Behavior therapy, however, is often helpful in assisting patients to acquire skills for daily living and social interaction. It can be combined with occupational therapy to prepare the patient for eventual employment(NIMH, 2009).

The Lived Experience of Families

Family therapy

Family therapy is often recommended for the families of schizophrenic patients, to relieve the feelings of guilt that they often have as well as to help them understand the patient's disorder. The family's attitude and behaviors toward the patient are key factors in minimizing relapses (for example, by reducing stress in the patient's life), and family therapy can often strengthen the family's ability to cope with the stresses caused by the schizophrenic's illness. Family therapy focused on communication skills and problem-solving strategies is particularly helpful. In addition to formal treatment, many families benefit from support groups and similar mutual help organizations for relatives of schizophrenics (NIMH, 2009).

Effect on the family

Family Support

Family Support is a relationship focused principle that strengthens the ever evolving journey with families. It is also a constellation of formal and informal services and tangible goods that are defined and determined by families. It is "Whatever it takes" for a family to care for and live with a child or adolescent who has an emotional, behavioral or mental disorder (Federation of Families for Children's mental health, 1992).

Objective Burden

Objective burden is the disruption of family routine, employment, social and leisure activities in relation to those outside the family. Some studies also include financial costs and assessment of family members' physical and mental health (Roberts, 1988:375; Falloon, *et al.* 1984:32; Lefley & lohnson 1990:271). "Objective burden" may be explained in terms of tangible things

(problems), which can be observed by others, and includes quantitative, measurable problems such as finance. (Compare Atkinson & Coia, 1995 :32; Hatfield, 1990:21 and Schene, 1990:289.) Relatives of patients suffering from schizophrenia commonly report financial and employment difficulties, difficulties in leisure activities and relationship problems within the family as objective burden(NIMH, 2009).

Because schizophrenia typically occurs in early adulthood and is likely to affect long term earning and development capacity, higher levels of burden occur if the patient has formerly been working in families where earning capacity and commitment have not yet been established. The loss of potential earnings is easy to underestimate, but at the very least the family's lifestyle is likely to be more impoverished than before (Kuipers, 1993:207).

Difficulties may arise because caring for a patient with a persistent psychiatric disorder limits opportunities for an adequate income. The most severe problems occur when the patient was formerly the breadwinner, particularly if circumstances prevent another relative from taking over this role. (Compare Fadden, *et al.* 1987:287; Lefley & lohnson, 1990:39 and Schene, 1990:290.)

Relatives report practical, objective problems related to a loss of employment and financial hardship which place them under financial stress. These problems appear to be worse when the carer is the spouse of the patient who was formerly earning and who had good pre-morbid functioning (Atkinson & Coia, 1995:36; Lefley & lohnson, 1990:39). Due to unemployment and financial problems, multiple problems such as crime, depression and lack of food may occur at home(NIMH,2009).

Subjective Burden

"Subjective burden" describes the psychological reactions that family members experience, for example, feelings of loss, depression, anxiety and embarrassment in social situations (Magliano, Fadden, Madianos, Caldas de Almeida, Held, Guarneri, Marasco, Tosini & Maj, 1998:412; Gillis, *et al.* 1989:375). The patient's caregiver or the relatives may experience feelings of guilt, worry, depression, anxiety and fear because of the patient's behavior which perhaps stem from their lack of insight into how to supervise such a patient. "Subjective burden" includes negative feelings such as anger, anxiety, guilt and blame, embarrassment and shame, rejection, stigma, loneliness, depression, withdrawal, emphatic suffering, grief and threat to security(NIMH, 2009).

Because of these false ideas, individuals may distrust and feel paranoid and confused regarding family members. Consequently, family members often feel hurt and frustrated. The tenacity of the consumer's delusions may render resolution of family conflicts quite difficult. These conflicts may be confusing and frightening for family members. Family members may have difficulty communicating effectively with consumers who are distracted by delusions and/or hallucinations(NIMH, 2009).

Seeing your loved one talking to him/ herself or responding to unseen stimuli can be frightening and confusing. Because of the consumer's odd speech and behaviors, family members may feel confused and frustrated. As a result of others' discomfort with the consumer's disorganized speech and behavior, the family may become socially isolated, withdrawing from their support network. Family members may feel embarrassed about their loved one's bizarre behavior in public(The free dictionary, 2007).

Individuals with schizophrenia may be emotionally unavailable because of preoccupation with their mental stress. As a result, family members may feel rejected and lonely. Family members often experience these negative symptoms as more disturbing than the other (positive) symptoms (Pollio, North & Foster, 1998). Unfortunately, psychiatric medications are less effective in treating these negative symptoms of schizophrenia than in decreasing delusions and hallucinations(Medical News Today, 2014).

Family Relationship and Exacerbation of Schizophrenia

Family relationship is defined as the expected interaction and occurring amongst family members and the community (Kavanagh, 1992:258). Family relationship has to do with family members' integration with one another within the family system and within the external systems. Social functioning aims at improving the functioning of patients suffering from mental health problems and facilitating on optimal quality of life (Weller & Muijen, 1993:39).

Family relationship may be disturbed if one family member, who is suffering from schizophrenia, performs strange and unacceptable behaviors which impact negatively on family functioning. A mental illness such as schizophrenia affects the relationships of the entire family system. Internal relationships and roles have to be adjusted to accommodate the illness. The patient suffering from schizophrenia may thus disturb the social functioning of the family subsystems and the entire family as a system, making a review of the family roles necessary (NIMH, 2009).

Exacerbation is defined as an increase in the severity of a disease or any of its signs or symptoms (Medical Dictionary,2015). Relationships between the patient suffering from schizophrenia and his relatives may also be disturbed because of negative attitudes and disrupted communication patterns. The effect is exacerbated even more if the communication style and

attitudes of the patient's family are negative towards him. This could even impact negatively on the patient's recovery process. If the patient suffering from schizophrenia lives in a stressful environment, such as being criticized and labeled as a mad person by relatives and friends or colleagues at work, he may not feel loved or accepted and may eventually suffer a relapse (NIMH,2009).

Coping Mechanismes

According to Medical Dictionary (2015), coping mechanism is defined as any effort directed to stress management including task oriented and ego defense mechanisms, the factors that enable an individual to regain emotional equilibrium after a stressful experience. It may be unconscious process. In relation to psychiatry, it is any conscious or unconscious mechanism of adjusting to environmental stress without altering personal goals or purposes.

Coping mechanisms are also defined as ways to which external or internal stress is managed, adapted to or acted up on. They are the sum of cognitive and behavioral efforts, which are constantly changing, that aim to handle particular demands, whether internal or external, that are viewed as taxing or demanding. Simply put coping is an activity we do to seek and apply solutions to stressful situations or problem that emerge because of our stressors. (Lazarus & Folkman, 2008)

Weiten (2007)in the psychology text book recognized grouping s of coping strategies, which includes the appraisal focused strategies, the problem focused strategies and the emotion focused strategies.

Appraisal Focused strategies are those coping mechanisms which involve the change of mindset or a revision of thoughts. Denial is the most common coping mechanism under this strategy. Problem Focused strategies are those that modify the behavior of the person. Emotion

focused strategies include the alteration of one's emotion to tolerate or eliminate the stress. Examples include distraction, meditation, and relaxation technique.

