# Exploring the Psychosocial and Spiritual Experiences of Family Caregivers for Relatives Diagnosed With Bipolar Disorder

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This is to certify that the thesis prepared by KidistHailegabriel, entitled: Exploring the Psychosocial, and Spiritual Experience of Family Caregivers for Relatives Diagnosed With Bipolar Disorder to Addis Ababa University School of Social Work in partial fulfillment for the requirements of Master of Social Work complied with the regulations of the Addis Ababa University and meet the accepted standards with respect to originality and quality.

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## *Abstract*

*This research explored the psychosocial and spiritual experiences of family caregivers for relatives diagnosed with bipolar disorder. The research questions, which the study addressed include, the family caregiver's attitude towards bipolar disorder, how the family caregivers describe their care giving experience, what the challenges are caregivers of people with bipolar encounter in caring for their family member with bipolar disorder, the coping strategies employed by themselves to deal with their challenges, and how they describe their experience regarding the existing services which are available for caregivers.To answer those questions adequately, the researcher employed a qualitative (phenomenological) inquiry with exploratory purpose and cross sectional design. By using non probability, purposive sampling, family caregivers of persons with bipolar disorder were selected for the study. Amanual Mental Specialized Hospital was the site for selecting the study participants. Twenty four family caregivers of persons diagnosed with bipolar disorder participated. The major data collection methods that this study employed in depth interview, focus group discussion, and document analysis. The collected data through in depth interviews and focus group discussions analyzed using the thematic analysis. The finding of the study revealed that family caregivers have no adequate understanding about bipolar disorder, got into different psychosocial and spiritual crisis, different challenges from different dimensions and used different coping mechanisms. Even if they lead a burdensome life, services which are provided for family caregivers are in adequate. The finding also revealed that different family caregivers need supports from any concerned bodies.Based on the findings, the study have implications on professional practice, education, research and policy and program.*

***Key words: Caregiver, Bipolar disorder, Mental disorder***

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# Chapter one: Introduction

## 1.1 Background of the study

Mental disorders are common and can affect all countries and societies, and individuals at all age group. Approximately 20- 25% of people can be affected by mental disorders at some time during their life (WHO, 2001). These disorders have large direct and indirect psychosocial impact on societies. Mental illness have a substantial impact not only on the quality life of a person with mental illness but also on his/her families as well (WHO, 2001). Serious mental illness includes schizophrenia, bipolar disorder, major depressive disorder and other disabling psychiatric conditions (Murphy, Barry, Vaughn, 2013).

Mental illness is highly interconnected with poverty which disrupting the normal functioning of the society as well as when it became serious cause of mortality (Federal Democratic Republic of Ethiopia Ministry of Health, 2012). People with mental illness needs a long term care service and support. They also use high level of service in comparison to people with other disability and they have also higher level of unmet need for many services (Kellett, Shugrue, Gruman, Robison, 2010).

Mental and behavioral disorders are present at any point in time in about 10% of the adult population. Around 20% of all patients seen by primary health care professionals have one or more mental disorders. One in four families is likely to have at least one member with a behavioral or mental disorder. These families not only provide physical and emotional support, but also bear the negative impact of stigma and discrimination (WHO, 2001, p 19).

Bipolar disorder is one of severe mental illness characterized by repeated occurrences of excited or depressed mood. It can be described as a pattern of episodes of severe depression, mania or hypomania, in addition to periods of relatively stable mood. People with bipolar disorder experience unusual mood changes. Among people with this problem, mood swings are serious enough to significantly disrupt their personal and family life (The British Psychological Society, 2010). In Ethiopia the prevalence of bipolar disorder is comparable to the prevalence reported from other countries (Alemayehu, 2009). Bipolar patient family caregivers were also found to be more burdened for about 8 to 10 months of the year than family caregivers of patients with diabetes, hypertension and asthma (Ababi, 2008). Additionally, the total economic burden of schizophrenia and bipolar disorders in Ethiopia ranged approximately $378.62 to $469.47 million. Out of this total economic burden the direct cost was found to be 1.25 percent to 3.66 percent of the country's public health expenditure in the year 2005(Ababi, 2008).

In low and middle income countries, mental health services are scares, cover a small proportion of the population and face chronic shortage of financial and human recourses. There is also a huge mental health service disparity between higher and low and middle income countries (WHO, 2015).  Ministry of Health with the collaboration of World Health Organization in 2006 provide report that, Ethiopia like other low and middle income countries, had services which provide help for those people's with mental illness but were inadequate.Because of that higher responsibilities are handled by family caregivers.

As Alemayehu (2009) stated psychiatric services in Ethiopia started in the only psychiatric hospital in the country located at the middle of the country Addis Ababa namely Amanuel Mental Specialized Hospital. The main psychiatric service is outpatient service, which is provided at all psychiatric centers. Inpatient service is also provided mainly by Amanuel

Mental Specialized Hospital. Amanuel Mental Specialized Hospital has 268 psychiatric beds that is 0.35 per 100,000 populations. The hospital has also only 0.02 psychiatrists, 0.3 psychiatrist nurses and 0.4 psychosocial staff per 100, 000 population (WHO and Ministry of Health, 2006). Some argue that even if encouraging changes taking place within Ethiopia, insufficiency in mental health service provision in terms of quantity and quality will continue for years (Alemayehu, 2009).

Family caregivers' experiences have been studied by different researchers in different time and space. Caregivers experienced physical, psychological, emotional, social and financial burdens associated with care giving. They used both emotion-focused and problem-focused coping strategies, depending on the ill family members' behaviors. Seeking spiritual assistance emerged as their most common way of coping ( Marimbe, Cowan, Kajawu, Muchirahondo, Lund,2016). Family caregiver's shouldered substantial and frequently unrecognized burden as a result of the mental illness of their family member (Marimbe-dube, 2013). In Ethiopia family caregivers provide different types of care for their relatives with mental illness, face challenges, and uses different coping strategies (Tizeta, 2016). On the other hand, caregivers need to be fully integrated into the planning, and delivery of health care. Health care and other professionals are in good position to dig out the negative experiences of family caregivers, to support, to advocate and acknowledge those negative consequences resulted in family caregivers (Schulz and Sherwood 2008, and MarGregor, 1994).

When I was placed in Amanual Mental Specialized Hospital for the first year social work field practice, I decided to conduct a study on the experience of family caregivers for bipolar patients. During my stay within the hospital I observed that little or almost no attention was given to family caregivers. Based on the understanding that mental illness has an impact not only on the person with mental illness, but also on his/her families, relatives, neighbors, as well as for the overall country. In cognizant of this I was initiated to conduct a study on this big problem. Even if there were few studies (Tizeta, 2016 and Gemachu, 2013) conducted on family caregivers experience of schizophrenic patients I believed that they cannot represent all family caregivers of patients with other type of disorders. Though the extent of burden resulted from care giving is almost similar, the experiences reported by caregivers are often varied, depended on the nature of the illness, and effects of different psychological factors (Oshodi, Adeyemil, Aina, Suleiman, Erinfolami, and Umeh (2012.p.104). Since bipolar disorder is one of severe mental disorder which is different from schizophrenia and other disorders, a research which focuses on the experiences of family caregivers of bipolar patients was needed to be conducted. Thus, the present study attempted to explore the psychosocial and spiritual experience of family caregivers for their relatives diagnosed with bipolar disorder and to provide available recommendations. The study will have its own contribution to enhance the existing service provision system.

## 1.2 Statement of the problem

Internationally, there are a number of researches conducted on family caregivers for relatives diagnosed with mental illness and the issues that are related with family caregivers, including roles of caregivers, care giving impacts, challenges, and coping mechanisms employed by family caregivers. However, in Ethiopian case the number of researches on family caregivers is very minimal.

Mphelane (2006) examined the role played by families in support of their mentally ill relatives in a rural community in Limpopo province (South Africa). This study came up with the finding that families provide physical, psychosocial, financial and developmental support to their relatives. The study showed family caregivers within frustrated stations they keep providing care and support for their relative with mental illness and ignore their negative emotional reactions.

Wankiiri,Drake and Meyer (2013) conducted a study on the lived experience of families with a mentally ill family member. Their study demonstrated that care giving for the mentally ill family member induces holistic negative impact on the caregivers’ life including poor social life, financial difficulty, and low psychological wellbeing. Jones (2004) also researched on families who have family member that suffers from serious mental illness. He investigated that families who have a family member suffers from serious mental illness experience a complex emotional loss. Macgregor (1994) research finding similarly indicated families who have a family member that suffers from serious mental illness experience a complex emotional loss and experience grief, but often it is not recognized or validated by society and either is not addressed by mental health professionals.

Bauer, Gottfriedsen, Dobmeier, Cording, Hajak, Binder, Spiessl(2011) studied on the burden of caregivers of patients with bipolar disorder. They came up with the finding that family caregivers for relatives with bipolar disorder experience multi-dimensional challenges. Some of the challenges indicated by the study comprises: emotional problems regarding their relationship in daily contact with the patient, poor physical and mental health, inability to employ, deterioration of finance, poor social relationship with in family and community are common challenges of family caregivers in their day today life. Goossens, Wijngaarden, Kiein and Achterberg (2008) also researched on family caregiving in bipolar disorder. Their finding revealed that caregivers in addition to caregiving burden experience distress.

Chakrabarti and Gill (2002) researched on coping and its correlates among family caregivers of bipolar patients. Their study revealed that caregivers of bipolar patient’s uses both problem focused such as positive communication, increasing social involvement of the patient, seeking information and talking with friends and emotion focused coping strategies e.g., coercion, collusion, resignation, avoidance, etc. to deal with challenges.The finding also validated that caregivers for the persons with bipolar disorder use more problem focus coping strategies then emotion focused coping strategies which are mostly employed by caregivers of persons with schizophrenia.

Within Ethiopia, case studies related mental illness gave higher emphasis for the persons with mental illness and less concern was given for family caregiver’s holistic experience who had undeniable contribution behind persons with any kind of mental illness. Even if there are a few studies conducted on the family caregiver’s experience, as shown below, almost all are focused on family caregivers of persons with schizophrenia.

Tizita (2016) has conducted her research on the challenges and coping mechanisms of care giving for relative’s diagnosed with schizophrenia at Addis Ababa in Amanual Mental Specialized Hospital. Her study revealed that caregivers experienced many challenges in the course of caring for their mentally ill family members such as, emotional distress, stigmatization, constraints, separation from social networks, challenging personalities from care recipients such as, financial being disappeared, disobedience, insulting, fighting with family members and with other, aggressiveness, hating family members, threatening the family, damaging property, lack of interest to change their cloth, and lack of initiation to comb their hair.These are some of the challenges that negatively affect the lives of caregivers. Gemachu (2013) studied on the experience of family caregivers who are relatives to people diagnosed with schizophrenia in Addis Ababa. His finding identified different coping strategies used by the caregivers to effectively manage and overcome their challenging situations. The coping strategies used by the caregivers were practically linked to problem and emotion focused, and using available resources which include tethering orbinding the patients with chain, crying, prayer, accept the situation, getting cooperation from neighbors and comparing their cases with others.

Eshetu, Möller-Leimkühler, Müller, SandraDehning, Froeschl and Markos (2014) assessed public stigma against family members of people with mental illness around south west Ethiopia. They revealed that people with high supernatural explanation of mental illness, high exposure to people with mental illness or having higher contact with people who are diagnosed with mental illness and high education background was significantly associated with lower stigma or positive attitude toward mental illness. On the other hand, the finding indicates that individuals with lower level of exposure to people with mental illness and lower educational status scores increased stigma.

Ababi (2008) studied about the economic burden of schizophrenia and bipolar disorders in Ethiopia. The finding shows that the higher economic burden of bipolar disorders in Ethiopia and the research finding substantiated that bipolar disorder caregivers were found to be more burdened than caregivers of patients with diabetes, hypertension and asthma and sick controls in the community. Similarly, Alemayehu (2009) who conducted a research on bipolar disorder in rural Ethiopia specific area of Butajira. He came up with the finding that the prevalence of bipolar disorder is comparable to the prevalence reported from other countries, and his finding also indicated that caregivers of bipolar patients experience a high level of difficulties in interfamilial relationships and social restrictions such as, unable to participate in different community activities, disruption in earning a livelihood, and financial difficulties.

All the above studies indicated that mental illness have an impact on families of care givers as well as the overall country but I could not come across research done in Ethiopian on the experience of family caregivers for their relatives diagnosed with bipolar disorder . Since bipolar disorder is one of the most severe forms of mental illness and the signs and symptoms of this disorder is different from other mental disorders, a research on family caregivers experience should be conducted on this type of mental disorder. As a result, family care giving experiences attached to bipolar disorder have been left untouched at least in the case of Ethiopia. As Oshodi et al., (2012) sated the experience of caregivers differs from one another based on the nature of their relative's illness. In accordance, research findings from developed countries shows unlike other caregivers bipolar patient caregivers' challenging situation varies in accordance with the two episodes which are manic and depression (Dore &Romans, 2001). Regarding to the use of coping mechanisms, caregivers of bipolar patients more likely use problem focused strategies than emotion focused strategies which are frequently used by caregivers of schizophrenic patients (Chakrabarti and Gill, 2002). Because of this and other caregiving experience differences,the researcher easily identified the gap in the existing literatures within Ethiopian. On the other hand, most researches investigate the family caregivers challenge, burden and coping mechanisms. However, these researches failed to examine the experience of family caregivers with services provided for them.

Thus, the present research sought to fill one of the existed gaps by exploring the psychosocial and spiritual experiences of family caregivers for a relative diagnosed with bipolar disorder. More specifically, the study explored the family caregivers' attitude towards bipolar disorder, family caregivers' care giving experience, challenges of family caregivers, coping strategies employed by family caregivers, family caregivers experience regarding services provided for family caregivers, and also the support needs of family caregivershave been explored within this study. Studying family caregivers experiences from different disorders helps all professionals to prepare valuable intervention plan to overcome the problems of caregivers as well as the overall service provision system. It is also helpful to indicate directions for different stakeholders to where they should contribute.

## 1.3 Research questions

1. What is the family caregivers’ attitude towards bipolar disorder?
2. How do the family caregivers express/describe their caregiving experience?
3. What are the challenges caregivers of people with bipolar disorder who are their family members?
4. What are the coping strategies employed by caregivers to deal with their challenges?
5. How do they describe their experience regarding the existing services for caregivers?

## 1.4 Objectives

### 1.4.1 General objective

The general objective of the study is to explore the psychosocial and spiritual experiences of family caregivers for relatives diagnosed with bipolar disorder.

### 1.4.2 Specific objectives

The study has also focused on the following specific objectives:

- To assess the family caregivers attitude towards bipolar disorder.
- To investigate how caregivers describe the caregiving experience.
- To analyze the challenges of caregivers of people with bipolar encounter in caring for their family member with bipolar disorder.
- To identify the coping strategies of caregivers to deal with their challenges.

- To explore caregivers experiences regarding the existing services available for them.

## 1.5 Significance of the study

This study is hoped to contribute in filling the existing knowledge gap regarding the experience of family caregivers for their relatives diagnosed with bipolar disorder. It is also hoped findings of this study will provide evidence based information about caregivers ‘attitude about bipolar disorder, family caregivers experience regarding their care giving course, their challenges and coping mechanisms, and their experience related to services provided for caregivers. Hence, Understanding and differentiating the experience of family caregivers with respect to different disorders is important for social workers and other professionals, this study give insights for further research in social work regarding the experience of families caring for persons with bipolar disorder and other disorders. Furthermore, it is hoped this study help policy makers to understand the real experience of family’s caregivers for individuals with bipolar disorder and to recognize the imbalance between the existed services and caregivers support needs and to take action .

In order to design effective community service, it is obvious to have good knowledge about the needs and capacities of the community. Therefore, the study also inform the type of services that is helpful for families caring for bipolar disorder patient member in the community.

## 1.6 Scope of the study

This study focused on family caregivers caring for their relatives diagnosed with bipolar disorder. Thus participants are immediate caregivers from the hospital. The study also focused only on caregivers of people with bipolar disorder (I and II) among different types of mental disorders treated by the hospital. Regarding the method the study used qualitative specifically phenomenological type, in this case to investigate the family caregivers psychosocial and spiritual lived experience only family caregivers were participated. The study also did not included caregivers of bipolar patients with comorbid conditions. Regarding the study setting, the study limited its scope at Amanual Mental Specialized Hospital.

## 1.7 Operational definitions

*Mental disorders:* are diagnosable conditions characterized by changes in thinking, mood, or behavior (or some combination of these) that can cause a person to feel stressed out and impair his or her ability to function.

*Caregiver:* an individual providing concrete assistance, care and mutual support to family members or relatives who are undergoing mental problem and not able to perform certain tasks on their own.

*Bipolar disorder:* a severe mental illness characterized by recurrent episodes of elated or depressed mood.

*Caregivers challenge*: the presence of problems, difficulties or adverse events which affect the life of the caregiver.

*Coping mechanism of caregivers*: strategies used by family caregivers to face their challenges.

*Lived experience*: personal knowledge about the phenomena through direct, first hand involvement in everyday events.

## Chapter two: Literature Review

This chapter presents the reviewed literatures regarding attitude towards mental illness, general overview of bipolar disorder, experience of family caregivers, challenges and coping mechanisms of family caregivers , intervention on family caregivers for relatives diagnosed with mental illness, and family caregivers need also discussed. The experience of family caregivers of persons with mental illnesses with in Ethiopia is also reviewed based on the existed literatures. Finally the family resiliency model is viewed.

### 2.1 Overview of bipolar disorder

Bipolar disorder is a chronic and recurrent illness that is included in the ten classification of mental and behavioral disorders usually causing severe disability when not treated adequately and which place a heavy burden on community (WHO, 2001). Even if different research results show different life time prevalence of bipolar disorder, according to Dell'Aglio, Basso, Argimon, Arteche (2013) from a systematic literature review of different population based studies revealed that the life time prevalence of bipolar disorder ranged from 0.1 to 7.5%. It is a major public health problem, the identification of the nature of illness often occurring years after the onset of the disorder.

As WHO (2006) stated bipolar disorder is characterized by episodes of mania and depression, often followed by relative periods of healthy mood. Mixed states with symptoms of both mania and depression also occur. Mania is naturally characterized by euphoria or irritability, increased in energy, and decreased need for sleep. Individuals with mania often show intrusive, impulsive or rash, and other irresponsible behaviors. They may be excessively involved in goal-directed behaviors characterized by poor judgment or unwise decisions. Their Self-esteem is also highly inflated, frequently reaching delusional or false belief proportions.

Their speech is often rapid and difficult to interrupt. Persons with mania also may exhibit cognitive symptoms such as, they cannot concentrate in one topic and may jump rapidly from idea to idea, trying to alter or train their thought is difficult. Psychotic symptoms are common during manic episodes. The depressive episodes of people with bipolar disorder are symptomatically indistinguishable from those who have unipolar depressions alone (WHO, 2006, p, 4).

According to diagnostic and statistical manual of mental disorders (2005) bipolar disorder have four subtypes based on the criteria's listed on the manual. (1) Bipolar I disorder which characterized by one or more manic or mixed episodes, usually accompanied by major depressive episodes. (2) Bipolar II disorder is characterized by one or more major depressive episodes accompanied by at least one hippomanic episode. (3) Cyclothymic disorder characterized by at least 2 years of numerous periods of hippomanic symptoms that do not meet criteria for a manic episode and numerous periods of depressive symptoms that do not meet criteria for a major depressive episode. (4) bipolar disorder not otherwise specified is included for coding disorders with bipolar feature that do not meet criteria for any of the specific bipolar disorders (p.318).

There is no single known cause of bipolar disorder, rather, many factors act together to produce the illness. From different factors genes inherited from parent's plays a great role. In addition other biological social and emotional factors also take part (American Academy of child and adolescent Psychiatry, 2009, p.7). Bipolar disorder can be treated by comprehensive treatments like medication, psychotherapy, education, and life style management (Smith, Segale, Segal, 2016). Medication of bipolar Medication offered to people with a diagnosis of bipolar disorder can be separated into three categories: mood stabilizers, anti-depressants (for depression), and neuroleptics (also called major tranquillizers –for mania) (The British Psychological Society.2010, p.7).Bipolar disorder is a complex psychiatric disorder to manage, even for psychiatrists. Several factors make treatment complex, including fluctuation of mood episodes and the effects of these episodes on patient well-being, treatment non adherence, and comorbid psychiatric disorders (Hilty, Leamon, Lim, Kelly, Hales, 2006).

