# ADDIS ABABA UNIVERSITY

## COLLEGE OF EDUCATION AND BEHAVIOURA STUDIES

## SCHOOL OF PSYCHOLOGY

# The Lived Experiences of Adults with Bipolar Disorder:

## The Case of Amanuel Mental Specialized Hospital

**By: Sewbesew Getnet**

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**Addis Ababa**

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**This thesis is submitted to the school of psychology in partial fulfillment of the requirement of ma degree in counseling psychology.**

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# ABSTRACT

The purpose of the study was to explore the lived experiences of persons with Bipolar disorders the case of Amanuel Mental Specialized Hospital. Ten interview participants and eleven FGD participants were participated in the study. The participants of the interview and FGDs were selected using purposive and snow-ball sampling techniques respectively. An existential (phenomenological) qualitative design was utilized. In-depth interview and FGD were conducted within two months. Four overall themes (i.e. perception towards their illness, negative and positive experiences of the illness, challenges of the illness and coping strategies with their illness) were emerged from the interviews and triangulated with two FGDs. The study result on the first theme shows that patients have limited perception to mental illness in general and to their bipolar disorder in particular. Regarding the second theme nearly all participants especially women participants have negative experience like forced sex (raped), socially or self stigmatized, physically and emotionally abused. In relation to the third theme, participants described their life with BD is complex and challenging. Regarding to the last theme, most of the participants employed negative and emotion focused coping mechanism.

# ACKNOWLEDGEMENT

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# ACRONOMY

**AMSH**: Amanuel Mental Specialized Hospital

**APA**: American psychiatric Associations

**BD**: Bipolar Disorder

**BPS**: British psychological Society

**DBSA**: Depression & Bipolar Support Alliance

**DSM-IV**: Diagnostic Statistical Manual for Mental Disorders, 4th edn.

**DSM-IV-TR**: Diagnostic Statistical Manual for Mental Disorders, 4th edn. Text Revised

**EE**: Expressed Emotion

**FDA**: Family Depression Awareness

**NCCMH**: The National Collaborating Centre for Mental Health

**NCCMH**: The National Collaborative Center for Mental Health

**NIMA**: National Institute for mental Health

**RCP**: Royal College of psychology

**SAMHSA**: Substance Use and Mental Health Services Administration

**WHO**: World Health Organization

**YLD:** Years of Lost due to Disability

# CHAPTER ONE

## 1. INTRODUCTION

### 1.1. Background of the Study

There seems a consensus these days that, for everyone, health on mental, physical and social aspects are all vital elements of life that are closely interwoven and deeply interdependent. As an understanding of this relationship increases, it becomes even more apparent that mental health is crucial to the overall wellbeing of individuals, societies, and countries (World Health Organization [WHO], 2001). Today, mental health problem is recognized as a public health problem in developed as well as developing countries; and the belief that mental health problems are less common in low and middle -income countries than in high –income countries has long been in doubt (World Bank, 1999).

A study by the World Health Organization (WHO, 2001), indicated that approximately 2-3% of the population at any one time suffers from seriously incapacitating mental disorders. In other words, 450 million people worldwide are estimated to suffer from mental or psychosocial problems; and one person in four is affected by a mental disorder at some stage of life (Georgie & MacArthur, 2008). In addition, the burden of mental illness is very substantial and studies show that the prevalence of mental disorders is likely to rise even further in coming years (WHO, 2000), and it is anticipated that this will increase to 15% by the year 2020.

Especially variations in mood are a natural part of life. People experience these variations in unique individual ways and have different strategies for dealing with them (Patrik, 2010). However, when the mood swings are manifested in extreme depressed or restless, euphoric states, over a period of time and in a way that differs strikingly from an individual's normal way of feeling, behaving and functioning in daily life, they can be symptoms of the mental illness called bipolar disorder (BD) (APA, 1994). BD is a recurring, episodic, but lifelong and severe mental illness affecting a person's mood (Patrik, 2010). It was Emil Kraepelin (1856-1926) who first described the concept of manic-depressive illness as a single disease entity and included it in a disease model (The National Collaborating Centre for Mental Health [NCCMH], 2006). However, melancholia was described in the literature as early as in the fourth and fifth centuries B.C.; and the link between melancholia and mania was described in the second century A.D. (Goodwin & Jamison, 2007). The illness manifests itself early in life and generally starts in teenage or young adulthood (Kessler *et al,* 2005). Since, schizoaffective disorder, schizophrenia and delusional disorder might share a number of presenting symptoms like grandiose and persecutory delusions, irritability, agitation, and catatonic symptoms with BD so it can take almost a decade for BD diagnosis to be established because of the complexity of the illness and the difficulties in identifying the course of the illness's cycle (Leverich *et al.,* 2002).