The general classification of coping mechanisms are defense, adaptive, avoidance, attack, behavioral, cognitive, self harm, and conversion.

-Defence : is the unconscious way of coping stress that include reaction formation and regression.

- Adaptive: tolerates the stress. Examples are altruism, symbolization.

- Avoidance: keeps self away from stress, examples: denial, dissociation, fantasy, passive aggression, reaction formation.

- Attack: Diverts one's consciousness to a person or group of individuals other than the stressor or the stressful situation. Example: displacement, emotionality, projection.

- Behavioral: Modifies the way we act in order to minimize or eradicate the stress. Example: compensation, sublimation, undoing.

- Cognitive: alters the way we think so that stress is reduced or removed. Examples: compartmentalization, intellectualization, rationalization, repression, suppression.

- Self Harm: intends to harm self as a response to stress

- Conversion: Changes one thought, behavior or emotion in to another. Example : somatisation.(Sincero, 2012)

Chapter Three

Method

Research Design

Qualitative method helps to understand complex social phenomena and allows the researcher to retain holistic and meaningful characteristics of real life (Yin, 2003). It also enables to study the topic at a detailed manner and allows to clearly answer the research questions of the study. Using qualitative method enables the researcher to collect any relevant information from the subjects based on their own experiences on their own words. The method is sought to identify recurrent themes (Cherry, 2000).

This study used qualitative data collection technique; particularly case study was used. Case study research excels at bringing us to understanding of a complex issue or object and can extend experience or add strength to what is already known through previous research. Case studies emphasize detailed contextual analysis of a limited number of events or conditions and their relationships. It is a research method and an empirical inquiry that investigates a contemporary phenomenon within its real life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used (Yin, 1984)

In the case study, the respondents will be allowed to construct and make meanings to their own reality. They will explain with their own words and understanding. Since the topic is very broad selecting a number of respondents will allow the research to be framed and focused. For the reason that such type of research is especially appropriate to the study of those topics for which attitudes and behaviors can best be understood within their natural setting than investigating a predetermined experiences because one of the strength of the qualitative study is

the comprehensiveness of perspectives it gives the researcher (Rubin & Babbie, 1993). Besides, Seidman (2006) explained well to the selection of this approach that people's behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them. Therefore this research used qualitative research method particularly case study for its appropriateness on exploring and gathering information related to relationships in family settings.

Data Collection Technique

Both primary data sources such as interview and secondary data sources like published and unpublished materials, journals and books were used.

Study Site and Participants

Addisu Michael Higher Clinic is the name of the clinic selected for this particular research. This area is found between 22 Mazoria station and Kidus Gebriel Hospital. The clinic was established in 1991 G.C as a small clinic and gradually grew to be higher clinic that provides a psychiatric service. It has 25 beds for in patients and provides service for more than 1000 out patients every month. The basic reason for the selection of this specific area is the availability of people with schizophrenia and their family members.

Family members for each 10 people with schizophrenia were selected for the study. 3 key informants who were health professionals at Addisu Michael Higher clinic were also selected from the clinic who added up on the required information concerning the socialization process of the schizophrenic loved ones with their family. The above mentioned groups of people were helpful in explaining the issue concerning the interaction and relationship between schizophrenic loved ones and care givers or families.

Sampling Technique

Purposive sampling is a non probability sampling technique that was used in this particular study. It is a form of non probability sampling in which decisions concerning the individuals to be included in the sample are taken by the researcher, based up on a variety of criteria which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research (Oliver, 2006) . It is also a deliberate choice of an informant due to the qualities thee informant possess. It is a non random technique that does not need underlying theories or a set number or informants (Tongco, 2007)

Purposive sampling techniques was used to select the samples. Participant of the study were families of people with schizophrenia. Addisu Michael Higher Clinic is a psychiatric clinic that treats patients with different kind of psychological problem. But my research was focused only on schizophrenia. According to the clinic administration, with only 25 beds, inpatients at the clinic were either people with schizophrenia or people with bipolar. Other mental illnesses were dealt at outpatient level. From the 25 inpatients, more than 15 were people living with schizophrenia. Therefore the convenient way to select respondents from the clinic was by choosing the families of the patients with schizophrenia.

Primary data source

Interview

Interviews and focus group discussion are the most common methods of data collection used in qualitative research. Interview can be used to explore the views, experiences, beliefs and motivations of individual participants. Interviews provide deeper understanding of social phenomena that would be obtained from purely qualitative method and it is most appropriate

where little is already known about the study phenomenon or where detailed insights are required from individual participants. It is also particularly appropriate for exploring sensitive topics where participants may not want to talk such issues in a group environment. Therefore, the research used in depth interview with the family members of schizophrenic loved ones, key informant interview with informants who are Doctors and health professional at Addisu Michael Higher Clinic, and focus group discussion with the family.

In depth interview with Caregivers

In depth interview were held with 10 family members or care givers of people living with schizophrenia. The major topics of the interview were about how the caregivers see and understand the disorder, how the family members interact with their schizophrenic loved ones and, what type of support caregivers provide for their schizophrenic loved ones, what kind of coping mechanisms caregivers use in time of stressful situation and the effect of schizophrenia on the day to day life of caregivers.

Interview with health professionals

Addisu Michael Higher Clinic gives service to those who are suffering from different mental disorders. One of the mental illness the clinic provides medical care is schizophrenia. Health professionals can be considered as witnesses that see the interaction between families and people with schizophrenia and understand the situation from their professional knowledge point of view. Therefore three health professionals were interviewed about the interaction between families or care givers and people with schizophrenia.

Secondary Data Source

Secondary Data sources are data collected by someone other than the user. Common sources of secondary data include censuses, organizational records, published and unpublished journals, books and research papers. Secondary data sources save time that would otherwise be spent collecting data and, particularly in the case of qualitative data, provide larger and higher quality databases that would be unfeasible for any individual researcher to collect on their own. Therefore secondary data sources were used on this study.

Scope

In this study, ten caregivers of schizophrenic loved ones who were in patients at Addisu Michael Higher clinic as well as three health professionals who were working at Addisu Michael Higher clinic were interviewed.

Limitation

It was very difficult to infer for the general population due to the small size of the samples. In addition, since the research used purposive sampling, the selection of case was determined by the availability of care givers at the clinic.

Ethical considerations

Respondents on this study got a precise clarification on the overall purpose of the research. They were informed that their names will not be mentioned on the information they provide, they have a right to stop the interviewer at any time if they do not understand the question, if they feel uncomfortable, tired or unwilling to respond. They were clearly told that they have every right to refrain from participating in the research; they will be participating in the research if and only if they are willing.

CHAPTER FOUR

FINDINGS

This chapter recounts the experience of ten care givers of schizophrenic loved ones. The main purpose for this analysis is to describe what caregivers of schizophrenic loved ones experience in their day to day lives while caring for their loved ones living with schizophrenia; to acquire a better understanding how caregivers understand their schizophrenic loved, how caregivers interact and support their schizophrenic loved ones and how caregivers cope up with stressful situations in time of relapse. In addition, this chapter covers the effect of schizophrenia on the day to day lives of care givers.

