

The Experience of Family Members Caring for a Relative Diagnosed with Schizophrenia:

The Case of Amanuel Hospital

Gemachu Fufa

College of Social Science

School of Social Work

Addis Ababa University

The Experience of Family Members Caring for a Relative Diagnosed with Schizophrenia:

The Case of Amanuel Specialized Psychiatric Hospital

By

Gemachu Fufa Mamade

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Advisor: Professor Margaret E. Adamek

College of Social Sciences

School of Social Work

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Approval of Board of Examiners

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### Abstract

This study examined the experiences of family members caring for a relative diagnosed with schizophrenia in Ethiopia. Previous studies indicated that family members providing care for their loved one with schizophrenia experienced many challenges in the course of care-giving. Though family members experience both enrichments and challenges in caring for their loved one with mental illness little attention is paid to the comprehensive experiences of family members. This study addressed the aforementioned issue and contributed to limited studies on psychiatric conditions in Ethiopia where there are limited services, community service organizations, or legal frame-works on mental illness. The study used a qualitative case study approach. In-depth interviews were conducted with eight purposely selected participants. Content analysis was used to analyze the data and identify themes. The study indicated a variety of impacts of caregiving such as psycho-social and economic as well as enrichments such as progress on the illness, teaching their experiences, deriving hope from the situation, and satisfaction from sharing experiences with others. The study also indicated that encouraging independence, fulfilling needs, ignorance for a while (no response on the situation immediately), communication and discussion with family as major ways of managing the caregiving responsibility. Understanding caregivers' experiences may be useful in prompting governments and service providers to invest in education and support programs aimed at helping caregivers to cope with this stress and deal with the problem behaviours associated with the illness.

*Key words:* schizophrenia – Ethiopia – caregiving– coping

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### ACKNOWLEDGEMENT

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The Experience of Family Members Caring for a Relative Diagnosed with  
Schizophrenia: The Case of Amanuel Specialized Psychiatric Hospital

**CHAPTER ONE: INTRODUCTION**

“An estimated 50 to 80% of persons with schizophrenia and related psychotic disorders live with or have regular contact with a family caregiver” (Gibbons, Horn, Powell, & Gibbons, 1984; Lehman & Steinwaches, 1998a cited by Mcdonell et al., 2003, p.91). In Ethiopia more than a million people are estimated to suffer from the two most common types of mental illness schizophrenia followed by affective disorders (Fekadu, Alem, Desta, & Martin, 2007). A joint report of World Health Organization and Ministry of Health (WHO and MoH), (2006) indicated that, in Ethiopia 35% of outpatient, 55% of inpatients and a total of 60% in the mental health hospital are patients with schizophrenia. In Ethiopia, as in most developing countries, services which could help people who suffer from mental disorders are insufficient; thus, families are the sole caregivers to their severely mentally ill relatives.

Mental illness is a diseased condition, which is deemed undesirable for both the affected individual and the society because it adversely affects the normal functioning of the mental, psychological and emotional make-up of the individual and so it blurs the capacity for insight, orientation, judgment, thought, mood and perception (WHO 2001; WPA 2002). Schizophrenia is the most debilitating mental illness. Worldwide, about 25 million people suffering from schizophrenia. Of these 24.4million (97.6%) cases of schizophrenia are in less developed countries.

Community surveys in Ethiopia have consistently shown that severe mental illness, for example resulting from schizophrenia or bipolar disorder is recognized as an illness that needs intervention. However, in Ethiopia severe mental illness is more often attributed to supernatural causes, for example spirit possession, bewitchment or evil eye, rather than as a

result of biomedical or psychosocial causes. As a consequence, affected individuals and/or their families often seek help from religious and traditional healers rather than health facilities (Federal Democratic Republic of Ethiopia Ministry Of Health n.d).

With regard to mental health facilities there is one dedicated psychiatric hospital namely Amanuel Specialized Psychiatric Hospital, the only hospital in the country located at the capital city of Addis Ababa with 268 beds that is 0.35 beds per 100,000 populations. Reports also show that there is only 0.02 psychiatrists, 0.3 psychiatrist nurses and 0.4 psychosocial staff per 100 000 population in Ethiopia (WHO & MoH, 2006). In terms of staffing in mental health facilities, there are 0.03 psychiatrists per bed in community-based psychiatric inpatient units and in the mental hospital. There are 0.4 nurses per bed in community-based psychiatric inpatient units in comparison to 0.2 nurses per bed in the mental hospital. The combined professional per bed rate for psychologists and social workers in the mental hospital is 0.01 (FDREMoH, n.d. p.17). Due to this, the experiences from family of persons with mental illness are greater.

The Federal Democratic Republic of Ethiopia Ministry Of Health n.d) (FDREMoH) in national mental health strategy depicted that mental illness in Ethiopia, is the leading non-communicable disorder in terms of burden on the family and community at large. The strategy also shown as in a predominantly rural area of Ethiopia, mental illness comprised 11% of the total burden of disease, with schizophrenia and depression included in the top ten most burdensome conditions, out-ranking HIV/AIDS. Mental illnesses are common in Ethiopia, and they are associated with a high burden due to disability and mortality, the illness constitute important but largely unrecognized and, despite the existence of affordable and effective treatments, less than one in 10 of the most severely affected people ever receive the treatment they need (FDREMoH n.d).

Families are now the lifeline for many people who experience mental illness. Studies show that as many as 75% of individuals discharged from psychiatric hospitals after an episode of illness return home to live with their families (Lefley, 2000 cited in cited in Shankar & Sonai 2007, p.1). In Ethiopia, the lack of mental health services or any kinds of financial support for families with a mentally ill member are the biggest factors contributing to caregiver burden. Due to this help-seeking is most often limited to the family or local community (FDREMoH n.d).

According to Tilbury, (2002, p.113) experiences of care givers and the meaning of caregiving vary across time or in stages. During the early stages, families are likely to be bewildered by the sufferers' symptoms and they are going through processes and experiences that are quite new to them, especially if a hospital admission is involved: with legalities and dealings with complex institutions with a wide range of different staff. According to Platt, (1985, as cited in Mendenhall & Mount, 2011, p. 183), the difficulty associated with caring for a loved one has been referred to as caregiver strain. This strain is described as the "presence of problem, difficulties or adverse events which affect the lives of psychiatric patients and their parents" (Platt, 1985, cited by Mendenhall & Mount, 2011, p. 183). However, the anxiety that comes from dealing with a serious illness, combined with the burden of care giving, can create strain in the relationship and stress for caregivers. At some points they may feel overwhelmed, guilty, resentful, angry, anxious, and even depressed.

Despite the challenges, some caregivers report positive aspects of caring for their loved ones. The positive aspects are referred to as caregiver enrichment, which may enhance the quality of experiences in a family's daily life. This enrichment aspect has received very little research focus (Yatchmenoff, et al, 1998 cited in Mendenhall & Mount, 2011, p. 183).

### **Problem Statement**

Due to the increasing stress experienced by caregivers, the experiences of family members of patients with mental illness warrant study. Understanding caregivers' experiences may be useful in prompting governments and service providers to invest in education and support programs aimed at helping caregivers to cope with this stress and deal with the problem behaviours associated with the illness.

There have been limited studies on the prevalence of psychiatric conditions in Ethiopia though currently it seems to be persistently increasing. The issue of mental illness in Ethiopia has been given less attention which is related to different factors. The main factors are lack of awareness within the community, considering behavioural problems as naughty or deviant, absence of appropriate policies and lack of attention from policy makers and poor formal support systems. This and other related factors make family members especially parents or guardians more vulnerable to various experiences of care-giving (Alem, 2001). While understanding the magnitude of the family burden and coping strategies is important to plan family intervention programmes, very little is known about the extent of the relatives' care-giving-related distress and other experiences in Ethiopia (Shibre et al. 2001).

A data from (FDREMoH n.d, p.11) in national mental health strategy indicated that, the patients admitted to the hospital were given primarily the following diagnoses: schizophrenia (60%) and mood disorders (25%). The source also depicted average number of days spent in the mental hospital is 63:92% spend less than one year in the hospital; 5% of patients spend 1-4 years; 0.21% spend 5-10 years; and 0.42% of patients spend more than 10 years in the mental hospital. Eighty-one percent of beds in the community based psychiatric inpatient units and all mental hospital beds in the country are located in or near the largest city (Alem et al, 1995). However, in the subsequent years, the country has shown some

progress and there is a positive improvement in the availability of mental health services (Mesfin et al, 2009, p. 61).

Brown's (2002, p.917) research in the United States depicted a variety of experiences, both positive and negative, in caring for patients with serious mental illness. Positive experiences were characterized by a collaborative approach that included good communication, access to and availability of psychiatric care, backup, and timely feed-back. Additionally, this positive experience linked with the stage/situation at which care givers find positive things about care giving, about the person and about themselves. Though, a few studies have indicated such angles in western countries, in Ethiopian enrichments and impacts of family caregivers of persons with schizophrenia have not received such research attention.

Although the important role the family plays in supporting a mentally ill member in the community is now emerging as a significant factor in mental health care, research has traditionally focused on the burden placed on the family. Little attention is paid to the comprehensive experiences from both enrichment and negative impacts of these phenomena on family members.

Despite the various experiences associated with family care-giving for their mentally ill loved one, family experiences remain largely unexplored in Ethiopia. Similarly, in Ethiopia where there are limited health care services, the absence of social service organizations and community-based support systems and legislations, the issue of care provision for family member(s) with mental illness entirely lies on the shoulders of the family.

In fact, limited studies are helpful to show the experiences of patients with mental illness, but it is believed that they do not provide understanding of the experience of family members caring for their mentally ill loved one. Two studies by Shibrei et al., (2001& 2003)

have examined the social challenges and influence of traditional culture and spirituality for family members coping with caring for persons with schizophrenia individuals in Butajira district. Another study by (Eyerusalem Azmeraw, 2010<sup>2</sup>) was entirely delimited to the experience and challenges of being parent of child with schizophrenia. However, being family of patients with mental illness and the experience of care giving for such individuals are different issues.

Above all, although families' experiences of care giving can have both positive and negative aspects no single study conducted in Ethiopia considered the issue from both sides. As a result, the fundamental nature, feelings and meanings attached to social relationships and general or comprehensive experience of this issue has been left untouched. This problem was seen as a gap in the existing literature on experiences of family members caring for their relatives diagnosed with mental illness in Ethiopia.

This gap in our understanding of the care-giving experiences of family members of persons with schizophrenia in Ethiopia is the primary rationale for conducting this qualitative study. Consequently, this study emphasized how family members manage their care giving experiences, the contexts and influences or impacts on their life, and the meaning of care-giving for their loved one with schizophrenia. Generally, the study focused on the care-giving experience, understandings and feelings of family members on the issue in Ethiopia.

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<sup>2</sup>In accordance with Ethiopian custom, the first name or given name is substituted for the surname and the father's name and grandfather's name is spelled out in full. Thus, Ethiopian names are spelled out in full and the citation format is: Given/first name Father's name (Grandfather's name is added if used), date.

## **Objectives of the Study**

### **General Objective**

The general objective of this research was to explore the experiences-both positive and negative experiences of family caregivers and contexts underlying the care-giving situation for mentally ill loved ones.

### **Specific Objectives**

To understand the meaning of their experiences in care giving for people with mental illness

To describe how care-givers manage their care giving responsibilities

To describe the impacts of care giving for mentally ill loved ones on various life spheres of family

To explore what people do when their relatives have mental illness and support they can get

### **Research Questions**

This particular research answered the following research questions.

How do family members feel about providing care for their mentally ill loved ones and how do they handle the care-giving tasks?

How involved have family members been in the care and treatment of their mentally ill loved one?

What meaning does their experience of caring for a mentally ill loved one have in their life?

What are their suggestions on how the needs of family caregivers can be better met?

### **Significance of the Study**

By compiling a detailed collection of family member experiences, this study raises awareness of the challenges and positive meanings families have in trying to support their loved ones in the community. By listening to family members recount their experiences, the study adds to the body of knowledge of families' experiences with mental health professionals so that the needs of caregivers, the nature and context of their care-giving experience, and other family members can be taken into account when treatments are being devised for their mentally ill loved ones.

This study fills the identified gap by clarifying the experience of family members in providing care for their relative with mental illness. By exploring the problem from the family caregiver's perspective, the proposed study aims to add to the advancement of empirical knowledge regarding the experience of care-giving and mapping comprehensive nature of care giving for mentally ill relatives in Ethiopia. This study enhances understanding of the issue from various angles and helps to contextualize it, and brings the issues to the surface. The study also informs social work practitioners about the experience of family members caring for individuals with mental illness and this can further initiate intervention programs and policies by responsible bodies. The study may assist with planning and implementation of future intervention programs to be based on empirical evidence thereby enhancing the likelihood of success.

## **CHAPTER TWO: LITERATURE REVIEW**

This part of the study presents the synthesis of literature that includes a general overview of schizophrenia, caregiving experiences of family members, challenges of the care provision, and impacts of the disorder on the family members particularly the caregivers. The experiences of family members caring for their relative with schizophrenia in Ethiopian context is also presented briefly based on the few available resources followed by a discussion on the models and description of the conceptual framework that is proposed to guide the study. The literature part concludes with an identification of the gaps in our knowledge base that prompted this study and that the proposed study seeks to address.