People who experience bipolar disorder often find that their lives are seriously affected by mood swings and difficulties in personal and family life (The British Psychological Society, 2010). Bipolar patients face similar problems and difficulties with in various European countries, regardless of the political, social or cultural settings. The disorder has many negative impacts on the perception and the quality of life, both with and outside the family (GAMIAN-Europe/BEAM survey II, 2004).

In Ethiopian context, Alemayehu (2009) indicates that prevalence of bipolar disorder in Ethiopia is comparable to the prevalence reported from other countries; unlike the developed countries the majority of cases are not treated. He also indicated caregivers experience a high level of difficulties in interfamilial relationships and social restrictions such as, unable to participate in different community activities, disruption in earning a livelihood, and financial difficulties. Bipolar disorder is also associated with a high level of functional impairment in several domains of functioning, including physical functioning. The magnitude of the impairment was predicted by the severity of manic and depressive symptoms (Abebaw 2010). Bipolar disorder has also higher impact on the country’s economy and family caregiver burden. Families with bipolar disorder patients have higher economic and family care giving burden than family caregiver burden of families with diabetes, hypertension and asthma patients or families with sick controls in the community (Ababi, 2008).

## 2.2 Attitudes towards mental illness

As Martin, Bernic, Pescosolido, Tuch (2000) stated that a person's attitude towards something encompasses his or her point of view about the topic (e.g. thought); how he or she feels about the topic (e.g. emotion), as well as actions (e.g. behaviors) he or she engages in as a result of attitude. Attitude towards mental illness includes people's perception, belief, and their tendency to behave negatively or positively. People's attitude also created and influenced by natural and environmental factors. On the other hand attitudes also directs people's reaction or behavior (Martin, Bernice, Pescosolido, and Tuch, 2000). According to Corrigan, Markowitz, Watson, Rowan and Kubiak (2003) individuals view toward the case of the person's mental illness in other words their causal attributions affect beliefs about persons' responsibility for causing their condition, beliefs which in turn lead to affective reactions, resulting in rejecting responses such as avoidance, coercion, segregation, and withholding help. People may link the cause of a person's mental health problem with different conditions such as, medical/genetic, social, and moral/individual level causes of the condition.

When individuals viewed that the onset of mental illness is being under one's control (person's behavioral character) they are committed to avoid persons with mental illness and endorse coercive treatment. Individual's perception toward persons with mental illness label of dangerousness also affects their reaction. On the other hand familiarity with mental illness impacts discriminatory and emotional responses. Those who are more familiar with mental illness are more likely to offer interpersonal help and less likely to avoid people with psychiatric disorders. Familiarity with mental illness was positively associated with pity (leads to more supportive responses and negatively associated with anger and fear) (Corrigan et al., 2003).

People’s causal attribution highly affects their reaction towards mental illness. Even if most people displays that they are unwilling to have social contact with the all individuals suffering from various mental health problem, people with substance abuse problem are not tolerable than people with other type of disorder. Because the causal attribution for substance abuse lies on the individual level source or bad individual character. For other mental disorders like schizophrenia and bipolar chemical/ biological attributes are given. However, this tolerance does not extend to a willingness to accept these people as either family members or coworkers (Martin,Bernic, Pescosolido, Tuch, 2000).

Attitude towards mental illness is highly affected by the educational level of an individual and age. The younger and more educated persons in the community have enlightened attitude for mental illness and for persons with mental illness, more scientific and humanitarian, more willing to associate with former patients, and more likely to stress interpersonal difficulties as contributory to mental illness. The association between education and the attitudes toward mental illness suggests that the formal educational process influences the individual's views regarding mental illness. Age also has another substantial impact on the attitude of the person not only it has a positive association with education which means youngsters have greater exposure to formal education but also age by itself have a greater impact on the attitude of the person. In addition to formal education other socialization agents (driving forces) system have operated differently on the younger and old population (Freeman, 1991).

Kawanishi (2005) conceptualized that people’s struggle to find the cause of their relative’s illness helps them to have positive attitude towards mental illness and the researcher also believes it is one of the first step for coping. He also indicates different causal attributions held by families who have a relative with mental health problem. Causal attributions related to early family socialization, genetic factors, and other spiritual causes are the major causal attributions held by families who have relative with mental illness. Regarding early socialization families' belief, parents' different type of personalities and their way of raising children are perceived as a factors for the onset of their relatives' mental illness. On the other hand, families also connect their relative's mental illness with hereditary factors. This causal attribution reduces families self-blaming. Other families also perceive the cause of their relative's mental illness is their ancestral sprite (Kawanishi, 2005).

In the Ethiopian case, people have different attitudes towards mental illness and causal attribution. Families also held different causal attribution for the onset of their relative's mental illness. This causal attribution influences their attitude and reaction. Eshetu, Leimkühler, Müller, Dehning, Froeschl, and Markos (2014) identified different factors that have potential impact on the people's reaction towards mental illness. People who consider mental illness is a result of supernatural, psychosocial, and biological factors have a positive attitude towards persons with mental illness and their families. Educational status and level of exposure (contact) with persons with mental illness are also the other factors which affect the people's attitude. According to their finding people who have higher educational background and higher exposure to persons with mental illness held higher positive attitude towards patients and their families. Regarding causal attribution like any other countries there are different causal attributions are held by families who have a relative with mental illness. Tizita (2016) revealed family caregivers held different causal attributions to explain their relative's onset of mental illness, such as traditional beliefs which indicates the association of mental illness with sprit and evil act done by people on others, psychosocial factors like conflict with in the family and outside the family, stress, migration are some psychosocial causal attributions, and genetic factors are other causal attributions held by families.

## 2.3 Experience of family caregivers of the mentally ill persons

The word caregiver indicates the person who provides tangible support and care to family member or relative with mental and physical problem (Gupta, Sharma, 2013). The provision of care and support for a family member to one another is a usual activity. Care giving due to mental illness is beyond the day today and regular mutual support within the family. It requires a significant expense of time and energy over extended period of time, holding tasks that are not comfortable to the caregivers (Biegel, Sales and Schulz, 1991, Cited in Biegel and Schulz, 1999). Family caregivers are an irreplaceable resource for the mental health services system and the pillars on which the system currently rests (Shankar & Muthuswamy, 2007. P. 302).

According to Mphelane (2006) family caregivers in the course of caregiving play a pivotal role. They provide physical support i.e. ensuring the patient had food, providing shelter, monitoring the patient and taking of medication and ensuring good hygiene, psychological support, such as counseling, building friendly relationship, involving in different community activities, financial support, and developmental support which indicates helping the patient to develop his talents and appreciating him/her to be what he/she want to be. Similarly Goldberg, and Rickler (2011) pointed out family caregivers function as advocates and provide physical, emotional and financial support, frequently without any training, often without recognition or support, and rarely with financial reimbursement. Many people living with severe illness could not live independently without family caregivers (p.41). Janardhana, Shravya, Naidu, Saraswathy, and Seshan (2011) also added social care which indicates protecting the patient from stigma, harmful treatment, and social rejection, denial of property rights, marital disagreement and legal separation are performed by the family caregivers to ensure the wellbeing of the persons with mental illness.

### 2.3.1 Challenge of family caregivers of persons with bipolar disorder

Bipolar disorder which is included in severe mental illness classification disturb and affect not only the patient’s life but also it highly affects the normal functioning of the families (Hilty et al., 2006). According to Dore, Romans (2001) family caregivers for relatives with bipolar disorder challenging situations are varied related to the patient’s changing behaviors (depressive and manic). Most commonly family caregivers disturbed by aggressive, violent behaviors of patents and by suicidal ideas and acts. When the patients are in manic episode (excited mood) family caregivers are challenged by behaviors, such as odd behaviors, over activities, over talkativeness and impulsive spending time money etc. On the other hand, when they are depressed suicidal ideas and attempts are the most common difficult situations.

Bauer et al., (2011) presented a multi-dimensional challenges which are experienced by family caregivers for bipolar patient relatives. Emotional problems regarding their relationship in daily contact with the patient is the one. The most challenging task experienced by family caregivers for their relatives diagnosed with bipolar disorder is that uncooperative behavior of the patient and refusal of their caregivers resulted the helplessness feeling by the caregivers. On the other hand, Poor health, inability to employ, deterioration of finance, poor social relationship with in family and community are common challenges of family caregivers in their day today life. Dore, Romans (2001) also adds other challenges experienced by family caregivers related to legal matters. The patient’s violence practice and the involvement of police led the family to experience high level of distress.

Family caregivers challenge can be classified in to two subjective and objective. Subjective challenge or burdens can be described as the caregiver's emotional feeling of shock, grief, anxiety, anger, worry, guilty and fear. Objective burden also defined as observable challenges within the family resulted from the family member's mental illness including financial challenges, disruption to the house hold, and impact on marital and other familial relationships (Thompson, and Doll, 1992). Family caregivers of patients with bipolar disorder experienced both subjective and objective problems. Subjective problems mostly resulted from patient's behavior; the most distressing behaviors are hyperactivity, irritability, sadness and withdrawal. In terms of the patient's role performance, the most distress factors are those related to the patients work or study and social interaction (Reinares, Vieta, Colom, Martínez-Arán, Torrent, Comes,Goikolea,Benabarre, Daban, Moreno,2006 and Dore, Romans, 2001).

As Vaddadia (1997) presented challenges or burdens have different dimensions, such as symptom specific challenges, social challenges, emotional challenges, and financial challenges. Peoples who care for a chronically mental ill relative feel a severe problem, but often do not complain, and need practical and emotional support in the ongoing care of their ill relative (p.150).

### 2.3.2 Coping mechanism of family caregivers for relatives with bipolar disorder

Coping refers to cognitive and behavioral efforts aimed at managing a troubled person–environmental relationship. This includes any response to external life strains that serves to prevent, avoid or control emotional distress and keep an individual away from damage from life strains. Coping is related to both the state of one's inner emotional life and life strains; it depends on subjective well-being, social functioning and somatic health, as well as the relevance placed on these by an individual at any given time (Lazarus & Folkman 1985; cited in Marimbe, Cowan, Kajawu, Muchirahondo, Lund, 2016. P.2).

Family caregivers for their relatives diagnosed with bipolar disorder uses different coping mechanizes to deal with different challenges which are resulted from their relative's illness. According to Chakrabarti and Gill (2002) family caregivers of bipolar patients uses both problem focused and emotion focused coping strategies to deal with challenges. Problem focused strategies are strategies which include direct activity responses for the problem, such as positive communication, increasing social involvement of the patient, seeking social support, and grasping information and talking with friends and professionals. Emotion focused coping strategies includes seeking spiritual support, coercion, collusion, resignation, avoidance etc.

Chakrabarti and Gill (2002) also show that caregivers of bipolar patients more likely use problem focused strategies than emotion focused strategies which are frequently used by caregivers of schizophrenic patients. Voort, Goosnsp,Bijl (2007) recognizes that different stages in the process of care-giving require different coping strategies depend on the challenges which are encountered during care-giving course. Coping and challenge or burden have direct relationship, reduction of burden and a deep understanding and knowledge about the illness and symptoms leads to use a more positive problem oriented coping strategies.

Similarly Voort, Goosnsp,Bijl (2009) shows different coping mechanism stages that are undertaken by spouse caregivers for their husband's/wife's diagnosed with bipolar disorder. In the first stage, the caregiver's try to understand the behavior of the patient and questioning to know causes the problem. In this stage if they perceive the cause of the problem is the patient's own his/ her problem, the caregiver's try to influence the behavior of a patient. Through process caregivers develop new opinions, ideas, and views to influence their experienced burdens. At the second, the caregiver's tray to find ways to balance self-effacement (putting the needs of the other first) and self-fulfillment (putting one's own need first). Mostly suppose caregivers putting their needs aside. To overcome this in balance caregivers undertake three kinds of activities; first caregiver's try to repair their relationship with the patient and try to communicate and share ideas feelings each other. Secondly, caregiver's try to find out the persons to share their experience and fillings related to care-giving. On the other hand, in this stage they also try to find support from family, friends, professionals, and from the society as well. At third caregivers give time for themselves to refresh their mind. Try to relax and work with in the house and outside the house.

As Shankar and Muthuswamy (2007) stated caregivers despite the physical, emotional and financial pressures associated with care giving, did not perceive their relative as a burden. They did not want to shut their doors on their relative or relieve themselves from providing care. It was evident that many of them were trying to do their best with the limited resources that were available (p.308).

## 2.4 Needs of family caregivers

Caregivers are an irreplaceable resources for the mental health service system and the pillars on which the system currently rests. They have different needs depending on several factors that they are existed in. (Shankar and Muthuswamy, 2007, p.302). The Canadian mental health association (2006) presented family caregivers need by dividing in to four classifications. The first one is that the need of service from professionals including education, support and care. Family caregivers provide care and support for their relatives may have no information and understanding regarding mental illness. The second one is the need of peer support. Family caregivers through peer group (mutual aid organizations) share their lived experience including coping mechanizes, feelings, their needs and financial burdens etc. Thirdly family caregivers need recognition as partners in care, rehabilitation and recovery. They need to play as advocator on behalf of the patient and given attention by service providers. Fourthly caregivers need to be included in system partner. They need to participate in program planning, implementation, evaluation, legislation critique, and mental health reform activities.

According to Marimbe-Dube (2013) family caregivers need different support and intervention from different bodies, such as they need financial/material support from the government or other well-wishers, support group, training from health care professionals, written materials, support, comfort and hope from health care professionals, and they also need divine intervention from God. Voort, Goosnsp,Bijl (2007) also indicates caregivers need information, accessibility of care and being able to talk with a professional. That help caregivers in gaining confidence in their ability to cope, support in appraisal of the behavior of the patient and not being judged by professionals. Informal interventions appear to be more important than formal interventions (p. 686).

Stress experienced by caregivers may be associated with the lack of essential supports and absence of a holistic approach to meeting the needs of caregivers. On the other hand, significant sources of frustration for caregivers may also resulted from professional attitudes that convey feelings of guilt and self-blame and exclusion from decisions related to the treatment and care of their relatives. Therefore knowing and addressing the needs of these caregivers is crucial for the survival of the mental health care system. (Shankar and Muthuswamy, 2007, p.302-308).

## 2.5 Interventions on Family caregivers

According to Miklowitz (2007) Intervention on family caregivers have different features such as psychoeducation, communication enhancement, and problem solving skill training. Psychoeducation includes providing information and having discussion about the symptoms signs, relapse prevention plans, risk factors and protective factors, and the importance of medication adherence. Communication enhancement training indicates behavioral practice of effective speaking, listening, and negotiating skill, with homework practice. Problem solving skill training beings by identify and define specific family problems, the next step will be brainstorm solutions, then evaluate the advantages and disadvantages of each solution, choose one or combination of solutions, and develop implementation plan. This interventions on family caregivers delays relapse.

Intervention programs whether provided by professionals, or by families themselves, accurate information can do much to allay fears, overcome misconceptions and address concerns. Education can help families develop successful coping strategies and enhance their contribution to the recovery of their loved one. Counseling on the other hand assists families in coming to terms with the implication of living with a loved one who has a serious mental health problem (Canadian mental health association, 2006.p.12).

## 2.6 Caregivers of the mentally ill persons with in Ethiopia

Federal Democratic Republic of Ethiopia Ministry of Health (2012) recognized that mental illnesses are common in Ethiopia, and they are associated with a high burden due to disability and mortality, largely unrecognized. Disability associated with mental illness is high with in the country. The lack of mental health services or any kind of financial support for families with their relative diagnosed with mental illness are the biggest factors causing caregiver burden in Ethiopia ( p.12).

As Tezeta (2016) stated caregivers of relatives with schizophrenia experienced different problems related to patients behavior, medication adherence, economic challenges, problems related family life relation, social problems, and psychological challenges. Caregivers also uses different coping mechanisms to deal with their problems resulted from the illness of their relative. Problem focused strategies, such as chaining the patient, guarding from dangerous acts, and calling police are coping strategies used by caregivers. Crying, prayer, believe and accept the situation are some of emotion focused strategies. Using available resources is the other coping strategy applied by caregivers of persons with schizophrenia.

Similarly Gemachu (2013) presented the negative impacts of family caring on the caregivers of schizophrenic patients. Psychosocial problem, separation from peers, problems resulted from patient’s behavior, uncertainty for how long to remain as caregiver, and economic impact are some of. The family caregivers also use different mechanizes to manage their care giving responsibility. Discussion with the family, responding to the needs of their relative, treatment, monitoring and adherence, encouraging independence, communication with the person living with schizophrenia, treating with dignity, maintaining spiritual practice, managing stress, and ignorance are mechanisms of family caregivers to manage their care giving duties.

Even if Ababi (2008) and Alemayehu (2009) gives a highlight that family caregivers of bipolar patients holds different responsibilities to help their relatives. They are also more burdened for about 8 to 10 months of the year than the family caregivers of patients with diabetes, hypertension and asthma and sick controls in the community and bipolar disorder have an economic impact for the country Ethiopia, I could not come across a research on the experience of family caregivers for bipolar patients with in Ethiopia.

## 2.7 The Resiliency Model on family care giving experience

The Family Resiliency Model is well suited to understanding the experience of family care giving for a person with a mental illness because mental illness not only affects the ill relative or a primary caregiver but all family members (Somporn and Catherine,2000,P.360). (McCubbin and McCubbin ,1993 as cited in Somporn and Catherine,2000,p.354) developed the Family Resiliency Model of Family Stress, Adjustment, and Adaptation, expanded from the Double ABCX Model and Typology Model of Family Adjustment and Adaptation.

The Family Resiliency Model is a midrange theory describing how a family works within a stressful situation. The model goes beyond a contextual view of individual resilience to a family system, focusing on the family as a unit (Somporn and Catherine, 2000, P.361).

According to Somporn and Catherine (2000) the model contains two phases: adjustment and adaptation. In the adjustment phase, the family makes only minor changes in how it typically operates and behaves; these could become permanent changes in family functioning. The adjustment phase is determined by the interaction of the following elements: (a) the stressor, such as an acute illness in a family member; (b) the family's vulnerability, which is influenced by the pileup of family stress, transitions, and strain occurring in the same period as the stressor; (c) the family typology, which is the established pattern of functioning; (d) the family's resistance resources; (e) the family's appraisal of the stressor; and (f) the family's problem-solving and coping strategies. These elements interact with one another to determine the level of adjustment in the family. However, the components cannot be examined separately as they work in relation to each other. If the family is successful in its response to the stressor, the family moves through the situation with relative ease and produces a positive outcome called *bonadjustment* (Somporn and Catherine, 2000, P.355). However, in illness situations, especially chronic illness, hardships are often numerous and severe, demanding more substantial changes in the family system (goals, rules, boundaries, and pattern of functioning). In this situation, the family is likely to experience maladjustment and a resulting state of crisis—a period of family disorganization, which moves to the onset of the adaptation phase.

In the adaptation phase, elements that operate include (a) the pileup of demands on or in the family system created by the illness, family life-cycle change, and unresolved strains (b) the family typology, determined in part by newly instituted patterns of family functioning and retained established patterns of functioning (generativity or resiliency); (c) the family's resources; (d) social support from extended family, friends, and the community; (e) a situational appraisal; (f) the family's schema appraisal and the family's meaning; and (g) the family's problem solving and coping. Family adaptation is the outcome of the family's efforts over time to meet both the needs of individual family members to achieve their personal growth and also the functioning of the family system and its transitions with the community ((Somporn and Catherine, 2000, P.356). In this study to enhance the researchers understanding regarding the experience of caregivers of individuals with bipolar disorder the Family Resiliency Model is helpful.