Socio-Demographic Characteristics of the Participants

In this study ten participants were interviewed. Of which, eight were females and two were males. For the purpose of anonymity and confidentiality, the names of the participants were replaced by different names that do not belong to them. Their age ranged from 28 to 64. Eight of the participants were living in Addis Ababa. One was living in Baherdar and one was residing in USA. Four of the care givers were mothers caring for their children. Two of the care givers were giving care for their husbands. Three of them were caring for their brothers and one was a hired nurse. Six of participants were married and four of them were single. Regarding their religious background seven respondents were Orthodox Christians, two respondents were Protestant and one respondent was Muslim. The educational status of the participants ranged from illiterate to college diploma. When this study was conducted nine of the ten schizophrenic loved ones of the care givers were admitted in Addisu Michael Higher Clinic, one was an outpatient.

In addition to the caregivers three health professionals were interviewed. Their real name is not mentioned for the purpose of anonymity and confidentiality. One participant was

psychiatrist doctor, one was a registered nurse and one was a psychologist. During the research was conducted, all of the health professionals were working at Addisu Michael Higher Clinic.

Table 2: depicts the Demographic and other characteristics of the respondents and their schizophrenic loved ones

Name	Sex	Age	Education	Religion	Relationship with patient	Years of care giving	Substance use	Former Profession of patient	Place
Tsigie	F	46	10^{th}	Orthodox	Wife	5 yrs	Yes	Dentist	AA
Eskindir	M	28	12	Protestant	Brother	10 yrs	No	Priest	AA
Fitsum	M	58	12	Orthodox	Brother	1 yr	Yes	Lawyer	AA
Fikirte	F	27	12	Orthodox	Wife	4 yr	Yes	Medical Doctor	Baherdar
Hiwot	F	43	Commerce	Orthodox	Sister	20yr	Yes	Merchant	USA
Seada	F	60	None	Muslim	mother	3 yr	Yes	Student	AA
Alem	F	65	Commerce	Orthodox	mother	5 yr	Yes	Medical Doctor	AA
Selam	F	28	Nursing	Protestant	Nurse	3yrs	Yes	Student	AA
Almaz	F	66	House wife	Orthodox	mother	16yrs	No	Merchant	AA
Roza	F	64	House wife	Orthodox	mother	7 yrs	Yes	Merchant	AA

The Care givers understanding about Schizophrenia and their Schizophrenic Loved ones.

One of the major questions this study aims was to examine the care givers understanding on the mental illness of their loved ones. After conducting in depth interview with the care givers and health professionals it was clearly seen that care givers were not fully aware of the sickness.

The Lived Experience of Families

None of the care givers knew the name schizophrenia, how it is caused or how is it treated. Even though care givers are aware that their loved ones are struggling with mental illness, they all have uncertainty on the cause or treatment. Caregivers who lived with their schizophrenic loved ones for a longer period of time have relatively better understanding about schizophrenia than the ones with a shorter period of time.

After conducting key informant interview with the health professionals, the research was able to clearly see the understanding level of caregivers about schizophrenia and their schizophrenic loved ones. When one of the health professionals explained about the level of understanding families have about schizophrenia, he said:

> Care givers have limited or no understanding about schizophrenia. They confuse the symptoms for other factors like behavioral problems, anger, disappointment or other spiritual issues. They take many years before they bring their loved ones to hospitals. They spend many years seeking other solution like Holy Water or prayer. They bring their schizophrenic loved ones after the illness exacerbates to the deepest level. After the treatment when schizophrenic loved ones show better results, they will refuse to take the medicine. Caregivers will also decide not to give medications for their loved ones and this create the opportunity of relapse.

In support of his idea, another key informant added by saying,

> Whenever I speak to families and caregivers of schizophrenic loved ones, they would tell me that their loved ones are not really sick. But they act as if they are mentally ill because they are angry of the family or they want to manipulate the family to achieve something. The care givers would tell me the things they

> consider as a family secret and relate the symptoms to that secret. They misunderstand their schizophrenic loved ones.

With this regard the third key informant has pointed out the following:

> I got a chance to talk to many people who are care givers for schizophrenic loved ones. I can tell you, their level of understanding about the illness is very poor. Schizophrenia is a mental illness that is very different than other mental illnesses. People living with schizophrenia are completely delusional. They might also be paranoid over things that are not happening. They listen to voices or see things that do not really exist. They don't like to be criticized, or to be told that they are wrong. But I always witness that caregivers or families misunderstand their loved ones. They sometimes think their loved ones are being difficult and stubborn. They sometimes say they pretend as if they are ill to get attention. The level of understanding of care givers is really important in order to deal with the schizophrenic loved ones in a healthier manner

The above mentioned ideas were gathered from the health professionals working with schizophrenic loved ones and their caregivers. key informant articulated that the level of understanding of caregivers about schizophrenia is very limited.

Cause of Schizophrenia from caregivers point of view

After conducting in depth interview with the caregivers, it was clearly seen that all of the care givers except one had a conviction that the cause of the illness is spiritual. They believed someone like a close friend or family did something bad to their loved one to cause the illness. They also believed substance abuse have contributed for the exacerbation of the sickness. One

care giver connected the cause of the illness with work related stress. Eight of the caregivers have agreed the mental illness have a direct relation with substance abuse.

One of the care givers, who is giving care for her 36 years old son, when explaining about the cause of her son's mental illness, she said:

> I am a hundred percent sure someone who wants to attack me and my husband did this to our child. It could be from my family or my husband's relatives. But there must be an evil hand who went to a *"tenquay bet"* or which crafts to cripple our son and destroy our family

Seada who is also a mother taking care for her 23 years old son has remarked the following in support of the above points by saying,

> I went to the "*Awaqi*" to ask what caused the illness to my 23 years old son. They told me it's his friends who took his books to "*Tenkuay Bet*" and made a spell to make him lose his mind. My son would have been graduating this year. But his friends screwed his life.

In support of the above mentioned ideas, Alem who was caring for her daughter explained by saying:

> My daughter is a 30 years old medical doctor, she was bright and genius. She has a sharp mind. She even went to the US and specialized. She was the one who used to help her friends on their studies. I suspect her best friend has something to do with the cause of her illness. Her friend used to spend nights at our house and borrow my daughter's clothes. I am sure she took my daughter clothes and did something with it to make her lose her mind.

Tsigie who was caring for her husband also has articulated the following to show her position of the problem:

> My husband used to be a nurse and worked very hard to become a dentist. We also have our own clinic. We have two beautiful children. We were happy and fulfilled in life. I am sure his friends got jealous of our success and did something to him to lose his mind.

With a similar view, the other caregiver Hiwot, who was giving care for her 52 years old brother added by saying:

> My brother was a successful business man. He used to help our family since he was the first born. He was the anchor of the house. One night his friends called him out to have dinner. When he got back he complained about a stomach ache. I am sure they put something in his food to make him lose his mind. That day was the last day we saw him normal and healthy."

The only care giver named Fitsum who related his love one's illness with a different view explained his belief by saying:

> My brother was a lawyer. His profession makes him communicate with different people. Sometime he might have problem with people he is working with. If he wins a case the other people who lost the case will be his enemies. So, when he first told us that people are following him to harm him, we all thought it would be people at his work place. We thought he was telling the truth. Most probably, his illness is related to work related stress. He also chews chat, smokes cigarette. This would be adding fuel on the fire

The Lived Experience of Families

The above informants have explained their views about the cause of schizophrenia in different ways. They perceived the cause mainly happened as a result of other people who were going to *tenquay bet* to attack their loved ones or themselves. They also linked the illness with substance abuse. Only one respondent connected the cause with work related stress

Treatment of schizophrenia from caregivers' point of view

All of the care givers agreed the medicine their loved ones take are somehow helpful to calm them down. But none of the caregivers want their schizophrenic loved ones to be dependent on medicine. They all wish their loved ones become totally healed and start a new life without depending on medicine. They believe the medicine only helps to calm down but they don't like the fact that the medicine makes their love ones dizzy and passive. Seven of the care givers hoped their loved one will be healed with the help of holy water, two of them believe their loved one will be free of schizophrenia if they constantly pray, and one caregiver is hoping to get helped by traditional medicine.