There are a number of different definitions for BD. Diagnostic Statistical Manual for Mental Disorders, fourth edition-text revised (DSM IV-TR, 2000) - encompasses the classic definition of manic-depressive disorder and requires that the patient has had a manic episode to confirm the diagnosis. Diagnostic criteria for BD include: the patient is or was recently in a manic episode, the patient has had at least one previous major depressive episode, manic episode, or mixed episode (DSM IV-TR, 2000). The National Institute of Mental Health [NIMH] (2006) defines BD as a severe psychiatric illness characterized by alternating manic and depressed mood states, with associated disturbances in energy levels, sleep, appetite, and cognition.

Epidemiological studies have reported the lifetime prevalence of BD to be around 2-4 % (Kessler *et al.,* 2005). However, recent studies from Hungary and Urban(Kebede & Alem, 1999) and Rural Ethiopia (Awas, Kebede & Alem, 1999) report lifetime prevalence rates for BD or BD-I of 0.0% to 1.5%(cited in Scott, 2001) and the general population in the US and UK meet the criteria for a diagnosis of bipolar accounts about 1 to 1.5% (Weissman et al., 1996). According to the World Health Organization (WHO, 2008), there are 29.5 million persons in the world living with BD; and the illness is ranked as the seventh (among males) and eighth (among females) highest cause of disability worldwide. It was also estimated to be the seventh leading cause of non-fatal burden in the world in 1990, accounting for 3% of total Years of Lost due to Disability (YLD), around the same percentage as chronic obstructive lung conditions (Prince, *et al.,* 2007). Moreover, according to the World Health Report 2001, *BD* remains in the top ten causes of YLDs at global level, accounting for 2.5% of total global YLDs. These mental disorders are as significant a burden in developing nations as they are in the developed nations (WHO, 2001).

Regarding local research findings conducted on islander population in southern and south central regions shows that there were no cases of schizophrenia but the research reported that there were a high prevalence of BD in the islander population (Fekad, *et al.,* 2004).

BD is a severe mental disorder with the highest rate of co-occurrence of substance use (Bizzarri et al., 2007). It also becomes a subject of increasing concern to the mental health community because adults with BD and co-occurring substance use increased risk for negative outcomes (National Institute of Mental Health [NIMH], 2006). Persons with BD are characterized by stress and limitations on psychosocial functioning as a result of the long-term changes caused by the condition (Lim *et al.* 2004). These include damaged relationships, poor job or school performance and suicide (NIMH, 2006). BD is also associated with a significant risk of attempted suicide (Hawton, et al., 2005).

Mental health professionals have identified a number of possible risk factors for BD. However, most of them agree that there is no single cause rather many factors likely act together to produce the illness or increase risks of BD (NIMH, 2008). Sometimes there is a false separation made between biological and psychological explanations of BD. It is important to remember that both have cyclic effects in which biological changes can affect psychological states and psychological states can affect biological states (The British Psychological Society [BPS], 2010). They also said that every thought or emotion can produce chemical changes in the brain so both levels of explanation are relevant.

Bipolar mood disorder affects each person differently (Goodwin & Jamison, 1990). There are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder. In a risk-protective model of resilience, a protective factor interacts with a risk factor to mitigate the occurrence of a negative outcome for example; high levels of sociopolitical control was found to limit the negative consequences of helplessness on mental health (Zimmerman, et al.,1999).

The frequency of mental illness is increasing globally and causes great harm in the life of the sufferers as well as for their families (WHO, 2001). This fact alone justifies the support and treatment of those affected. Socialstyrelsen (2010) emphasized the importance of gaining specific knowledge about the person and his/her environment, vulnerability and needs, as well as about the opportunities for family and network to support recovery. However, these concerns are not the primary focus for mental health care, which by tradition primarily have focused on treating the illness and controlling the symptoms (Patrik, 2010). The illness perspective, and interventions focusing on facilitating the daily management of the person affected and their family are still lacking in mental health care. Many of the needs that follow living with BD still remain unnoticed. An important point for improvement is, therefore, to incorporate the assessment of advanced care needs of those living with the illness into the treatment process (Goossens et al., 2008a).

During my practical attachment taking the course “Practicum in Counseling Psychology”, in both in-patient and out-patient units of the Amanuel Specialized Mental Hospital (AMSH) for persons with different types of mental disorders, I have met many persons with BD under various Bio-psycho-social status/ circumstances. Many of those I met were the same persons who came to the hospital with recurrences of either depression or mania. I was shocked by the complexity and instability that characterize these persons’ daily life. During my stay in the hospital, I had a feeling that there is a discrepancy between the treatment rendered by the mental health professionals and the actual need of the bipolar patients who came to the hospital with diverse and complicated problems. These experiences have strengthened me in my efforts to gain a richer understanding of what it means to live with the illness from the point of view of persons affected.