### **Overview of Schizophrenia**

Schizophrenia is considered to be chronic, severe, and disabling mental illness that affects an increasing number of people in the world, particularly in developing countries. Approximately 1 out of 100 people suffer from schizophrenia (Mental Health Research Association, 2006).

According to Pompili and colleagues (2009) persons with schizophrenia may experience distortion in thought processes which influences their behavior. Generally, their behaviors are odd and maybe harmful to themselves or others, including suicide or violence. A massive challenge with schizophrenia is that the person affected by the disease may relapse during treatment and recovery. Due to this, persons with schizophrenia are frequently hospitalized and may need long term care and treatment to reduce the negative impacts of the disorder (Bostrom & Boyd, 2005).

A report from the World Health Organization (2001) indicated that schizophrenia is a severe disorder and begins in late adolescence or early adulthood. The disorder is characterized by fundamental distortions in thinking and perception, and by inappropriate emotions. Men and women are found to be equally affected, though the onset tends to be later in women. Women tend to have a better course and outcome of this disorder. The finding from this report also indicated that, different symptoms such as, social isolation, odd thinking or speech, having beliefs that seem strange and peculiar to others, seeing objects invisible to others and hearing voices when none are present may occur when the illness first develops. The aforementioned are the main symptoms that may make it difficult for persons with schizophrenia to retain interpersonal relationships, fulfill personal needs, and lead an independent life.

The severity and negative outcome of the disorder's symptoms over the course of a person's lifetime varies across persons. In some persons with schizophrenia only a small number of episodes of the illness occur while others experience symptoms continuously (WHO, 2001).

Schizophrenia is likely to be caused by a combination of factors. Some of these factors are genetic (inherited from the person's biological parents), some are biological (stemming from abnormalities in a person's body), and some are psychosocial, which implies it is caused by the environment in which one was raised and in which one lives currently (Siever & Davis, 2004, p.398).

According to the National Alliance on Mental Illness (NAMI) - (2008), although some individuals will always be subject to recurring symptoms of schizophrenia, studies show that most people suffering from schizophrenia can be trained and supported to live productive, non-institutionalized lives. Thus schizophrenia is a manageable disease (p4).

A person with schizophrenia can be treated in various ways. One component of the treatment to relieve symptoms and prevent relapse is antipsychotic medication. Though, these drugs do not “cure” the disorder, they typically lessen the intensity and rate of recurrence of the psychotic symptoms and may allow the person to function more appropriately. A psychosocial intervention is another treatment option which helps patients and their families to cope with the disorder and its complications. Finally, rehabilitation helps persons with schizophrenia reintegrate into the community and regain educational or occupational functioning. Though, this kind of rehabilitation not found specifically for schizophrenia in Ethiopia, Gefersa Psychiatric Rehabilitation Center currently providing service for people with retardation. However, the real challenge in the care for such people is the need to organize services that lead effortlessly from early identification to regular treatment and rehabilitation (National Alliance on Mental Illness, 2008, p4).

### **Schizophrenia and Family Caregivers**

“An estimated 50 to 80% of persons with schizophrenia and related psychotic disorders live with or have regular contact with a family caregiver” (Gibbons, Horn, Powell, & Gibbons, 1984; Lehman & Steinwaches, 1998a cited by Mcdonell et al., 2003, p.91). In Ethiopia, it is estimated that more than a million people suffer from the two most common types of mental illness with schizophrenia as the leading disorder followed by affective disorders (Fekadu, Alem, Desta, & Martin, 2007). The joint report of World Health Organization and Ministry of Health (WHO and MoH), (2006) indicated that, 35% from the outpatient and 55% of inpatient units and a total of 60% in the mental health hospital are schizophrenic patients. Based on the limited health care service in general and psychiatric health service in particular context of Ethiopia as raised in introduction part one can easily understand the number of persons with schizophrenia live with their relative/family caregivers.

Since many persons with schizophrenia live with their families, it is important for the family to have a clear understanding of the disorder. Many psychiatric rehabilitation programs include the family in their work to reduce the family's stress and help make the family setting a more supportive environment for the person with schizophrenia. These programs also help families learn about the different kinds of outpatient and family support services that are available in the community. Family caregivers must learn to balance the needs of their ill loved ones, their own activities and other businesses (Goodman et al, 2007, p.2). Though, such services are not available in Ethiopia, it is important to raise this point in order to show that the issue is hardly addressed by concerned bodies in Ethiopia.

The family caregiver is the most important person who cares for the person with schizophrenia (Clement et al., 1995 as cited in Rafiyah &Sutharangsee, 2011). Caregivers usually helps the persons with schizophrenia in performing their daily activities such as, bathing, eating, cooking, dressing; taking medications, and going for checkups. Most family caregivers may deal with responsibilities at work environment and that of home when a loved one gets ill. Caregivers' personal need for rest and attention to their own health may be neglected though not well addressed. This leads to dealing with multiple responsibilities, some of which may conflict with one another (Rafiyah &Sutharangsee, 2011). In providing care for their loved ones, caregivers face challenges of both making sure the person they care for has access to treatment and services, as well as taking care of themselves. Among the most common challenging situations reported by family caregivers are feeling secluded, worried, and burned out (NAMI, 2008, p.10).

Family caregiver burdens leads to negative consequences both for themselves and for the patients, other family members, and the health care system. Care-giving burden negatively affects the physical, emotional, and economic status of caregivers (Bostrom &

Boyd, 2005 cited in Rafiyah & Sutharangsee, 2011). Burden experienced by family caregivers' may also cause family conflict and financial problems for individuals, the family unit, and the health care system. However, these impacts may not be equal for all caregivers, as the level of burden is related to various factors (Rafiyah & Sutharangsee, 2011, p.30).

Chesla (1991 as cited in Jeon & Madjar, 1998) identified four styles of interaction and caregiving: engaged, conflicted, managed, and distanced.

Engaged care, characterized by continued care with understanding and acceptance of the sometimes difficult and inappropriate behaviours of the person with schizophrenia. With regard to conflicted care, parents showed little understanding or acceptance of their relative's illness and behaviour and tried to minimize any impact on their own lives. In this form of care, continuous care is provided, but their approach often resulted in conflict and extreme displeasure with their life situation. On the other hand managed care is characterized by being enthusiastically active and objective in managing and learning to cope, yet they found the experience very draining, and they expressed a strong need for breaks from the work of caring. Lastly, distanced care was mostly common in fathers who entrusted the direct caregiving work to another member of the family, most often their wives, yet reported feeling emotionally hurt and excluded from their son's or daughter's lives (Chesla, 1991 cited by Jeon & Madjar, 1998). With regard to Ethiopian context, no one has studied the patterns and styles of interaction in caregiving for their relative with schizophrenia and interested researchers can address this issue.

### **Experiences of Care-Giving for a Family Member with Schizophrenia**

Summerville and Atherley, (2012), showed that care-giving for person with schizophrenia demands a variety of activities and roles. Thus, the caregivers not only had to deal with the demands and stresses related to the care for the ill relative, they also had to battle the health care system and the professionals who worked within it. In his message for

family caregivers Dr. - Summerville when interviewed by Atherley indicated that the feelings of frustration, guilt, and powerlessness due to underestimation of the caregiver's role by health professionals may hurt caregivers. The cumulative impact on the caregivers could be devastating and admitting to such anger and despair is not easy (p.2).

According to Goodman and colleagues- (2007), despite such negative experiences, most caregivers did, at times, experience support from a few people who understood or tried to understand. Caring for a loved one who is ill often creates a deepened sense of closeness and connection between the caregivers and the person with schizophrenia. Family caregivers may also experience increased intimacy, satisfaction, and pride in the course of caring for their loved one with schizophrenia. However, the anxiety that comes with dealing with a serious illness, combined with the burden of caregiving, can create strain in the relationship potentially stress caregivers. Similarly in some situations caregivers may feel beset, guilty, resentful, angry, anxious, and even depressed. The aforementioned varied and complex emotions in care-giving for person with schizophrenia are among the most common. Thus, feeling both positive and negative emotions when providing care for a loved one who is ill is normal (p.1).

Yatchmenoff and colleagues- (1998 cited by Mendenhall & Mount (2011))- also found some positive associations for caregivers including pride in fulfilling spousal responsibilities, enhanced closeness with a care receiver, and satisfaction with one's competence in care-giving. These perceived uplifts of care-giving are associated with lower levels of caregiver burden and depression (p. 183).

Sometimes circumstances thrust people into the role of caring for a relative, with whom they may have a strained relationship. This situation can intensify the usual negative emotions caregivers feel, especially guilt and resentment. Under such circumstances since the

adverse effect of caregiving may occur it is important for family caregivers to seek help both for the actual hands-on care and for emotional support (Goodman, et al. 2007, p.1.3).

The finding from phenomenological study conducted by Jeon & Madjar in Australia indicated that in the course of care-giving for person with schizophrenia support from community groups was particularly meaningful, reducing the caregivers' feelings of isolation and increasing their feelings of confidence is important. Feeling the difference came through recognition that there were others, including some health professionals, who could understand and be sympathetic (Jeon & Madjar, 1998, p.9).

### **Caregiving Challenges**

Findings from on line survey conducted by NAMI (2008), in United States, indicated that; mental illness affects the entire family, -

More than two-thirds of caregivers (68%) are the parents or step-parents of the person living with schizophrenia to which they provide care. Brothers and sisters comprised 12% of caregivers and 7% are spouses or significant others. Seven percent of caregivers are the children or grandchildren of the person under their care. The greatest challenge for all these family members is simply finding treatment providers and services for their loved ones (p.9).

The challenges caregivers face can be as significant as those affecting people living with schizophrenia. Studies show that most caregivers of persons with schizophrenia worry about the future of their loved ones when they die. An especially stressful challenge encountered by family caregivers caring for family members with schizophrenia is high-risk behaviours. These create emotional stress for family members arising from constant worries that the family member is going to develop high-risk behaviours or is actually engaged in them (NAMI, p.10).

Summerville and Atherley, (2012)-, identified some risky behaviours with schizophrenia. Among these are not taking prescribed medications which is the most high-risk behaviours with schizophrenia. This kind of behaviour mostly resulted from side effects of medication and persons' believing themselves well enough to continue without medication. The other related high-risk behaviours are substance abuse, including the abuse of street drugs and alcohol. If the person with schizophrenia was inclined to volatile or risky behaviours, such as unprotected sex, prior to the disorder, these will likely exhibited during the course of schizophrenia, in a more complicated form. The most alarming behaviours occur with paranoid auditory hallucinations which may take the form of different voices (p.8).

From another angle mental illness is not always the greatest challenge. Rather such challenge resulted from factors that breed physical, psychological and financial stress and strains for family caregivers of persons with schizophrenia. These situations heavily bear on the family and may create disagreement among family members that too often goes unaddressed and as a result, the illness and tensions among the family unit is exacerbated (Summerville and Atherley, 2012, p.8).

Generally, a lot of challenging situations confronted by family caregivers of persons with schizophrenia and this may range from voices and unnecessary activities attempted to be performed during the disorder.

### **Impact of Disorders**

The impact of mental health problems is not a simple factor that only affects the individual with the disorder. Mental and behavioural disorders have a large impact on individuals, families and communities at large. Individuals who provide care for their loved one with mental problems also suffer from the distressing symptoms of disorders. Family

caregivers also suffer due to the fact that they are incapable to deal with their own businesses- including work and leisure, which may result from discrimination. They may be troubled about their unmet needs and may not be able to carry their responsibilities towards family and friends. Family care givers are fearful of developing dependency syndrome in which he/she may incline to depend on other individuals (Zauszniewski, Bekhet & Suresy, 2010, p2).

The burden on families ranges from economic difficulties to emotional reactions to the illness, the stress of coping with disturbed behaviour, the disruption of household routine and the restriction of social activities (WHO, 1998). Expenses for the treatment of mental illness often are borne by the family either because insurance is unavailable or because mental disorders are not covered by insurance.

A study conducted by Shibre et al.- (2003) shows that the impact of schizophrenia on family members is high even in traditional societies such as Ethiopia where the family network and informal social control is said to be strong and important. This study also indicated that more burden is experienced by female relatives than male relatives. This finding is relatively similar with the study conducted by NAMI in the United States in which they indicated a strong relationship between being parents of persons with schizophrenia and family caregivers. The aforementioned study conducted in Ethiopia indicated disorganised symptoms as the most important factor affecting the family members of persons with schizophrenia. Prayer was the most often used coping strategy Shibre et al. (2003).

### **Schizophrenia and Family Caregivers in Ethiopia**

Mental health is one of the most disadvantaged health programs in Ethiopia, both in terms of facilities and trained manpower. The average prevalence of mental disorders in Ethiopia is 15% for adults and 11% for children. The psychiatrist-to-population ratio for Ethiopia is 1:6 million. The only institutions that provide psychiatric services by specialist

doctors are found in Addis Ababa; actually inpatient service is provided at only two hospitals (WHO/Regional Office for Africa, 2012).

Community surveys in Ethiopia have shown consistently that severe mental illness, resulting from schizophrenia or bipolar disorder is recognized as an illness that needs intervention at different levels. However, in Ethiopia severe mental illness is more often attributed to supernatural causes, such as spirit possession, bewitchment or evil eye, rather than as a result of biomedical or psychosocial causes. As a consequence, affected individuals and their families often seek help from religious and traditional healers rather than health facilities (Federal Democratic Republic of Ethiopia Ministry of Health, n.d).