During the in depth interview, caregivers where asked what they think of the medicine that their loved one were taking. The respond of caregivers were similar. All of the caregivers were not satisfied with the treatment their loved ones are getting. They all were looking for another solution. They all were searching for a spiritual way outs either with Prayer or holy water.

When caregiver Seada explained about the possible solution for her schizophrenic loved one she said:

> I will do everything to help my son stop the medicine. People told me the "*Awaqi Bet*" or the place where they do Quran for prayer or even traditional

> medicine helps to heal people with mental problems. Even though I am a Muslim, I heard that there is a Holy Water at the Christian Church that might heal my son. I am willing to take him there as long as he gets the healing. I will do everything; I will go anywhere to help my son. I don't want him to depend on the medicine for the rest of his life

In support of her idea, another caregiver Almaz explained:

> When I see my son being very dizzy and weak I always wish he could get free of the medicine. He had been taking his medicine for the last 16years. I hope he will stop it one day. His Doctor told me to admit him in the hospital and add some more medicine to help him. But I am not willing to do that. I can handle the relapse than seeing my son getting weak with the influence of the medicine.

Roza who is taking care of her 37 year old son also believed her son should get spiritual treatment. She showed her stand by saying:

> The medicine does not help him. My son will be healed with the help of Holy water "*Tsebel*", he just needs to believe in it. I am waiting for him until he converts from protestant to orthodox. *Tsebel* can only work when you believe in it. When that day comes that my son believes in *Tsebel*, that the day he will be totally healed.

Another caregiver Eskindir , who was giving care for his brother also shared similar stand with the above mentioned caregivers. He believed prayer was the only solution. He also argued the psychotic medicine was not helping his brother. He showed his stand by saying:

> My brother is an orthodox priest. He lives in the church. I wish he could come to my church for prayer. That is the only solution. I have seen so many people got

> healed at my church. Medicine can only make him slow and passive. I don't believe the medicine helping my brother

Caregiver Fitsume had a different opinion than the above mentioned caregivers. He did not suggest spiritual solutions as a treatment. But he had similar view with the other caregivers regarding the use of antipsychotic medicines. He explained his view by saying :

> My brother is a 35 years old lawyer. He was very smart and helpful young man. I will do everything to help him out of this illness. He has to get back to his normal life. I did not know that he was going to depend on the medicine for the rest of his life. I wish there is a way out. I hope there will be a solution, I don't know what it is but something must be done for him.

The above mentioned caregivers explained that the antipsychotic medicine were not solutions for the mental illness their schizophrenic loved ones are suffering from. They also added that they will be looking for other solutions like prayer or holy water.

Interaction between Caregivers and Schizophrenic loved ones and Support

Eight of the caregivers were living with their schizophrenic loved ones. Two of the caregivers interacted with their schizophrenic loved ones from outside since their loved ones were livng alone. The interaction between caregivers and schizophrenic loved ones was based on the help and support the schizophrenic loved ones need. The nature of the mental illness forced the schizophrenic loved ones to be dependent on their caregivers. Therefore the caregivers were interacting with them to fulfill the demand of their schizophrenic loved ones.

During in depth interview and FGD, caregivers explained that they provide different help and support for their schizophrenic loved ones according to their need. One of the support

caregivers provide for their schizophrenic loved one is financial support. The other support provided by caregivers was Emotional support.

Financial Support

Since none of the schizophrenic loved ones are currently working to support themselves their financial need from their basic necessities like food, shelter, clothing, and medicine to their cravings of substance like cigarette and chat are provided by their care givers. Even though the impact varies from one caregiver to the other, based on their financial strength; seven of the caregivers agree on the financial burden they are carrying because of their schizophrenic loved ones.

When caregiver Fikirte was explaining how she was affected by the financial burden that was caused from the mental illness her husband was suffering from, she said:

> I am giving care for my husband. We live in Baherdar. He was the bread winner. My 4 years old son and I were totally dependent on him. But now everything has changed. He does not work anymore. I am the one who struggles to make money and supports the family. He chews chat, smokes cigarette and drinks alcohol. I have to get him everything he needs at home otherwise he will chock me, insult me and leave the house. Finding him back is not easy, therefore whenever he wants to fulfill his addiction I will ran and get him everything he needs and lock the door.

Caregiver Tsigie, who was also giving care for her husband supported Fikirte's idea by saying:

> I give care for my husband. He was the most loving and caring person. And he was also very hard working and neat. He used to keep himself and our house very clean. But after the illness, he stopped changing his clothes, taking bath or keeping the house clean. I beg him to change his clothe and take a bath. It is my every day struggle. We could not run our clinic since he can't work anymore. I am the only one who works to raise my two children and to support my husband. Life is very tough now. He also chews chat and smokes cigarette, he wants to spend 300 or 400 birr a day for his addiction. This is something that I can't afford. We always fight.

Financial burden was also a complaint of caregiver Almaz. She explained how her son always takes money from her by saying:

> I do everything for my son. He does not eat at home because he thinks we put medicine or poison in his food. He forces me to give him money to eat outside. I am thankful he doesn't have any addiction. He only takes money for food. I know sometimes he gives money for friends or even for strangers but I don't want him to get angry. So I give him what I have. He keeps himself clean but he messes the house. He is 36 years old but acts like a baby. I will help him until my last breath.

Caregiver Fitsum had also explained how his brother is financially dependent on the family. He described the situation by saying:

> My brother lives alone. But I and my sisters provide him with everything he wants. We provide his food, pay his rent, get his food and buy his cigarette and chat. Our mother is very old to help him but still she gives him his medicine and sees him every day.

The above mentioned caregivers clearly explained that their schizophrenic loved ones are totally dependent on their caregivers for their financial needs mainly basic necessities and substance use like chat and cigarette.

Emotional Support

Emotional support is another factor that caregivers articulated to provide for their schizophrenic loved ones. Caregivers explained how the nature of the illness creates frustration and panic on the schizophrenic loved ones. They also described how they support their loved ones when they become emotionally unstable and disturbed. They also added that it was the caregivers' duty to calm them down and give them comfort in time of stress. All of the caregivers state that it is emotionally tiresome to deal with their loved ones in time of relapse. But it is also the only option they have to help them get through the emotional ups and downs by being patient and understanding.

When describing how it is tiresome and stressful to provide emotional support, care giver Almaz said:

> My son always talks about the same story for the past 16 years. It is about the people who do different things behind his back to kill him. I listen to him every day. Once he starts talking about the story, he will take 5 hours to stop. The stories are similar and frustrating. I wish he wouldn't tell me. He talks about things that do not really exist. This is like a torture to me, but I listen to him

In support of the above idea, caregiver Tsigie added by saying said:

> My husband made up a story that does not really exist and talks about it every day. It is about me doing things to hurt him. I tried to tell him that the story is not true. He could not listen to me. So I have to listen to the same story again and

> again. Since the stories are frustrating and horrible at the end of our conversation he always tries to hit me. He always tells me that he will kill me if I don't stop what he thinks I do to hurt him.