## Summary

This chapter provided us overview of bipolar disorder, attitudes towards mental illness, family caregivers' caregiving experience, challenges and coping mechanisms, and finally the chapter presented the resiliency model on family care giving experience. In the Ethiopian case even if there are few studies that informed us about the experience of family caregivers for their relatives’ with mentally illness, almost all studies interested on schizophrenia patient caregivers. These studies on family caregivers experience were not comprehensive enough and did not examine the issue from different angles including different disorder patient caregivers experience.  Therefore, the proposed study attempts to contribute to see the experience of family caregivers of relatives diagnosed with bipolar disorder.

## Chapter three: Research Methods

This chapter shows the research methods employed in conducting this study. Under this chapter, the study design, description of study settings, participant selection technique, inclusion criteria, data quality assurance, methods of data collection, method of data analysis and ethical consideration are discussed in details.

### 3.1 Research Design

A qualitative research (phenomenological) with exploratory purpose and cross sectional design has been employed to achieve the research objectives. A common and valid rationale for choosing this design is the nature of the research problem. As the objective of the study was exploring the psychosocial and spiritual experiences of family caregivers for their relatives diagnosed with bipolar disorder, the study should be guided by qualitative approach. Qualitative research enables to study human knowledge, attitudes, experiences and realities through sustained contact with persons in their natural environments, and producing rich, descriptive data that help us to understand those persons' experiences (Alston and Bowles, 2003).

From the different forms of qualitative study, this study applied a phenomenological research approach. The goal of phenomenology is to achieve a deeper understanding of the nature and meanings of everyday experiences from those who have the lived experience (Lisa, 2006). Similarly, the focus of this research was exploring and understanding the psychosocial, and spiritual experience of family caregivers for their relatives diagnosed with bipolar disorder from their everyday experience. Hence, phenomenology was best research design to investigate the phenomenon.

Regarding the purpose an exploratory research was applied. Because, when there is little or no knowledge regarding a given situation, it is advisable to conduct an exploratory study before applying descriptive or analytical studies where the problem and factors contributing to are not well defined (Kruger and Neuman, 2006, p. 21). As far as my knowledge goes, only few researches are conducted in Ethiopian regarding the experience of family caregivers for their relatives diagnosed with schizophrenia. Family caregiving experiences attached to bipolar disorder has been left untouched. A phenomenological qualitative research with the exploratory purpose was appropriate design to explore the experience of family caregivers for their relatives diagnosed with bipolar disorder which was essential to investigate the new uninvestigated experience. With regards to time dimension, the study was cross-sectional. In cross-sectional research, researchers observe at one point in time (Kruger and Neuman, 2006, p.31). For this study the researcher met selected participants at least two times to clarify interview reports.

Research is also influenced by the theoretical paradigms individuals tend to adhere with; the researcher's personal belief regarding this was the social constructivist view of reality. Social constructivist argues that, there are multiple realities which are subjective. As researcher we need to develop subjective meanings of experience which is directed toward certain object or things. "This meanings are varied and multiple leading the researcher to look for the complexity of view rather than narrow the meanings into few categories" (Creswell, 2009, p.8). For this particular study the researcher listened, accepted, respected and presented the participant's subjective view, belief and experiences.

## 3.2 Research site

The study setting is Amanual Mental Specialized Hospital which is the only public psychiatric hospital in Ethiopia. The hospital is found in Addis Ababa, Addis Ketema sub city near Mesalemia adjacent to Amanuel Church. This hospital was constructed by Fascist Italy for general purposes during its five-year occupation of the country from 1936-1941. Since the defeat of the Italians, the hospital has been functioning as a mental hospital (Alemayehu, 2009, p.19). The hospital has only 268 psychiatric beds for all populations. It provides both in-patient and outpatient services (WHO and Ministry of Health, 2006). The researcher selected the hospital because it is the only public mental specialized hospital where persons who need psychiatric service can come from different area of the country. The hospital is appropriate to reach participants from different cultural background and lived experience and also to get enough participants.

## 3.3 Research Participants and Selection criteria

The study participants for this research were family caregivers for relatives diagnosed with bipolar disorder who are available during the time of the research. Amanual Mental Specialized Hospital was the study site, from which the researcher was able to access the study participants.

Persons with bipolar disorder who have been gaining care from their relatives was selected from Amanual Mental Specialized Hospital. Persons with bipolar disorder were identified with the help of social workers, psychologists, nurses and other health care professionals based on the medical records of the patient. After the identification, the researcher contacted the family caregivers of those selected and created awareness regarding the purpose of the research; and lastly identified families who became voluntary to participate on the study.

The following inclusion criteria were used: (a) family caregiver for the person with bipolar disorder who receives in patient service, (b) family caregivers who lives with the person with bipolar disorder, (c) family caregivers who have minimum of two years caregiving experience(d) persons who are voluntary to take part on the study and willing to share their lived experience.

### 3.3.1 Selection of research participants

Purposive sampling of non-probability sampling techniques was used for selecting the respondents. The reason for using purposive sampling is that respondents of research should have particular experiences or characteristics. According to Kumar (1996), this sampling technique helps to select participants based on predefined criteria relevant to the topic at hand. Accordingly, this sampling method was used in this study to select family caregivers who provide care for their relatives diagnosed with bipolar disorder.

### 3.3.2 Sample size

The sample size in purposive sampling may or may not be fixed because purposive sample sizes are often determined on the basis of data saturation (Kumar, 1996). Therefore, the number of sample in this study was determined by theoretical data saturation. Meaning, the data was collection continued until no new data was forthcoming or at a point of information redundancy. In consideration of all factors, this study had conducted in-depth face to face interview with eleven individual caregivers for persons diagnosed with bipolar disorder.

Besides, two focus group discussions were included in the study.Creswell (2014, p. 190) recommends maintaining participants number in focus group in the range of six to eight in order to gain in-depth detailed information on the topic. The focus group discussions conducted in this study comprised six and seven participants in each group. Therefore, a total of twenty four people have participated in the study.

### 3.4 Methods of Data Collection

As Marshall & Roseman, (2006) point out, qualitative researchers uses five methods for data collection, such as observation, interview, participant observation, focus group discussion and document review. For this particular study, interview (in-depth interview) and focus group discussion were used. The justification of selecting these techniques is because they are time and cost effective; and helped us in getting adequate information about the family caregivers'attitude toward bipolar disorder, their challenges, coping mechanisms, their experience regarding the existing services available for caregivers.

In-depth interview: In-depth with interviews are one of the main methods of data collection used in qualitative research that involves conducting intensive individual interviews to explore their experience on a particular issue and often described as in a form of conversation (Boyce & Neale, 2006). As a data collection instrument the researcher used semi-structured interview guide. In this study in-depth interviews were conducted to gather information or data from the family caregivers of persons with bipolar disorder.It gives participants the opportunities to freely share their views, experiences, and testimony.

And this method enabled the researcher to collect abundant information about caregivers' daily experience. The interview wasconducted inside the hospital settings and outside the hospital setting based on the preference of the study participants i.e. two interviews conducted within the participant's home, the other nine interviews conducted with in the hospital setting by using the offices that are available for different individual counselling and therapeutic services.

The interview took 60-90 minutes depending on the situation. In conducting the interview, Amharic was the medium of language with all participants.

Focus group discussion: The focus group technique is a type of qualitative research methodology, generally defined as a structured discussion with a small group of people, run by a facilitator or using a moderating team, to generate qualitative data on a precise topic of interest, using a set of open-ended questions (Masadeh, 2012. P, 63). Focus group discussion helps the researcher to generate a better insight into a topic of a particular interest (Polak, Mishkov and Williams, 2015).

For this study, two focus group discussions which comprise six and seven participants in each group conducted with family caregivers of persons with bipolar disorder.This method enabled the researcher to understand caregivers experience from different dimension. For facilitating the data collection processrefreshment was arranged by the researcher which is given at the middle of the discussion.The discussion was planned to be conducted within a time range between forty to sixty minutes. But it has taken seventy nine and ninety minutes.

Document Review: The researcher reviewed the medical record of patients in order to identify bipolar patients from the rest of patients who were admitted with in the hospital and to get the family caregivers address .Documents include written materials and other documents forms from the organizational, clinical or programmed records; memorandum and correspondence, official publications and reports; and personal diaries, letters, artistic works, photographs, memorabilia and written responses to open ended survey data (Patton, 2001).

## 3.5 Data Gathering Procedures

The first step of data gathering was taking support letter and gown from School of Social Work. Then by providing the school's support letter to the hospital the process of getting approval continued. To get the Amanuale MentalSpecialized Hospital's approval I gave the copy of the proposal for the Hospital's Ethical Review Committee. After the committee ensures that noting unethical in the methodology of acquiring data or the overall content of the thesis proposal, the committee allowed me to continue the research in the hospital setting by providing approval letter. After having the agreement, patients of bipolar disorder were identified by reviewing their medical record and the addresses of the family caregivers were taken. Therefore, family caregivers of bipolar patients was communicated, written informed consent was obtained from participants and they were informed that participation was on voluntary basis and have full right to withdraw at time of need during the interview process and caregivers who are voluntary to take part with in the research recognized.Then in-depth interview with caregivers' persons with bipolar disorder were conducted in both within and outside the hospital setting where the respondent feel comfortable. The two focus group discussions were conducted within the hospital by using rooms which are used for group therapy session. Through designed proper time schedule and taking into consideration all the ethical elements, I tried to create conductive atmosphere with the participants to facilitate the data collection. And I also asked permission to use audio recorder while interviewing the participant from themselves. The interviews with the participants wererecordedbased on the consent of the participants to maintain coherent flow of ideas and facilitate data analysis. Different name/code was assigned for each participant to maintain confidentiality of information obtained from the participants.

### 3.6 Data analysis procedure

Qualitative data analysis strategies will be used specifically thematic analysis. The data collection and analysis will be carried out at the same time which is common in qualitative data analysis (Padgett, 2008). The primary data obtained was transcribed, themes was identified and thematic analysis used in order to compare, contrast and categorize the data into themes. Moreover, the following procedureswas followed during data analysis for this particular study.

#### Pre-coding

The data analysis of this research started with transcribing the gathered data. Every day after data collection field notes and voice records transcribed in to paper. In this stage attentive listening and careful note taking was employed to get the real massage of the participant's. Within this pre coding stage since all interviews conducted in Amharic the noted data was translated in to English. Then I go through the data (interview transcription) repeatedly until understanding of the main points is achieved through highlighting "significant statements" that provide an understanding of the participants experience.Pre-coding will be done by circling, highlighting, bolding, underlining, or coloring rich or significant participant quotes or passages that strike the researcher (Saldana, 2008, p.16).

#### Coding

After the preparation of pre coding, coding procedure followed. According to (Kruger and Neuman, 2006), coding is arranging things in systematic order or making classification. This process helps the researcher to reduce the data into meaningful segments and will assign names for the segments. In this sage firstly I gave pseudo names for the participants to be analyzed. It helped to assure ethical issues of confidentiality. Then Isimplified, focused, and identified some specific characteristics of the data.

### Categorizing

Categorizing in qualitative data means searching for grouping exactly very much similar data or data which have something in common within coded data. Categorizing transcribed data helps to sort out texts into various segments, which make the data to be manageable (Tuckett, 2004). In this study, the coded data categorized depending on the similarity and relationship of codes under different headings. A category contains related codes explored from the analysis of the data.

### Themes

After categorization themes were developed. All themes examined to make sure that they derived from the categories. Saldana (2008) argues that, a theme is an outcome of coding, categorization and analytical reflection and is not something that is in itself coded. Themes are concepts that explain how ideas or categories are connected.

## 3.7 Data Quality Assurance

For this particular study the researcher used different method to assure the data quality. First, before the beginning of data collection the researcher build rapport with research participants to develop trust and collaboration between the researcher and the participants. On the other hand as Creswell, (2007) stated one of the methods to assure trustworthiness of qualitative data is triangulation, a methodological approach that contributes to the validity of research results when multiple methods, sources, theories, and/or investigators are employed (p. 377). After the data collection the quality of the data assured through data triangulation. Triangulation applied through comparison data from different data sources that data collected through in-depth interview was triangulated with focus group discussions.

In every research, truthfulness, honesty and unbiased approach are very important for the quality of the study. In qualitative approach, it is advisable for the researcher to get intimate with research participant and the study setting as a whole (Kruger and Neuman, 2006, p. 138). In this study, the researcher involved to familiarize oneself with participants and the study setting. During this involvement I restricted myself from showing any expectations, judgment and use of personal values. In addition the researcher left the participants to be free and provide information freely.

## 3.8 Ethical Consideration

Ethical consideration is very crucial for any research which involves human subjects. The researcher has an obligation to respect the rights, needs, and values of participants. In this study following ethical considerations applied in each level of this thesis project. The autonomy of research participants respected through seeking the consent of participants for intervening and tape-recording of information without any influence/pressure. The purpose of the study and for what purpose the information will be used was informed for study participants; keeping the information confidential and identities anonymous; establishing respectful and supportive relationships; conducting the interview in a private and safe place; avoid noises and destructions are some of the basic code of conduct that are employed in this study. The beneficence of study participants insured by informing that their involvement in this study would not result any risk in services which are provided for the patient as well as for the family caregivers. Moreover, even if participating in this study requires to recall bad moments and feelings, this study finding will have its own contribution to enhance the existed service provision system and to initiate different concerned bodies to contribute some on the identified needs of family caregivers. So that, the study believed to be beneficial for family caregivers.

## 3.9 Limitation of the study

Since this study only used Amanuale Mental Specialized Hospital as only study sit to select research participants, it is difficult to generalize the findings of the study to the whole family caregivers. Another major limitation of this study was the absence of direct observation of the experiences of family caregivers during their caregiving course. In addition this study in terms of time dimension uses across sectional research method due to this reason the study doesn't included different changing situations.

## 3.10 Challenges in the study

This study was conducted by passing some pressing challenges during the time of data collection. The first challenge within this study was in adequacy of literatures regarding caregivers of persons' with bipolar disorder, especially with the Ethiopian context. I have not found at all. The other challenge encountered with in this study was the Hospital's bureaucracy to give approval letter to conduct the study within the hospital's setting. The hospital required the copy of proposal, then after the hospital's ethical review board discussed on the study proposal the approval letter was provided. This process took some days and before the provision of the approval letter data collection with in hospital was not allowed. On the other hand, before the beginning of data collection screening bipolar patients from the rest of inpatient service receivers was the first task. Thus, to identify those patients the patients' medical record were needed. However, getting patients' medical record was very challenging because all the cards are accompanied by all service providers for different purposes. For example: some medical records taken to follow up the patient's progress, some others also taken for prescribing medications. The other challenge was without wearing the white gown entering in the patients wards has exposed me to different offenses from patients. To get the acceptance and respect of patients wearing the gown was mandatory. Different emotional reactions during the interviews and informal observations including fear and grief were other challenges. On the other hand, since all family caregivers are given the all attentions for provision of care for their relatives, getting their consent, proper time and space was very challenging.

# Chapter four: findings

This chapter of the paper presents the finding of the stud. It has six main sections comprising socio-demographic data of all participants, caregiver's attitude towards bipolar disorder, caregiver's care giving experience, challenges, coping mechanisms, and caregivers experience with services.

## 4.1 Socio-Demographic Data of Participants

This section of the paper presents the socio-demographic information of all participants in in-depth interview and focus group discussion. Pseudo names have been given to all participants. Data from document analysis indicated that study participants were those the caregivers of persons with bipolar disorder I and II.

Table1:- Socio-Demographic Information of in- depth interview Participants

| Participant pseudonym | Age | Sex | Marital status | Religion | Educational Level | Occupation | Relationship With the patient | Duration of care giving |
|---|---|---|---|---|---|---|---|---|
| Mohammed | 68 | M | Married | Muslim | 1st grade | Business | Nephew | 10 years |
| Asetyer | 35 | F | Married | Orthodox | 12th grade | Business | Brother | 13 years |
| Yesufe | 60 | M | Married | Muslim | Did not attained | Ironing clothes | Daughter | 8 years |
| Almaz | 36 | F | Married | Orthodox | 5th grade | Employed | Brother | 4 years |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Meryem | 28 | F | Married | Muslim | 1st grade | House wife | Brother | 4 years |
| Hadeja | `75 | F | Widowed | Muslim | Did not attained | House wife | Daughter | 12 years |
| Ashenafi | 28 | M | Married | Orthodox | 8th grade | Athletics | Sister | 2 years |
| Kebede | 38 | M | Married | Orthodox | Diploma | Employed | Wife | 5 years |
| Medina | 45 | F | Widowed | Muslim | Did not attained | House wife | Son | 7 years |
| Almitu | 45 | F | Married | Orthodox | 10th grade | Employed | Daughter | 7 years |
| Abebe | 31 | M | Un married | Jehovah Witness | 1st degree | Employed | Sister | 8 years |

Table 2:- presents the socio-demographic data of focus group participants. In this study thirteen caregivers (six caregivers in one group and seven participants in the other group) had participated in the discussion.

Table2:- Socio-Demographic Information of focus group discussion Participants

| Participant pseudonym | Age | Sex | Marital status | Religion | Educational Level | Occupation | Relationship With the patient | Duration of caregiving |
|---|---|---|---|---|---|---|---|---|
| Almu | 38 | M | Married | Orthodox | 10th grade | Business | Son | 9 years |
| Msekrme | 45 | F | Married | Orthodox | 8th grade | Employed | Daughter | 6 years |
| Shmesu | 47 | M | Married | Muslim | 3rd grade | Farming | Wife | 3 years |
| Beretukan | 56 | F | Married | Orthodox | 2nd grade | House wife | Daughter | 5 years |
| Abeba | 29 | F | Not Married | Orthodox | 1st degree | Employed | Brother | 4years |
| Mustefa | 55 | M | Married | Muslim | Did not attained | Business | Daughter | 11 years |
| Rukeya | 50 | F | Married | Muslim | Did not attained | House wife | Nephew | 6 years |
| Mulu | 67 | F | Married | Orthodox | Did not attained | Farming | Son | 5 years |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Helene | 56 | F | Married | Orthodox | 2nd grade | House wife | Son | 6 years |
| Melaku | 60 | M | Married | Orthodox | 6th grade | Farming | Wife | 7 years |
| Rahel | 35 | F | Married | Adventist | 10th grade | House wife | Son | 6 years |
| Husen | 45 | M | Married | Muslim | 8th grad | Farming | Sister | 6 years |
| Meserake | 24 | F | Not married | Orthodox | 10th grad | Student | Mother | 5 years |

### 4.2 Family caregiver's attitude towards bipolar disorder

This section presents the family caregivers attitude towards bipolar disorder. In this study the family caregivers' attitude has been expressed through their understanding and feelings related to the illness and the patient. Consequently, the two important teams that emerged in this domain were family caregivers understanding and caregiver's feelings related to the illness and the patient. Under caregivers understanding socioeconomic link causal attribution, biological factors as a cause of illness, psychological factors as a cause of the illness, and spiritual link causal attribution developed as a sub teams. The other teams that emerged under family caregivers' feelings related to the illness and the patient shame, guilty, grief and stress.

#### 4.2.1 The family caregivers understanding about bipolar

The respondents who are the family caregivers of the study were asked whether they knew the kind and classification of mental illness that the patient they are giving care has suffered from. Their response revealed that the majority of the caregivers reported that they had no adequate understanding about mental illness as well as the existence of different mental illness classifications. However, they already developed the knowledge that mental illness had different signs and symptoms. To distinguish their relative's illness instead of using bipolar disorder, they use the expression 'my relative's mental illness'. One focus group discussion participant explained this knowledge gap as follows:

> I didn't know the existence of different type of mental disorders. Even I have no enough knowledge about mental illness. But when my daughter was admitted to the hospital I observed different and at the same time similar signs and symptoms experienced by the different patients.

Even if the majority of participants had no enough understanding that directly fit with the scientific explanation of bipolar disorder they held different level of understanding. Most participants built their understanding about the illness from their day today socio-cultural interaction. And mostly they know about the illness after the onset of their relative's illness. But few participants built their understanding about bipolar disorder from the explanations of psychiatrists who are employed with in Amanual Mental Specialized Hospital and by reading different brochures and materials with in the hospital and from different websites. The data gathered through in depth interview and focused group discussion revealed that all caregivers understand that bipolar disorder is a severe mental health problem which results impairment on the patient's life. They also realize that the illness can be treated by modern health care centers as well as traditional and spiritual healing mechanisms. On the other hand, caregivers held different understanding regarding the causes of the illness. Caregivers understanding the cause of the illness are presented here under four sub themes including socioeconomic link causal attribution, biological factors as a cause of illness, psychological factors as a cause of the illness, and spiritual link causal attribution.