Taking all these variables/things into account, there is a felt need for a research that place great consideration on the person-centered active processes in relation to becoming ill with BD (Perlick *et al.,* 2004). Since knowledge about the illness based on the experiences of those with BD was limited, particularly in Ethiopia, I decided to contribute a little in the endeavor to fill this gap by working my thesis on "the lived experiences of adults with BD" so that I would contribute something on the improvement of their treatment, care and support.

## 1.2. Statement of the Problem

Now a day's mental health problem is accepted as a public health problem in developed as well as developing countries (World Bank, 1999). Recent studies (such as Georgie, 2008), using samples from diverse populations, have suggested that the burden of psychiatric morbidity existing in Africa is very similar to that prevailing in Western countries. In Ethiopia, where malnutrition, preventable infectious diseases, and other socio-economic trauma are very common, mental health problems which are regarded as non-life threatening problems are not given due attention (Abdullahi, et al., 2001). However, mental health problems account for 12.45% of the burden of diseases in Ethiopia and 12% of the Ethiopian people are suffering from some form of mental health problems of which, 2% are severe cases ( Abdulahi, et al.,2001; Mesfin & Abdulahi, 1993). Geil and his colleagues (1968) also reported that 18.5% of patients in a teaching hospital in Addis Ababa suffered primarily from psychiatric disorders compared with 9.5% that are diagnosed as suffering from infectious diseases.

Substance use in patients with bipolar disorder is also common that leads to negative mental and physical health outcomes. These change the course of illness, including presentation increasing the incidence of mixed or dysphonic mania, rapid cycling, increased symptom severity, and higher levels of novelty seeking, aggressiveness, and impulsivity (Frye & Salloum, 2006). The increase in negative effects on the presentation of symptoms and course of BD leads to poor treatment response and compliance. This increases the risk for negative outcomes, including hospitalization, violence, legal problems, homelessness, victimization, HIV infection, hepatitis, overdose and suicide up on clients with bipolar disorder (Dalton *et al.*, 2003; McDermott, 2007).

Stigma is also one of the major barriers that discourage adults with mental illnesses and the families of children and adolescents with serious emotional disorders from seeking treatment, lowered self-esteem, disrupted family relationships, and increased difficulty in building connections in the community, securing housing, and obtaining employment (Substance Use and Mental Health Services Administration [SAMHSA], 2003). In addition, the local research finding shows that wrong perception is one of the challenges of the society that affects help seeking behavior which in turn results in increasing the severity or complexity of the illness. Regarding to this Girma & Tesfaye, 2011 found that the most common explanations given for the cause of the mental illness were spiritual possession 198 (51.6%) and evil eye 61 (15.9%), whereas 73 (19.0%) of the respondents said they did not know the cause of mental illnesses. Although almost all participants gave priorities for traditional and spiritual healer, nearly all of the respondents 379 (98.7%) believed that mental illness can be cured with modern treatment. Half of the patients sought traditional treatment from either a religious healer 116 (30.2%) or an herbalist 77 (20.1%) before they came to the hospital. Thus, help seeking behavior regarding mental health problems may be affected by different factors such as tolerance and support in the family, lack of money, knowledge and attitude (Amare & Yonas, 2005). Moreover, in developing nations, poverty, rapid socio-cultural, technological and political changes, in addition to overcrowding, unemployment, rural-urban migration and lack of modern health care facilities make mental health a major health problem (Republic of Namibia Ministry of Health and Social Services, 2005).

As I have tried to mention in the background section, during my attachment in AMSH, I have observed multitude of factors that affect the health care and health needs of individuals with BD which might have a negative impact on compliance to treatment and symptom management. There are also substantial social and economic implications for these individuals. These personal observation and practices instigated me to explore and to understand how individuals with BD perceive the factors affecting their health care and health needs. There is also need to begin to understand what coping mechanisms persons with BD use to manage their challenges and how they perceive their illness.

This study, therefore, is carried out to answer the central question of “what lived experiences adults with BD have?” Accordingly, the following basic research questions related to the lived experiences of adults with BD were raised.

- How persons living with BD perceive their illness?
- What are the positive and negative experiences of persons with BD?
- What challenges persons with BD face when they live as BD patients?

- How persons with BD cope with their challenges?