In Ethiopia, as in most developing countries, services which could help people who suffer from mental disorders are insufficient; thus, families are the sole caregivers to their severely mentally ill relatives. While understanding the magnitude of the family burden and coping strategies is important to plan family intervention programs, very little is known about the extent of the relatives' caregiving-related distress in Ethiopia (Shibre et al., 2003, p.27).

Among different groups of relatives of persons with schizophrenia, female relatives experienced more work which may be around home/house maid or employed at different levels. Due to this female caregivers faces a number of challenges in terms of going to work or stopping work to care for a relative with schizophrenia. This higher burden might be due to the compassion of mothers, female spouses and sisters of the ill relatives. It is also possible that males try to employ more isolating strategies such as becoming more involved in work and in hobbies to deal with their tension, while women have no time to go to work, but stay at home to look after the person with schizophrenia. The difficulties in care and disorganized symptoms pose additional difficulties due to limited caring institutions (Shibre et al., 2003. p.32).The fact that as many as 17.6% of friends and neighbours are involved in the care for the ill person in addition to the first-degree relatives shows the importance of the family

network in care-giving for persons with schizophrenia (Magliano et al. 1998, 2000 cited in Shibre et.al., 2003. p.32).

### **Summary**

The literature reviews, informs us about factors related to care provision for persons with schizophrenia. Most of the literature examines various issues of family care-giving experiences of persons with schizophrenia though almost all of them focus on the challenging aspects only.

The few studies conducted in Ethiopia on family care-giving experiences were not comprehensive enough and did not examine the issue from different angles including the enrichment aspects of the care-giving experiences. They are all interested in the burden of care-giving for persons with schizophrenia. The existing studies do not explain the comprehensive experiences of family members in the course of providing care for their loved ones with schizophrenia in Ethiopia. The studies that investigated these issues were mainly based on surveys in rural areas and focus only on the burden of caregiving for persons with mental illness. Therefore, the studies conducted did not fully reveal the multidimensional aspects of family caregiving experiences for persons with schizophrenia. The proposed study attempts to contribute to the understanding of these issues.

## CHAPTER THREE: RESEARCH METHOD

### Research Approach and Rationale

The research approach employed for this particular study was qualitative research. To conduct research on the various factors that revolve around the care-giving experience by family members of persons with mental illness, applying a qualitative research approach is considered appropriate. Qualitative research methods allow recognizing peoples' own perceptions and attitudes using the language and meaning respondents give to their experience in the existing context (Dyck, 1993). Qualitative research methods help to uncover the various factors affecting the discourse of care-giving involving mental health problems and helps to explain the context and meaning of the situation. Applying qualitative research methods also enabled the researcher to explore in-depth the general situation of care-giving for people with mental illness within the particular context of experience by the family.

### Research Design

Methodologically, the research design of the study was informed by a qualitative case study approach. This is due to the relevancy of basic assumptions and approaches behind case study of the study subject. According to Yin (2003), case study is "an empirical inquiry that investigates a particular phenomenon within its real life context and produce contextually rich and meaningful interpretation" (p.13).

This design was selected for its merit to answer the 'how' research questions listed in the study and its predominant advantage of describing the existing situation from different cases perspective to provide an in-depth understanding of the issue (Yin, 2003, p. 3-4). According to Gerring (2007), "case connotes a spatially delimited phenomenon observed at a single point in time or over some period of time" (p. 19). Since not much has been written

about the family care-giving experiences of people with schizophrenia, and as previous researchers have not yet discovered holistic experiences of family caregivers of people with mental health problem in Ethiopia, a case study research design provides a ways to gain an in-depth understanding of the situation. Beyond this, it is a research design used to explore how individuals construct the situations behind their experience, and how these phenomenon shape group or cultural meanings focusing on particular phenomena.

According to Kreuger and Neuman (2006, p. 34), a case can be a group, community, school, family, organisation, individuals, geographic unit or an event. In the study a case refers to family caregivers of schizophrenic patients.

### **Method of Data Collection**

Before the actual fieldwork begins a site visit was performed to introduce the purpose of the research, to agree upon the appropriate time for beginning the data collection, and to get permission from the research and training directorate of the hospital.

Both primary and secondary data was employed in this study to obtain basic and relevant information that are required to carry out this study. The primary data collected through in-depth interviews with family members who have primary responsibility for providing care to a person with schizophrenia.

### **In-depth Interview**

In-depth interviews provide an opportunity for detailed investigation of each person's personal perspective, for in-depth understanding of the personal context within which the research phenomenon is located, and for very detailed subject coverage. Interviews are the only way to collect data where it is important to uncover the perspectives within the context of personal history or experience; where delicate or complex issues need to be explored at a detailed level, or where it is important to relate different issues to individual personal circumstances (Ritchie & Lewis, 2003, p.58).

An in-depth interview was administered to family members providing care for their mentally ill loved one using an open-ended interview schedule. In-depth interviews employed to gather insight into what family caregivers experience, the context and situation of giving care for relatives with serious mental illness, and the meaning it has in their life sphere.

Semi-structured questionnaires employed for the interview to gather information about the demographic and socio-economic characteristics of the participants.

In terms of secondary data collection, in order to get clearer pictures of the general setting attempts made to assess relevant studies carried out by other scholars. Similarly, various publications of agencies who work on the identified issue sought to gain more comprehensive information pertaining to the issue and this includes materials such as books, magazines, different published and un-published materials and journals.

### **Sampling Methods**

Purposive sampling was employed to identify participants from the study population. This non-probability sampling technique is very often employed in the context of field research. At this juncture respondents that best fits objective of the study and fulfilled the inclusion criteria which discussed under study participants and inclusion criteria selected consciously.

### **Sample Size**

According to Yin (2003, p. 211), the evidence from more than one case is often considered to be stronger than evidences from a single case. Among the different types of case studies, in this study, more than single cases studied in order to have holistic and better understanding of the participants' life experiences in providing care for loved one with schizophrenia.

To have a more compelling and robust outcome in the study, a sample of eight participants selected using purposive judgemental sampling for the detailed open-ended interview in line with the purpose of the research.

Mostly qualitative studies focus on an in-depth and highly contextualized understanding of specific phenomena, and such emphasis is compatible to small sample sizes. Due to this, qualitative researchers are well justified in using criteria of data saturation or redundancy during data collection, than employing statistical criteria, to decide on sample size. Generally, large sample sizes in qualitative research not recommended since it is difficult to extract thick and rich data. Similarly, too small sample is not advisable since it is difficult to achieve data saturation (Flick, 1998; Morse, 1995; cited by Onwuegbuzie & Leech 2007).

### **Study Participants and Inclusion Criteria**

This study conducted at Amanuel Specialized Psychiatric Hospital, the only mental health hospital in Ethiopia. Participants of this study were family members of persons with schizophrenia who are receiving services at the hospital. The site was deliberately selected in order to easily gain access to study participants. The study participants were family members having the experience of care-giving for their relatives with schizophrenia.

Based on purpose of the study, the persons with schizophrenia who have been gaining support from their family were selected from the patients of Amanuel hospital. The identification of patients with schizophrenia was made based on the medical history of patients detained in the hospital setting. This particular activity was accomplished with the support of psychiatric nurses and psychosocial workers in the hospital. Following identification of persons with schizophrenia, the families of patients were contacted and the researcher discussed the purpose and procedures of the study in order to select research participants who are willing to be part of the study fulfilling inclusion criteria.

The overall inclusion criteria were: (a) family members of persons with schizophrenia, (b) family members who live with their ill loved ones, care for them and help them manage daily activities, (c) family members who are adults, (d) those who are willing to be part of the research voluntarily and who are open to disclosing their stance with the situation. To this effect attempts was be made to keep the homogeneity of the sample in order to synthesize similar experiences of the situation.

### **Data Recording and Analysis**

Yin (2003) encouraged researchers to make every effort to produce an analysis of the highest quality. In order to accomplish this, four principles that should attract the researcher's attention: (a) show that the analysis relied on all the relevant evidence, (b) include all major rival interpretations in the analysis, (c) address the most significant aspect of the case study, (d) use the researcher's prior, expert knowledge to further the analysis.

There are various approaches to analyze data in qualitative research. Content analysis in which both the content and context of data are analyzed is one approach. In this approach themes are identified, with the researcher focusing on the way the theme is presented (Spencer, Ritchie & O'Connor, 2003). Accordingly, in order to manage and analyze the data properly and to form a coherent flow of ideas, interview with respondents was tape-recorded based on the consent of the participants. Each interview was transcribed at the end of the recording and the transcribed data was sorted by these categories, identifying similar phrases, patterns, relationships, and commonalties or disparities. During transcription, in order to maintain confidentiality different name was given for the respondents that have been written on each page of transcription. After the transcription of interviews, it became translated in to English language for further analysis.

The sorted information from the interview was coded according to the categories and a common theme was selected, each interview assessed and classified with the selected theme. For the analysis at the end 22 different categories were clustered under 4 main themes of the study. In this case the numbers of categories under the selected themes vary based on the nature of the theme and the first hand information gained in the area. Identified patterns are considered in light of previous studies and theories (Berg, 2001). Sorted materials were examined to isolate meaningful patterns and processes. Accordingly, after the data broken down into categories, interrelated as well as discrepant points was conceptualized and discussed in parallel to the literature review and the stated objectives of the study; so that whether the findings are consistent or not with those literatures was seen. The information was summarized by using related categories according to the main thematic issues.

Detailed cases were interpreted to get answers to the stated research questions. Critical cases were selected for more detailed analysis. Data brought together by a triangulation process and organized in themes according to the given coding categories. Direct quotes, common and typical responses from the interviews were presented.

### **Ethical Consideration**

This is one important component of research where the relationship between the researcher and respondents needed to be explained. Taking ethical considerations into account is imperative and a basic part of any research study with human participants.

Before the study was conducted, all the participants of the research were well informed who the researcher is in terms of role, status and full name, as well as the purpose and design of the study. Beyond this, the researcher followed the following ethical considerations while conducting the study:

Risk versus benefit, the researcher conducted the study only when the potential benefit outweighs any known risks. Second, no harmful procedure was used. Here the researcher not used procedures that could harm the participants physically or psychologically. The third ethical issue is informed consent. The researcher explained the purpose, procedures and all known risks and benefits of the study to the participants. The fourth ethical issue is unforeseen consequences. If a research procedure results in any negative consequence to the participant, the researcher must do whatever is necessary to correct the situation. The fifth issue is privacy. The researcher kept all information obtained from participants confidential by using pseudonyms. The interview conducted in Amharic language. Interview with single participant was not long more than one hour and the place for the interview was arranged as to protect privacy of the participants. The last ethical issue relates to the implications of the research. The researcher was conscious of social, political, and human implications of the study. Therefore, based on the aforementioned scientific research procedures the participants interviewed in the actual engagement of the field work.

### **Trustworthiness of the Study**

The trust-worthiness of the study is one of the requirements of contemporary research. Reactivity, researcher bias, and respondent biases are the major challenges for trustworthiness of qualitative studies. Becoming a researcher, especially for a person doing qualitative research, is partly a matter of learning how to deal with bias (Stake, 2010).

A study is assumed to be trustworthy when carried out honestly and ethically and its findings represent experiences of the respondents as much as possible (Padgett, 2008). In order to ensure the trustworthiness of a study, it is important to know the possible threats and how to deal with them. In order to minimize respondents' biases and the risk of reactivity I attempted to state my biases or expectation about family caregivers before data collection.

The other most important technique to minimize risks to trust worthiness in qualitative research is triangulation (Stake, 2010). In order to carry-out fair and ethical research that represents as much as possible the real experience of the participants, the researcher employed different relevant mechanisms as rose above.

### **Limitation of the Study**

This study is limited to the experience of family members caring for a relative diagnosed with schizophrenia: the case of Amanuel Specialized Psychiatric Hospital. The study limited to eight family caregivers of persons with schizophrenia. This number of participants and sampling method used makes difficult to develop inferences or generalize findings from the study. Additionally, preconceived information on the area and prior knowledge gained through reading different literature might influence the procedures from data collection to analysis stage. To minimize biases related to the aforementioned factor and others I tried to give special priority for learning from my participants experiences.

## CHAPTER FOUR: FINDINGS

This chapter presents the results of the eight caregiving cases. The goal of the analysis was to describe the experience of family members caring for a relative diagnosed with schizophrenia; to better understand their meaning and perception about caregiving for persons with schizophrenia, how they have seen the situation, how they continued to provide care and other services and what factors influenced in the course of caring. The findings are presented in four main sections. In the first part, the socio-demographic characteristics of the participants, participants' awareness of mental illness and comprehensive meaning of caregiving are presented. The second part describes caregivers' enrichment experiences in provision of care for their relative. In the third part, the negative impacts of caregiving on the caregivers are presented. Finally, the ways participants manage the caregiving situation and responsibilities including supports that facilitate caregiving are presented.

### **Socio-Demographic Characteristics of the Participants**

In this study eight participants were interviewed five males and three females. Their ages ranged from 20 to 38. Three of the participants were from Southern nations and nationalities, three were from Oromia regional state, and two were from Amhara region.

Two participants were married and the other six were single and never married. With regard to their religious background four respondents were Orthodox Christians, three were Muslims, and one respondent was Protestant. The educational status of the participants ranged from illiterate to grade five. The length of time participants were providing care for their relative ranged from one year to eight years. All of the persons for whom they have been providing care have a history of hospitalization with different frequency of admission. When this study was conducted all of the participants were admitted in Amanuel Specialized Psychiatric Hospital. The details of the participants' background are presented in table 1.