Caregiver Alem also supported the above mentioned statements. She explained her experience by saying:

> My daughter locks her door and will not open for days. But we hear her laughing out loud or crying nonstop. That's the time I would be in agony. The pain she is passing through is unbearable to witness. I and her father will cry and beg her to open her door. She will open after days. We broke the door and she can't lock it anymore. I moved in to her bedroom and we are sleeping together now. When she is ill, she curses me, she tells me how she is going to kill me, how much she hates me. I will cry and beg her to calm down.

The above coats reviled that how caregivers provide emotional support for their schizophrenic loved ones.

Medical Support

Caregivers explained how they support their schizophrenic loved ones to take their antipsychotic medicines. They also described that it is their duty to take their loved ones to hospitals for their follow-ups. Caregivers said both of the tasks are difficult and tiresome. The also explained that they use force or get help from police to take their loved ones to hospital.

Caregiver Tsigie when explaining how it was difficult to bring her husband to the hospital for treatment, she said:

> I tricked my husband to get admitted to hospital. He always tells me that I am the one who is mentally ill. He always tells me to go to the hospital. So one day I told

> him that I am really sick and must go to the hospital. We came to Addisu Michael Clinic together and he got admitted.

In support of Tsigies's idea, caregiver Hiwot also explained how she tricked her brother to make him take his antipsychotic medicine. She also explain how she brought him to hospital by saying:

> My brother was never been willing to go to hospital or take his medicine. We used to put medicine inside his food and feed him without his knowledge. But we couldn't continue with his trick, therefore we arranged with the police and they forced him to come to the hospital.

In support of the opinion made by the previous informant, Almaz said:

> My son is the one who goes to hospital to get his monthly injection. Since he is not willing to swallow medicine I found the injection easy and convenient. But sometimes, I know he doesn't go and get it on time. I call and check and the hospital will tell me he didn't take his medicine. I beg him to get injected. When I nag him, he will finally go. But if he does not get the injection, after a few weeks he will get really sick and will start to be out of control. Then I will call police to force him go to hospital.

As it was clearly seen, caregivers used different method to help their schizophrenic loved ones take their antipsychotic medicine or to follow up their hospital checkups.

Coping mechanism of caregivers in time of relapse and stressful situations

When people with schizophrenia are stressed and disturbed they might create a stressful atmosphere for caregivers. They even might be dangerous and harmful to their caregivers. Some of the caregivers handle this kind of situation by leaving their house and hide until their loved ones are calmed down. Others would treat them very nice and soft so that they will get over the disturbance. Some would force them to go to hospital and get injected medicine. But all caregivers find this a very stressful task to handle. They all agree that it is very frustrating and heart breaking to see their loved ones disturbed and suffered from the illness.

Caregiver Alem remembered the stressful nights she spent with her daughter. She explained how her daughter threatened to kill her. This was what she said in her own word:

> One night, when I was sleeping with my daughter she pulled out a knife from under her pillow, she said she was going to stub me. I begged her, I told her how much I love her, I even cried and made her change her mind. I slowly took the knife and hid it. We don't keep knifes in the kitchen anymore. There was also another incident, my daughter holds a cord of her laptop and threatens me that she was going to strangle me, I begged her not to kill me.

In support of the previous opinion caregiver Tsigie added:

> My husband always threatens that he will kill me. He sometimes gets violent and tries to hit me. That is when I always ran away and hide inside neighbors' house. I will wait until he calms down. Sometimes it takes four days till he gets over his anger.

Caregiver Fikirte had also similar opinion with the above respondents. She said:

> My husband bits me and chokes me whenever he is angry. Specially whenever he wants to get chat or cigarette. I have learned how to handle him. Before he gets to that anger I get everything he wants and calm him down.

Caregiver Roza had a different experience from the above mentioned statements. Her son didn't threaten to kill. Instead, threatened to kill himself. When she explained her situation, she said:

> My son always threatens me that he will commit suicide. Whenever he gets angry that's what he says. He tells me that he will hang himself and punish me. I will kneel down and cry under his feet and beg him not to kill himself. That's the only way I can make him calm down. Until he sees me under his feet crying, he will not get over his anger.

Caregiver Seada had also a different opinion than the above mentioned experiences. Her 23 years old son never threatened to kill his family or himself. But he tried to burn their house assuming he would kill those whom he considered his enemies. This was what she said about the situation:

> My son tried to burn our house not once but three times. He snicked to the backyard while everyone was sleeping and sat a fire. Other family members in the house smelled smoke and extinguish it. We are always anxious and alert. We beg him not to do this. He thinks people who want to hurt him got in to the house, and burning them is the only solution.

The Effect of Schizophrenia on Caregivers day to day life

Giving care for schizophrenic loved ones is a very tough job. When a loved one is diagnosed with schizophrenia the whole family living with him or her will be affected. All of the

care givers agree that their life is completely changed after their loved ones started living with schizophrenia. They stated that peace and happiness are no more in existence in their house. They also argued that interaction with other family members in the house was not smooth and healthy. Their social life with their extended family and community was affected. Their health and finance is also affected because of schizophrenia.

Caregiver Alem in explaining how her social life, marriage and health is highly affected because of the day to day stress she experienced, she said:

> I have no social life anymore. I don't go to Weddings or funerals. I don't have my Maheber" or family meetings. I always watch my daughter at home. I go to church whenever she feels better. I pray day and night. I beg St. Mary to heal my daughter. I don't communicate with my children anymore. I am always fighting with my husband. Especially concerning the help we provide for our daughter, he always does things opposite to mine. We don't agree on the medicine she takes, we don't agree on the handlings whenever she relapses. When I beg her to calm down he yells at her and threatens her that he will force her to get admitted to the hospital. Our marriage doesn't exist anymore. Even at my work place, my friends think I have a daughter who is a medical doctor, who is beautiful and successful, no one knows what I am struggling with. I couldn't function at my work place anymore. So I quit my job and I stay at home with her now. My health is affected. Both me and my husband developed high blood pressure and became diabetics.

Care giver Tsigie also had similar view with Alem. She argued that her social life was highly affected after her husband started living with schizophrenia. She also explained how she became impatient and quick to anger. She pointed out her experience by saying:

> I was a very happy and active woman. I have known my husband for the past 26 years. We are married for 16 years now. He was the most loving and caring person. But after the sickness, he considers me as his worst enemy. He insults me and threatens me; he shows hatred instead of love. I feel like I lost that loving husband of mine. I don't communicate with friends or family anymore. If I have to go out, it will be to church for prayer. I only tell God what I have inside my heart. I don't want people to know that he has the sickness; I lie to friends that he is not in town. I tell them he is outside the city for work. I feel embarrassed because my husband is mentally ill. I am lonely and sad. I am so quick to anger and have no patience anymore.