## 1.3. Objectives of the Study

The overall objective of this study was to explore and describe the lived experiences of persons with BD. Specifically, the study has designed:

- To understand how persons with BD perceive their illness.
- To describe the positive and negative experiences of persons with BD
- To investigate the challenges that persons with BD face due to their illness
- To find out how persons with BD cope with challenges related to their illness

## 1.4. Significance of the Study

From the findings that are obtained from this particular study, different groups like persons living with BD and their primary care givers, health care providers, mental health Society-Ethiopia, and researchers would benefit.

**For Persons with BD and Their Primary Care Givers**: The considerable influence of BD on the person with the illness and their family members whole lives, give rise to a growing need for support for these individuals. So, finding of this study would provide an insight on what issues/ daily lives they need support to strengthen their ability to manage the illness and to promote their own wellbeing. The study would help them to indicate some coping strategies that persons diagnosed with BD have experienced or learned and developed to stay well in their real life context.

**For Health Care Providers:** The study would help to ease the burden of health care providers by helping them to use a more holistic view that incorporates the person’s own experiences of the illness and whole life context in the care and treatment of them and their families, instead of focusing only on symptom management and preventing recurrences. For example, if health care professionals understand the problem as how the patients perceive their illness, it can ease the management of mood swings and relapses from periods of sobriety along with selection of treatment modalities (comprehensive therapy, different kinds chemotherapy and psychotherapy) will be improved or done with great focus. These in turn may fill the perception gap and ease the interpersonal communication between the health service provider, and the person with BD.

**Implications for Clinical or Counseling Psychologists**: Since the research have been done on phenomenology of persons with BD, the research may help them to give more emphasis on the person-centered active processes in relation to becoming ill with BD and how they can recover from it. Moreover, the research addressed the unique experiences of persons with BD in their different context so psychologists may benefited by using an integrated part of the care where the knowledge, understanding and insight of the person affected and their families are a condition for them to be involved in and be able to influence their own health care and treatment.

**Implication for Mental Health Society-Ethiopia**: Mental Health Society-Ethiopia might be benefited from this study since it should address the unique situation of persons with BD and further developed and designed to best meet all the different needs of persons with BD. It also helps to identify the specific meanings and needs experienced by adults when they live with BD.

Moreover, it can help to evaluate what kinds of support that best meet their needs and are most beneficial for their coping strategies in the management of their challenges.

**Implication for Research**: In Ethiopia, there are some mental health researches, which are mainly epidemiological and discussed the status of the various aspects of mental health services (WHO-AIMS, 2005). However, as to my knowledge, there is no research conducted on/about the lived experiences of people living with mental illness. Therefore, this research is expected to fill this gap in the literature by exploring Lived experiences of adults with BD focusing on perception of their illness, various challenges faced when they live with BD, how they try to cop their challenges and what are the negative and positive experience persons with BD.

### 1.5. Delimitation

The study setting is AMSH which is located in Addis Ababa, the capital city of Ethiopia. It is the only referral Mental Health Hospital in the country. The Hospital is selected since it provides both inpatient and outpatient treatment services. As a result, it is the best place to get informants. In addition, since the researcher is living near to the hospital, she had better opportunity to get participants in time of their medical appointment and develop rapport which helped to explore detail information from informants. The study was also delimited to find out subjective meanings and descriptions of the disorder when patients live with BD perception of the illness, negative and positive impact of the Illness, the challenges and their coping were addressed. The study also focused on adults aged 18 and above and diagnosed as bipolar disorder.

## 1.6. Limitation of the Study

The limitations of this study are those inherent in the use of a qualitative research approach. This study is limited to the conditions under which the study was carried out, specifically the sample. In addition, this study was limited to ten interviewees and two FGDs. Of those interviewees, eight of them were outpatients who were fully functioning and experiencing the challenges of the illness and the rest two were inpatient who were candidate for discharge and regarding participants of FGD the reverse is true in which nearly all participants were selected using snow-ball technique from inpatients' primary caregivers or families. Since the sample size of inpatient and outpatient were not proportional so generalize-ability of these findings is limited to the participants only. Lack of gender diversity especially with interview data in which most of them were female participants due to the sampling technique used was another limitation. Therefore, out of ten participants the purposive sampling technique yielded seven female participants.

The researcher planned to conduct two session interview but due to patients' uncertainty in keeping appointment and unwillingness of some patients (e.g. due to distance they were not comfortable to have other meeting). So the research limited to have one session interview which might have some effect on the depth of the data and this also limited not to test/crosscheck the reliability of the information with participants themselves. Unavailability of local research on the lived experience of persons with BD limited the researcher to focus only on western literature for discussion. The final limitations were from the researcher side who has limited knowledge and being beginner with regard to phenomenological research.

## 1.7. Operational Definition of Basic Terms

The following terms were defined operationally as they were used for this study.