Table1. Socio-demographic and other Characteristics of Respondents

Name of participants	Sex	Age	Work condition	Educa tion	Years of having mental health problem	Years of caregiving	Relationship with care recipients
Birke	F	38	Housewife	10	10	10	wife
Shuna	F	32	Unemployed	5	4	2	Brother
Lamesa	M	45	Farmer	8	10	6	Father
Tilanesh	F	23	Unemployed	4	6	6	Father
Tolesa	M	20	Farmer	7	1.5	1	Brother
Burtukan	F	25	Librarian	Diploma	6	2	Sister
Nuritu	F	28	Unemployed	5	10	4	Father
Mujib	M	38	Merchant	4	10	3	Brother

### **Awareness of schizophrenia and caregiving experience**

This section addresses the first objective of the study, regarding participants' awareness of schizophrenia and meaning of care provision for persons with schizophrenia. Except for Burtukan, all the participants named the illness using the general term "severe mental illness" and they reported that they do not know the name of specific problem their relatives' diagnosed with. Burtukan has good communication with the doctors and she has been striving to understand the details of the disease, the side effects of the medication, and causes of the illness.

Except for Burtukan, who has concept about schizophrenia the rest participants reported that the cause of severe mental illness is linked with evil spirits. Lamesa reported that "this severe mental illness is a kind of temptation from God since I have been told at church to serve as a leader of that particular church and refused to accept duty given to me from church". The participants Nuru, Birke, and Shuna attributed the illness to evil acts people did to their relatives.

With regard to how they developed knowledge of the illness, the majority of the participants reported "we developed the knowledge from unusual behaviours and personalities seen from their relatives especially new and emerging never seen conditions from them are indicators". Participants also attributed the knowledge to behaviours such as missing sleep, poor hygiene, attempts to burn things, suicide attempts, laughing without any pre-condition, hallucinating and delusion.

In this study, all the respondents attributed their knowledge and awareness about mental illness, and its causes and treatment mainly based to what they personally experienced. They also reported they had information from the community, the church, hospitals, other people with mental health problems, and from reading which enhanced their

understanding of mental illness. Burtukan explained the way she developed knowledge of her brothers' mental illness in relation to hallucinations and delusions during night. As she said:

One day I remember that his problem was not this much severe while we were simply sitting at home he raised something out of topic and he rose as he cursed by somebody. Following this he shifted his face to one side of the corner and said "look at this all these are my enemies; they held fight with me in which I killed all the enemies". Following this he showed me dead body's skeleton which he collected from outside and explained as he came up with the skeleton after he accomplished the fight with victory.

Another respondent Shuna also explained,

I have developed knowledge of my brother's severe mental illness when he altered behavioural change through time. One day there was mini sport festival in our area and came up with unusual event in which he round the whole field without any concern in the mass. Returning from the field he started crying and passed the whole night under same scenario without any harm though, he didn't encounter any problem at that time.

### **Meaning of Caregiving for Persons with Schizophrenia**

The majority of the participants explained the meaning of care giving for people with serious mental illness as doing something good in order to address the problem, preventing the worst from happening, contesting situation between enriching and challenging, sacrificing for the person as well as for the rest of family, developing a sense of sympathy, and developing knowledge that helps to work in challenging situations. Shuna, Mujib, Lamesa and Birke argued that caregiving is kind of service or combination of activities that bring new

conditions in your life due to intense intimacy between you and the person. The intense intimacy of study participants with their family members contributed to their ability to deal with care provision.

The other participants Tilanesh, Burtukan, Nuritu and Tolesa viewed the meaning of caregiving as adopting responsibility since the problem successively influenced the life of the whole family. Tolesa provided care for his only brother with schizophrenia starting from the year 2012. He explained the meaning of caregiving as:

I think caregiving is flexible situation for me and I can't simply determine or set purely in one direction. Basically it is the experience of developing conscious to improve the challenging conditions. The nature of confronting such challenging situations determined by unpredictable phenomena in our life which linked to developing sympathy so that one can become determinant enough to connect with such optimistic ideology.

Lamesa who had been caring for his son for the last six years stated,

My son only hears me but not others and it is only me who can handle the problem so that I was forced to become caregiver. Whatever the challenges from the caregiving maybe in order to save his soul and since I don't have any son without him it is all about accepting the situation as it is. In this caregiving meaning is all about the ability and way to know how to develop sympathy for others. I link particularly the experience with the way to learn something new when you face challenging situation. It is a kind of exposure that enhanced me to develop the aforementioned ability. This all priorly linked with preventing the worst not to happen in my family members.

Mujib, who cared for the senior brother of his family, explained:

The illness was like accidental and no one knows what “Allah do”, Due to this, rather than crying for him only at the end of time after his death he might return back to his normal health one day and it is not good to be in the state of despair. In my context care giving meaning is prohibiting him to left home and wander in the field and also it is expecting hope from future without giving up. For the accomplishment of handling such responsibility relies on ability to be committed enough in sacrificing your life despite your basic interest.

### **Reasons for Becoming a Caregiver**

This section presents participants’ reasons for becoming a caregiver, including their caregiving experiences. The description of respondents in this study suggested that, their concerns about becoming a caregiver for their relative with mental health problems ranged from being the only one who can serve the persons with schizophrenia to having sensation like responsibility adopter as primary caregivers from family members. For participants like Tolesa, Shuna, and Birke, the reason for becoming a caregiver was their preference to not get outside help for the person with the mental health problem.

However, all of the respondents started to provide care as a potential caregiver since those persons with the mental health problem were a part of the family and it is by their choice, not by any enforcement. As Lamesa explained,

First and foremost, no one can handle the situation like me. I was the only option to provide care for my son. Additionally, he accepts what I command him in the actual course of caregiving but not the rest of the family. And when he encountered something offensive, his problem is worsened more than ever and I better care for him. When he was offended by some others’ attempts to provide care, I worried about

his problem will never get resolved. I prefer myself and I know this is also his preference.

Tilanesh's explanation also highlighted how she became the caregiver for her father who did good things in the past though, he faced problems through time. She said:

My father is the reason for my present existence even and this can be justified from his long time effort in backing up me. Due to this caring for a person like my father when he has faced such an unfortunate problem which I ever seen in our family or largely relatives is my personal choice and I'm good in relationship with him.

Similarly, Burtukan asserted that:

Previously I do have fear of approaching persons with mental health problem but I understood how far my mom is challenged from the situation since she is emotional and easily upset. When I started to approach him despite my misunderstanding for mentally ill person I became conscious as being caregiver is not this much worsening. The first reason I decided to care for my senior brother who was awarded by great distinction several times while he was student is that, he is part of my family, the case is something unexpected, and to prevent or limit adverse effects from the illness not to negatively affect the whole family.

The study conducted indicated and strengthened as potential justification behind different factors has its own influence on the engagement of ones in some sort of complex situation but meaningful by itself. Similarly the participants attested that their meaning for becoming potential caregivers for their relative with schizophrenia is linked with their meaning of care-giving and what it meant by in the actual implementation.

### **Enrichments from Caregiving for Persons with Schizophrenia**

In relation to the enrichments the respondents received from caring for their relative with schizophrenia, almost all of the participants described; improvements in the life of their relatives which enhanced the self esteem of family caregivers from their care and provided evidence of the fruits of their efforts. The most commonly raised improvements were related to the in health status of the relative with schizophrenia such as eating normally, using the bathroom independently, taking showers, and facilitating some minor cases.

One participant reported his rewarding experience from caregiving differently. He said that: "it has been long since I started to deal with the situation of my son but the improvement in his health condition is not very significant. However, still the situation is temptation linked with my spiritual life and I'm grateful since I am healthy enough first of all which approved as to be capable of standing for my son".

The other enriching experience reported by five participants was absence or reduction of negative impacts. This is due to the fact that their relative's confined under the care provided and had it not been the case or if they were created problems the problem might be worsened by two or three folds and the existing improvements might not be recognized. Despite some negative experiences, most caregivers did at times, experience support from a few people, in most cases from their relatives and sometimes from community members who understood or tried to understand. To feel understood was to feel supported and to "feel the difference," across caregiving which kept them going and helped them continue to care. Respondents shared that interpersonal communication, often taken for granted before, could be a source of meaningful support that made all the difference to people who provide care for relatives with schizophrenia. Support from the community in different ways was particularly meaningful, reducing the caregivers' feelings of isolation and increasing their feelings of confidence which contributed to enrichments from caregiving. Feeling the difference came

through recognition that there were others, including some health professionals, who could understand and be sympathetic. For example, Lamesa indicated that prayers from religious personnel and discussions of their challenges enriched them.

Most participants' also shared enrichment attributed to their thinking of unexpected nature of the problem and the situation which needs intense care and treatment. They reported that during the post episode periods their relative became completely different and became conscious of such conditions linked with positive thinking and accepting the confronted situation and provide care for their relative. The study conducted indicated as such kinds of justification in the actual discourse of care giving enhance caregivers to have mixture of enriching and similarly challenging experiences. This simply indicates whatever the case it is there are moments situation perceived positively when faced unconditionally.

Similarly Nuritu, Mujib, Birke, Shuna, and Tolesa reported that being capable of serving persons with mental health problems has its own value for the caregivers since it is an opportunity to develop sympathy in such areas with potential to influence your life.

Shuna said:

I am really happy in the progress altered and to see this day in relation to the health status of my brother though, my personal businesses were underestimated. The reason I'm saying this is that initially I have thinking of "in case if he harmed somebody in our area" it is crisis but right now though he is not fully recovered from his problem I can attest that he never engaged in such condition. This result of intense care and treatment including antipsychotic medication service I have been collecting from Amanuel Specialized Psychiatric Hospital by three months and this is one sort of enriching experience.

Despite their awareness of the impact that caring for a relative diagnosed with schizophrenia could have on family relationships, Burtukan, Tilahun, Birke, and Mujib also described that in situations of conflict, most caregivers felt that it was important and natural to consider the ill relative's needs before anyone else's. This was exemplified in the notion of looking at a situation through the eyes of the other, the one who suffered emotionally and physically and whose life was affected by mental illness.

Caregivers perceived their own concern and commitment as different from the care provided by health professionals or others. The care they provided involved unconditional love that continued even when it went unrewarded by others. Thus, it was not surprising to find that even when the caregivers experienced physical and emotional health problems, almost all of them continue their commitment to provide care.

Depending on how their ill relative experienced so many different situations, family caregivers developed a sense of making the situation more accepting and tolerant. Looking at the situation as seen by the person with mental illness, they wanted to make home a less threatening place. As Burtukan compared her life with her brother's for whom she provided care, she reflected:

Despite the challenges that caring for my brother brought into my life, by looking at the world through the eye glass of the other, I was able to understand that life was more difficult for him than that of mine. This aspect of the caring relationship helped me to see the pain and suffering of my brother, and enhanced me to sustain a quite remarkable spirit of generosity which enriches me morally.

Combination of services including medication services also indicates a kind of support system beside family caregivers. This one additional aspect of caregiving helped to develop a sense of positive thinking in the mind of caregivers since it is a kind of external support contributing to improvements in the health status of their relatives. For example

respondents pointed out that they were entertained by the funny talks and comedy nature of arguments with their relatives with mental health problem when their health status improved.

### **Negative Impacts of Family Caregiving on the Caregivers**

With regard to the negative impacts from caregiving for persons with schizophrenia all of the male respondents emphasized the severity of problems from caregiving situation. All of the respondents described the negative impacts from caregiving in terms of financial and psycho-social impacts.

Birke, Shuna, Mujib, Burtukan, and Lamesa described that taking each day as it comes involved more than passive acceptance of one's situation. They also think it is a situation full of hitherto unfamiliar, frightening, and unpredictable behaviours and events. Much of that learning occurred by trial and error, what the participants referred to as "learning by experience."

**Psycho-social problems.** Respondents indicated that over time, caregivers came to know that they needed to have physical and emotional respite in order to be able to maintain their caring responsibilities. All of the participants also indicated learning from their own and others' experience was a slow and often frustrating process, adding to the feeling of struggling in the dark.

Tolera, Shuna, and Nuritu similarly described as they suffered from ongoing grieving for the loss of the past, present, and future in the sense that both the in relative and they themselves had lost possibilities for a different kind of life. The grieving was not limited to one's own losses; rather, it focused on the persons with schizophrenia and what he or she had lost. As Tolesa, whose brother diagnosed with schizophrenia a year before said:

There is ongoing grieving for the person that I am caring for. He had excellent educational performance before he was back from grade eight. I feel angered when I heard of his past from community members saying “what expected to be good in the future, and people hold their eyes on will not meet the expected goal”. This and the other information I heard of from the community influence my life and this occur mostly as my personal challenge in caregiving situation.

There was an almost a blatant, embodied sense of sorrow for the parents watching the struggle of the chronically ill son or daughter, father or mother or other relative trying to cope and lead some kind of normal life. Although they grieved for the loss of what might have been and the loss of hope, their fear for the future grew as well.

Most of the respondents indicated that, the loss of the *hoped-for future* was painful and filled with fear, particularly when they were sole caregivers or when they knew that no one else in the family wanted or was able to be responsible for the person with schizophrenia.