## Socioeconomic link causal attribution

Some family caregivers understand their relative's mental health problem (bipolar disorder in this case) associated with day to day social interactions as well as economic conditions. Yesufe was caring after his daughter about eight year's explained his understanding regarding the cause:

> Based on my understanding the value we give for love, life and social interaction is different from one another as the color of our faces. Some might give high value and in contrast other might give minimal value. Since someone give high value for love and social relationship and when he/ she failed from this social contact or when the contact is harmed during interaction, the illness might be created/happened.

Some family caregivers also held the understanding that their relative's mental illness or (bipolar disorder) is an illness that happens when a person could not get what he/ she wants for his/ her living. They understand the illness related with economic life. Mareame who provides care for her brother about four years said:

> My brother's economic situation causes his illness. Why I say this is his father passed away while he was a child and our mother does not have anything to properly grow him up. I am currently the only bread winner for him and our mother but I became ill that I couldn't afford the necessities of the house hold. Because of that he lacked things which are basic for all human beings. He couldn't do what his friends do such as attending education. This condition also had its own impact on him. We also couldn't do anything to ensure his wellness even in terms of meal. So I believe that our economic condition creates his illness.

The data collected from the research participants indicated that family caregivers also held the understanding that their relatives mental illness had resulted from unsettled home environment which resulted in migration from rural to urban and migration out of country. Some others also perceive losing the beloved ones because of death might be the cause of their relatives' mental health problem.

### Biological factors as causes of illness

Under this a few of the caregivers understand their relatives' illness as something related with different biological conditions such hereditary cases, imbalance among different hormones with in mind, braking the limitation of brain capacity to work etc. Some others also describe their understanding saying something wrong with in the mind because of nature. As the participants said, hereditary factor is a main factor that causes mental illness. For example, Mohammd who provides care for his nephew for ten years described:

> I am aware that such kind of illness might be hereditary, might develop from family members and a severe illness. I know this because I have been once diagnosed with this illness and passed through this problematic condition; I felt the symptom and the pain. The problem my nephew is having right know is similar to that of I had been living with.

Some other caregivers have the understanding that the imbalance among different hormones with-in the mind causes their relative's mental illness (which is bipolar disorder). As to the participants' understanding, this imbalance of hormones with-in the mind disturbs the mental activity of a person. Abebe who has been caring his elder sister about eight years said: "Based on my understanding my sister's illness (bipolar disorder) means the lapse of brain activities or agitation of mental activities. It might occur by both the excessive and deficient existence of hormones with-in the mind."

Some others also had the understanding that brain has its own capacity to do and not to do things. It has its own limitation but if the mind is required to do more than its ability and capacity mental illness can happen. For example, Kebede who provides care for his wife about two years explained:

> This mental illness happens on my wife because my wife had worked more than her capacity. My wife had served for several years in a government office and after a time she has started working beyond the regular time to increase our family's income. After some time, her busy work schedule makes her to be ill. Based on my experience I guessed that my wife's cause of the illness will be her over loaded work.

**Psychological factors as causes of the illness**

Caregivers of patients with bipolar disorder also had the understanding that psychological causes such as stress, anxiety, complicated grief, dissatisfaction, and jealousy might be the causes of this illness. Almaze caring for her brother about the last four years explained her understanding as:

> I think too much stress is the cause of my brother's illness. He gets stressed by things which are not happened in his own life. He aspired to be a doctor when he was a child and he gets frustrated and stressed because he is not a doctor now. Sometimes he also thinks he should have been in a ruling position in the country and when his illness gets worse he shouts saying I am a doctor, I am a ruler. He quite from college education saying I already have enough knowledge and this will not do better. I can be a doctor or a

> ruler with no education. For this reason he lags behind from the youth he grew up with. Then he started to get stressed.

The other participants also presented the perception that is connected with complicated grief. As the participants said, complicated grief is a factor that causes mental illness. Losing someone in life because of death and inability to accept the new situation causes mental illness. For example, Headja who is taking care of her daughter for twelve years said “Even if my daughter started showing bizarre behaviors when she was 8 years old, after she got married and losing her husband her condition highly worsened. “

There are also participants who showed their understanding through their response by stating that dissatisfaction in life is also another factor to the incidence of mental illness. In this regard Almitu who has been caring for her daughter for seven years explained her understanding as follows:

> I kept this understanding from my child’s behavior that she is highly dissatisfied by her life. She is always exposed to competition with persons around her. This behavior of complex usually results in anxiety, agitation, and madness on her. So I think this character of my child caused this illness.

**Spiritual link causal attribution**

Some family caregivers also had understanding that the cause of bipolar disorder is related with spiritual enactments. According to the family caregivers spiritual enactments such us spell by witchcraft, and evil eye contact might have been the main causes of the illness. In accordance with this understanding, Medina who provides care for her son for about seven years described her experience:

> My son was one of the best student even praised in a regional standard. Suddenly, while he was prepared to take a grad 10 matriculation exam one of his best guide books was stolen and he couldn’t find out that. After this condition happens he couldn’t attained his class properly. After that things are changed dramatically. From this experience I understood that my son’s mental illness (bipolar disorder) can be resulted from someone’s ‘Jealousy spell’ “□□□□□□□”. So I assumed that someone who had jealousy on my son’s good academic status planned the spell on him.

From those who have the understanding that main cause of bipolar disorder is evil eye contact, Ashenafi who provides care for his little sister for two years said:

> Before my sister lives with me she used to live in the countryside. While she was living there she was affected by evil eye. That was the reason why my sister became a psychiatric patient. When we took her to ‘holly water’ the religious fathers told us that her situation was due to an ‘evil eye’.

Focus group discussion participants also share the understanding that there is spiritual involvement on mental illness. Some focus group discussion participants of caregivers believe that any kind of mental illness by itself is the work of devil or curse from God.

### 4.2.2 Caregiver’s feelings related to the illness and the patient

This section presents the family caregivers who experienced feelings due to the incidence of bipolar disorder on their relative. This study reveals that family caregivers experience different feelings because of their relative’s mental illness. The data has been presented into four categories: feeling of guilty, shame, grief and stress. As the gathered data indicated even if family caregivers experience such kind of feelings, all caregivers believed that nobody gets diseased by his/her will. Due to this believe they all have positive attitude and tendency to take care of their relatives' as far as they can.

**Shame**

Some respondents' response shows that shame is the feeling usually experienced by some caregivers due to their perception that the illness might be curse of almighty God and also the understanding that the illness is unique from other illnesses and is dangerous. Accordingly, they experience shame to talk about their relatives' mental health problem and if it is known by others they also feel humiliation. Medina who provides care for her son for seven years explained her experience:

> I feel down and blue. My Son's condition hurts me a lot. The community considers me as I am a sinner or someone who has a bad behavior like having evil eye. Because of that I am ashamed on my son's condition; I can't even move freely and express my feeling aloud within the community.

Some caregivers' were ashamed to disclose their relatives' mental health problem because of different factors. As the caregivers stated they restrict themselves from disclosing their relatives' mental health problem to protect their relatives and themselves from stigma and discrimination. Almitu who provides care for her daughter for seven years described her experience:

> I was ashamed to announce my daughter's condition especially for my neighbors. Because I don't want to see my daughter considered as mad and dangerous. I don't want to see my neighbor's response after they got informed about my daughter's illness. So

> when she was admitted to the hospital and when they asked me where she has gone, I told them, that she went to country side to visit our families.

Similarly Almaz who provides care for her little brother for about four years explained her feeling of shame as follows:

> I feel shame to talk about my brother’s mental health problem; because if my working mates know about my brother’s illness they also consider me as a mentally ill person. Why I say this is that I had one experience before. One of my colleagues insulted me that you are mad. So as far as I can I try to hide my brother’s illness.

The most prominent feeling among focus group discussion participants was feeling of shame to talk about their relatives’ illness because of the fear about social isolation. Explanations among focus group discussion participants regarding shame repeatedly announce feeling of shame.

**Guilty**

This is the other feeling experienced by some family caregivers. Family caregivers experience feeling of guilty because of the thought that the cause of their relative’s mental illness might be they themselves and their fault. Yesufe who provides care for his daughter for eight years described his feeling in this regard:

> Seeing my child with this illness, I always ask what wrong I did in life or what her mother did. I thought there is something that is done by me or her mother. As a result I really feel guilty. When child suffers from the sin of mother and father it is called BERCHE “□□□”in Gurage culture.

In line with this Ashenafi who provides care for his sister for two years described his experience as follows: "I always feel guilty because of the thought that may I couldn't understand my little sister's wants. I always feel that there is something that my little sister lost and I failed to fulfill those gap as a result she became ill."

Some others also experience feeling of guilty because of their low economic status and previous un-peaceful familial relationship. They always accuse themselves and consider the primary cause of the problem might be themselves and their own faults.

## Grief

Grief is the other sensation that almost all family caregivers passed through. Family caregivers experience grief because of the thought that they had no power to heal their relative and they already lost their beloved relative because of the illness. Others reported that they experience grief because their relatives lag behind from their partners in schooling, having marriage and children. In line with this, Mareame who provided care for her elder brother for the last four years explained her experience:

> I feel sorry that his friends exist in good position in work place as well as in familial status but when I see him in this condition I feel really sorry. He was supposed to lead a decent life with his own families but he is in this mess. Because of this I really passed through extreme grief.

Others experience grief even if the family caregivers did anything to heal their relative but the outcome of the measures might be unsatisfactory and the patients might not have recovered. At such times the family caregivers' entered in dual crisis. Hadja provides care for her daughter for twelve years and said:

> I always sense that, I succumb in the battle. Because I couldn’t do anything to cure may daughter. Even if the medication gives her some relief it couldn’t completely cure my daughter. Most things that I did for my daughter enter me in crisis without any outcome. I feel that I couldn’t help my daughter.

Similarly, the other caregivers experienced grief because of the felling that they lost their beloved ones. Though their relative is alive his/her personality is changed and sometimes they may act as stranger. With regards to this Medina who provides care for her son for the last seven years explained her experience:

> I passed through extreme grief because before his illness my son was really good and he used to loves his mother very much, cares for me, he also used to worry about me and my futurity. He tries to do things to make me happy. But after his illness, he was totally changed even sometimes he wanted to kill me. I always feel sorry because I feel that I already lost my child who was an Angel for me.

Besides the above findings the changing life circumstances including deterioration in economic condition and social bonds were also the other factors for the feeling of grief raised by focus group discussion participants. For example, one participant said: “I feel really sorry when I compare my economic status and my social attachment before and after my daughter’s illness and my care giving activity.”

**Stress**

Some caregivers also experienced too much stress. Especially when they feel uncertainty about for how long the illness continues and for how long their care giving role will go on with. Stress due to the patients’ dangerousness for the family members as well as for others, stress for unpredicted future life of the patient, and stress due to social responses were common points for the participants of this study. In line with this Medina described her experience as follows:

> I get stressed by his unexpected behavior that when I feel he is well and is to recover his condition totally got changed and he became danger for me and for others. This kind of things that comes from his behavior as well as negative social responses makes me stressed. Today, my stress worsened and I already started to take medication to overcome my stress.

In contrast to the above findings Kebade who provides care for his wife about two years explained his feeling experience as follows: “I feel noting, I think God wants to teach me something. That is why He gives me as such. I thought He wants to test my strength and patience. This happens for good. Because of that I feel noting bad about my wife’s illness.”

### 4.3 Family caregiver’s care giving experience

This section presents the family caregivers experience under five categories of sub-themes including factors to become a caregiver, perception of care giving which developed from their care giving experience, types of care that they provide within their care giving experience, and effects of care giving on their own personal life.

#### 4.3.1 Factors to become a caregiver

There are different factors identified in this study that impose family caregivers’ to become a caregiver. Having blood relationship with the patient had a great influence to become a caregiver. Caregiver religious belief has also its own pressure on caregivers to be a caregiver, passing through this kind of mental illness, and the previous behavior of the patient were other factors reported by participants of this study. Hadja said thefollowing regarding parent-child relationship:

> I care because I’m her mother and I cannot leave her as others did. Even her brothers, sisters and other family members forced me to stop taking care of her and told me to let her die so as to get relief “□□□□□□□□□□□□□□□□□”. But I cannot stop caring since I’m her mother who gave birth to her.

Other caregivers also reported that they give a higher emphasis for their religious belief and commandments of their religion in addition to their blood relationship with the patient to be a caregiver. In line with this Abebe provides care for his elder sister for eight years said:

> In addition to our blood tie there is something that forced me to become a caregiver. That is my religious obligation since I believe in the bible; it is one requirement to be the son of God. He obligates us to help persons who are impaired because of different cases; that is why I provide care for her when our other sisters and brothers deny to tack care of her.

Passing through this kind of mental illness had its own great influence on the caregivers’ decision to provide care and support for the patient. Mohammd provides care for his nephew about ten years explains his experience as follow: “The first reason why I came to assist her is because; I once also was the victim for such type of illness. I want to understand and help her when she feels ill other than any family members who lived with us. I know the pain and the ways of the treatments.”

In addition, some participants from focus group discussion reported that the previous behavior of their relative is also the other factor to become a caregiver. According to the study participants even if providing care for the person with mental illness is very hard and burdensome the behavior of the patient before the onset of the illness had its own impact on caregiver's contribution in care giving duty. As to the explanation of some focus group discussion participants when they provide care and support for their relatives, their relatives' responded to try to hit and kill them; however, they couldn't stop giving care for their relatives because they always recall the past good doings and behaviors of their relative with bipolar disorder. So that, they reported that besides their blood relationship the past behavior of the patient can be considered as a factor to become a caregiver.

### 4.3.2 Perception of care giving

The data gathered through in depth interview and focus group discussion revealed that the family caregivers have different perception towards care giving. This section presents the family caregivers understanding about care giving by categorizing three sub themes including, meaning, range, and requirement.

#### Meaning

Almost all caregivers participated in this study have similar concept on the meaning of care giving regarding to its definition and the ways it can be applied. By basing these two variables caregivers articulate that care giving is the activity of caring for the sick, fulfilling what the patient wants, answering or responding any requests that a patient rises, and protecting them from danger. Besides, doing things that are essential for the patient even without being asked is part of the care giving. In general terms, participants reported that care giving means ensuring the patients' wellness holistically.

Even if their level of expression differs from one another, all family caregivers participated within focused group discussion and in depth interview had the above understanding of care-giving. The finding of this study also shows that family caregivers perceive that care-giving can be applied through words, action, and facial expression. Regarding to its difficultness, all caregivers argue that it is the most difficult and problematic activity. In line with this argument Mohammd said:

> I have no words to explain clearly about care-giving but it is the most hard but very important activity. If you have never experienced the illness, the caregiver might get frustrated or overwhelmed by care-giving. In addition the caregiver will be facing conditions that are harm full for the caregiver him/herself. When the care giver tries to help the patient the patient as he/she may beat, bit, insult and do other stuffs on you. If you are not able to handle such things you might put yourself as well as the patients' life in danger. It leads to both physical and mental disability and finally to the wish of death. It is very difficult that currently I'm on a level that one chooses dying than living.

In addition to the above finding which shows some factors that makes care giving activity so difficult, some participants from focus group discussion revealed the factor that inability to discuss and reaching an agreement with the patient makes it very burdensome. Almost all participants within the discussion considered taking care of an individual with a psychiatric problem is a big temptation of God or 'Allah'. They indicated it is the most difficult job because, they cannot discuss, communicate and reach to an agreement with a patient with mental illness like others do with a patient with other kind of health problem.  Patients only want things must go the way what they need. But the things that they want to be fulfilled are those that can be harmful for them and others.

### Range

Family caregiver also expresses their views regarding the range of care-giving. The range implies the initial care-giving up to the maximum efforts applied for care-giving. On the other hand, study participants' uses range to express their level of involvement in the care-giving activities. Regarding potential level of efforts used for care-giving Aster who provides care for her brother for about thirteen years said:"Care-giving ranges from providing everything that the patient wants, making him/her happy and doing things; what benefits him most and protecting him from danger up to strengthening and empowering them, to be in a better condition and reaching them to independence."

Participants also use range to indicate their level of involvement in caring activities. Family caregivers reported that they involve in the activities that required the minimal energy of the caregiver as well as involve in the activities that needed the caregiver's potential scarification of desire and wishes, even the caregivers sacrifice everything they have for the wellness and safety of their relatives. Almaz describes her experience as follows:

> I involved in the activities which are easy for me but have a great importance for the wellbeing of my brother up to activities that might results a higher loss on my desires or the activities that might have harm for me. From the life I passed through despite the difficulties I faced and if I feel bad I need to look happy for him as far as I can. Because if I do differently I fear his condition might get worse. I ignore my feeling and desire and repress myself for the wellbeing and happiness of my brother.

## Requirements

Family caregivers reported that care-giving for relatives diagnosed with bipolar disorder, requires different mental, physical, and financial capabilities of the caregiver. For its positive outcome it also requires the contribution of different governmental and non-governmental institutions and professionals, as they indicated. Some caregivers explains that care-giving from the caregivers dimension requires understanding and holding all the negative impacts of care-giving and keep the caring up, it also demands a great deal of patience, endurance, commitment, dedication, hope , and good economic status.  Generally, it needs good physical mental and economic status.

According the family caregivers report care giving had also different requirements from professionals and from both governmental and nongovernmental institutions. From professionals and institutions, care giving needs a vast amount of awareness creation, commitment, and follow up or holistic support. Training is also another requirement of care giving from the whole concerned bodies.

Similarly, all focus group discussion participants indicated care giving required moderate level of awareness and understanding. They indicated that to identify the behaviors of the persons which are out of the normal condition and to take appropriate measurement, knowledge about mental illness within their care giving course is mandatory. In line with this one of the participant in the discussion explained:

> Everyone within our town lacks awareness about mental illness. If someone encounters such kind of problem their misunderstanding leads them to take wrong measurement like using traditional healers. So as to avoid this kind of practices and to provide patients with

modern treatment creating awareness for family caregivers about mental illness and building the societies understanding is required.

### 4.3.3 Types of care

All family caregivers reported that they provide different types of care and support for their relatives. Almost all caregivers articulated that their relatives' diagnosed with bipolar disorder are not responsible for their illness. In other words family caregivers believed that their relatives with bipolar disorder involved in this problematic condition not by their willingness. As a result all caregivers reported that they are voluntary to provide any kind of care and support by their consent without any coercion. As far as possible, all caregivers provide holistic care and support for relatives diagnosed with bipolar disorder. Family caregivers' willingness to provide care for their relatives is very high. For example: Medina who provides care for her son about seven years express her level of willingness as follows: "I am ready and devoted to do whatever kinds of support as much as possible even till death if there is a change after."

This study Participants reported that they provide physical care, medical care, and psychological care, and social care.

### Physical care

All family caregivers participated in this study reported that they provide holistic physical care and support such as, preparing the patients meal, helping them to eat and drink, tack care of their personal hygiene by showering their body, washing their hair and their clothes; cutting their nails and under taking other related physical cares. Family caregivers reported that the patient's tendency to take care of their personal hygiene and to have food is always changing. Sometimes their tendency to take care of their personal hygiene and to do other activities is very high but in other times without the help of family caregivers they don’t want to perform any activity by themselves. During such times the family caregiver’s contribution is highly significant. Hadja provides care for her daughter for twelve years and explained such kind of experience:

> My child’s behavior is always changing and is unpredictable. Sometimes she keeps her personal hygiene very well even she uses different cosmetics and makeups to beautify herself. But in other times her behavior changes dramatically and she refuses to take any kind of personal hygiene, have food, taking medication and other activities. During such times, I did all the things which are available for her.