**Adult**: An individual with the age of 18 or above who is no longer considered a minor.

**BD**: It is a disorder in which patients have had mood swings from high to low (manic to depression) or at least one previous major depression and recently he/she might be in hypo-manic, mixed or manic episode.

**Adults with BD**: is a person whose age is 18 years old and above, and who was diagnosed as BD patient by mental health professionals using DSM-IV 2000 criteria of BD.

**Lived experience**:, It is a persons' subjective belief, values, feeling and practice on their specific phenomenon or what they observes , hears and perceives the phenomenon and gave meaning for that specific phenomenon (being bipolar patient in this case).

# CHAPTER TWO

## 2. REVIEW OF RELATED LITERATURE

### 2.1. Historical Overview of BD

The concept of BD grew out of Emil Kraepelin's classification of manic depressive insanity (Lauren, et al., 2005). Before 80 years ago, he described manic-depressive illness as a recurrent "circular" psychosis involving mania and melancholia (as having a fluctuating course, with periods of normality alternating with periods of illness (Ward, 2008). However, descriptions of frenetic activity associated with the manic state can be found in the writings of Hippocrates and as far back as the ancient Egyptians (The British Psychological Society & the Royal College of Psychiatrists [BPS & RCP], 2006). In 1957, Leonhard coined the term 'bipolar' for those patients with depression and who experienced mania (the National Collaborating Centre for Mental Health, 2006). In 1966, Angst and Perris independently demonstrated that unipolar depression and BD could be differentiated in terms of clinical presentation, evolution, family history and therapeutic response.

In 1980, the name BD was adopted to replace the older term manic-depression, which was tightly associated with psychosis. It became recognized that not all patients who experience mania and depression become psychotic and therefore psychosis should not be required for a diagnosis (BPS & RCP, 2006). In the modern conceptualization, BD is a cyclical mood disorder involving periods of profound disruption to mood and behavior combined with periods of more or less full recovery (BPS, 2010).

## 2.2. Definition of BD and Its Diagnostic Criteria

**Definition of BD:** There are a number of different definitions for BD. The Cambridge Dictionary of Psychology (2009) defined BDs as a family of disorders characterized by swings from depression to mania or hypomania including bipolar I disorder, bipolar II disorder, bipolar disorder not otherwise specified, and cyclothymic disorder. According to DSM-IV-TR (2000) BD classified as a mood disorder, is a chronic, recurrent illness associated with high rates of morbidity, disability, and premature death from suicide. Phillips and Frank (2006) said that the Diagnostic and Statistical Manual of Mental Disorders (DSM) fails to reflect the multisystem presentation of BD. They recommended that the upcoming fifth edition of the DSM should reflect a symptom-based definition of BD as a multi-systemic disorder involving disturbances in physical, psychological, and social domains. It is now recognized that because individuals with BD suffer from a marked disruption in sleep rhythms and social relations, it cannot be narrowly defined as a disorder characterized by episodic mood disturbances (Andrea & Jane 2009). Psychiatrists now recognize that BD is not a variant of unipolar depression or other mood disorders (Phillips & Frank, 2006) but a complex condition that often requires multimodal treatment (Leahy, 2007).

The DSM IV-TR (APA, 2004) encompasses the classic definition of manic-depressive disorder and requires that the patient has had a manic episode to confirm the diagnosis. Diagnostic criteria for BD include: the patient is or was recently in a manic episode. The patient has had at least one previous major depressive episode, manic episode, or mixed episode (APA, 2006). The US National Institute of Mental Health [NIMH], (2006) also defined BD as a severe psychiatric illness characterized by alternating manic and depressed mood states, with associated disturbances in energy levels, sleep, appetite, and cognition.

**The Diagnostic Criteria of BD**: Symptoms of BD are different from the normal ups and downs that everyone goes through from time to time (Ward, 2008). BD symptoms can result in damaged relationships, poor job or school performance, and even suicide (NIMH, 2006). BD often develops in a person's late teens or early adult years and at least half of all cases start before age 25 (WHO, 2000; Kessler, et.al, 2005). Some people have their first symptoms during childhood, while others may develop symptoms late in life (NIMH, 2006). Criteria for the length of manic and depressive episodes in adults are specific (APA, 2000). The duration in children and adolescents, however, is not clear and adolescents who have BD may vacillate between depressive and manic symptoms on a weekly, daily, or hourly basis. This rapid cycling is a hallmark symptom of BD in children and adolescents (Wolf & Wagner, 2003).