Caregiver Almaz also supported the above mentioned experience as she had had similar experience. This was what she said in explaining her experience,

> We did everything we could to hide our son's problem from the community and from extended family. I personally feel very bad and guilty for my son's illness. I don't know what we have done to receive this. I am unhappy and life has changed a lot. My son has lived with the illness for the past 16 years. The first 10 years was different. My son used to take his medicine properly. He gained a lot of weight, he was dizzy and passive. He was not keeping himself clean. He used to sleep for longer period of time. Watching him like that was really painful. And the last six years, after we lost his father he quit his medicine for six months. His

> sickness exacerbates and he became out of control. He was admitted to Addisu Michael Psychiatric hospital and was treated for a month. After that he couldn't get back to his former self. He became aggressive, he lost his weight and he is no more dizzy and weak. All the extended family and neighbors knew he had mental illness. I couldn't keep it as a secret anymore. The guilt and embarrassment is unbearable. I got disconnected from my social ties. I don't visit friends and family any more. And when family or friends come to visit and if my son is disturbed, he will scream at me in front of them and I will be embarrassed. Since my son fights with his sisters and with other family members, the interaction I have with the rest of the family is not smooth. My daughters complain on my way of handling my son. They say I spoil him, they think I should force him to get admitted to hospital to get him a proper treatment. I prefer to keep him like this with his aggressiveness and anger than seeing him dizzy and weak after his treatment. I am suffering to choose between my daughters and my son.

Caregiver Hiwot remembered how her late mother suffered while giving care for hiwot's brother. She agreed with other caregivers on the difficulty and stressful events that were caused by the day to day experience with schizophrenic loved ones. She described her mother's experience by saying,

> My brother has suffered with the illness for the last twenty years. My mother had been taking care of him for twelve years. I can't forget how she suffered to take care of him. She was desperately seeking a solution for his sickness, she cried the whole time, she was hurt, she was sick. And eight years ago, she died of a broken heart. My brother couldn't still believe she is not alive.

In support of the previous opinion Caregiver Roza also said :

> We don't sleep at night. My son always listens to music very loud and turns on the TV at the same time. He thinks people in the TV communicate with him. Since he sleeps the whole day, he will be active during the night. His younger siblings spend the day working and we all need to sleep at night. But we can't.

The above mentioned caregivers clearly explained how it was difficult to lead a normal and stress free life while having a schizophrenic loved one in their lives. They pointed out how their social tie was broken, how their interaction with other family members is not smooth, how their sleeping habit and their health is affected.

Chapter Five

Discussion

The caregivers understanding of Schizophrenia

The caregivers understanding about the illness is very limited. As the health professionals described it, most of the care givers do not really understand about the illness. Caregivers who have participated on the in depth interview have reviled that they never heard the name schizophrenia. They also have different opinion about the cause and the treatment. The level of understanding that caregivers have determines the care and support they provide for their schizophrenic loved ones. The more caregivers understand about schizophrenia, the better support they will provide for their schizophrenic loved ones.

During in depth interview, caregivers who cared for loved ones for longer period of time showed better understanding than the caregivers who cared for shorter period of time. The caregivers who cared for shorter period of time were full of questions and misunderstanding, the caregivers who cared for longer period of time were explaining on issues related to care giving of schizophrenic loved ones.

In addition, it was clearly seen that the people who lived with schizophrenia for longer period of time were relatively easier to be communicated with than the ones who just started the walk. Those people who lived with schizophrenia for a longer period of time showed better communication and interaction with their caregivers than the ones who are new for schizophrenia.

The cause of schizophrenia from Caregivers Point of view

Caregivers who participated on this study have similar opinion on the cause of schizophrenia. They believe the mental illness is caused either by evil spirit or by substance

abuse. Nine respondents out of ten said they are sure that their loved ones got the illness from other people's evil deeds. Similar view was concluded by one study as evil spirit possession to be the commonly held perception of the community to interpret mental illness, which is a result of deeply rooted traditional belief, cultural and religious views (Atalay Alem, 1997, p. 4; Teshome Shibre, 2002, p. 3). Eight of the respondents also added that their loved ones are addicted to substance use like chat, cigarette and alcohol drinks. Bimerew (2007) wrote about substance abuse and the risk of readmission of people with schizophrenia at Amanuel Hospital in Addis Ababa, Ethiopia. The study suggested that alcohol and khat abuse were contributing factors for the rate of readmission of people with schizophrenia in the mentioned hospital. It is true that 90% of people living with schizophrenia are addicted to different substance like chat and cigarette, but substance abuse is not the main reason for the cause of schizophrenia.

The cause of schizophrenia is not clearly known, but a combination of genetic, neurobiological, and environmental factors can be considered as possible causes. A leading neurobiological hypothesis looks at the connection between the disease and excessive levels of dopamine, a chemical that transmits signals in the brain (neurotransmitter). The genetic factor in schizophrenia has been underscored by recent findings that first-degree biological relatives of schizophrenics are ten times as likely to develop the disorder as are members of the general population. Another hypothesis suggests that schizophrenia may be caused by a virus that attacks the hippocampus, a part of the brain that processes sense perceptions.

Even though the cause of schizophrenia is not clearly known, the participants on this study believed that people who want to hurt them did something evil and caused the illness. This belief is not backed up with any scientific evidence. The caregivers themselves do not have evidence to come with this conclusion. They decided to conclude this way because they could

not understand what happened to their schizophrenic loved ones. Therefore there is a visible gap between the caregivers understanding about the cause of schizophrenia and the possible cause of schizophrenia suggested by experts.

Treatment of schizophrenia from Caregivers' point of view

The care givers agree that their schizophrenic loved ones should take their medicine to be calmed down. But they believe spiritual help like prayer or traditional medicine would be the right medicine for such kind of illness. They also do not want their loved ones to stick to their medicine for a longer period of time. But in reality, people living with schizophrenia must take and stick their medicine in order to lead a healthy life and avoid relapse.

The primary form of treatment of schizophrenia is antipsychotic medication. Antipsychotic drugs help to control almost all the positive symptoms of the disorder. They have minimal effects on disorganized behavior and negative symptoms. Between 60-70% of schizophrenics will respond to antipsychotics. In the acute phase of the illness, patients are usually given medications by mouth or by intramuscular injection. After the patient has been stabilized, the antipsychotic drug may be given in a long-acting form called a depot dose. Once their acute symptoms have been brought under control by antipsychotic medication, schizophrenic loved once can benefit out of psychotherapy.

Family therapy is also helpful for caregivers of schizophrenic loved ones. Caregivers on this study were aware of the benefit of antipsychotic drugs. But they all wished their loved ones could feel better without the drug. One caregiver said her son has stopped the medication for two months and she is hoping he might get better. She said she will not force him to start taking the medication until he becomes out of control. This shows that caregivers are not fully aware of the

treatment. Regarding psychotherapy and family therapy, caregivers on this study said neither their schizophrenic loved ones got psychotherapy nor they were given family therapy.

People living with schizophrenia can take time with their psychiatrists if they need counseling. But caregivers on this study said their loved ones never got psychotherapy. It is true that there is a family education that caregivers attend every Saturday at Addisu Michael Higher Clinic. That's the place where caregivers get educated about mental illness and where they can share their experience with one another. This would help caregivers to understand their loved ones' struggle with their illness. But care givers on this study never used family therapy to treat their loved ones with schizophrenia.