Birke described her experiences from caregiving and social connection as follows:

Caring for persons with mental illness dramatically changed my social life. It is hard for me to get out and socialize unless someone from my family breaks me for a while and this hardly occurs since we have small family size. Friends may no longer come to visit or include me in their activities since I do have busy schedule most of the time. In most cases I feel socially isolated.

Mujib reported points to the indefinable yet extremely real sense of loss related to the past that cannot be recaptured, the present that is different and uneasy. Shuna also said in caregiving discourse, accepting events in the situation is a way of living through a challenging and often stressful experience.

All of the participants shared significant social challenges. Most of the time, social stigma or the way society labels individual with mental illness are the main problem that influences the caregiving situation.

Tolera, described his social challenge “the way community members showed my brothers’ past assertiveness influence my life when I heard of information that reminds me his well constructed past history”. Similarly, Birke and Lamesa viewed “misunderstandings from the community as affecting extent of support from someone close to you”. This problem attributed to inability to participate in different social events due to caregiving activity.

As Nuritu reported,

The most challenging situation in the community that affected our social relationships is conflicting relationship with neighbours. At the moment I left him in the compound for break, my father attempted to hurt our neighbours in most cases. In such situation I try to bargain and improve the problem as much as possible though those in conflict with him most of the time insult him using dehumanizing words and during this I’m the second person to deal with the conflict. From my point of view the problem is with healthy individuals who consider him as causing problems deliberately underestimating his mental health problem.

**Separation from peers.** Most of the participants reported that mental illness needs intense care and treatment in which caregivers cannot expect their social life to be as usual before the start of the episode. The participants also indicated that the separation from peers subsequently leads to lack of a social network, diminishing motivation in pursuing occupational goals, and poor psychological well-being.

**Problems from the mentally ill individuals.** Participants also reported challenging personalities and behaviours from their relatives with mental illness, especially during the first or early stage of the illness. Shuna and Mujib described stressors and trauma including observing their relatives' mental hygiene arrests, severe drug abuse, physical threats or assaults, relapses, and frightening behaviors.

Mujib, Birke and Burtukan similarly described challenging experiences in caregiving as becoming angered of their relative to selected individuals up to attempt for fight, non-adherence to medication therapy, resistance to eating, doing what told frequently not to do. However, they also attested that such behaviours experienced prior to schizophrenia though, not extreme to this level. On the other extremes two participants Birke and Mujib also reported changing personalities and behavior related with sexual behaviour in which sexual interest of Birke's husband as almost dead though, they had three children prior to schizophrenia. The second participant Mujib also informed by brother's wife as it was too long since she had sex with her husband.

Tolesa reported challenging experiences from his only brother with schizophrenia as follows:

During the early stage of the episode he resisted to have any kind of medication therapy so it was difficult to bring him to Amanuel Hospital. One day I remember that we arrived Addis Ababa in the morning since we do have appointment on that day. Unfortunately when I registered him for that day we failed to finish medication therapy prescribed and since we were from country side we were enforced to stay at hotel for the next day's appointment. Due to his great fear to return back to the hospital he argued that "I can go to another hospital with you but I will never return back there". Despite the fact I have tried to persuade him he was even not interested to stay at the pension and the situation became beyond my capacity and I called police

and when re-entered to the bed room he started disturb the whole compound by noise induced with crying. Finally I was enforced to pass that nigh on the street and we passed sitting along the street.

Participants Birke and Shuna also described their personal challenges encountered in care provision. Both of them reported misunderstanding about the deep realities of the illness in which they simply understood the condition by intuition than from its scientific realities. They shared the experience of wrongly perceiving the illness and attaching some worst situation to it especially when unusual personalities seen from the care receiver.

**Uncertainty for how long to remain as caregiver.** All of the participants shared their personal challenges were linked with uncertainty about how long they would remain as caregivers. Whether their relatives may become cured and return back to their normal health could not be determined easily and similarly developing detachment protection without any conscious of the problem. The participants also described how such uncertainty stemmed from slow improvements or progress from the disease and relapses which occurred in the middle, making them wonders how long they are expected to stay as caregivers. Participants mentioned the lack of proper orientation about the illness and the medication therapy being provided from time to time which aggravates uncertainty of the caregivers. Tilanesh who cared for her elder father expressed her concern like this:-

I always wonder when I am going to see the perfect fruit of my effort from caregiving for my father with schizophrenia. Sometimes seeing improvements in his health status I think he will get cured soon, but the disease relapses again. In general, uncertainty about the length of treatment is the major cause of frustration for the respondents.

**Economic impacts.** Worry of financial constraints for transportation and buying medication and to fulfill other needs was another challenge mentioned by respondents. Participants also described financial and other supports provided by family members, though, it is not suffice and problems faced by caregivers at different time when imbalance between the need and allocated finance mismatch. All of the participants began with the realization that if they were to be able to meet the needs of the person with mental illness, then at least for a time they needed to attend to their own needs as well. As Shuna said:

There's a tendency to sort of put all your energies into the person with serious mental illness. Look I'm from rural area I have sold all the cattle in order to afford transportation cost for medication follow up from country side to Addis Ababa every three months. I'm economically backward at this time when compared with past time though God knows what will be in the future.

All the male participants of this study reported intense economic impact of caregiving in which they sold things at their hand when faced some problems and attempt to address the problem encountered.

### **How Caregivers Manage their Caregiving Responsibility?**

This section is describes how participants manage different responsibilities in caregiving including treatment seeking as a gate-keeper and following up on process in addition to the various roles played in the caregiving situation. This section also describes factors that make the caregiving situation easier including factors associated with their social support and access to treatment. The ways caregivers manage their caregiving responsibilities vary based on the situation in the discourse of caregiving.

**Discussion with the family.** To effectively manage the caregiving situation for their relatives with schizophrenia, participants engaged in detailed discussion with family members on activities performed and the general setting. Nuritu determined to be the primary caregiver for her father lives in Osana town and she started caregiving after she reached a consensus with her brothers who live in Addis Ababa. She described that:

I try my best to make the discourse of caregiving for my father better and interesting using maximum potential in order to manage well the responsibilities assigned with caregiving for persons with serious mental illness. In this case most of the time we held communication at the family level most of the time regarding problems of my father, progress altered including the way out for problems.

Tolesa and Tilanesh also described detailed discussion from time to time on the caregiving process even with individuals outside of their family. Both indicated that such kind of communication is one way of managing caregiving responsibility in such a way that they can easily capitalize existing opportunities and designing reliable way outs for the constraints.

**Responding to needs of their relatives.** The other way of managing caregiving responsibility is by responding immediately to the needs of their care recipients. All participants indicated that they try to fulfill what their relatives want so they will not be angered due to unmet needs. The respondents also indicated that the more you fulfill the needs of persons with mental health problems, the more manageable the situation of caregiving is. Here is the way Tilanesh described management of caregiving in line with the interests of the care receiver:

You know every person has a basic human need and right to be treated with respect and dignity. This need doesn't change when a person becomes ill or disabled - it often

gets stronger and stronger. Since I know well the person I'm caring for I have identified the whole person, including his likes and dislikes, strengths and weaknesses, and his wants and needs. Due to this, I can easily manage the interests of my care receiver which has its own contribution for the healthy relationships between me and my father for whom I have been providing care.

**Treatment monitoring and adherence.** All participants reported treatment monitoring and adherence as one way of managing caregiving responsibility. Burtukan, described her caregiving in monitoring different therapies and adherence as follows:

My caregiving looks like good in monitoring and keeping him adherent and currently he is even good by himself in facilitating some portion of caregiving activity. I influence him to keep his safety and strongly influence him when he fails to do so. Such monitoring makes easy the condition to address it when it is not this much complex.

**Encouraging Independence.** Except for one, respondents reported that though, their relatives' health condition is not suffice for independence in all dimensions keeping them active and creating sense of independence is one way of managing one's caregiving responsibility. Similarly, Tilanesh, Nuritu, Mujib and Tolesa reported that they have seen changes when they watch themselves and guard against overprotecting the person or taking over for their care receivers. Participants shared as concept of empowerment has its own contribution to positive improvements of mental health problem. Tolesa described his experience from this dimension:

When I provide him some opportunity to experience independence the progress from the illness was good. However, if the situation changed unfortunately and he loses some level of independence, he often suffers from low self-esteem. When I see such condition I feel like my care receiver may feel worthless or like he's a burden to me.

What I have learned from such error and trial method is that my attitude can have a positive effect on his sense of worth and independence which create conducive environment for the management of caregiving situation.

Allowing care receivers the freedom to make decisions about their own lives and choosing what and how they want things done effectively enhances the caregiving situation.

**Communication with the persons living with Schizophrenia.** Except for Lamesa, all of the participants showed that communicating with the persons with serious mental health problems is the most effective way of managing caregiving responsibility. The participants similarly described that even- though, communicating with each other provided insight for the caregivers, in most cases their relative was not responsive to the expected level. Birke described her communication with her husband who has schizophrenia as follows:

In bargaining and detailed communication with my husband he supported me to handle the discourse with good behaviour as much as possible. Even when I communicate with him and get response to what I have raised for him, I became capable of understanding some change from his speech which enabled me to have more patience with the uncertainty of how long he will stay under such condition.

**Treating with dignity.** All of the participants reported that there are some challenging behaviors and personalities from the care receiver. Managing such behaviours needs to be considered as one caregiving responsibility. Burtukan, Lamesa, Birke and Tilanesh think that the stress of an illness or disability can lead to a care receiver's behavior becoming difficult. Similarly, they asserted that the personality and behavior of persons with mental illness may change because of the emotional and physical changes he/she is experiencing. Such conscious of the problem by the caregivers paved by treatment induced with dignity.

Similarly, participants reported at times the way they manage their responsibility is through making appointment with the doctor. But this is not common for all caregivers, rather for those who are not much apart from Addis Ababa. For those who are apart from Addis Ababa or country side remaining calm and balanced preferred due to the fact one can't always control the other person's behavior, one can control his/her response to it. This resulted from the fact those who can communicate doctors brought their relatives to the hospital while those apart from Addis Ababa prefer to stay patience due to its economic costs and others. The majority of the participants prefer remaining calm and balanced as an important goal when dealing with any type of difficult behavior since they know their family member is not doing it deliberately.

**Maintaining spiritual practice.** Based on their religious affiliation as per their sects and religious doctrine participants asserted that prayer support organized by their church or mosques and support from religious personnel including holy water (for those who are orthodox Christians) are the other way of managing the caregiving situation. The respondents described prayer and holy water as their main component of spiritual practice used most commonly to simplify their problems or to totally detach from the problem from a religious point of view.

Lamesa described support from his spiritual practice which makes caregiving easier for him:

The search for meaning and spiritual connection provides me a great deal of support and comfort when I'm experiencing a health crisis or long-term illness which counts around ten years. Basically religion has been an important part of my life, and it is important to continue to create opportunities for spiritual connection since I consider the illness of my only son as one kind of temptation when I refused to serve as a leader of church. The ritual of physically going to church, and inviting man of God for spiritual activity makes it possible to get out into the community and connect with

others. Beyond this, my spiritual practice will serve me to get out of such problem since everything impossible for me is possible for God.

Apart from this, the other three respondents who were Muslims also follow their religious outlook and this makes caregiving easier for them.

**Managing Stress.** All of the study participants indicated that stress is part of the caregiving situation. Although the caregivers experienced stressed due to some challenging conditions from the care receiver or from the activity of providing care itself, the stress is one responsibility expected to be managed by the caregiver. Mujib described his experience of managing stress in caregiving as follows:

Stress is a normal part of everyday life for the one experienced from caregiving situation. Although small amounts of stress can keep you alert, too much stress for long periods of time is difficult and can distort your long time effort with some progress. Since this puts me at risk due to its some adverse effects, I immediately try to manage it through asking help from family and friends. Most of the time I try to make sure that I have realistic goals and expectations from myself before commencement of the activity as a caregiver and this balances my emotions immediately since I have convinced myself initially.

**Ignorance.** This is also one aspect of managing caregiving responsibility by caregivers especially when the situation is beyond the capacity of caregivers. The study indicated ignorance as not complete detachment but keeping silent from responding or giving reaction on the issue immediately as one way of balancing emotions.

### **Factors That Make the Caregiving Situation Easier For Caregivers**

**Family Support.** All of the participants accepted their family system as potential sources of support which makes caregiving easier though the level of family involvement may vary across caregivers. The respondents described that caregiving would

not be easy without the support from family beside them. In this context, support from family ranged from family of origin to family of procreation or extended family in general term. Extended family members were also source of support for meeting the challenges of caregiving.

Burtukan, Nuritu, Mujib and Shuna reported that although it is hard to ask for help, it is even harder to provide care alone, especially in terms of finance. They also agreed that asking for help is not a sign of weakness rather; it is the mechanism to make sure the care receiver gets the help she/he needs.

**Medication therapy.** Participants also replied that their relatives' free access to mental health services helped them get treatment at the out-patient and in-patient departments. All of the participants reported that medication therapy helped make the caregiving situation easier.

A majority of the respondents alleged that their relatives sleep better when they get medication therapy and they get break during such times. Lamesa and Birke talked about the possibility of having a break from any kind of challenges from caregiving during medication therapy and when their relatives' get sleep. But this does not mean that improvements from medication therapy are limited to this level only.