According to DSMIV-TR (APA, 2000) the diagnostic criteria first specify four types of mood episodes, the presence of which may lead to a diagnosis of BD. These are major depressive episode, manic episode, mixed episode and hypo-manic episode. In Each episode, except in hypo-manic episode, the symptoms must be severe enough to cause clinically significant distress or impairment in occupational, social, or other important areas of functioning.

**Table-1:** Diagnostic criteria for major depression, hypomania and mania, in BD types I and II, taken from the DSM-IV (APA, 1994)

| No | Major Depressive Episode | Hypo-manic or Manic Episode |
|---|---|---|
| 1 | Depressed mood | Inflated self-esteem or grandiosity |
| 2 | Diminished interest or pleasure in activities | Reduced need for sleep (e.g., feels rested after only 3 hours of sleep) |
| 3 | Sleep disturbance (Insomnia or hyper-somnia) | More talkative than usual or pressure to keep talking |
| 4 | Decrease or increase in appetite/ weight | Flights of ideas or subjective experience that thoughts are racing |
| 5 | Psychomotor agitation or retardation | Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli) |
| 6 | Fatigue or loss of energy | Increase in goal-directed activity or psychomotor agitation |
| 7 | Feelings of worthlessness or excessive or inappropriate guilt | Excessive involvement in pleasurable activities that have a high potential for painful consequences e.g., the individual engages in unrestrained buying sprees, sexual indiscretions, or foolish business investments) |
| 8 | Diminished ability to think or concentrate, or indecisiveness | |
| 9 | Recurrent thoughts of death (not just fear of dying) | |

- The diagnosis of a major depressive episode requires the presence of at least five symptoms during a two-week period, one of the symptoms being either (1) depressed mood or (2) loss of interest or pleasure, representing a clear change from previous functioning

- For a manic episode or a hypo-manic episode there must have been a distinct period of abnormally and persistently elevated, expansive or irritable mood, lasting at least 1 week (manic episode) or 4 days (hypomania)
- Episodes of mania and depression characterize BD I, while episodes of hypomania and depression indicate BD II
- A mixed episode is one in which the criteria are met for both a manic episode and a major depressive episode nearly every day for at least a week. Mixed episodes are sometimes referred to as “dysphoric mania.”

## 2.3. The Prevalence of BD

The lifetime prevalence of bipolar I disorder (recurrent episodes of depression and mania) is estimated to be 0.4-1.6% and bipolar II disorder (milder mania that alternates with depressive moods) as 0.4-0.5% (APA, 2000). Similarly, a research by Awas, Kebede & Alem (1999) in rural Ethiopia showed that the life time prevalence of BD or Bipolar I disorder was 0.0%-1.5 %. Recent studies of prevalence in clinical populations also suggested that BD is common. The American Psychiatric Practice Research Network reported that 12% of patients in psychiatric practice have a principal diagnosis of BD (Pincus et al. 1997, cited in Scott, 2001). Widely accepted estimates of the prevalence of BD in adults range from 1%–2% (American Psychiatric Association, 2000), and incidence is similar in adolescents (Wolf & Wagner, 2003)

BD is the sixth most common cause of disability in the United States, the fifth leading cause of disability among 15-44-year-olds globally, and the ninth leading cause of years Lost due to death or Disability worldwide (WHO), 2001). BD was estimated to be the 7th leading cause of non-fatal burden in the world in 1990, accounting for 3% of total years of lost due to disability (YLD), around the same percentage as chronic obstructive lung conditions (Jose, 2006). In addition, five of the 10 leading causes of disability worldwide (major depression, schizophrenia, BD, alcohol abuse, obsessive compulsive disorders) are classified as mental disorders (Murray & Lopez, 1996).

## 2.4. Risk Factors in BD

Despite its long history, little is known about what causes BD. Explanations in terms of psychosocial factors were main-stream in the 19th century, but recent research has concentrated on identifying possible biological underpinnings of the disorder including genetic components, neuro-hormonal abnormalities and structural brain differences (NCCMH, 2006).There has also been some recent but very little revival of interest in psychosocial research, including life events and social rhythm (Malkoff-Schwartz *et al.*, 1998), and behavioral activation system (Depue *et al.*, 1987). However, currently there is no overarching explanation and the heterogeneous clinical presentation of BD suggests that a number of different mechanisms are involved (BPS, 2010).

### 2.4.1. Biological Risk Factors for BD

Scientists are learning about the possible risk factors of BD. Most scientists agree that there is no single cause. Rather many factors likely act together to produce the illness or increase risks of BD (NIMH, 2008).