Interaction between Caregivers and Schizophrenic loved ones and Support

The interaction between caregivers and schizophrenic loved ones revolves around providing help and support for the people with schizophrenia. Caregivers provide everything for their schizophrenic loved ones. The life of the schizophrenic loved ones is totally dependent on their caregivers. From the food and shelter to the medicine and additional substance like chat, cigarette and alcohol drinks, the need of the schizophrenic loved ones is fulfilled by their caregivers.

Studies also showed that many people with schizophrenia have difficulty holding a job, or caring for themselves, so they rely on others for help (NIH, 2014). Caregivers also help their schizophrenic loved ones on their hygiene. Since most of schizophrenic loved ones do not take care of themselves and do not keep their surrounding clean, it is the duty of their care givers to keep their loved ones and their surrounding clean.

In addition to these, caregivers are the only ones who follow up with hospital checkups and medicines. And during the time of relapse, it is their responsibility to take their loved ones to

hospital. Listening to the stories that schizophrenic loved ones everyday like to talk is emotionally draining and tiresome, but caregivers are the ones who help their loved ones to vent. This is also true and confirmed with other researches as well. Families are the primary care givers for schizophrenic loved ones Families and society are affected by schizophrenia (Cohen, 2003).

Coping mechanism of Caregivers in time of relapse

Coping mechanism is defined as any effort directed to stress management including task oriented and ego defense mechanisms, the factors that enable an individual to regain emotional equilibrium after a stressful experience. It may be unconscious process(Medical Dictionary, 2015). During the time of relapse, caregivers calm down their schizophrenic loved ones by begging and pampering. One participant on this study claimed that, being a 64 years old mother, she kneels down under the feet of her 36 years old son and cries when he threatens her that he would kill himself. According to one study about coping mechanism, this way of coping mechanism is called problem focused coping strategy (Sincero, 2012). The strategy this mother used was focusing on her schizophrenic loved one's problem and tried to solve it according to his behavior.

One caregiver claimed that she would leave the house until her schizophrenic loved one gets back to his senses. According to Sarah Sincero (2012), this way of coping mechanism is called defense and avoidance. Most of the care givers used problem focused and emotion focused strategies to help their loved ones calm down. They also use adaptive and behavioral methods to cope with the stress caused by relapse. The participants on this study also reviled that they use prayer as a coping mechanism. When using prayer as coping mechanism it is called

emotion focused strategy. Eight of the ten participants claimed that they frequently go to church for prayer.

The effect of schizophrenia on caregivers' day to day life

All participants have said their social life is not the same anymore. They don't interact with extended families or society as they used to in the past. On one study it was concluded that families may become socially isolated. They may also feel embarrassed about their loved ones unpredictable and bizarre behavior. The stigma associated with mental illness is also another factor they will have to encounter with (Veague, 2007). Care givers on this study claimed that their interaction with other family members is also highly affected.

The family members disagree over the handling of their schizophrenic loved ones. They also have disagreement on medications and treatment. . (Compare Fadden, *et al.* 1987) Economical burden is also another factor that caregivers are suffering from (Lefley & lohnson, 1990) Since schizophrenic loved ones are not currently working, all the financial responsibility lies up on the shoulder of caregivers (Schene, 1990). In one study, it was clearly stated that, the most severe problems occur when the patient was formerly the breadwinner, particularly if circumstances prevent another relative from taking over this role,and Some of the care givers claimed that their life was totally depended on the income their schizophrenic loved ones used to bring. Some studies also include financial costs and assessment of family members' physical and mental health (Roberts, 1988:375; Falloon, *et al.* 1984). Relatives of patients suffering from schizophrenia commonly report financial and employment difficulties, difficulties in leisure activities and relationship problems within the family (Lefley & lohnson 1990:271)Because schizophrenia typically occurs in early adulthood and is likely to affect long term earning and development capacity, higher levels of burden occur if the patient has formerly been working in

families where earning capacity and commitment have not yet been established. The loss of potential earnings is easy to underestimate, but at the very least the family's lifestyle is likely to be more impoverished than before (Kuipers, 1993:207). In addition, the schizophrenic loved demand chat or cigarette on a daily basis. Fulfilling their need costs money that created financial burden on care givers who participate on the study. The emotional burden is also what caregivers claimed to have on their everyday life. Since schizophrenic loved ones are most of the time delusional, dealing with them puts caregivers on emotional burnout. The caregivers said they are impatient and easily disappointed on things that are considered minor. They also claimed to be unhappy and lonely.

Different studies also showed this to be true. One study showed that family members experience, for example, feelings of loss, depression, anxiety and embarrassment in social situations (Magliano, Fadden, Madianos, Caldas de Almeida, Held, Guarneri, Marasco, Tosini & Maj, 1998:412; Gillis, *et al.* 1989:375). The patient's caregiver or the relatives may experience feelings of guilt, worry, depression, anxiety and fear because of the patient's behavior which perhaps stem from their lack of insight into how to supervise such a patient

Chapter six

Conclusion and Recommendation

This paper was able to answer questions that describe and characterize the lived experience of families living with schizophrenic loved ones. The study also highlighted on the understanding level of caregivers about schizophrenia and their schizophrenic loved ones, as well as the cause and treatment of schizophrenia. The study also covered the interaction between caregivers and schizophrenic loved ones, the support caregivers provide for their schizophrenic loved ones and the effect of schizophrenia on caregivers day to day lives

Findings from the current study revealed that the level of understanding of caregivers about schizophrenia is very limited. The caregivers don't really know the cause and the proper treatment of schizophrenia. This affects the healthier and better way of living on both the caregivers and schizophrenic loved ones. This implies that awareness about schizophrenia and it's cause and treatment of mental illness has an impact on the healthier communication and interaction between caregivers and schizophrenic loved ones. Therefore basic information and education about the nature of the illness, course and outcome of treatments are needed for the caregivers and family and the general society.

This study has recognized the importance of caregivers' understanding about the cause and treatment of schizophrenia. Caregivers on this study have similar opinion about the cause of schizophrenia. Caregivers claimed that the illness is caused by evil spirits. This affects their perception about the use of treatment. The proper treatment of schizophrenia is antipsychotic drugs with psychotherapy and family therapy. But caregivers on this study were looking for other treatments like prayer and holy water than letting their schizophrenic loved ones use the antipsychotic drugs. Therefore, sticking to antipsychotic drugs should be encouraged.

Psychotherapy should also be in use. Family therapy should also be available for caregivers. In addition, proper education should be given to caregivers regarding the possible cause and treatment of schizophrenia.

This study has concluded on the importance of caregivers and family supports on the healthier life of people living with schizophrenia. The interaction between caregivers and schizophrenic loved ones bases on the support caregivers provide to their schizophrenic loved ones. The caregivers on this specific study are helpful and supportive. The day to day lives of schizophrenic loved ones depended on the support and care of the caregivers. Therefore, a better understanding of how and why caregivers' supports influence the healthier and better living standard of schizophrenic loved ones is encouraged and needed.

The effect of schizophrenia on care givers has clearly showed that the caregivers are carrying a huge burden because of the illness. Caregivers on this study showed they have suffered from subjective and objective burdens. Economical and emotional burdens were reported by the caregivers on this study. The caregivers' burn out affects both schizophrenic loved ones and the caregivers as well. Caregivers reported to experience health problems on top of the economical and emotional burdens. In order for caregivers to provide support for their schizophrenic loved ones, caregivers should keep themselves healthy and strong. Caregivers should encourage their loved ones to stick to their antipsychotic drugs. There should also be psychotherapy available for people with schizophrenia. This will help schizophrenic loved ones not to relapse. This will help schizophrenic loved ones to stay in a healthier state. There should also be family therapy for caregivers to decrease the stress. Caregivers should be aware of the consequence on their lives and protect themselves and their schizophrenic loved ones.