### Medical care

The caregivers participated in this study reported that in addition to physical support they participated in medical care through taking them to hospital to get professional support, communicating with the doctors/ physicians, nurses and other health care professionals about the signs and symptoms of their relatives’ illness and also the different side effects of the medicines, and being in the hospital to support professional caregivers. After the patient is discharged from the hospital, family caregivers provide medical care for their relatives by taking and buying the medicine from the hospital and private pharmacies, by keeping the medicine safely, supervising their relatives to make sure they took it timely and properly.

Participants with in focus group discussion also discussed about the provision of medical care. As their discussion revealed, when their relative receive outpatient care, they take the medicine from the hospital every three or two months based on the prescription of their physicians. Sometimes the medicine is not available at hospital’s pharmacy; at this time they try to find out the medicine from private pharmacies, and they always supervise their relatives medication in-take because sometimes patients could deny taking it at all and in other times they wants to take over the prescribed dose.

### Psychological support

The study participants reported that care-giving is beyond the provision of physical and medical support. Almost all caregivers reported that they provide psychological support for their relative's diagnosed with bipolar disorder. Caregivers provide psychological support in terms of advice and counseling to avoid unwanted behaviors of the patient and to build up their positive doings, self-esteem, and self-confidence. Family caregivers in addition to physical care and medical care they provide psychological care to help to lives their own live independently and to develop the sense of importance. To explain her experience Almitu said:

> I do any kind of care for my daughter. I am really positive to help her for those of good things that help her life to be happy and make her satisfy. But when she ask and do things that are harmful for her as well as for others, I had advised her - to quit doing things that are bad and I tried - to show her that her question is not good politely. I also try to give her hope that tomorrow will be better and encourage her to have good communication with others.

Other caregivers also try to empower their relatives and help them to develop sense of independence. In this regard Abebe was caring his elder sister for eight years explained his psychological care for his elder sister as follow:

> I do all the necessary treatments but sometimes I let her do things by herself. Then I tell her to do some works. Since it is not my intention to make her feel a feeling of

> dependence, I appreciate and help her to feel able and strong. I give her advice, inspire her spirit and tell her that she can do everything she wants and I tell her how our family loves her to build her feeling of importance and to avoid her unwanted feelings.

## Social care

Participants of this study also reported that they provide social care for their relatives. In addition to ensuring the patients wellness family caregivers try to make their relatives social life conducive and easy to interact with their environment. Almza who provides care for her little brother explained her experience regarding the provision of social care as follows:

> I try to build his social relationship strong and good thus when I am invited to friend's house, I take him with me so that he can feel welcomed, happy to talk with others and share experiences. I assume such kind of social interactions reduces his stress and builds his social relationship. In addition, when he gets better and work I show him how he can help needy people.

Ashenafi provides care for his elder sister for about two years and explained the way how he provided this social care as follow:

> When she is out of hospital, I will take her to different recreational center to enhance her social contact. I take her to somewhere to visit; buy some materials; take her to refreshment places. When she is at hospital I do my best also for her to have good social approach with physicians and different members of the institute.

### 4.3.4 Care giving effects on caregiver's life

Almost all caregivers reported that their caregiving experience affects their own life in different ways. According to the respondents of this study though they were not disappointed of taking care of their relatives, care-giving highly affected their life situation. This section presents the family caregivers experience in terms of care-giving effects by categorizing under four sub themes including, effects on personal life, effects on social life, effect in the spiritual life, and economic effects.

#### Personal life effect

All family caregivers reported that they believe they would have lead a different life since they started caring for relatives lots of things have been changed in their physical and psychological welling. It also determines their potential to be what they want to be and it makes them not to succeed their plans, desires and goals. Some caregivers reported that doing this care giving activity exposed them to experience different physical and psychological health problems. In line with these negative results in physical wellbeing Yesufe said:

> After my child's illness my leg was injured because I always spent much time to protect her by being here and there. Today, I couldn't even move freely. For instance, previously I was relatively healthy but now I become diabetic and hypertensive; I am devoid of mental peace, I become anxious and mad in most silly things. I don't have proper sleep and happiness. I become helpless, fearful and sad by any cases. Generally, it impacted my physical and mental health. Even my weight and energy turn down time to time.

The finding of the study indicates that some study participants in addition to passing through cumbersome life events they may be experiencing different mental health problems. For example- Medina said: “Above all the physical and psychological problems I also experience mental health problem due to my care giving experience. So that the doctor subscribed a medication for me and I begin to take, to avoid my problem.”

Some caregivers also consider their care giving duty as an obstacle to fulfill their goals and desires. It determines them from using their maximum level potential to reach on their goals. To describe this Ashenafi who provides care for his little sister for about two years explained:

> Since my job is athletics it needs so much potential like having regular trainings and participating in different contests to check my capability. After the training or the contest we are obligated to take enough breaks and have food stuffs which are nutritious. But after my sister’s illness I am not doing all of these since I have to be with and always be besides her whether she is in the hospital or at home taking care of her. Even today, I got up from bed at 4 AM and had training and in the morning at 6 AM I should be at the hospital; I was moving without enough break and come to hospital which made me to go asleep wherever I sit. Therefore, taking care of her I ruined my life in different ways; it made me not to reach to the position I demanded, and also not to get the rank that I was wishing to take in the athletics world.

### Effect on social life

Caregivers participated in this study reported that they have passed through many unpleasant experiences when they provide care for their relatives. Based on this experience they recognized that care giving have a high negative effect on their harmonious social relationship within their own family, neighbors , Idirr, Mahibr, and Ekube members, working mates, religious partners and others. Almost all participants believe that care giving changes their life up down.

Before they begun to provide care they used to participate in the social life activities within the community such as asking a person who is sick, went to Idirr and different mourning activities, participating in weeding and other ceremonies. But after their care provision starts all these participations are almost lifted. Since they could not attend people in their good and bad times, they lost their social ties as well. Caregivers also reported that they also lost their peaceful relationship with in home because they are unable to spend good time with the rest of family members. In line with these social effects Abebe explained his experience as follows:

> Besides my social interaction crisis within the community I lost my social relationship with my work mates. Because before my sister's illness I do my job cooperatively with my colleagues and we used to work as a group. But now, a time which is appropriate for work to them is not appropriate for me; in this case I do my job independently. Due to this case my relationship with my working mates is not as such strong.

These social life effects of care giving were repeatedly voiced by focus group discussion participants. They indicate that their care giving experience makes them isolated and even they do not have good communication and acceptance in the community. Most of their free will and good reputations have been deteriorated and darkened from time to time as they indicated.

## Economic effects

Family caregivers also reported the higher effect of care giving on their economic life. All family caregivers reported that, when they compared their life before and after the illness of their relatives they got themselves in great crisis. Care giving negatively affects their ability to work freely and earn adequate money. On the other hand, their economic status highly deteriorated by different additional costs connected with the illness. Some of them reported that care giving make them to be dependent on others. According to this study, participants also left different advantageous opportunities because of their relative's illness. In line with the care giving effect in day to day working life Almaz said:

> The life I had before and now is so different. Previously, I was productive in my work and be paid good money. Now I get fired because I used to get absent from organization to take care of him and I lost many clients from my business. That happened a lot of time and I could not work for a longer time in one organization. Today covering household costs by itself is difficult for me.

The study finds out that family caregivers spent higher costs for traditional healers which involved them in great crisis in addition to costs which are spent for the needs of the patient. In line with this a mother caring for her son said: "Within my care giving experience I lost my money and property to heal my son. For example, I spent above 250,000 birr for the traditional healers, what they called "□□□□□□□□□□□□□" though we haven't seen any change."

The finding of this study also indicates that the caregiver's economic destruction had a great impact for the overall family life. Most caregivers play a dual role as primary bread winners for their families as well as the primary caregivers. Due to that reason conflicting role within the family is common and the impact of caregiving with the families' economic status is undeniable. The focus group discussion participants have shared the experiences regarding economic status deterioration that it has negative impact for the whole family members. For example, one participant with in focus group discussion said:

> When we look at my experience, my business is not doing well because of that our experience is greater than our income. My family and children are not getting enough

> attention and money because I cannot work properly. For this reason we are now living with the support of others.

**Effect in the spiritual life**

Study participants experience different effect of caregiving within their spiritual life. All participants reported that after the illness of their relative their religious practices such as praying, reading Bible/Qur'an, attending different church and mosque programs, attending sermons and other spiritual routines got deteriorated. In this regard Hadja explained:

> My life before is very peaceful. For instance, I had strong participation in religious activities; I do not get mad and become anxious; I even eat and dress comfortably. I always pray my regular prayer and have a recite of Qur'an. But now I am unable to have my regular prayer; and even I cannot recite Qur'an regularly. As a result I get mad and anxious by anything around. I am not in peace internally and externally.

As participants stated participations and serving within church and mosque declined in lines with their care giving duties. Abebe provided care for his sister about eight years and explained his experience as follows:

> Within my care giving experience the basic thing which dramatically changed is my spiritual participation within the believers' association. For example, before my sister's illness I was participating in preaching activities within the street but today I couldn't. It seems things are out of my control. I don't see any hope and feel living. Because I couldn't do things that are meaning full for my spiritual life.

In contrast to the above findings one family caregiver believed that his wife's illness develops his spiritual attachment with God. Kebede who provides care for his wife for about two years:" Even if my wife's illness hurts me a lot, after the illness I made strong my relationship with God. Because I believe that God is the answer for my wife's illness. So I hope that one day God will cure my wife."

## 4.4 Family caregiver's challenges

This section presents family caregivers challenge within their day to day care giving course. Caregivers reported that care giving by itself is a very burdensome activity and it also exposed them to different challenging situations. It highly needs the help and understanding of the others. Study participants' experience different level of challenges from different directions. The first challenge experienced by almost all caregivers is the lake of adequate knowledge about mental illness. Almost all participants sound out that they have no information about mental illness classifications and their symptomatic similarity and differences. All family caregivers didn't know the initial signs of the bipolar disorder. Due to this reason they ignore the initial signs and symptoms of the illness. Almost all family caregivers didn't recognize the mood swing problematic condition of the patient until the problem gets worsened. From the two polar or episodes of the illness (manic and depression) caregivers confused and questioned when their relatives are depressed rather than manic episode. Mostly the manic episodes of the patient's behavior considered as normal. In line with Almaze said:" previously before I informed the signs of the illness, when my brother is happy and when he showed his happiness by dancing and laughing, I feel relief and I assume that he become well. But when he is depressed and when he refuses to went out from the house I thought that there is something wrong."

According to these research participants the first preference to get treatment for their relatives is the use of traditional and spiritual healing mechanisms. Some research participants fear the treatment provided in the modern health centers like Amanuale Mental Specialized

Hospital due to the oral tradition that ‘the hospital fantasize patients’. This misunderstanding leads them to determine themselves not to get treatment for their relatives from modern health care centers until the illness impaired patients. Besides this misunderstanding family caregivers had experienced and reported different challenges. These reported challenges are presented in this section by categorizing under five sub themes including challenge from the patient’s behavior, challenge from the society, challenge from work place, challenge from the hospital, and financial challenges.

### 4.4.1Challenge from the patient’s behavior

Almost all family caregivers reported that the challenging conditions have resulted from the patient’s behavior and is always changing and unpredictable in accordance with their mood swing behaviors. To explain such changeable behavior of the patient one participant used Amharic word “□□□□□□□□□□□□□□□□” “It makes her ones a human and another time soil”. Caregivers of patients with bipolar disorder are facing the challenging situations in accordance with the behavior of the patient. Family caregivers reported that they identified two major changing behaviors of the patients. The first one is overexcitement (manic) and the second one is unconditional grief (depression). These two episodes had their own signs and symptoms on the patient brought different challenge for family caregivers.

All family caregivers described that when their relatives are overexcited (manic path) they had positive behaviors such as working hard, commitment, peaceful relationship with in home and outside, happiness, high protection of personal hygiene and other. However, it seems things are going well and good at such times there are also a lot of conditions disturb the caregivers comfort and involves in different challenging situations. According to the study participants during such manic path even the positive behaviors and doings of the patient go extreme out of the normal condition of the healthier person. Family caregivers challenging situations in this period are the patients behavior of lack attention and concentration for some basic things at their hand, irritability and reckless, extravagance, inflated self-esteem, trying to do things that are difficult and harmful, binge disappeared, and other deviant behaviors such as laughing alone, dancing on the street, insult and try to bit and beat the family members and others are the behaviors that brought family caregivers with in challenging situations.

According to this research participants the above behaviors of the patient highly challenges family caregivers. It also results fear, stress, anxiety, and crisis in terms of economy, social ties peaceful family relations. To describe challenges related to the patients' behavior when they are overexcited (manic path) Almaz who provided care for her brother about four years explained:

> During these times he is good in handcrafts and he creates new designs. It is so impressive and that brings a great amount of money. He likes to be with people and has good relationship. He is active and smart in some dimensions. At this time, what challenges me is to take care of him because he gets too hyper and active and I fear he might get to trouble or face danger. He becomes extravagant, he drinks and likes to invite everyone for free drinks. If he finishes his money he will start to sell even the clothes he wears and come naked, sell home items too. In general even if his good doings are there, his irresponsible actions and decisions are most.

The finding of this study revealed that even if this elevated mood period of a patient have its own positive outcomes, patients might involve the activities which are problematic and challenging for people's around. Abebe who provides care for his sister about the last eight years described his experience as follows:

> Sometimes she gets happy and laughs even without any reason when she was alone. At that time she is protecting herself in terms of personal hygiene and she performs as a healthy person actively. The problem at this time is that when she sees any man walking nearby she shows some ridiculous character. She tries to seduce them by showing wrong manner. If she is unsuccessful she starts insulting and intimidating them. Other big problem at such time she tries to do things that are almost impossible for her level of consciousness. For instance, one day she tried to show she is so brave by climbing on a big tree that was at the verge of a cliff. Unless peoples around her tried to rescue her she could have died. So I spend my time by looking after her. But I still could not protect her. I remember one time as I was looking her she crossed a road suddenly, was about to be hit by a car. When she gets hyper she gets lost once. We all family members were so frightened and she was back after a week from police station.

Contrary to the above scenario, caregivers' challenges get altered when patients are immersed in the period of depression. As family caregivers reported during this time their relatives' illness totally get changed from overexcitement to depression. According to the participants of this study this depressive path of the illness is the more burdensome and challenging than the manic episode of illness. In this time family caregivers challenged by different behaviors and doings of their relatives such as, taking longer time at bed, feel lonely, get depressed and refuses to take any food ,drink, and medicine, disobedience, insulting, harassing family members as well as others. Aggressiveness, hitting all persons specially primary caregivers, damaging property, lacking interest to protect their personal hygiene, feeling of down or low self-esteem , lack of interest to do any work, lacking interest to share their idea (lack of interest to talk) loss of happiness and work performance, suicidal attempt, crying, and sadness. In this regard Medina who has been caring for her son more than seven years said:

> During this times he lets himself down and considered himself he is valueless and as if he is good for nothing, he is stressed anxious even tried to suicide himself and he became dangerous for his family. When I see these changing behaviors on him, I became very stressed by his situation even I wanted to be dead. When he was crying in front of me, I also was crying with him, I fell badly, totally I lost my mind. One day hits me badly and I get admitted in hospital for a long time. In this period he is very strong and dangerous, nobody can control and challenge him. Any materials that are sharp hided with in home unless there is something bad happens. Even when he was chained he uses any moment to harm somebody. I have no supporter with in my home by this case it is very hard to take care of him. It is out of my capacity to control and supervise him.

Participants within the focus group discussion also indicated that they had similar experience regarding the depressed episode of their relatives. The challenge voiced prominently by focus group discussion participants within this period is suicidal attempt through hanging themselves, taking too much medicine, holding electric wire and the like. Besides the other challenging situation with in this episode, the patients' annoying and aggressive behaviors challenge family caregivers adversely.

### 4.4.2 Challenge from the society

Family caregivers who participated in this study reported that they experience different type of challenge from the society. All family caregivers indicated the society's awareness towards mental illness is still low. The society considered the patient as well as the families of the patient as sinners. Thus the society's tendencies to understand and help the family caregivers in their problems are still less. In contrast, the society adds additional problem for them. Family caregiver's get stigmatized and accused by the society for the wrong doings of their relative. Yesufe to explain his experience said:

> From the community, I have faced many challenges "□□□□□□□□□□□□□". I have been accused saying she (my daughter) frightened our children, took our clothes; every one accuses me as if I deliberately made her to do all those things. No one is willing to understand and help me. For that matter, my social relationship by itself is a challenge for me. I do not have good social life after all.

The result of this study indicates that the family caregivers have been pushed by the society to leave alone the patients and send them in other area; otherwise they were told to leave the area where they live. According to some family caregivers the community members believed and said that the person's mental health problem negatively affects the happiness and peaceful community relationship, so that the community members suggest that family caregivers to leave the patient to go anywhere and die. Medina who came from a small town and caring her son for about seven years said:

> From the society there are so many problems I faced. Since I live in small town the society knows me and my son's condition. The society totally alienates me from any

> social life; nobody wants to have a relationship with me. Furthermore they always told me to chain my son or to leave him alone and to go somewhere leaving the town "□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□". Even my family member's doesn't support me and in contrast forced me to stop taking care of him. Their pressure on me added much anxiety but I cannot leave him die by his illness because I am his mother though I was facing different difficulties in my life.

In addition to accepting the above findings, some focus group discussion participants revealed that even when their relatives become well and try to do work, the society assumes he/she is always ill and not capable for any kind of work. According to the data from the focus group discussion, no one is voluntary to cooperate with the person with mental health problem even when he/she got recovered. In line with this, one focus group discussion participant explains her experience as follows:

> When he became well he drives a Bajaj and he tries to support our family's income. He is very interested to do the work. But all the society members were not voluntary to travel by his Bajaj. They said 'he is ill' he took a medicine from Amanual; he will crash the Bajaj "□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□".

The finding of this study indicates the community's misunderstanding and lacking adequate knowledge regarding mental illness brought that family caregivers in a big problem.

### 4.4.3 Challenge from work place

Participants of this study also experience challenge from their working place. Caregivers reported that after the illness of their relative they had no peaceful relationship with their work mates as well as their bosses. Due to their caring duty they may be late to arrive in work place and they may be absent without getting formal permission. As such times, almost all family caregivers who are both government and private employees reported that their working mate's tendency to understand and help them is very low. Though family caregivers provide evidence for their absence from Amanuale Mental Specialized Hospital no one is voluntary to compromise their problem. In line with this experience, Kebade who provides care for his wife for about two years and who is employed in government office said:

> Despite other problems I have a big problem with in my work place. To provide care for my wife sometimes I am late in my work and when the problem worsens I may be absent. In this case everybody judges me as lazy. Nobody tries to understand my problem even I provided a document as evidence from the hospital. Because of that I have no peaceful relationship with my bosses. In addition, I accused and I lost my wedge so many times.

Similarly, other participants who participated in the focus group discussion and in depth interviews reported that they encounter a big problem from their working places to get their annual lave and other benefits. There are also caregivers who reported that they got fired from their job due to low tendency of their working mates to cooperate and share problem.

In contrast some family caregivers reported that they had positive experience with in their working place. In this regard Almitu who is employed in government office and caring her daughter for about seven years explained:

> Everybody working with me knows everything about the situations that is going on. They are positive to help me in my job. They sometimes cover my duties in other times I will do so for them. They have high positive tendency to help me. They try to understand in what situation that I am; my work meets help me a lot.

### 4.4.4 Challenge from the hospital

As the caregivers report they experienced different problematic situations within Amanual Mental Specialized Hospital. They experienced hospital related challenges when their relatives receive different inpatient and outpatient treatment services from the hospital. Especially when patients admitted in hospital, caregivers are exposed to experience various challenge from the hospital. The study participants report indicates that their relatives' mental health problem relapsed so many times, in this case patients repeatedly admitted in hospital. In line with patients admitting family caregivers expected to provide care with in the hospital by cooperating with professional caregivers As family caregivers report the hospital strongly announces that without the family caregivers support the hospital by itself do nothing for patients. Thus all family caregivers are obligated to stay within the hospital at least until their relatives get recovered. During such times they passed through different challenging conditions.