The first biological risk factor for BD is **Genetics**.BD tends to run in families, so researchers are looking for genes that may increase a person's chance of developing the illness (BPS, 2010). Mortensen (2003) stated that someone with a sibling or parent with a diagnosis of BD is over 10 times more likely to receive the diagnosis themselves compared to someone from an unaffected family. Moreover, according to Faedda, et al., (2004) BD is considered one of the most heritable mental illnesses. In contrast to these research findings, studies of identical twins have shown that the twin of a person with bipolar illness does not always develop the disorder (NIMH, 2006). Rather, it is likely that many different genes and a person's environment are involved. However, scientists do not yet fully understand how these factors interact to cause BD (Steven et al., 2010, NIMH, 2006).

**Nero-chemical Change:** It is the second biological risk factor for BD. There is evidence that certain neurotransmitters (brain chemicals) – for example serotonin and dopamine – may play a role but all thoughts and emotions involve chemical changes in the brain and cause-and-effect relationships are unclear (BPS, 2010).

**Brain structure and functioning**: It is the third biological risk factor for BD. Some imaging studies show how the brains of people with BD differ from the brains of healthy people or people with other mental disorders (Soares & Mann, 1997). For example, one study using MRI found that the pattern of brain development in children with BD was similar to that in children with "multi-dimensional impairment," a disorder that causes symptoms that overlap somewhat with BD and schizophrenia (Gogtay, 2007). Moreover, there is evidence that some brain areas may function differently in people with a diagnosis of BD when performing specific tasks, for example tasks involving sustained attention (Strakowski et al., 2004). However, cause-and-effect relationships are unclear; for example, some differences could be the result of prolonged use of certain medication (BPS, 2010).

**Combination of factors**: It is the fourth biological risk Factor for BD**.** A great deal of research has investigated possible biological causes of BD. Whilst significant advances have been made in our understanding of how vulnerability to BD might be increased, for example, by inheriting particular genes, our knowledge of biological factors cannot tell us with certainty who will or will not develop BD and the chain of events by which this occurs (Steven et al., 2010). Therefore, to think in terms of a single cause is probably incorrect. Instead it is likely that the experiences labeled as being part of BD are the result of a combination of factors that interact with each other across time (BPS, 2010).

### 2.4.2. Psychological Risk Factors for BD

There is sometimes a false separation made between biological and psychological explanations of BD. It is generally accepted that biological changes can affect psychological states and psychological states can affect biological states. Every thought or emotion also involves chemical changes in the brain (Steven et al., 2010). BD affects each person differently (Goodwin &Jamison., 1990). There are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder. In a risk-protective model of resilience, a protective factor interacts with a risk factor to mitigate the occurrence of a negative outcome, for example; high levels of sociopolitical control were found to limit the negative consequences of helplessness on mental health (Zimmerman, et al., 1999).

One of the psychological risk factors for BD is positive *and negative thinking styles (BPS, 2010).* Some people with a diagnosis of BD appear to show certain characteristic patterns of thinking. These have been termed ‘thinking styles’ by psychologists and include both positive and negative styles (Steven, et al., 2010). Negative thinking styles can include a tendency to self blame when things go wrong and to see the self, other people and the wider world in a negative light (Alloy et al., 1999). Another factor is a tendency to ruminate when feeling low, which can make the person feel even worse. These styles are most prominent not only in individuals who experience depression but people with a diagnosis of BD also tend to engage in risk taking behavior in response to low mood. These may include risky sexual behavior, use of alcohol, street drugs or taking other health risks (Thomas et al., 2007).

Positive thinking styles are also often prominent in people diagnosed with BD. However, just as negative styles are clearest when mood is low, positive styles are clearest when mood is higher. For instance, when an individual experiences increase in alertness or activity or reduced need to sleep, some people with BD are more likely to interpret these as reflecting their true self rather than as being caused by external events (Steven, et al., 2010). The positive thinking style likely to cause individuals to engage in more behaviors (such as taking on new challenges or increased creativity and working harder, taking less rest, feelings of optimism, sparks of inspiration, increased motivation and productivity) when their mood starts going up (Jamison et al., 1980). This can increase the likelihood of mania or hypomania in the first instance and can lead subsequently to depression for some people if they cannot meet the commitments they have taken on in elevated mood (Jones, et al., 2006).

Another feature of thinking styles is their tendency to fluctuate. Specifically, the way the person thinks about themselves can change substantially across mood episodes (Bentall et al., 2005). Even between episodes people often experience rapid changes in self esteem and mood, and can also experience contrasting thinking styles at the same time. So, when experiencing an elevation of mood someone might on the one hand feel this is a marvelous opportunity to get on with all the tasks they wanted to do before they became ill, but on the other hand feel fearful that their mood might rise into an episode requiring hospitalization (BPS, 2010). The tension between these possibilities can clearly be a source of stress in its own right (Steven, et al., 2010). There is also evidence that some people with a diagnosis of BD have difficulties with *decision making and planning* (Murphy et al., 2001). These people are more likely than others to make more impulsive decisions and less likely to take into account future consequences of decision making. These tendencies can sometimes interact with the thinking styles noted above and increase risk for mood episodes (Swann et al., 2004).