Social Work Implications

Social work is all about empowering people. It is a profession that works towards the better life of vulnerable groups of people. As it is indicated in this study caregivers of people with schizophrenia are in a great deal of burden and stress because of the nature of the illness. The limited understanding of caregivers about schizophrenia, the unavailability of psychotherapy and family therapy made it very difficult for caregivers to lead a healthier and better way of living.

As the study indicated the challenges participants encountered are multi dimensional and interrelated. As a result holistic interventions are needed at different levels such as individual, family, society and organizational levels. Providing direct social services to patients and their caregivers is one of the major roles that social workers play. These include psychosocial interventions which comprise individual, family and group interventions that are used to achieve specific therapeutic outcomes based on the clients need. This could include psychotherapy and family therapy.

Social workers should work on creating awareness about schizophrenia at a family and community level. Social workers should also strengthen the interaction and relationship between caregivers and their schizophrenic loved ones during their hospital stay and when they get out from the hospital so that caregivers and schizophrenic loved ones could achieve a healthier interaction and communication. Assisting caregivers and their schizophrenic loved ones to use maximum benefit from the health facilities and community-based social and health resources by advocating for access and fare distribution of resources in the long term care of patients are also enhance the healthier and smoother interaction between caregivers and schizophrenic loved ones.

The Lived Experience of Families

As it is described in the study the day to day life of schizophrenic loved ones is completely dependent on the care and support of care givers. Therefore, family level interventions are needed. These are; organizing family sessions to create awareness about the nature of mental illness, the cause and treatment, provision of safe care to their ill family member and enhance family members' participation on the care giving processes also very helpful in the.

Advocating for treatment centers expansion, the establishment of rehabilitation and vocational centers for people with schizophrenia can help improve their mental health services use participation. Moreover social workers with their skills of social work research should conduct various studies for the development of healthier communication between people with schizophrenia and their caregivers.

Reference

Abebaw Fekadu, Menilik Desta, Atalay Alem, Martin Prince, 2007. A descriptive Analysis of Admissions to Amanuel Psychiartic Hospital in Ethiopia, *Addis Ababa University*

Angelo Barbato, 1998. Schizophrenia and Public Health. *World Health Organization, Geneva*

Amare Deribew, Yonas Shiferaw Tamirat, 2005. How are Mental Health perceived by a community in Agaro Town? *Ethiopia Journal Health Development*

Christina M Hultman, Ing Marre Wieselgren & Arne Ohman, 1997. Relationships Between Social Coping and Life Events in the Relapse of Schizophrenic patients, *Scandinavian Journal of Psychology*

Carl I. Cohen, 2003. Schizophrenia in to Later life, *American Psychiatric Publishing Inc*

D. Kebede, A. ALem, T, Shibrie, A. Negash, A. Fekadu, D. Fekadu, N. Deyassa, L.Jacobosson, G.Kullgren, 2003. Onset and clinical course of schizophrenia in Butajirra Ethiopia. Addis Ababa University.

Heather Barnett Veague, 2007. Schizophrenia, Psychological Disorder. *Infobase Publishing.*

Jeffery A Lieberman, T. Scott Stroup, Diana o. Petins, 2006. Text Book of Schizophrenia, *The American Psychiatric Publishing.*

Jerome Levine & Irene S Leven, 2009. Schizophrenia for Dummies, *The American Psychiatric Publishing*

Leyouget Abebe Taye, 2011. Mental Health Services Use Experience of people with Schizophrenia. *Addis Ababa University.*

Michael G.M Donells, Robert A, Short Christopher, M Berry, Dennis G . Dyck, 2003. Burden in Schizophrenia Caregivers

Michelle D Sherman, 2007. Support and Family Education, *Mental Health Facts For Families*

Ms Bimerew M, 2007. Substance Abuse and the Risk of Readmission of People with Schizophrenia at Amanuel Psyciatric Hospital, *Ethiopia. University of the Western Cape*

Pharaoah F , Mari J J, Rathbone J, Wong W, 20012. Family Intervention for Schizophrenia, *The Cochrane Collaboration, John Wiley @ Sons Ltd*

Pamela Grandone, Cristina Janero, Serafin Lemos, 2007. Primary Care givers of Schizophrenia out patients, *The Psychiatry &Mental Health Unit, Spain.*

T Shibrie, D Kebede, A ALem,, A Negash, N Deyassa, A Fekadu, l JAcobsson, G Hullgren, 2003. Schizophrenia: Illness Impact on Family Members in Traditional Society- rural Ethiopia, *Addis Ababa University*

T Shibrie, A Negash, G. Kullgren, D Kebede, A Alem, A Fekadu, G medhin , L Jacobsson, 2001. Perception of Stigma Among Family Members of Individuals with Schizophrenia and Major Addictive Disorders in Rural Ethiopia, *Addis Ababa University*

APPENDIX A: Interview Guides

For Care givers

Thank you for being volunteer to participate in this study. I would like to start by letting you tell me a about yourself such as your age, where and with whom you live, your educational marital and occupational status, your relationship with your schizophrenic loved one Years since his or her mental health problem start, years of mental health services use and number of hospital admissions.

Tell me about your schizophrenic loved one?

How do you interact with him?

How much do you understand about schizophrenia?

What type of support do you provide to your schizophrenic loved one?

How do you cope with the stress?

Interview Guides for health professionals

How do families interact with their schizophrenic loved ones?

How do you see the understanding level families have concerning schizophrenia?

How should families treat their schizophrenic loved ones?

APPENDIX B: INFORMED CONSENT

My name is Salem Ayele, a Masters student at school of social work, Addis Ababa University. I am doing a research to fulfill my study of social work on The Impact of Family Relationship on the Exacerbation of Schizophrenia. I would like to ask for your permission to participate voluntarily in this study. I am interested in learning how the relationship between people with schizophrenia and their caregivers impacts on the exacerbation of schizophrenia. Your participation in this study will help me to know the effort you made to obtain a healthy and smooth communication in the family, the coping mechanisms you use to handle stressful situations resulted from the exacerbation of schizophrenia.

I will do one to one interview. During this process, I would like to assure you that your identity will not be disclosed to anyone. This is to protect your privacy and confidentiality of the information you provide. I will use tape recorders to correctly record the conversations we did, and the recordings will be locked in a safe place and will not be exposed to anyone. The notes and tapes will be destroyed after the study is completed and approved by the School of Social Work. By participating in this study, you will contribute to the success of my studies. You will also contributing to the advancement in the field of mental health as there are very few researches done in this area and the study results of this research will make some enhancements in understanding the impact of family relationship on the exacerbation of schizophrenia. Apart from the time you spend with me, I do not see any risk that you will under go by participating in this study. Participating in this study will only depend on your decision. You are free to answer questions only if you want to do so. You may not answer questions if you feel uncomfortable. You can ask questions at any time during the interview and in case you do not understand the questions or in case you feel tired and you want to continue later, that will be

your choice. You have all the right to ask and get clarification at any time. Finally I would like you to confirm your agreement by signing.

Participant Signature _____ Date _____