The major problems reported by caregivers when they are within the hospital include the problem related with food, bed, and materials to protect their personal hygiene. Those caregivers who came from the country side are highly venerable for these challenges from the rest of caregivers. In line with this Almitu said:

> When my daughter got admitted with in the hospital, the hospital situation is not comfortable not only for family caregivers but also for the patients. Within ward

> (patient's bed room) there is no place for family caregivers' even a piece of chair. Anyone who is expected to take time with the patient at night takes a rest on the floor.

Other family caregivers also reported that there are challenges related to the shortage of medicine and also in the hospital's bed room arrangement for patients. These two conditions within the hospital indirectly creates additional burden for caregivers and make their caring activity worthless. Some family caregivers indicated that most of the time there is shortage of medicine within hospital. As a result the physicians prescribe alternative medicines which mostly cause different strange side effects. Those times create additional problem for family caregivers. On the other hand, the hospitals bed room arrangement for patients that the new comer patients is mixed and shares one bedroom with ones who have been there for long. It also creates additional problem for caregivers.

Similarly, focus group discussion participants' shared the experience that the challenge resulted from the hospital's bed room arrangement. They indicated the hospital's bed room arrangement adds additional burden for family caregivers. They indicated that even if they do all the bests to help their relatives' this bed room arrangement problem makes their care giving effort worthless. In line with, one participant explained:

> I remember that, before one year my wife was admitted to the hospital and after long time treatment my wife got recovered and was preparing to discharge. However, when she has left with three or four days to discharge the new comer patient came to her bed room. Within those three days all patients within that ward including my wife were disturbed and some of the problems of my wife got aggravated.

Some others also reported that the provision of service without considering the family caregivers' condition, disrespect, weak control of substance use, weak security, lacking recognition, and inadequate awareness creation are challenges experienced by caregivers when their relative receives service from the hospital. Regarding disrespect Almitu said that:

> Some staff members with in the hospital treated us in wrong way. For example, since there is no chair, within the patient's ward we are obligated to sit on the patient's bed, during such time when someone saw us sitting on the patient's bed, they insult us and they didn't communicate us politely.

Participants with in focus group discussion also raised the problem related with weak security. As they indicated, even if Amanual Mental Specialized Hospital provides care for the persons with different mental disorders the security to protect patients is still weak. They reported that until now there is a problem related with patients' disappearance from the hospitals compound and also problems related with conflicts and disturbances with in the hospital setting.

### 4.4.5 Financial challenge

Financial challenge is also the other challenge experienced and reported by caregivers. Family caregivers due to their relatives' illness involve in different crisis and encounter additional expenses to take care of their relatives. On the other hand, since the family caregivers' mostly leave their home and provide care within the hospital they had additional costs to expand. According to the family caregivers report costs such as transportation cost, cost for food for themselves as well as for the additional food for the patient, house rent, and medical cost are costs that involve the family caregivers with in a big problem. Medina who provides care for her son and comes from the country side said:

> I brought him in Addis Ababa by the money which is offered from my religious partners. After we arrive to Addis even if he is admitted to the hospital without any payment and

> he got everything freely with in the hospital. I was challenged by different financial cases. Mostly, I lost money at least for transport and for food.

Other costs for the replacement of properties damaged by the patients, for persons who support their caring, and cost for the traditional healers are costs reported by caregivers as a financial challenge within their care giving course.

### 4.5 Coping mechanisms

Family caregivers used different coping mechanisms to face various challenges within their care giving life. Coping mechanisms applied by family caregivers vary from one another based on their attitude towards the problem and the nature of the problem. If they perceive that the problem can be solved they may discuss with the family members, neighbors, friends, professionals, and religious fathers or they may use another problem focused coping mechanisms. In contrast if caregivers perceived that the problem cannot be solved and the problem is above their capacity, they may pray or perform religious activities and they may also use other emotion focused coping mechanisms or they may ignore the problem and try to get other alternatives.

According to the family caregivers’ report they try to find out different coping mechanisms within their day to day care giving activity. As a result most of the coping mechanisms employed by caregivers are the result of their caring experience. But some family caregivers reported that the coping mechanisms used by them have been gained from reading books, from experiences of other caregivers who have the similar lived experience, and from different websites.

As reported using different coping mechanisms help them to minimize or solve their challenges and get relief. The data from in depth interview and focus group discussion revealed that this study participants used acceptance, giving priority for the patient ,discussion, seeking support, empowerment, preserving spiritual practices, advice and tolerance, and ignorance as coping mechanisms to deal with their challenges.

### 4.5.1 Acceptance

Almost all caregivers indicate that the first measurement which is taken by family caregivers after they know the existence of this problem is accepting the problem of their relative. Most family caregivers believe that this problem happens on their relative by the will of God or Allah. Accepting and considering the problem as a problem like any other problems and having the attitude that the problem can happen in any person’s life-time makes their care giving easier. Accepting the problem facilitates the way to find different methods that are helpful to manage their care giving. Abebe who have eight years caring experience said:

> Firstly, when hearing the diagnosis of my sister, I accept that my sister has mental problem. After that I try to find ways to deal with problems. I also try to see the positive dimension of the problem, strengthening myself by telling this problem is not only mine and there are people living in a bad condition which might be very difficult as compared with mine.

### 4 5.2 Giving priority for the patient

This is the other form of coping strategy reported by caregivers, which is giving priority for the tasks that are related with the patient from other duties that are expected to be performed by caregivers. Giving priority for the need and inquiries of patients rather than the rest of the family members as well as from the need, desires, wants and dreams of family caregiver's themselves is the other coping mechanism used by most family caregivers who participated in this study. Most family caregivers reported that they invest much energy, time, and different resources for the will of their relative's with bipolar disorder. They also miss different advantageous opportunities by placing their relative's illness condition at first. With regards to giving priority, Ashenafi explained;

> To be with her and to provide care, I try to change the times that I used to perform different duties to comfort my sister. For example, let us say my running contest is in September but I should be besides my sister, I postpone my training and contest for some other time because if I lose a contest, I can have another sometime later but losing my sister has no replacement. Therefore, I resolve all my challenges by making her my first priority.

Similarly, focus group discussion participants strongly announced that they give priority for the needs of their relatives with bipolar disorder as a major coping strategy. They revealed that putting first the need and requirements of the patients help them to get immediate relief. As to the participants', explanation, giving priority for the need and requirements of their relative demands letting aside the requirements and needs of other family members. Regarding to this idea one focus group discussion participant described her experience as follows:

> I always try to respond for all needs of my daughter to make her condition safe and to manage my care giving. I try to give priority for the need of my daughter from my family members as well as mine. For example, if there is shortage of money with our family and

> if the medication of my daughter is not available within hospital, I use all my money to buy the medication rather than other house hold costs.

### 4.5.3 Discussion with concerned bodies

Discussion is the method employed by most family caregivers to deal with their challenges. Discussion with family members, persons with bipolar disorder, friends, religious fathers, and health care professionals has been highly employed by family caregivers who participated in this study. The opportunity to deal with the family caregiver's problem with health care professionals is very low. According to participants mostly they discuss about the patient's condition with health care professionals but if they got the opportunity to discuss about their problems, they speak frankly about their problems. In lines with this Alemitu caring her daughter for about seven years described her experience as follow:

> Discussion is one of the main strategies I always employ to face and solve all my problems that are related with the behavior of my daughter and challenge related to my work. When I tell my problems to some people, I feel relief. In addition the person who shares my problem gives a new insight to the way how I solve my problems and she/ he may link me with persons who had adequate knowledge and resource to cope up from different challenges.

In contrast to most of the family caregivers experience regarding discussion, Yesufe who provides care for his daughter (for about eight years) said he doesn't prefer and use discussion as a coping strategy. To describe his idea he said: "Even if I want to talk with people' I fear if they might feel I am contacting and discussing with them to get money from them. Because of that fear, I didn't prefer to discuss with persons to deal with my problems. Within my family also nobody is voluntary to discuss because everybody got tired hearing about her issue."

### 4 5.4 Seeking support

This is also other mechanism applied by family caregivers to deal with those challenges experienced in their day to day care giving course. According to the family caregivers report they try to get support from family members, work mates, friends, local administrators, and religious groups. To cope up from their financial challenges caregivers mostly seek support from local administrators, family members and friends. As caregivers stated that if the local administration writes the paper about their economic inability to pay for the service, they got free service from Amanual Mental Specialized Hospital. On the other hand, if they encounter financial problem with in their day today activity they also ask their family members and friends. To solve challenges within their work place caregivers seek support of their work mates to help them by covering their duties. To cope up from their emotional challenges they also seek the help of their religious fathers. In this regard Hadja described the following:

> When I got short of ability or money, I ask people around to help and they help me as per their ability without discriminating one religion follower from others. But now, people are not as of the previous time, they stopped helping each other. As a result, I try to stop taking this as measure of coping problems.

Focus group discussion participants discussed about their social support seeking behavior and argued with the idea support from any direction managed their care giving activity. They also indicated that they use seeking support from the society as a measurement to face challenges. They indicated that this seeking social support behavior as a coping strategy helps them to minimize their burdens. For instance, one focus group discussion participant said: I ask help from my friends and neighbors to look after my cattle's and my farm land when I came to Addis to take care of my brother.

### 4 5.5 Encouragement

Some participants of this study have also reported empowering patients as mechanism to deal with challenges related to patient's behavior. According to family caregivers report persons with bipolar disorder perceive that they are dependent on their caregivers. Because of that thought they are angry and sad when they get recovered. And they also said "I made your life miserable" "□□□□□□/□□□□□□□□□/□", "I made you to spend too much of your money "□□□□□□□□□□". Therefore, they considered themselves as something valueless and unimportant and as a burden. To avoid such kind of mentality of the patients, caregivers leave the patients to do something by themselves. Caregivers also try to create conditions to the participation of persons with bipolar disorder indifferent decision making discussions with in their family. They also try to talk openly about their life condition. By doing such strategies the family caregivers try to develop a sense of importance in the patients' mind.

Some focus group discussion participants have shared the experiences regarding encouragement as coping strategy. As caregivers indicated, like any other family members with in the house holed they assigned some duties to their relatives with mental health problem to encourage their relatives to do tasks by themselves. At that time persons with mental health problem feels something good and use all potentials to perform that task which are assigned to them. So as much as possible they give some tasks to do by their own and try to understand their taught, feelings in a particular decision and they also give all the chances for their relatives to reflect their attitude and choice.

### 4.5.6 Performing spiritual practices

Preserving spiritual practices was also reported by participants as one of the main type of coping strategy used by all caregivers. According to the participants report, maintaining spiritual practices has been used for all kind of challenges resulted from different directions. All caregivers indicted praying, using Holy water, reading Bible/Qur'an as their first choices to cope from their problems. Ashenafi said: "I always want to take her to "holly water" rather than taking her to a modern health sectors since I believe that my sister's condition was not of a mental condition rather it was of a satanic possession."

Similarly, almost all participants within focus group discussion indicated that praying is the major preferable coping mechanism performed by them to get relief from their day today stressful situation. In line with this one participant said: for getting relief from my problems I pray to Allah. I prefer to pray to Allah rather than any other coping mechanism.

On the other hand, family caregivers indicated that in addition to praying and using Holly Water, reading and learning Bible/Qur'an helps them to get hope and develop their believe on God/Allah to solve their problem which is above their capacity. Abebe who provides care for his sister described this experience:

> When I read the bible I understand that God can do anything which is impossible for humankind. Then I come to believe that if God wants to cure my sister He can. Additionally, during my reading I understand that life will not end on this earth and there is a life after death. Due to this understandings and belief I try to take my problems easily.

### 4.5.7 Advice and tolerance

This is the other form of strategy reported by Family caregivers to deal with problems from patient's behavior. According to the report of caregivers they provide advice for patients to avoid unwanted behaviors. They also give advice for the patient to be wise and to restrict their irresponsible decisions. Almaz explained:

> When my brother is in the period of overexcitement (manic episode) he made decisions carelessly and rapidly which might have harm and danger for him and for the family as well. At this time by being with him I advise him to deicide wisely and do things responsibly. I help him to see things from different dimensions.

Tolerance is the other form of strategy reported by caregivers to cope up from different challenges. As participants stated during care giving, destruction or losing something important might happen; at that time they try to tolerate and manage ones emotion in the best way. Regarding to this tolerance Ashenafi described:

> Currently, my familiarity with the challenges and knowing the way to resolve them helped me a lot. For example, previously I used to get mad when she does things wrong. But now, I try to tolerate whatever she do, but I do not get mad for her wrong doings rather I advise her with love not to do similar things in the future.

### 4.5.8 Ignorance

Ignorance is also reported by participants as one of coping strategies. Some caregivers reported that short term ignorance of the problem and finding some other alternative help them a lot to deal with psychological challenges. In lines with this Kebede who have been providing care for his wife about the last two years explained: " When my wife's condition get worsened and when I feel tired and I couldn’t face that challenge, I let her within the hospital and I went to my home and play with my baby. After I clam myself, I will come back to the hospital and continue my care giving.”

Mdina who provides care for her son explained her experience as follows:“As a human being I need to eat three times a day but when I encounter a short of money I ignore my feeling of hunger and I eat just once in a day to cope up with my financial challenge. In addition, I may walk along distanceto reduce my transportation expenses through ignoring my tiredness.”

Other coping mechanisms such as chaining the patient, locking room on the patient, and hitting are used to face challenges related with the patients’ behavior as reported by some caregivers.

## 4.6 Family caregivers experience with services provisions

These study participants voiced prominently the absence of adequate service for the family caregivers. Caregivers reported that there is a huge incompatibility between their support needs and the existing service. Almost half of the participants didn’t know the existence of any kind of service for family caregivers. But the rest of participants reported the existence of family therapy which is the only service for them provided by Amanual Mental Specialized Hospital. All family caregivers have no any kind of experience related to services available for them except the family therapy service at Amanual Mental Specialized Hospital. This section presents the family caregivers experience with the service provided for them. The support needs of family caregivers have also been presented in this section.

### 4.6.1 Family therapy

According to the caregivers family therapy is the only service provided for family caregivers with in Amanual Mental Specialized Hospital. As to the family caregivers, the service is provided for them once with in a weak. Mostly the therapy is prepared for Friday morning at 10 AM and the therapy will be staying for about forty up to sixty minutes. Within this therapy, different issues regarding mental illness such as meaning, cause, treatment mechanisms, challenges, and problem management mechanisms and other issues will be discussed by family caregivers by themselves and the discussion will be managed by clinical psychologists and social workers. Within this therapy everyone is allowed to share their experiences, raise equations and ideas. After the discussion the conclusion will be made by those professionals. During these conclusion session things that must be done by family caregivers are highlighted, different misunderstandings corrected and different advises offered.

The focus group discussion participants have shared the experiences regarding the benefits they obtained from such sessions. They indicated that even if they get informed about this group discussion (family therapy) after they spent some time with in the hospital, they approved that this group therapy helped them a lot. They reported that at first place seeing a person who have similar problem with them avoids their sense of loneliness."They said, within this group therapy, we caregivers share our experiences; on the other hand, the professional's guidance and awareness creation helps us a lot."

All the family caregivers who knows the availability of this family therapy session and who have participated in the sessions reported that though the time allocated is too short and is not adequate, it is has been helpful or family caregivers to share their experiences. It is also helpful to enhance their understanding regarding to mental illness and care giving. These study participants also reported that this group therapy shows them how they manage their own problems. Data from in depth interview and focus group discussion indicate that family caregivers had no adequate experience related with services provided for them. Rather family caregivers have different experiences with informal supports which are provided from the family, their workmates, religious partners, and from the overall society. As family caregivers explanation even if Amanual Mental Specialized Hospital provides a higher support for the persons with mental illness, it should expand its service for family caregivers. The family caregivers pointed out their need of support from any governmental and non-governmental bodies.

### 4.7 Support need of family caregivers

Family caregiver's reported that they have different needs of supports from the government, private sectors, charity organizations and from different community members that are helpful to enhance their livelihood. The family caregivers' support needs have been presented in this section by categorizing them under five sub themes: social support, psychological support, financial support, legal support, support from the hospital and education and training.

#### 4.7.1 Social support

All caregivers participated in this study reported that they need a higher social support from their community and from the overall society. Family caregivers reported that they lead the most burdensome life as they are totally possessed by their relatives' health condition. Due to that case they ignore their duties and responsibilities within the community. But the community should try to understand such conditions and try to help them. Avoiding stigma and discrimination, providing encouragement, moral support, and lovehave been expressed by the research participants as needsfrom the society and from different social institutions including Idirr, Ekub and Mahibre. Yesufe said:

> For instance, in the community I am living, everyone is leading an independent life behind closed doors. No one is voluntary to help and support me from the society. I thought that if there is something bad on me beyond this condition I could not rely on the community. I am in true darkness. I wish to get support at least to hear a word of comfort from others.

Similarly, participants with in focus group discussion gives high emphasis for the need of social support in their report. Participants indicated due to their economic problem their participations with in different social institutions like Idirr and Mhibre deteriorated, because they can't pay monthly dues. They suggest such social institutions to have a different way of dealing with people like them who needs extra support. They need to see different supportive chances that enable them to be included in different social institutions.

### 4.7.2 Psychological support

This is other need of family caregivers for their care giving engagement. Family caregivers reported that they are highly exposed to experience psychological distresses because of their burdensome life. To address such mental stresses, to make their care giving activity fruitful and to ensure their psychological wellbeing, they demanded psychological support from health care professionals and from the rest of the society. According to family caregivers counseling service, recognition and appreciation, guidance and advice, are some of their psychological needs that every concerned body should look. In this regard Ashenafi who has been providing care for his sister for about two years said:

> My great desire was to get counseling and advice. Everybody needs counseling and advice on how to lead his life and individuals like us taking care of someone even need much more special counseling and advice; we need someone who wants to discuss and shares our problems with us.

Similarly, psychological needs such as acknowledgement have been raised by focus group discussion participants. One the participants said:

> In my opinion what must be done first is acknowledging our job and appreciating us. It is better if the entire society consider this. This is because if someone gets appreciation and acknowledgement the result will be extremely positive and good. We also develop hope and believe that somebody knows our work and can support us.

### 4.7.3 Financial support

Caregivers also have the need to obtain financial support from the government, nongovernmental organizations, from private sectors and from the society at large. According to study participants due to their care giving duty, they are restricted to do their work and earn adequate money. Besides, they had also additional expenses beyond their household costs. Most family caregivers reported that they always experience short of finance to the extent of not havingfor food and transport. Yesufe, for instance said:

> I wish there will be collaborative work with government and other private and nongovernmental charity organizations to support us in food and finance. Because of my financial shortage, I neglected my needs and interests even to eating on time because I knew I need to prioritize my child's needs. This is really hard to do this caring without having food; walking by itself is so difficult.

Focus group participants also argue with the financial support need of family caregivers. As they stated financial support is helpful for the holistic wellbeing and at least to overcome finance related problems with in family and its consequences. They explained that, since they spent much time to take care of their relatives when they were at hospital and home, they can't respond for the needs of other family members. Due to that reason some participants reported that their children were obligated to stop their education. Today, they become dependent for the help of others.

### 4.7.4 Legal support

Some family caregivers expressed the need of legal protection in terms of setting some laws as well as requiring legal support within a court. As the family caregivers reported they also provide support for their relatives to protect them from injustices. As the family caregivers explained since they have the duty to ensure the wellbeing of the persons with mental illness in different dimensions they need legal support. Similarly, participants with in focus group discussion revealed the need of legal support. In line with this idea one participant explained her experience as follows:

> My daughter has marital disagreement and her husband asked legal separation from the court. Since I am the only caregiver for my daughter I couldn't even attend the appointment of the court. Because of that I am afraid that the court's judgment might be illogical because no one is there to advocate for her. I wish to have somebody who has knowledge about legal terms on behalf of her.

Some others also need legal support in terms of law that can be applied in their work place to protect the right of the family caregivers. They believe that some laws/rules should be clearly stated for the caregivers so that they would exercise them. For instance, it was indicated that things should be facilitated and caregivers should get permission from their work place when they are accompanying patients at hospital or home. Caregivers stated that care giving adds additional burden on the day today normal life challenges. As reported, this legal support is needed to see the family caregivers issue in different ways, to protect family caregivers from illegal accusation, to ensure their wellness regarding income, physical, and psychological health.