**Deep love and emotional attachment.** Nuritu said that there are supports from family members to address economic challenges though it is often not sufficient. She described that deep love and emotional attachment with her father is the main factor that makes caregiving easier despite the challenging situation. Burtukan said that "the caregiving situation linked with love and emotional support and I do have the intention of providing care for my brother". Accordingly, she asserted that "my deep love and expectation to see him better than his current condition in both personal and spiritual life is one kind of support for me in care provision".

## CHAPTER FIVE: DISCUSSION

This section of the study aimed at uncovering the contexts that underlie the overall experiences of family members caring for their relative diagnosed with schizophrenia in line with the literature reviewed. The analysis of the findings was organized around the specific research questions designed. This section puts the findings of this study in the context of the existing literature.

### **Awareness and Perception of Family Caregivers about Schizophrenia**

Given the different backgrounds of study participants in terms of culture, health care and economics, the family caregivers offered different explanations for the cause of mental illness. Except one the rest of participants did not know the type of the mental illness their care receiver had. Though some of the respondents consider mental illness as any other illness, others associate the cause of schizophrenia with some kind of evil work like being possessed by an evil spirit, evil eyes, or the superstitious evil acts of people against their relative. As indicated by Federal Ministry of Health this overall picture corresponds well with findings of different community surveys in Ethiopia which indicated severe mental illness is more often attributed to supernatural causes, for example spirit possession, bewitchment or evil eye, rather than as a result of biomedical or psychosocial causes. Such interpretation is due to the fact it is deeply rooted in traditional belief, cultural and religious views (FDREMoH, 2012/13).

This study also shows a high degree of consensus among some participants who predominantly attributed mental illness to emotional and socioeconomic problems. Thus, some participants perceived the environment around them to cause mental health problems. In other words, they have this assumption that mental illness could be caused by external factors; or to some kind of abnormalities or ill functioning inside their body. This finding

confirms the bio-psycho-social view which explained human behavior can be affected positively or negatively by biological, psychological, social and environmental factors (Kaplan & Coogan, 2005, p. 18).

Participants in this study also developed knowledge of their relatives' mental illness and its treatment from what they experienced, what they heard from the community, the church, their personal observation of other people with mental health problems and their reading from relevant text-books. The perception of respondents regarding mental illness was highly influenced by their personal experience. The more they see different unusual personalities in line with what they heard and observe from the community the more they perceive the real context of the problem. This shows how the awareness and perception of the participants was influenced by the type of information they have access to. This is consistent with the ecological model of health behavior that argues specific health behaviors are influenced by intrapersonal (biological, psychological), interpersonal (social, cultural) and organizational factors (Glanz et al., 2008).

### **Meaning of Caregiving for Relatives with Schizophrenia**

Participants' description of the meaning of caregiving for their relatives' with mental illness was highly associated with preventing the severity of the illness and worsening of the symptoms, developing sympathy, dealing with contesting situation that can generate both negative and positive attitudes from caregiving, and developing knowledge that helps with challenging situations. This finding is consistent with the report on caregiving meaning which stated that the family caregiver is the most important person who cares for the person with schizophrenia (Clement et al., 1995 as cited in Rafiyah & Sutharangsee, 2011). Caregivers usually help the person with schizophrenia in performing their daily activities such as bathing, eating, cooking, dressing, taking medications, and going for checkups. Many family caregivers may deal with responsibilities both at work and at home when a loved one gets ill.

Caregivers' personal need for rest and attention to their own health may be neglected. This leads to dealing with multiple responsibilities, some of which may conflict with one another (Rafiyah & Sutharangsee, 2011). The findings also point out that caregiving is the experience of developing conscious to improve challenging situations in which the health and needs of the caregiver may not well addressed.

Some participants described caregiving meaning as accepting whatever the condition could be for your loved one having no more chance to be served without you. For example, Lamesa stated "whatever the challenges from caregiving may be in order to save the soul of my only son I have already accepted the situation". Chesla (1991 as cited in Jeon & Madjar, 1998) identified styles of interaction caregiving particularly engaged care, as continued care with understanding and acceptance of the sometimes difficult and inappropriate behaviours of the person with schizophrenia.

Caregivers who experience managed care, which is characterized by being enthusiastically active and objective in managing and learning to cope, still found caregiving to be very draining, and they expressed a strong need for breaks from the work of caring (Chesla, 1991 cited by Jeon & Madjar, 1998). The finding from the study also corresponds with developing ways for effectively managing caregiving responsibility while maintaining hope for good health in the future without giving up. Caregivers tried to cope positively rather than being in a state of despair.

### **Enrichment Experiences from Caregiving for Relatives' With Mental Illness**

Study participants described their use of and satisfaction with caregiving related services such as mental health care service and medication. Caregivers were especially grateful for medication provided for their care receiver since this had its own positive effect on the health condition of the person with schizophrenia. This study also indicated that care

givers have both positive and negative attitudes about caregiving. The enriching experiences are important to educate others about their experiences, to benefit from the experiences of others, and to appreciate their experiences. In addition, being able to take advantage of advances in care for the care receiver give them hope.

The progress seen in relation to the mental illness condition of the care recipients is also the other wing of the enriching experience of family caregivers. Different relatives of the cases with schizophrenia were more satisfied with small improvements and successes achieved by patients (Shibre et al., 2003, p.27).

Most participants also adopted responsibility for preventing adverse or worst effects of mental illness and such management of unexpected problems also contributed to the positive attitude of family caregivers. This argument is consistent with the idea of systematic organization framework (Friedemann, 1995) which describes dimensions of strategies used by families to function. This strategy is system maintenance which includes all family processes that provide organization and structure and that help maintain the family's stability. The other dimension of coherence consists of strategies that lead family members to bond and commit time and energy to one another.

Similarly, Goodman and colleagues (2007) indicated that despite some negative experiences, most caregivers did, at times, experience support from a few people who understood or tried to understand. Caring for a loved one who is ill often creates a deepened sense of closeness and connection between the caregivers and the person with schizophrenia. Family caregivers may also experience increased intimacy, satisfaction, and pride in the course of caring for their loved one with schizophrenia. The aforementioned varied and complex emotions in care-giving for persons with schizophrenia are among the most common. Thus, feeling both positive and negative emotions during providing care for a loved one who is ill is normal.

Yatchmenoff and colleagues (1998 cited by Mendenhall & Mount, 2011) also found some positive associations for caregivers including pride in fulfilling spousal responsibilities, enhanced closeness with a care receiver, and satisfaction with one's competence in care-giving. These perceived uplifts of care-giving are associated with lower levels of caregiver burden and depression (p. 183). But participants in this study did not indicate such a reverse association between burden and depression with enrichment. Lamesa reported "I have been for a long time in this situation but I don't want to be in the state of despair since I consider it as linked with temptation and I will challenge it through spiritual practice."

### **Negative Impacts of Caregiving for Relatives with Schizophrenia**

Participants indicated emotional distress, stigmatization, financial constraints, labelling of individuals with mental illness, separation from social networks, challenging personalities from care recipients, physical conditions and employment as factors that negatively affected their lives. Most of these issues appear to also influence the caregiving experience of any other individual part of the family. This confirms assertion of World Health Organization (WHO) report which indicated various impacts on caregivers including: the economic burden related to the need to support the patient, emotional reactions to the patient's illness such as a feeling of loss about the future; the stress of coping with disturbed behaviour; problems of coping with social withdrawal or awkward interpersonal behaviour, and curtailment of social activities (WHO.1998).

The interviews with participants have also shown that the burden of caregiving influences their social life including their caregiving experiences. Besides directly limiting their social network and consequently their ability to develop their personal advantages, caregiving burden leads to negative consequences not only for themselves but also for patients, other family members, and the health care system. This study found that the emotional distress is linked with the apparent negative labelling and uncertainty about how

long they will remain as caregivers. Such personal and social challenges influence their caregiving experiences and feelings.

These findings are consistent with those of Summerville and Atherley (2012) who asserted that even if most of the participants thought caring for persons with schizophrenia is challenging many families say that the worst thing about living with mental illness is not the mental illness itself, but the persistent effects of the stigma that they experience in their interactions with the public and with healthcare service providers. Family members identify stigma, social pressure such as labelling persons with schizophrenia as violent, dissatisfaction with the support from family members, and financial problems as bigger stressors than the illness of the care recipients by itself. As the literature reveals, the mental illness is not always the greatest challenge. Rather such challenges result from factors that breed physical, psychological and financial stress and strains for family caregivers of persons with schizophrenia (Summerville & Atherley, 2012, p.8).

A study conducted in Ethiopia also indicated that mental illnesses can affect persons of any age and they can occur in any family. Over a million Ethiopians are estimated to suffer from mental illness (Schizophrenia and Affective Disorders) and millions of their family members struggle to cope with its social consequences. The attitude of the public towards such an illness has only recently been addressed (Alem et al. 1995).

Consistent with previous literature in Ethiopia mental illness still generates misunderstanding, prejudice, confusion and fear. People with mental illness faced stigma at times worse than the illness itself. There is no doubt that such prejudice has substantial negative social, political, economic and psychological consequences for stigmatized people. In common language, stigmatization involves a separation of individuals labelled as different from "us" who are believed to possess negative traits, resulting in negative emotional reactions, discrimination, and status loss for the stigmatized persons (Eshetu

Wencheko, Shibiru Temesgen, Nigusie Dejene, Girma Taye, Nigusie Galatu (eds), 2008). A study conducted by Shibire et al., (2003) also shows that the impact of schizophrenia on family members is high even in traditional societies such as Ethiopia where the family network and informal social control is said to be strong and important.

With schizophrenia, the most risky of the high-risk behaviours involve persons' not taking prescribed medications. Volatile or risky behaviours, such as unprotected sex, prior to the schizophrenia, will likely exhibit by person with schizophrenia during the illness, in a more complicated form (Summerville and Atherley, 2012, p.10). Behaviour of the care recipients as described by participants configured the idea of non adherence as mostly occurred problem. However, participants' arguments challenge the second assertion in which they attested as exhibition of complex behaviours not evenly seen in all dimensions such as sexual behavior and interest. Two participants Birke and Mujib reported that though they are not sure of the factors behind, the complex exhibition of behaviors prior to schizophrenia not commonly seen in their care recipient's situation. Birke who had three children before her husband became schizophrenic described her husband's sexual interest as almost dead. The second participant similarly described remarkable differences in the sexual behavior. The brother's wife reported that it was a long time since he had sex with his partner and he even ignored her when she communicated on this issue. He also shared that she was offended by the condition of her husband and requested that they separate though they convinced her to stay and be patient with the progress of his illness.

### **What Makes Caregiving Discourse Easier For Family Caregivers?**

Participants of this study evidenced different types of help that would facilitate a healthy balance their lives of family caregivers, and in the lives of their loved ones. Their needs include: information about available supports ranging from bio-psycho-social to spiritual; recognition so that family caregivers' services are utilized meaningfully; validation

and response not only from their extended families, but also from their service providers, communities; skills development to help them in promoting recovery and in preventing relapses through medication; and emotional support. For most participants, especially female respondents', active engagement in religious practices and similar opportunities for spiritual self-expression are key components of the recovery and community integration journey for many individuals. The study indicated religion can be a rich source of emotional and social support, as well as a tool for coping. However, it is not known whether or not these interventions reduce care recipients problem than family burden though caregivers expect it from both dimensions.

This overall picture corresponds well with findings from a phenomenological study conducted by Jeon & Madjar which argues that support from family and community groups was particularly meaningful for family members caring for a person with schizophrenia. Reducing the caregivers' feelings of isolation and increasing their feelings of confidence is important. Feeling the difference came through recognition that there were others, including some health professionals, who could understand their challenges and be sympathetic (Jeon & Madjar, 1998, p.9).

### **How Family Caregivers Manage Their Caregiving Responsibility**

Participants used their own individual strategies to effectively manage and overcome challenging situations related with their caregiving responsibilities. Participants said they held discussions with family members, fulfilled the needs and interest of their care recipients, intensely and monitored and strengthened treatment adherence, encouraged independence and provided care with caring with dignity and communication with care recipients. Commenting on different styles of coping, Shibre et al. (2003) noted that there are some people who are action oriented and cope by doing something, whereas others are motivated towards self-understanding and use introspection to manage stress. In the presented study, coping

mechanisms of most the relatives were inclined towards prayer for guidance or strength to cope with the difficulties, talking with someone about their problems and taking pride in small successes.

## CHAPTER SIX: CONCLUSION AND SOCIAL WORK IMPLICATIONS

### Conclusion

The study participants' own perceptions of what it is like to provide care to a family member with mental illness indicate the existence of a unique life of the person who develops mental illness and is seen as needing ongoing protection care and treatment. The meaning of caregiving is defined subjectively by a strong sense of responsibility, and therefore this responsibility constructs the caregivers' life in particular ways, including both challenging and enriching dimensions.

Caring for a family member with mental illness is a lived experience that is embodied both personally and in the structure of family relationships. Nevertheless, family caregivers need skills to manage strong emotions and difficult and often challenging situations. This and other studies suggest that family caregivers do not often receive help to develop such skills. The study indicated that individuals with chronic mental illness are best cared for within a family home, where they may be expected to experience a better quality of life. However, the substantial personal, social, and financial costs that family caregivers often have to endure can be taken for granted and may be neither recognized nor eased by others.