### 4.7.5 Support from the hospital

All family caregivers participated in this study reported that they are provided with free service from the hospital. Even if they receive all services without any payment, they also had different things they want to be fulfilled. Depending on the problematic conditions within the hospital they identified different needs from the hospital including hospital setting arrangement, adequate medical supply, changes in the bed room management, giving enough time within the hospital for patients, strong security and strong control of substance abuse are the major ones. Almaz who provides care for her elder brother said:

> The hospital setting by itself is not comfortable not only for family caregivers but also for the patients. Within ward (patient’s bed room) there is no any free space to take a rest. When family caregivers take time at hospital to provide care, it is hard to stay within the patients ward. Patients may come and try to offense us. In general, the environment within the hospital alone creates stress. Preserving comfortable space or safe places for the family caregivers is expected from the hospital.

Caregivers said that since the hospital needs the family caregivers support to provide treatment for patients and to get adequate outcome, the hospital must provide comfortable environment in terms of bed room and rest place for the family caregivers.

On the other hand, the family caregivers also reported the need to have adequate medicine supply. Most family caregivers stated that an immediate action should be taken by the concerned body to overcome problems related with shortage of medicine. Facilitating to easily access the medicines that are suitable for the patients is expected from the hospitalas voiced by many caregivers.

### 4.7.6 Education and training

This is also another support need of family caregivers. All family caregivers reported that education about mental illness for the overall society as well as for family caregivers is very essential to change the existing problematic condition regarding mental illness. Caregivers indicated that society's awareness about mental illness is very low. Continuous awareness creation is mandatory to alleviate the problem from its root. In line with this Abebe who provides care for his sister said: "Leave alone the illiterates; even those can be regarded as literate they feel shocked when they hear someone is treating a patient with mental illness. This misguided and wrong awareness of mental illness is a great hindrance for getting help for the patients and for us."

Caregivers reported that awareness raising for the family caregivers as well as for the whole society about the meaning of mental illness, classifications of mental disorders and differences between them, ways by which this disorders occurred, preventive measures, signs and symptoms  of the disorders, treatment modalities, measures expected from the patient and ways of caring is highly needed. Caregivers reported that understanding those issues helps them to know the patient when he/ she show such manifestations and consequently so as to take immediate measures as fast as possible.

In addition, focus group participants speak loudly about the need of training towards care giving. To explain this idea the focus group discussion participants mentioned tailored trainings on caring and enhancing coping skills. For instance, one participant said the following statement: “Expertise training and support is much more than anything, food only relieves an abdominal query not an internal or mental stress. So I need training on methods of caring, forecasting challenges and coping mechanisms.”

## Summary

The chapter presented major findings of the study regarding family caregivers’ attitude towards bipolar disorder, family caregivers care giving experience, challenges and coping mechanisms of family caregivers, and family caregivers experience with the existed services which are available for them. The presentation comprised the data gathered through in-depth interview and focus group discussions. Subsequent to this, the discussion of the study findings in relation to relevant literatures will be following in the next chapter.

## Chapter five: Discussion

The findings of the study are discussed in relation to the objectives of the study and some findings from previous studies in the area. The discussion is presented under the following six teams: family caregivers attitude towards bipolar disorder, the family caregiver's experience, challenges of family caregivers, coping mechanisms, experiences of family caregivers with services provided for them and support needs of family caregivers.

### 5.1 Caregiver's attitude toward bipolar disorder

The study showed the caregivers' attitude towards bipolar disorder through their understanding and feeling. This is supported by Martin, Bernic, Pescosolido, and Tuch (2000) argument that a person's attitude towards something encompasses his or her point of view about the topic (e.g. thought); how he or she feels about the topic( e.g. emotion), as well as actions( e.g. behaviors) he or she engages in as a result of attitude.

The result of the study showed that family caregivers held different level of understanding about bipolar disorder but in general terms they understand that bipolar disorder is a severe mental health problem which results impairment on the patient's life. They also realize that the illness can be treated by modern health care centers as well as traditional and spiritual healing mechanisms. Caregivers held different understanding regarding the causes of the illness. Their understanding towards the cause of about bipolar disorder interconnected with four major dimensions such as: socioeconomic, psychological, biological, and spiritual. In line with this finding Corrigan et al. (2003) indicates that people may link the cause of a person's mental health problem with different conditions including medical/ genetic, social, and moral/ individual level causes of the condition. Kawanisi (2005) also conceptualized that families a relative with mental health problem held different causal attribution related with early family socialization, genetic facts, and other spiritual causes.

This study also showed that family caregivers experienced different psychological emotions because of their relative's diagnosed with bipolar disorder. This emotional experiences include shame, grief, stress, and guilty. This finding is also in agreement with the idea of Glasdam, Timm,Vittcup (2010) who argued the mentally ill patients close family members experience poor psychological wellbeing ( as cited in Goldberg and Rickler, 2011, p. 41)

The finding of this study indicated that all family caregivers believe that their relative with bipolar disorder is not responsible for his/ her illness. Based on this understanding, this study's participants showed their willingness (positive tendency) to provide care for their relative with bipolar disorder. This finding is consistent with the finding which indicates that people's causal attribution highly affects their reaction towards mental illness. The person with mental illness like bipolar disorder is much tolerable than the person with substance abuse. Because the causal attribution for substance abuse lies on the individuals level source or related with the persons bad personality character (Martin,Bernic,Pescosolido, and Tuch, 2000).

### 5.2 Experience of family caregivers

Finding of the study reveal that there are different factors that have their own influence on family members to become a caregiver. The first, factor is having a blood relationship with the patient. The second factor is the caregiver's religious belief and their perception towards care giving. The third factor which identified by this study is the previous good behavior of the patient, and the fourth one is passing through this kind of illness. In line with this, Gemchu (2014) indicated the existence of different factors as a reason to become a caregiver including being a family member, past good doing of the patient, and caregiver's preference to support and help for the person with the mental health problem. The study showed how these were cases used as reasons to become a caregiver.

This study also showed that family caregivers held different understanding regarding care giving. Participants perceive that care giving is the activity of caring for the sick, fulfilling what the patient wants, answering or responding for any requests that the patient raises, and protecting them from danger. This finding is consistent with what Gupta and Sharma (2013) reported as meaning of care giving that caregivers in his study indicated as the person who provides tangible support and care to family member or relative with mental and physical problem.

Participants of this study indicated that care giving for relative diagnosed with bipolar disorder requires different mental, physical, and financial capabilities of the caregiver. In addition for its positive outcome, it also requires the contribution of different governmental and non-governmental institutions and professionals. The caregiver within care giving course is expected to understand and hold all the negative impacts of care giving and keep caring, it also demands a great deal of patience, endurance, commitment, dedication, hope and good economic status. This is supported by the finding of Biegel, Sales and Schulz (1991 as cited in Biegel and Schulz, 1999) which revealed the provision of care and support for the family member to one another is a usual activity. Care giving due to mental illness is beyond the day today and regular mutual support within the family. It requires a significant expense of time and energy over extended period of time, holding tasks that are not comfortable to the caregivers.

Study participants reported that they provide different type of care and support to their relative with bipolar disorder. The provided cares include physical care, medical care, psychological care, and social care. For physical care they provide holistic support such as preparing the patients' meal, helping them to eat and drink, take care of their personal hygiene, by showering/bathing their body, washing their hair and their clothes, cutting their nails, and under taking other related physical cares. For medical care they take them in hospital, work in collaboration with health care professionals, taking and buying the medicine from the hospital and private pharmacies, keeping the medicine safely, supervising their relative's medical intake. On the other hand, participants also indicated that they provide psychological support through advice and counseling. Regarding social care they also try to make their relatives social life conducive and easy for interaction with the social environment. This is consistent with Mphelne's (2006) findings that family caregivers in the course of care giving play a pivotal role. They provide physical support and psychological support. Janardhana et al. (2011) also reported family caregiver's provide social care through protecting the patient from stigma, harmful treatment, social rejection and other social cares to make the patients environment safe.

As found in this study, caregivers within their care giving experience recognize the potential negative effect of caring on their quality of life. Participants identified the different dimensions of care giving effects on their life. Such effects classified under four categories including personal life effects, social life effects, economic life effect and spiritual life effect. According to family caregivers' explanations personal life effect involves physical and mental health problem of care giving. Social life effect on the other hand indicates the deterioration of harmonious relationship with in the society because of care giving engagements.

Economic life effect also indicates the economic crisis of caregivers due to their inability to work freely on different income generating activities and because of the different extra expenses. Spiritual life effect indicates the weakening of the spiritual connection of caregivers with God or Allah and the declining participation in the religious activities. In line with this, Lseselo, Kajula, Khadja, and Yanya-Malima (2016) find out care giving as a cause of economic problems of family caregivers due to having limited time for work and having different costs related to their relative's illness. They also showed that care giving can result in lack of family harmony and conflict with neighbors and lack of social support on the care giving life.

Similarly, Pratima, Bhatia, and Jena (2011) revealed that care giving for persons with bipolar disorder affect the quality of caregiver's life. It can highly affect the physical and mental health of the caregiver. Wankliri, Drak and Meyer (2013) also find out that care giving for the person with mental illness resulted in depriving of their social life, had financial ramification, and brought unpleasant feelings.

## 5.3 Family caregivers Challenges

The findings of this study showed that family caregivers have been firstly challenged by lacking awareness about mental illness in general and specifically about bipolar disorder. The mood swing behavior of the patient had been considered and accepted by the family care givers as the normal behavioral condition of the patient until the problem came to be worsened and made the patient impaired. This is related with Tezeta's (2016) study that pointed out family caregivers for people with schizophrenia within their care giving courses mainly challenged by lack of enough information about the illness.

This study's participants also reported that they prefer spiritual and traditional healing mechanisms to modern health maintenance approaches to help their relatives. They had a fear to get treatment from modern health centers because they heard about the hospital that the hospital fantasize patients. Due to this misguided information they determine themselves not to get support from health care centers. This is related with Ogivie, Morant and Goodwin (2005) who indicated that caregiver's previous experiences of health services may influence their belief about the illness and their responses to it.

The participants of this study also showed that care giving by itself is a very burdensome activity. Besides, caregivers reported that they experience different level of burden from different directions. Accordingly challenges from the patient's behavior, challenges from the society, challenges from work pace, challenges from the hospital and financial challenges are what the study participants' experienced and reported. In line with this finding, Bauer, Gottfriedsen et al., (2011), realized that family caregivers for persons with bipolar disorder experienced multidimensional challenges. Their study showed that family caregivers experienced challenges from the patient's behavior, from the work place, as well as from the society including financial challenges. This current study's finding also confirms Vaddadia's (1997) argument that caregivers' challenges have different dimensions such as symptom specific challenges, social challenges, emotional challenges and financial challenges.

As to the research participants challenges from the patients behavior has always been changing and was unpredictable. Caregivers of patients with bipolar disorder challenging situations vary in accordance with the two behavioral changes (overexcitement or manic and depression). According to caregivers within their relatives overexcitement mood period even if the behavior had its own positive outcomes, in the other side the behaviors like irritability, irresponsibility, lacking attention, extravagance, inflated self-esteem and being disappeared brought family caregivers in challenging situation. In contrast, when persons with bipolar disorder involve in the period of depression family caregivers are challenged by some behaviors of the Patients such as taking longer time at bed, feel lonely, get depressed and refused to take any food, drink and medicine, disobedience, insulting, low self-esteem, lake of interest for any work and suicidal attempt. Similarly, Dore and Romans (2001) indicated that family caregivers for relatives with bipolar disorder faces challenging situations related to the patients changing behaviors (depressive and manic). When the patients are in manic episode (overexcited mood) family caregivers are challenged by behaviors such as odd behaviors, over activity, over talkativeness, impulsive spending time and money and others. On the other hand, when they are in depressed mood suicidal ideas and attempts are the most difficult situations.

As founded in this study, depressive related behaviors of the person with bipolar disorder are the more burdensome and challenging ones than behavior of the patient with in manic path. This is consistent with what Ogilvie,Morant, and Goodwin (2005) reported. They indicated that depressive episodes were rated as significantly more burdensome than manic episodes.

This study finding also revealed family caregivers encountered different challenges from the society. The society's tendency to understand and help the family caregiver's problem is less. In contrast the society adds additional problem for them. Family caregivers are stigmatized and accused by the society. This is consistent with what Wankiiri, Drake and Mayer (2013) indicated that caring a mentally ill family member resulted in different social responses. One of the responses was that society was callous with the families of the person with mental health problem. The community was unsympathetic, heartless, pitiless or insensitive to families of the person with mental illness.

As family caregivers reported they also have been highly challenged by financial constraints. Their care giving duty indirectly and directly affects their economic position. In their day today life experience cost for transport, food, house rent, medicine positioned them in problematic situations. In line with Iseseo, Kajula, and Khadija, and Maima (2016) found out that financial constraints related with cost for transportation and cost for medication were a concern for all participants of their study. Similarly, a survey report from twenty two European countries by the European Federation of Families of People with Mental Illness (2015) revealed that family caregivers highly experienced financial challenge.

### 5.4 Coping strategies of family caregivers

Study participants used different coping strategies to deal with those challenges that emerged from different dimensions. This is consistent with Voort, Goossens and Bitl's (2001) argument that different phases in the process of care giving require different coping mechanisms. The result of this study showed, caregivers use problem focused coping mechanisms such as discussion, giving priority for the patient, seeking support and empowerment. They also used emotion focused coping strategies for problems that are beyond their capacity. This emotion focused coping mechanisms include acceptance, preserving spiritual practice and ignorance. In lines with this finding, Chakrabriti and Gill (2002) revealed that family caregivers of bipolar patients' uses both problem focused and emotion focused coping strategies to cope up from their problems. According to their explanation problem focused coping strategies includes direct activity responses for the problem such as positive communication, increasing involvement of the patient, seeking social support, gathering information and talking with friends and professionals. Emotion focused coping mechanisms also includes seeking spiritual support, coercion, collusion, resignation, avoidance etc.

This study revealed that from those the above problem focused and emotion focused coping strategies preserving spiritual practice is the most preferable coping mechanism from the rest. Similarly, findings from Marimba, Cowan,Kajawu, Muchrahondo and Lund (2005) showed that the most commonly used coping strategy was seeking spiritual assistance from both traditional healers and faith healers.

### 5.5 Caregivers experience with services provisions

The result of this study indicated the absence of adequate service for family caregivers. Some of the participants totally had no information about services which are provided for the family caregivers. This finding confirms Ogilvie, Morant and Good win's (2005) argument that even if the burden of care giving on caregivers is high it is largely neglected and lack's attention from the concerned bodies. In contrast to this finding Tezeta (2016) showed that the existence of different services in Amanual Mental Specialized Hospital for family caregivers such as psychosocial service, counseling/ psychotherapy services and individual counseling service. The participants of this study indicated that except for the family therapy which is grouped under counseling/ psychotherapy service other services have never been given to them.

Some participants who know the family therapy service for caregivers reported that this therapy session is provided for them once within a week and it highly helped them in their caregiving activity. Within this session caregivers share their experience with one another, enhance their awareness about mental illness and care giving, get guidance and advice, get the chance to ask and discuss about the issues which happens in the hospital. Even though this family therapy alone is not adequate; caregivers reported it to be helpful in many directions so as to make easier their care giving course. This finding is consistent with the Canadian Mental Health Association's (2006) report that indicates intervention programs on family caregivers overcome misconceptions and address concerns. Education and discussion help family caregivers develop successful coping strategies and enhance their contribution to the recovery of their beloved ones.

Study participants strongly announce that the incompatibility between their support need and the existing service available for them. This finding is related with the report of the European Federation of Families of People with Mental Illness (2015) which revealed that family caregivers of persons with severe mental illness are less satisfied with the support they receive from professionals.

On the other hand, in contrast to this formal support service this study participants showed the existence of informal support from families, neighbors, working mates, and religious partners. This finding confirms the argument of Dunst, Trivette and Deal (1988, as cited in Savage and Bailey, 2004, p.106) that social support can be provided informally by family, friends, neighbors, social groups and so on.

### 5.6 Support needs of family caregivers

Study participants indicated that they had different support needs from the government, nongovernmental organizations, private sectors, and from the whole society. In line with this Marimbe-Dube (2013) showed family caregivers need different support and intervention from different bodies such as from government, nongovernmental organizations, support group, health care professionals and from God. In this current study caregivers indicated that they need social support, psychological support, financial support, supports from the hospital and education and training supports. In terms of social support participants required to participate in different social institutions (Idire and Ekube), support groups and having cooperation and love instead of stigma and discrimination. This finding is supported by Marimbe,Cowan, Kajawu,Muchrahondo and

Lund (2016) who indicated that family caregivers need social support and this social support would help them to cope better.

In this study support need from health care professionals and health care centers were identified to include the following:  getting recognition, counseling advice and hospital setting arrangement. In line with this finding the Canadian Mental Health Association (2006) showed family caregivers had support need from professionals regarding care, support and counseling; on the other hand, they also need recognition as a partner in care, rehabilitation and recovery.

Regarding education and training, study participants declared that education and training have to be offered for the family caregivers and for the rest of society. As to the caregivers explanation education and training helps them to enhance their understanding towards the illness. On the other side education for the overall society helps them to get the societies acceptance and support as any family members could fall in the problem. This is consistent with what Marimbe et al., (2016) showed that caregivers required education and training to avoid challenges and problems which have resulted because of lack of education. Similarly Voort, Gooensp, Bijl (2007) revealed that family caregivers need education and training that helps to have confidence in their ability to provide holistic care and support.

## Chapter six: Conclusion and social work implication

### 6.1 Conclusion

This study was conducted to explore the psychosocial and spiritual experience of family caregivers for person's diagnosed with bipolar disorder. It had the objective of assessing the family caregiver's attitude towards bipolar disorder, investigating caregiver's description regarding care giving experience, identifying challenges and coping mechanisms and investigating caregivers experience regarding the existing services for family caregivers.

To achieve those objectives a qualitative (phenomenological) method has been employed with exploratory purpose with cross sectional design. Data have been gathered through in depth interviews and focus group discussions. The interviews were made with eleven caregivers, and two focus group discussions (six and seven participants in each) were conducted. The collected data were analyzed using thematic analysis approach. All the analysis process was done manually.

As the finding of the study indicated the majority of the caregivers had no adequate understanding about mental illness as well as the existence of different mental illness classifications. However, all caregivers understand that bipolar disorder is a severe mental health problem which results impairment on the patient's life. They also realize that the illness can be treated by modern health care centers as well as traditional and spiritual healing mechanisms. On the other hand, caregivers held different understanding regarding the causes of the illness, for some, it is the result of day to day socioeconomic negative interaction. For others, it is caused by psychological distress. Others also conceptualized that bipolar disorder as a gift of nature through biological / genetic cases. Caregivers also understand it related with spiritual enactments. Caregivers due to their relatives' mental illness experience different emotional reactions such as feeling of shame, guilty, grief, and stress.

There are different factors that impose the caregivers to become a caregiver including having blood relationship with the patient, their religious belief, passing through such kind of illness, and the previous behavior of the patient. They perceive care giving is the activity of caring for the sick, fulfilling what the patient wants, and responding for the need of the patient. Caregivers also understand care giving as the activity that requires the caregiver's physical, mental and financial capabilities. They believe for its goal achievement it also requires the contribution of different governmental and non-governmental bodies. Within their care giving course family caregivers provide different type of care for the person diagnosed with bipolar disorder. Types of care given to the person with bipolar disorder include physical care, medical care, and social care.

Study participants indicated that care giving had a great negative impact on their own personal, social, economic and spiritual life. In addition, within their day to day care giving activity they encounter different challenges from different directions. The first challenge which they experienced within their care giving course is that lack of knowledge about mental illness in general and specifically about bipolar disorder. Other challenges including challenge form the patient's behavior, challenge from the society, challenge from the work place, and challenge from the hospital are the major ones for family caregivers in their care giving activity.