In light of current trends toward greater emphasis on community based care, it is essential that professionals including social workers, nurses and others recognize and understand the human experiences that are the outcomes of family caregiving. This study has documented the very real and ongoing challenges of family caregivers of relatives with schizophrenia. Society and the health care system depend on families taking on the responsibility for the long-term care of their ill and weak members. Several factors may significantly affect the lives of family caregivers including: emotional distress, stigmatization, financial constraints, labelling given for individuals with mental illness, separation from social networks, challenging personalities from care recipients, physical

conditions and employment challenges. Prayer was the most often used coping strategy to ease caregiver burden. The existing limited services should also be expanded to offer support at least in educating the family members about the nature of schizophrenia and how to deal with stigma and family burden.

Several personal and social challenges related to caregiving had a negative impact on family members which in turn influenced their caregiving experiences and feelings. The burden of family caregivers also causes family conflict and financial problems for individuals, families, and the health care system. However, these impacts might vary among caregivers, as level of burden is related to various factors. Despite the challenges, feeling positive is also one of the aspect of caregiving experience. Study participants indicated that usage and satisfaction with caregiving related services by caregivers resulted in progress in the illness condition of the care recipients. Additionally, educating others about their experiences, benefiting from the experiences with others, appreciating their experiences, and taking advantage of advances in care for the care receiver gave them hope.

Findings from the current study revealed that there are relationships between caregiving meaning experiences and the situation by the study participants. This implies that the meaning of caring for their relatives with mental illness has an impact on the experience of caregiving. Therefore basic information and understanding about the nature of the illness, including the course and outcome of the illness are needed for the patient, family and the general society.

This study has recognized the importance of families and social supports for family caregivers of persons with schizophrenia who participated in this study. With all the challenges, various resources were used by participants' from different support systems available in their environments. These are mainly support from their family members' formal and informal institutions. Other information about available supports ranged from

biopsychosocial to spiritual; recognition so that family caregivers' services are utilized meaningfully; validation and response not only from their extended families, but also from service providers, communities; skills development to help them in promoting recovery and in preventing relapses through medication; and emotional support. Hence much can be accomplished with the available resources if the importance of addressing social needs is understood in a comprehensive manner.

This study has also recognized different ways of managing caregiving responsibility such as discussion with the family, communication based service delivery with the care recipients, caring with dignity and respect, developing sense of empowerment in the minds of care recipients, strengthening treatment monitoring and adherence as one way of addressing problems before they become worsened than expected level.

### **Social Work Implications**

People with mental illness are considered to be vulnerable individuals. Their vulnerability and different unusual personalities may adversely influence the lives of their family caregivers and the family unit at large. Social work is a profession that works towards bettering the life of vulnerable groups of people. As indicated in this study, the negative impact of caring for such vulnerable groups of people with schizophrenia is an area that needs holistic intervention. In addition to challenges that caregivers encountered due to their relatives; mental illness they were also challenged to seek and use mental health services. As the study indicated the challenges participants encountered are multi-dimensional and interrelated. Due to this holistic intervention at different levels such as individual, family, and societal levels are needed.

Providing direct social services to patients and their family caregivers is one of the major roles of social workers. These include psychosocial interventions which comprise individual, family and group interventions that are used to achieve specific therapeutic outcomes. Social workers should also strengthen the communications and relationship, encouraging independence, improving safety, keeping their relatives' active among persons with schizophrenia and their relatives during caregiving discourse.

As one part of implication for education Social Workers should provide trainings for persons with schizophrenia and for their caregivers on the nature of the illness, update them from time to time the relapse condition, improvement indicators, and largely the name of the disease which this study recognized as a remarkable gap though they have full right to know and should have to be well informed. Social workers should also provide different trainings on various aspects of caregiving and they should develop an encouraging environment for such groups. The current study suggested that when family caregivers receive assistance from support groups, family members and the community at large, caregiving becomes easier. Advocacy is one tool for access and fair distribution of necessary resources is one way of assisting persons with serious mental illness to use maximum benefit from the health facilities and community-based social and health resources.

Family caregiving experiences are greatly influenced by a variety of challenges such as financial constraints meeting their own needs and that of their care recipients, uncertainty about how long to stay as caregivers and social stigma including their own personal challenges as family caregivers. Therefore, family level interventions such as organization of family sessions to create awareness about mental illness, provision of safe care to their ill family member, and enhance family members' participation in the care giving processes are needed and can be very helpful in the overall caregiving process.

From the challenges described in the study, social challenges are especially stressful to caregivers especially labelling and stigma. Social workers can work to help minimize stigma against recovering clients in both families and communities by creating awareness and improving understanding of mental illness.

Social workers should also advocate for the social services and needs of people with schizophrenia and their respective family caregivers since they are potential partners for such individuals to minimize relapse rates and promote positive progress in the illness. In addition, social work can also use their research skills to conduct different studies in the areas of family caregiving and mental illness. The current study indicated experiences family caregivers of person with schizophrenia and detail experiences should be conducted across demography of family caregivers.

In line with the other intervention strategies, concerned bodies should also design comprehensive social policies that can address problems of persons with serious mental illness and their family caregivers. To these effect types of support policies address various problems of caregivers beyond problems of person with mental health problem. Policies and programs address different needs of caregivers, respite care programs and other policy gaps in this area should addressed. The study indicated remarkable change and positive outcomes in caregiving situation and progress from the illness when the appropriate support strategies are in place. Informal support systems at the family and community members level has potential positive impact on the course of caregiving and the more formal and recognition of community caregiving system the more potential benefits of keeping delicate balances of the society. Beyond this the enrichment aspects of family caregivers is one remarkable indicator for the half full glass which pave ways for developing and shining out role of psycho-social intervention more significant.

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### **Appendix 1: Interview Guides**

Hello! Thank you for participating in this study. I would like to start by having your background information. Can we start by telling me about yourself such as your age, where and with whom you live; your educational, marital and occupational status, Years since your relative's mental health problem start, periods/years of care giving.

Can you tell me what you know about the type of mental illness your relative has?

What do you think is the cause of your relative's mental illness?

How do you develop your knowledge or what situation helped you to know about the illness, its causes and treatment?

What was the reason for you becoming the caregiver for your relative?

What are your general views about the caregiving course?

Thinking back to when you heard and initially entered the caregiving, what did that process look like for you?

Were you asked about your thoughts and observations during the assessment of your relative?

Were you given information about (name) of illness?

What factors influenced you to continue, with care-giving?

What have been subsequent experiences of caregiving?

Do you think that caring for someone with mental disorder type of your relative can be a rewarding experience?

What, if anything, would have been more helpful had you known about it earlier?

What factors make care provision for your relative easy for you?

What do you think might have helped you to be successful in care provision?

Do you think that caregiving has tremendous personal satisfaction?

How do you explain such experiences?

Do you provide love and emotional support?

Is that due giving back to those who have given you before?

How do you give meaning to the caregiving experience for your relative with schizophrenia?

Are you grateful since you are caregiver for your relative?

Is your relationship deeper, meaningful that develops over the course of caregiving?

Do you think it requires tireless effort, energy and empathy?

How does caregiving affect your daily lives? How do explain it in terms of physical, social, emotional, and financial impacts by virtue of being caregiver?

Do you think that you are the backbone of the long-term care system?

What does your caregiving for your relative looks like?

In monitoring treatment and adherence?

Keeping your relative active?

In improving safety

Supporting independence

Communicating

What do you think is challenging in caregiving from the care recipient?

Did your relative get upset, worried and angry more easily?

Act depressed or not interested in things?

Hide things or believe other people are hiding things?

Imagine things that aren't there?

Hit you or other people?

Misunderstand what he or she sees or hears?

What do you think is significant impact of caregiving on a caregiver's own life and health, both (physical and emotional)?

Is there any economic impact of caregiving for person with this type of mental disorder?

Have you ever been challenged by your relative disorders and illnesses?

What are the personal challenges you encountered while you provide care?

What are the social challenges you encountered in the course of caregiving?

What other challenges you encountered for the betterment of caregiving situation?

Are there times when you need more support than others? When would those times be?

How do you respond to your relative with mental illness?

To moral failure in your personal lives; ethical failure in your community?

For what are you responsible when you are perfectly caring for your relative with this type of disorder?

What has been the most effective way to find out about better caregiving?

How do you cope with various challenges of caregiving?

Were you given advice on how to cope with illness type of your relative?

Have you attended any workshops, trainings on how to help you cope at home with the illness?

What are your feelings regarding the social support and resources for supporting individual with illness?

What information do you need more in caregiving? (Such as, diagnoses, medication information, side effects of medication, social events, vocational events)

Have you ever received information on how to care for your relative?

Are workers with potential information and doctors accessible for you? (After hour availability, returning calls)

Is it enough information?

How this can determine your experiences in caregiving as a family member?

What would be adequate support for you as a family member?

What do you think caregivers need to seek and do for the betterment of service provision?

## **Annex 2: Informed Consent Form**

My name is Gemachu Fufa, a masters student at School of Social Work (MSW), Addis Ababa University. I am planning to conduct a study on the experiences of family members caring for a relative diagnosed with schizophrenia to fulfill my study of social work. The purpose of the study is to understand the various experiences in the course of caregiving, negative impacts, enrichments, and challenges family members like you face during care provision for their relative with schizophrenia. The overall aim of the study is to understand the experiences of family members who are providing care to mentally ill relative. For the successful accomplishment of the study, the cooperation of caregivers who are experienced from caring for their relative with mental disorder is crucial and I would like to ask for your permission to participate voluntarily in this study. Your participation in this study will help me to know the effort you made to care for your relative and understand at least some of the challenges including enrichments you might get from caring for your relative.

The following selection criteria for identifying potential participants of this study will be considered. The inclusion criteria will be: (a) family members of persons with schizophrenia, (b) family members who live with their ill loved ones, care for them and help them manage daily activities, (c) family members who are adults, (d) those who are willing to be part of the research voluntarily and who are open to disclosing their situation.

The procedures to be used in this research are in-depth interviews. The time and conditions required to participate in this project will be scheduled at a time and place convenient for participants. In the course of data collection, any possible risks or discomfort to the research participant will be minimal. The researcher will clarify any unclear question(s) during the interview. If needed, the researcher will provide you a telephone number or his full

address. During the whole process of the study and after that, I would like to assure you that your identity will not be disclosed to anyone. In this case the information you provide will have your name removed and only pseudonym or other codes will identify the participants during analyses and any written reports of the research. This is to protect your privacy and confidentiality of the information you provide. All tapes, transcripts, and written memos and field notes after completion of the study and will be locked and kept in safe place for a limited periods of time and be destroyed after the study is completed and approved by the School of Social Work.

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 mental illness treatment. Apart from the time you spend with me, I do not see any risk that you will under go by participating in this study.

I grant you for any data collected are to be used in the process of completing a Master of Social Work and 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 to be part of the project by signing this form show your agreement to participate in this research under the provided conditions.

Name of participant (pseudonym) \_\_\_\_\_

Date \_\_\_\_\_

Annex 3

An Interview Guide (Amharic Version)

የቃለ መጠይቅ መመሪያ

ውድ የጥናቱ ተሳታፊ እንደምን አደሩ/እንደምን ዋለ?

በቅዲሚያ በዚህ ጥናት ስለተሳተፉ አመሰግናለሁ። ስለእርስዎ አጠቃላይ መረጃ በማግኘት እጅምራለሁ። ስለዚህ ስለራስዎ ለእኔ በመንገር መጀመር እንችላለን ማለትም እድሜዎትን፣ ይት እና ከማን ጋር እደሚኖሩ፣ የትምህርት ደረጃ፣ የጋብቻ ሁኔታ፣ የስራ ሁኔታ፣ ከመቼ ጀምሮ ዘመዶዎ ስኪዞፍራይዝ ችግር እንደጀመረዎት፣ ለምን ያህል ጊዜ ዘመዶዎን ትንክባክቡ?

ዘመዶዎን ስለያዘዉ የአይምሮ ህመም አይነት የሚያወቁትን ንገር ሊንግሩኝ ይችላሉ?

የዘመዶዎ የአይምሮ ህመም ምክንያት ምንድን ነዉ ብለዉ ያስባሉ?

እንዴት እዉቀተዉን አዳበሩ ወይም ስለ አይምሮ ህመም፣ ስለ መነሻዉ፣ ስለህክምናዉ ለማዉቅ ምን ሁኔታዎች ናቸዉ የረዳዎት?

ዘመዶዎን ለመንከባከብ ምክንያተዉ ምን ነበር ?

በአጠቃላይ ስለ መንከባከብ ሂደት ምን አመለካከት አለዎት?

ለመጀመሪያ የሰሙብትን እና ወደ መንከባከብ የገቡብትን ጊዜ ወደ ኃላ ተመልሰዉ ያስታዉሱ እና ለእርሶዎ ሂደቱ ምን ይመስል ነበር?

ስለ ዘመዶዎ ዳሳሳ/ በሚደረግበት ወቅት እርሶዎ ያለዎትን አመለካከት እና አስተሳሰብ ተጠይቀዉ ነበር?

ስለ ህመሙ ስም መረጃ ተሰጥተዎታል?

በ መንከባከብ እንዲቀጥሉ ምን ሁኔታዎች ናቸዉ ግፊት ያሳደሩባችሁ?

የመንከባከብ ሂደት ምን ይመስላል?

የአይምሮ ህመም ያለበትን ዘመዶዎን መንከባከብ የሚያስደስት /የሚያረካ ልምድ ነዉ በለዉ ያስባሉ?

ለ ዘመደዎ እንክብካቤ በሚያደርጉበት/በሚያቀርቡበት ወቅት ለእርስዎ ምን ሁኔታዎች ናቸው?

እንክብካቤዎን ቀላል የሚያደርግለዎት?

1. በእንክብካቤ አቅርቦት ውጤታማ ለመሆን ምንደን ነው የረዳኝ ብለው ያስባሉ ?

እንክብካቤ ማድረግ ትልቅ የሆነ ግላዊ እርካታ አለው ብለው ያስባሉ?

- ይህንን ልምድ እንዴት ይገልጹታል?
- ፍቅር እና ስነልቦናዊ ድጋፍ ያደርጋሉ?

እርስዎ ስኪዞፍሬንያ ያለበትን ዘመድዎን የመንከባከብ ልምድ እንዴት ነው ትርጉም የምትሰጠው/የምትሰጩ?

- እርስዎ ዘመደዎን መንከባከብ ከጀመሩ ጀምሮ ደስተኛ ነዎት?
- በመንከባከቡ ሂደት ውስጥ የዳበረ ጥልቅ እና ትርጉም ያለው ግንኙነት ነው ያለዎት?
- መንከባከብ ብዙ ድካም፣ጉልበት እና መረዳት/ግንዛቤ ይጠይቃል ብለው ያስባሉ?
- መንከባከብ በእለት ተለት ኑሮዎ ላይ አንዴት ነው ተጽዕኖ ያደረገው፣ አንዴት ነው ተጽዕኖውን በአካላዊ፣ በማህበራዊ፣ በስነልቦናዊ እና ኢኮኖሚያዊ በተመለከተ የሚገልጹት?

ለረጅም ጊዜ የመንከባከብ ስረአት ውስጥ እርስዎ የጀርባአጥንት ነኝ ብለው የሰባሉ?

የ ዘመደዎን የመንከባከብ ሁኔታ ምን ይመስላል?

- ህክምናውን ከመከታተል አንጻር
- ዘመድዎ ንቁ እዲሆን ከማድረግ አንጻር
- እራሳቸውን እንዲችሉ ከመርደት

በመንከባከቡ ወቅት ከተጠቃሚዎች ዘንድ ያለው ተግዳሮት ምንድን ነው ብለው ያስባሉ?

- ዘመድዎ በቀላሉ ይቆጣሉ፣ ይጨነቃሉ፣ ይናደዳሉ?
- የድብርት ስሜት ያሳያሉ ወይስ በነገሮች ላይ ፍላጎት ያጣሉ?
- ነገሮችን ይደብቀሉ ወይስ ሌሎች ሰዎች ነገሮችን ይደብቀሉ ብለው ያስባሉ?
- የሰሉትን ነገሮች ያልማሉ?
- እናንተን ይመታችኋል ወይስ ሌሎች ሰዎችን ይመታሉ ?
- ያዩትን ወይም የስሙትን በትክክል አለመረዳት?

መንከባከብ በተንከባካቢዎች ህይወት፣ በጤና፣ በአካላዊ እና በስነልቦናዊ ምን አይነት ትልቅ ተጽእኖ አለው ብለው ያስባሉ?

በእንደዚህ አይነት የአእምሮ ችግር የተያዙ ሰዎችን መርዳት የኢኮኖሚ ተጽእኖ አለው?

በዘመድዎ ህመም ምክንያት የገጠመዎ ችግር አለ?

አንክብከቤ በሚያደርጉበት ጊዜ የገጠመዉት የግል ተግዳሮት ምንድን ነው?

በእንክብካቤ ሂደት ውስጥ የገጠመዉት ማህበራዊ ተግዳሮት ምንድን ነው?

የእንክብካቤዉን ሁኔታ የተሻለ ለማድረግ የገጠሙ ሌሎች ተግዳሮቶች ምንድን ናቸው?

ከሌሎች ጊዜያቶች በተለየ ድጋፍ የሚፈልጉበት ጊዜያቶች አሉ፣ መቼ ናቸው እነዚያ ጊዜያቶች?

እንዴት ነው ለአእምሮ ህመም ላለባቸው ዘመድዎ መልስ የሚሰጣቸው?

- የምራል ወድቀት በግል ህይወተዎ ውስጥ፣ የምራል ወድቀት በህብረተሰብዎ ውስጥ
- በእንደዚህ አይነት በሽታ የተያዘዉን ዘመድዎን በትክክል በሚንከባከቡበት በ ጊዜ የእርስዎ ሀላፊነት ለትኛው ነው?

የተሻለ እንክብካቤ ለመፍጠር ውጤታማ የሆነው መንገድ ምንድን ነው?

በመንከባከቡ ምክንያት የመጡ ችግሮችን/ተግዳሮቶችን እንዴት ነው የተቋቋሙት?

ከእንደዚህ አይነት ህመም ከለባቸዎ ዘመድዎ ጋር እንዴት መቋቋም እደሚችሉ ምክር አግኝተው ነበር?

እንዴት ቤት ውስጥ ከበሽታው ጋር መቋቋም እንደሚችሉ የሚረዱ ስልጠናዎች፣ዎርክሾፖች ላይ ተሳትፈው ያዉቃሉ?

በበሽታው የተያዙ ገለሰቦች ለመርደት የእርሰዎ ስሜት መሃበራዎ ድጋፍን እና ሀብት በተመለከተ ምንድን ነው?

በመንከባከቡ ሂደት ውስጥ ምን መረጃን በይበልጥ ይፈልጋሉ ለምሳሌ ህክመናን በተመለከተ፣ስለመዳህኒቱ በተመለከተ፣ማህበራዊ ክስተቶች፣ስለስራ ክስተቶች በተመለከተ?

**2. አንክብካቤ ውስጥ በመግባተዎ ምን አይነት ዕድል አግኝተዋል ?**

ከገጠመዎት እድል ውስጥ የትኛው ነው በጣም የረዳኝ ብለው የሚያስቡት ?

ዘመደዎን እንዴት እንደሚንከባከቡ መረጃ ተቀብለው ያዉቃሉ?

በቂ መረጃ ያላቸው ሰዎች ማለትም ዶክተሮችን ማግኘት ለእርሰዎ ቀላል ነው(ከስራ ስአት ውጪ፣ስልክ ከመመለስ አንጻር)?

በቂ መረጃ ነው?

ልክ እንዳአንድ የቤተሰብ አባል ለእርሰዎ በቂ ድጋፍ ምንድን ነው?

ስለ እንክብካቤ አቅርቦት እና የእንክብካቤ ልምድ የእርሰዎ አስተያየት ምንድን ነው?

ለተሻለ አገልግሎት አቅርቦት ተንከባካቢዎች ምን ማግኘት እና ምን ማድረግ አለባቸው ብለው እርሰዎ ያስባሉ?

Annex 4

የስምምነት ቅፅ

ውድ የጥናቱ ተሳታፊ እንደምን አደሩ/እንደምን ዋለ?

ገመቹ ፉፋ እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት ክፍል የድህረ ምረቃ ፕሮግራም ተማሪ ስሆን ለሁለተኛ ዲግሪ መመረቂያ የሚሆን የማሚያ ጥናት በማድረግ ላይ እገኛለሁ።

የጥናቱ ዓላማ እንደእርስዎ ዓይነት የቤተሰብ አባላት በአስተሳሰብ የስሜት እና የባህሪ መታወክ (ስኪዞኖራንያ) የተጎዱ ሰዎችን በሚንከባከቡበት ጊዜ ያጋጠማቸውን ልዩ ልዩ አወንታዊ እና አሉታዊ ተጽእኖዎችን፣ መሻሻሎችን እና ተግዳሮቶችን ልምድ ለመረዳት ነው። በአጠቃላይ የጥናቱ ዓላማ የአእምሮ ችግር ያለባቸው ቤተሰቦችን የሚንከባከቡ የቤተሰብ አባላት ያላቸውን ልምድ መረዳት ነው። ለጥናቱ በስኬት መጠናቀቅ የአእምሮ መታወክ ያለባቸው ዘመዶቻቸውን የመንከባከብ ልምድ ካላቸው ሰዎች ትብብር ማግኘት ወሳኝ ስለሆነ በጥናቱ ላይ ለመሳተፍ ፈቃደኝነትዎን እጠይቃለሁ። በጥናቱ መሳተፍዎ ለዘመድዎ እንክብካቤ ለማድረግ ያደረጉትን ጥረት ለማወቅና ዘመድዎን በመንከባከብ ያገኙት ለውጦችን እንዲሁም ተግዳሮቶችን ለመረዳት ያስችለኛል።

በዚህ ጥናት የሚሳተፉ ታሳቢ ተሳታፊዎችን ለመለየት የሚከተሉት መስፈርቶች ከግምት ተወስደዋል። በጥናቱ ለመሳተፍ የማካተቻ መስፈርቶች፡- (ሀ) ከቤተሰብ አባላት መካከል በአስተሳሰብ የስሜት እና የባህሪ መታወክ (ስኪዞኖራንያ) የተጎዱ ሰው መኖር፣ (ለ) ከታመሙ ቤተሰቦቻቸው ጋር እየኖሩ የሚንከባከቡ እና የቀን ተቀን እንቅስቃሴዎቻቸውን

በመቆጣጠር የሚያግዙ፣ (ሐ) የአዋቂ እድሜ ላይ የደረሱ የቤተሰብ አባላት፣ (መ) የጥናቱ አካል ለመሆን ፈቃደኝነት ያሳዩና ያሉበትን ሁኔታ መግለጽ የሚችሉ።

በዚህ ጥናት የምንጠቀመው አሰራር ጥልቅ ቃለመጠይቅ ነው። በዚህ ኘሮጀክት ውስጥ ለመሳተፍ የሚያስፈልገው ጊዜ እና ሁኔታ ለተሳታፊዎች በሚመች ሰዓትና ሁኔታ ይመቻቻል። በቃለመጠይቁ ጊዜ ግልጽ ያልሆነ ጥያቄ ቢኖር ተመራማሪው ያብራራሉ። የሚፈልጉትን ጥያቄ ብቻ የመመለስ ነጻነት አለዎት። ካልተመቸዎች ጥያቄን አለመመለስ ይችላሉ። በቃለ መጠይቁ ጊዜ ያልተረዷቸው ጥያቄዎች ቢኖሩ መጠየቅ የሚችሉ ሲሆን ድካም ከተሰማዎትና በኋላ መቀጠል የሚፈልጉ ከሆነም ምርጫው የእርስዎ ነው። በየትኛውም ጊዜ የመጠየቅና ማብራሪያ የማግኘት መብት አለዎት። ካስፈለገም አጥኚው አንድ ስልክ ቁጥር ወይም ሙሉ አድራሻውን ይሰጥዎታል።

በጥናቱ ጊዜና ከዚያም በኋላ ማንነትዎን ለማንም ግልጽ አይደረግም። በዚህ ሁኔታ የሚሰጡት መረጃ ስምዎን ከላዩ ላይ ይሰረዝና በጥናቱ ትንተና እና የጽሁፍ ዘገባ በሚቀርብበት ጊዜ መለያ የሚሆን ምልክት ወይም ቁጥር ይሰጠዋል። ይህ የሚደረገው የእርስዎን ማንነት እና የሰጡትን መረጃ ሚስጥራዊነት ለመጠበቅ ነው። ጥናቱ ከተጠናቀቀ በኋላ በቴኝ የተቀረጹ፣ የተገለበጡ ጽሁፎች እና የጽሁፍ ማስታወሻዎችና የመስክ ማስታወሻዎች ለተወሰነ ጊዜ ተቆልፎባቸው በጥንቃቄ ይያዙና ጥናቱ ከተጠናቀቀ በማህበራዊ ስራ ጥናት ት/ቤት ከተረጋገጠ በኋላ ይደመሰሳሉ።

በዚህ ሂደት ማንነትዎ ለማንም ተላልፎ እንደማይሰጥ ላረጋግጥልዎት እወዳለሁ። ይህ የሚደረገው የእርስዎን ማንነት እና የሰጡትን መረጃ ሚስጥራዊነት ለመጠበቅ ነው። ያደረግነውን ውይይት ለመቅረጽ ቴኝ የምጠቀም ሲሆን በጥንቃቄ ተቆልፎበት ይቀመጥና ማንም እንዳያገኘው ይደረጋል። በዚህ ጥናት በመሳተፍዎ ጥናቶቹን ለማሳካት አስተዋጽኦ ያደርጉልኛል። በዚህ ዙሪያ ከተደረጉ ጥናቶች በጣም አነስተኛነት የተነሳ የዚህ ምርምር ውጤት ለአእምሮ ህመም ህክምና አስተዋጽኦ ስለሚያደርግ በአእምሮ ጤና ዘርፍ ለሚደረግ

ለውጥ አስተዋጽኦ ያደርጋሉ። ከእኔ ጋር የሚያሳልፉት ጊዜ ውጪ በዚህ ጥናት በመሳተፍዎ የሚያገጥምዎት ምንም ዓይነት ስጋት አይኖርም።

በመጨረሻ ይህንን ቅጽ በመፈረም ከላይ በተጠቀሱት ሁኔታዎች ላይ ተስማምተው በኛሮጀክቱ ላይ ለመሳተፍ ፈቃደኛ መሆንዎን ማረጋገጥ እወዳለሁ።

የጥናቱ ተሳታፊ (መለያ) .....

ጥናቱን ያካሄደው

ፊርማ \_\_\_\_\_

ፊርማ \_\_\_\_\_

ቀን \_\_\_\_\_

ቀን \_\_\_\_\_