As a result, family caregivers employed different coping strategies to deal with those problematic conditions. They use both problem focused and emotion focused coping strategies. Formal services from governmental and nongovernmental organizations to support family caregivers are very scarce; almost it can be said there is no Agency which provides inclusive service for the family caregivers. Some participants had no information about services which are provided for them. Some other participants who have the information about the service provided by Amanual Mental Specialized Hospital indicated that the existence of only one family therapy session. Except this service within the hospital they had never got any kind of service which is directly related with family caregivers. This study participants reported that they had more experience with informal supports form the family, their work mates, religious partners, and from the overall society. Caregivers reported that there is a huge incompatibility between their support need and the existing service.

Participants reported that family caregivers had different support needs from the government, nongovernmental organizations, private sectors and from the whole society. This support need of family caregivers includes social support, psychological support, legal support, financial support, education and training and support from the hospital.

In conclusion, care giving for persons with bipolar disorder had brought different personal, social, economic and spiritual impacts. Caregivers to deal with those negative impacts and day to day challenges use different strategies. However, the contribution of governmental and nongovernmental organizations to support those caregivers is very low. To ensure the wellbeing of the patient, to minimize the impacts of caring on family caregivers, to enhance the outcome of family care giving and to minimize the rate of relapse collaborative work from governmental, nongovernmental organizations, private sectors, and from the whole society is required. On the other hand, responding for the whole needs of caregivers helps to alleviate the problem from its root.

## 6.2 Social work implication

The findings of the study had different social work implications in terms of social work practice, education, policy and research.

### 6.2.1 Practice implications

The finding of the study show care giving for persons with bipolar disorder had a great impact and challenge on caregiver's personal, social, economic, and spiritual life. Though care giving has a huge negative impact on family caregivers, it is untouched area of intervention for any health care professions including health care social workers. Since social work profession and other professionals are expected to intervene and take part on the areas that the society failed to address, a comprehensive intervention is necessary and expected on different areas.

As the finding of the study indicated caregivers' awareness towards mental illness in general and specifically about bipolar disorder is very low. Therefore, this study provides social work practitioners to do much on awareness creation about mental illness in general and bipolar disorder in particular, it's meaning, causal factors, risk factors, different signs and symptoms in accordance with different disorders, measurements that must be taken by the patient as well as by family members and its treatment mechanisms. In addition, about its potential impacts on the patient, family, and for the overall country through different means of communications with the collaboration of different stakeholders for the whole society.

The findings of this study demonstrated that family caregivers' experience different challenges from different directions including challenges from the behavior of the patient. This challenges which are resulted from the patients behavior varies in accordance with the signs and symptoms of the illness. On the other hand, the study indicated that the absence of adequate interventions that targeted the family caregivers. Thus, it indicated the importance of working on assessing, screening and distinguishing patients and caregivers based on their specific diagnosis and developing system specific intervention plan and provide integrated care for care recipients and caregivers by understanding  and recognizing the important connected relationship between the caregiver and their loved one is needed.

This study finding revealed that care giving involves family caregiver's in different socioeconomic crisis.  Caregivers due to their low economic status are fired from different social institutions and also they are expected to passes through in different regional offices bureaucracies to get the permission paper for free mental health services. So that, this study finding imply that there is a need for building and strengthening patients and family caregiver's socioeconomic status by dealing with different stakeholders such as social institution leaders, regional principal offices, religious leaders and so on. On the other, hand linking both patients and family caregivers with resources services and opportunities is another area of intervention for the social workers.

The study finding showed that caregivers also challenged by hospital related problems when their relatives receive both inpatient and outpatient mental health care services. Accordingly, the findings imply that there is a need for designing and enhancing different psychosocial services for family caregivers with in health care sectors and making the hospital environment safe.

### 6.2.2 Implication for education

Regarding to education, School of Social Work should extend its mental health course boundary through giving high attention for different disorders like bipolar disorder to purely magnify specific impacts on the person, family, society as a whole. Moreover, social work education should also incorporate major intervention areas of social workers in the provision of psychosocial support for the patient as well as for his/ her family caregivers.

As the study indicates leave alone the illiterates the literates also have no adequate understanding about the existence of different disorders. To build up the professional's awareness about different mental illness classifications in general and particularly about bipolar disorder, the school should do more on the provisions of different short term trainings, seminars, workshops etc.

### 6.2.3 Research implication

Research on the experience of family caregivers diagnosed with mental illness is rare in Ethiopian case. To clearly articulate the impacts of care giving on family caregiver's personal, social, economic, and spiritual life, as well as to explore the level of burden additional researches are needed. Researches on the family caregiver's experiences that are focused on different types of disorders will enable to understand the different lived experiences of family caregivers and to develop diagnosis specific intervention plan. Additional researches in the area not incorporated in this study, such as the outcome of service provisions for family caregivers, costs and outcomes of traditional healers, and family caregivers experience with co-morbid conditions are suggested to be investigated by other researchers. The existence of different researches on family caregivers in accordance with different diagnoses helps any concerned body to easily identify the level of burden from one another and to take an immediate action.

### 6.2.4 Policy and program implications

Federal Democratic Republic of Ethiopia Ministry of Health (2012), showed that lack of metal health services or any kind of financial support for families with a mentally ill member are the biggest factors causing caregiver burden in Ethiopia (p. 12). Since it is known that the absence of services for family caregivers creates and increases their burden, the strategy should give a higher emphasis for services that must be provided for family caregivers integrated with the patients. It is clear that there is much work to be done in the advocacy arena at the local, state, and federal levels to address the growing need of family caregivers. Thus the national strategy should address the growing needs of family caregiver during the time of its revision.

This study finding substantiated that family caregivers in addition to psychosocial and economic challenges face different challenges from their work place and challenges related the legal system when their relatives are accused by others. The finding indicates the need to design several important programs and strategic initiatives to support family caregivers holistically such as strategic initiatives and programs to provide a variety of financial incentives and compensations, strategic initiatives to provide support for family caregivers in employment based through allowing additional leave and facilitating unpaid leave and initiatives for awareness creation and education should be incorporated. In order to protect and improve the health and wellbeing of family caregivers' rules and regulations should be enacted that can be applied in different areas including the hospital, the work places and within the courts.

The findings of this study identified that the availability of different infrastructures with in health care centers is very low including medications. The findings also inform that, above all, availability and enhancement of mental health treatment centers with their sufficient infrastructure including medications should be established as well. As mental illness treatment medications mostly in scarcity, measures that accommodate medication provision and affordability of the costs by families should be established considering socioeconomic status of families as well sustainability of treatment.

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# Annexes

## Annex 1: Informed Consent Form

My name is Kidist Hailgbrial, a master's 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 bipolar disorder to fulfill my study of social work. The purpose of the study is to understand the various experiences in the course of care giving, challenges family members like you face during care provision for their relative with bipolar disorder, coping mechanizes that you undertake to cope up from those challenging situations, and experiences related to the existed services available for caregivers. The overall aim of the study is to understand the psychosocial and spiritual experiences of family members who are providers of care for mentally ill relative. For the successful accomplishment of the study, the cooperation of caregivers who are experienced from caring for their relative with bipolar 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 feature of caregiving experience regarding your efforts to provide care for your relative, challenges that you face during your caregiving course and also some other important points.

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

The procedure to be used in this research is in-depth interview. 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 questions during in the interview. 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. . 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. 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.

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 2: Interview Guide Questions (for family caregivers of persons with bipolar disorder).

First of all I would like to thank for your agreement to take part in this study. The information that you provided for me is the basic input for my study. I, therefore, kindly request you to feel free to provide your responses honestly.

Part I: Background information

Pseudo name------------------

Age -------------------------

Sex -----------------------------

Religion ------------------------

Education -------------------------

Marital status -------------------

Occupation ---------------------------------------------------

Relationship of the caregiver with the person with bipolar -------------------

For how many years is your relative with this illness? -------------------

When do you start to provide care? -------------------

Part II: Interview guide in-depth interview with caregivers

1. What do you know about bipolar disorder?(probe-how and when)

2. What do you think about your relative’s cause of illness?

3. What do you feel because of your relative’s illness?

4. What factors initiated you to become a caregiver? (probe-spiritual/religion; economic )

5. What is care giving for you?
6. How do you describe your care giving experience? (Probe- in relation to personal life/social life/spiritual life, economic status)
7. Is there any training or orientation for your care giving? If yes how do you describe the training and its benefit?
8. What type of care that you provided for the patient?( physical care, medical care, psychological care, social care)
9. What are the challenges that you face in your care giving experience?( Probe- related to patient's behavior, economic, social, spiritual)
10. How care giving affects your personal life?
11. What type of conditions that provides hope or despair?
12. What type of coping mechanism that you used in times of difficult situations?
13. You think that you are successful in your care giving course? If yes what conditions played a great role for your success?
14. What is your reward/benefit that you gain from care giving?
15. Is there any support that you gain in your care giving course? If yes describe from whom and your experience in obtaining the support?
16. To provide adequate care, what you need? From whom?
17. Based on your experience what is your advice to other caregivers?

## Annex 3: Focus group discussion interview guide

### Part I: Background information

Pseudo name-----------------

Age ------------------------

Sex ----------------------------

Religion -----------------------

Education -------------------------

Marital status -------------------

Occupation ---------------------------------------------------

Relationship of the caregiver with the person with bipolar -------------------

For how many years is your relative with this illness? -------------------

When do you start to provide care? -------------------

### Part II: Focus group discussion interview guide

1. What they know about bipolar disorder? (probe-when and how)
2. What are the factors to become a caregiver?
3. What dose care giving mean for them? ( probe_ activities, requirements, and effects)
4. How family caregivers describe their care giving experience? (Probe- with the comparison from the previous life, their challenges, coping mechanisms).
5. How family caregivers describe their experience regarding services which are available for them? (Probe- what are services, what are their needs, their compatibility)
6. To enhance their care giving activity, what they need? From whom?

## Annex 4: Informed Consent (Amharic Version)

### የስምምነት ቅፅ

ቅድስት ኂይለገብርኤል እባላለሁ፡፡ በአዲስ አበባ ዩኒቨርስቲ በማህበረሰብ አገልግሎት (ሶሻል ወርክ) ትምህርት ክፍል የድህረ ምረቃ ፕሮግራም ተማሪ ስሆን ለሁለተኛ ዲግሪ መመረቂያ የሚሆን የማሟያ ጥናት: በከባድ የአእምሮ መታወክ ያለበትን ሰው የሚንከባከቡ ሰዎች የሚያጋጥሟቸውን እንቅፋቶች እና እንቅፋቶቹን የሚቋቋሙበትን መንገዶች በማጥናት ላይ እገኛለሁ፡፡

የጥናቱ ዓላማ እንደ እርስዎ ዓይነት የቤተሰብ አባላት በአስተሳሰብ የስሜት እና የባህሪይ መታወክ (ባይፖላር) የተጎዱ ሰዎችን በሚንከባከቡበት ጊዜ ያጋጠማቸውን ልዩ ልዩ አሉታዊ ተጽእኖዎችን፣ ችግሮችን ለመፍታት የሚወስዱአቸውን እርምጃዎች ፣ እንዲሁም ለቤተሰብ አባል እንክብካቤ ለሚያደርጉ ሰዎች ከሚሰጡ ግልጋሎቶች ጋር ያላቸውን ልምድ ለመረዳት ነው፡፡ በአጠቃላይ የጥናቱ ዓላማ የአእምሮ መታወክ ችግር ያለባቸው ቤተዘመዶችን የሚንከባከቡ የቤተሰብ አባላት ያላቸውን ማህበራዊ፣ ስነልቦናዊ እና ኢኮኖሚያዊ  ልምድ ለመረዳት 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 ያሉትን ልምድ ለመረዳት ያስችለኛል ፡፡

በዚህ ጥናት የሚሳተፉ ታሳቢ ተሳታፊዎችን ለመለየት የሚከተሉት መስፈርቶች ከግምት ተወስደዋል፡፡በጥናቱ ለመሳተፍ የማካተቻ መስፈርቶች፡-(ሀ)ከቤተሰብ አባለት መካከል በአስተሳሰብ የስሜት እና የባህሪይ መታወክ (ባይፖላር) የተጎዳ ሰው መኖር፣ (ለ) ከታመሙ

ቤተሰቦቻቸው ጋር እየኖሩ የሚንከባከቡ እና የቀን ተቀን እንቅስቃሴዎቻቸውን በመቆጣጠር የሚያግዙ፣ (ሐ) የጥናቱ አካል ለመሆን ፈቃደኝነት ያሳዩና ያሉበትን ሁኔታ መግለጽ የሚችሉ:;

በዚህ ጥናት የምንጠቀመው አሰራር ጥልቅ ቃለ መጠይቅ ነው፡፡ በዚህ ጥናት ውስጥ ለመሳተፍ የሚያስፈልገው ጊዜ እና ሁኔታ ለተሳታፊዎች በሚመች ሰዓትና ሁኔታ ይመቻቻል፡፡ በቃለ መጠይቁ ጊዜ ግልጽ ያልሆነ ጥያቄ ቢኖር አጥኝው ያብራራሉ፡፡ የሚፈልጉትን ጥያቄ ብቻ የመመለስ ነጻነት አለዎት፡፡ ካልተመቸዎት 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፡፡

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፡፡ ያደረግነውን ውይይት በተገቢ ሁኔታ ለመያዝ ይረዳ ዘንድ መቅረጸ ቴኘ የምጠቀም ሲሆን በጥንቃቄ ተቆልፎበት ይቀመጥና ማንም እንዳያገኘው ይደረጋል፡፡ በቴኘ የተቀረጹ፣ የተገለበጡ ጽሁፎች እና የጽሁፍ ማስታወሻዎችና የመስክ ማስታወሻዎች ለተወሰነ ጊዜ ተቆልፎባቸው በጥንቃቄ ይያዙና ጥናቱ ከተጠናቀቀና በማህበራዊ ስራ ጥናት ት/ቤት ከተረጋገጠ በኋላ ይደመሰሳሉ፡፡

በዚህ ጥናት በመሳተፍዎ ጥናቶቼን 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 በጥናቱ ላይ ለመሳተፍ ፈቃደኛ መሆንዎን ማረጋገጥ እወዳለሁ**:;

**የጥናቱተሳታፊ(መለያ)-------------------**

**ፊርማ-------------------**

**ቀን-------------------**

## Annex 5: An Interview Guide (Amharic Version)

### የቃለ መጠይቅ መመሪያ

በቅድሚያ ጥያቄን ተቀብለው በዚ ጥናት ላይ ለመሳተፍ ፍዳደኛ በመሆንዎ አመሰግናለሁ፡፡ በመቀጠልም እርሶ የሚሰጡኝ መረጃ ለጥናቴ በጣም ጠቃሚና አስፈላጊ ግብአት መሆኑን ላስረዳወት እወዳለሁ፡፡ ስለሆነም ነጻ ሆነው እና በእውነት ላይ ተመስርተው ልምድዎን እንዲያካፍሉኝ በትህትና እጠይቃለሁ፡፡

ክፍል አንድ፡ የሗላ መረጃ

ኮድ ______________________________

እድሜ_____________________________

ጾታ ______________________________

ሃይማኖት__________________________

የትምህርት ደረጃ______________________

የጋብቻ ሁኔታ________________________

የስራ ሁኔታ__________________________

ከሕመምተኛው ጋር ያላችሁ ዝምድና_________________________

ሕመምተኛው ሕመም ከጀመረው ስንት ጊዜ ሁነው?__________________________

እርሶ እንክብካቤ መስጠት ከጀመሩ ምን ያህል ጊዜ ሆኖት?_________________________

ክፍል ሁለት፡

1. ስለ አእምሮ መታወክ (ባይፖላር) ምን ያውቃሉ? (መቼ እና እንዴት ሊያውቁ ቻሉ?)
2. የዘመድዎ ሕመም መነሻ ምክንያት ምን እንደሆነ ያስባሉ?
3. ሕመሙ በቤተሰብዎ አባል ላይ በመከሰቱ ምን ይሰማዎታል?

4. ለሕመምተኛው እንክብካቤ እንዲደርጉ የገፋፋዎት ነገር ምንድ ነው? (ዕምነትዎ፣የሚገኙት ጥቀም)
5. እንክብካቤ ማድረግን እንዴት ይገልጹታል?
6. የዕርሶን የመንከባከብ ልምድ እንዴት ይገልጹታል?( በፊት ይኖሩት ከነበረው ሕይወት አንጻር ለምሳሌ፡በፊት ከነበረዎት ማህበራዊ ተሳትፎ አንጻር፣ እምነት ተቋም ላይ ከነበረዎት ተሳትፎ አንጻር፣ የስራ እንቅስቃሴ እና የሀብት መተን አንጻር)
7. እንክብካቤ ለመስጠት የሚያስችል ስልጠና አግኝተው ያውቃሉ? ካገኙ እንዴት ይገልጹታል? ጠቀሜታውስ?
8. ምን አይነት እንክብካቤ ለታማሚው ደርጋሉ?( አካለዊ፣ ህክምናን በተመለከተ፣ ስነ-ልቦናዊ እና ማህበራዊ)
9. እንክብካቤ በሚደርጉበት ጊዜ ምን አይነት ተግዳሮቶች ይገጥሞዎታል? (ከታማሚው ባህሪ በኩል፣ ከማህበረሰቡ፣ ከዕምነት ተቋዋማት እና ከምጣኔ ሀብት አቅጣጫ)
10. ለታማሚው እንክብካቤ ማድረግ የግል ሕይወትዎን በምን መልኩ ያቃውሳል?
11. ምን አይነት ሁኔታዎች ተስፋዎ እንዲሟጠጥ ወይም እንዲያብብ ያደርጋሉ?
12. ተግዳሮቶችን ለመፍታት ምን አይነት እርምጃ ይወስዳሉ?
13. በእንክብካቤዎ ውጤታማ ነኝ ብለው ያስባሉ? ከሆኑ ውጤታማ ዕንዲሆኑ የረዳዎት ነገር ምንድ ነው?
14. እንክብካቤ በማድረግዎት ምን አይነት ጥቅም ያገኛሉ?
15. ድጋፍ አግኝተው ያውቃሉ? ካገኑ ከማን እንደሆነ እና ያገኙትን ድጋፍ በተመለከተ ያለዎት ልምድ ምን ይመስላል?
16. የእርስዎን እንክብካቤ ለማሳደግ ምን ፈልጋሉ? ከማን?
17. እንክብካቤ በመስጠት ካገኙት ልምድ ተነስተው ለሌሎች ምን መልክት ያስተላልፋሉ?

## Annex 6: Focus group discussion interview guide (Amharic Version)

### የመወያያጥያቄዎች

### ክፍል አንድ፡ የሗላ መረጃ

ኮድ ______________________________

እድሜ_____________________________

ጾታ ______________________________

ሃይማኖት__________________________

የትምህርት ደረጃ______________________

የጋብቻ ሁኔታ_________________________

የስራ ሁኔታ___________________________

ከሕመምተኛው ጋር ያላችሁ ዝምድና_________________________

ሕመምተኛው ሕመም ከጀመረው ስንት ጊዜ ሁነው?__________________________

እርሶ እንክብካቤ መስጠት ከጀመሩ ምን ያህል ጊዜ ሆኖት?_______________________

### ክፍል 2 የመወያየ ጥያቄዎች

1. ስለ አእምሮ መታወክ (ባይፖላር) ምን ያውቃሉ? (መቼእናእንዴት)
2. ለታማሚው እንክብካቤ እንዲያደጉ የገፋፏቸው ነገሮች?
3. የአእምሮ ህመም ለላለበት ሰው እንክብካቤ ማድረግ ማለት ምን ማለት ነው?
4. የቤተሰብ ተንከባካቢዎች ታማሚውን በመንከባከብ ያገኙትን ልምድ እንዴት ይገልጹታል?(ካለፈው ሕይወት ጋር በማነጻጸር፣ ያጋጠሙዋቸው ተግዳሮቶች እንዲሁም ተግዳሮቶችን ለመፍታት የወሰዱዋቸው እርምጃዎች)
5. የቤተሰብ ተንከባካቢዎች ከሚያገኙዋቸው ግልጋሎቶች ጋር ያላቸውን ልምድ እንዴት ይገልጹታ?
6. ተንከባካቢዎች እንክብካቤያቸውን ውጤታማ ለማድረግ ምን ይፈልጋሉ? ከማን?