### 2.4.3. Social Risk Factors for BD

Inherited tendencies, life experiences and the way we see the world and interpret events can all play a role (Steven, et al., 2010). No-one can ever know for sure exactly what elements combined together to cause problems for a particular individual. Similarly, people who have themselves received the diagnosis hold a wide variety of views about the nature and causes of their difficulties (Van der Gucht, 2009).

One of the key aspects of social circumstances is a **Family Characteristic**. According to Steven et al., (2010) life circumstances and family characteristics can influence not only whether or not someone experiences the problems which can lead to a diagnosis of BD, but also how the problems develop over time. It can, of course, also work the other way round (having a member who experiences mood problems can affect family and social relationships). Two main areas are particularly important. Firstly, people in families with overly protective or critical patterns of family communication (known as high expressed emotion; Miklowitz et al., 1988) are at increased risk for future mood episodes. Secondly, the range of genuine friendships and other sources of informal support that the person has access to (social support and social networks; Johnson et al., 1999; 2003) can be crucially important. These patterns of communication can be addressed using family based psychological help (Weinstock et al., 2006).

Another key aspect related to social circumstances is **friendship and social support.** The range of genuine friendships and other sources of informal support can be crucially important (Johnson et al., 2003). Like acute schizophrenia, EE research findings have been reported in relation to BD with people having more relapses of mania or depression and gaining fewer benefits from drug treatment if they live in high EE environments (Honig et al., 1997; Miklowitz et al., 1988). In many cases the protectiveness or criticisms of family members represent their efforts to cope with day-to-day life. It is also important to note that these patterns can be changed through family therapy (Miklowitz & Goldstein, 1990; Miklowitz et al., 2000).

Patients’ **life events** are *also* important social factors responsible for BD**.** Individuals who have had more stressful life experiences seem to be at more risk for the development of BD and these seem to be particularly important in triggering earlier episodes of mania or depression (Ambelas, 1987). There is evidence that individual with a bipolar diagnosis who had greater problems in their childhood have more frequent problems with mood episodes as adults (Dienes et al., 2006). Also, people with a vulnerability to extreme mood states sometimes find day-to-day problems more stressful than do individuals with no bipolar diagnosis (McPherson et al., 1993; Myin-Germeys et al., 2003). Stressful life events also influence people's outcomes after BD has been diagnosed. So, research has shown that higher levels of life stress are linked to higher rates of relapse and slower recovery from mood episodes in individuals with a bipolar diagnosis (Ellicott et al., 1990; Johnson & Miller, 1997).

## 2.5. Challenges of Persons with BD

**Psychosocial challenges.** The DSM alone cannot convey the devastating effects that bipolar disorder has on a patient's quality of life Andrea & Jane (2009). The conventional view that bipolar disorder has a better prognosis than schizophrenia has been challenged due to the large percentage of patients who exhibit chronic residual affective symptoms and unpredictable mood cycling and therefore experience significant impairment in psychosocial functioning (Zaretsky, Rizvi, & Parikh, 2007). Murray and Michalak (2007) stated that "if bipolar disorder develops in a woman at the age of 25, she may lose 9 years in life expectancy (due to medical problems), 14 years of productivity, and 12 years of good health" (p.24).

Bipolar mood disorder affects each person differently (Goodwin, Jamison, 1990). There are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder. Increasingly, researchers are pointing to the importance of individual differences in resilience and vulnerability as key determinants of the intensity and duration of episodes of illness (Zimmerman et al., 1999). In addition, social and personal costs of BD patients can be very high. The marked changes in mood, thinking, and behavior during episodes can have immediate and delayed consequences. An episode may include mood liability, financial extravagance, fluctuations in levels of sociability, sexual indiscretions, or violent behavior (Basco & Rush, 1996), for which one may have to "pay later."

The major life consequences reported by high percentages of those with the diagnosis include financial difficulties, divorce or relationship difficulties, losing jobs or dropping out of school, and injury to self or others (Lish, et al., 1994). Substance use is also highly associated with BD. The lifetime rate for completed suicide among people with BD has been estimated to be 60 times higher than that for the general population (Baldessarini, Pompili, & Tondo, 2006). Other study also found that two-third of the patients with BD are at substantial risk for suicide and among patients with BD, 42% reported that their work is markedly affected by their symptoms, and social activities were at least markedly affected in 37% (Paul, et. al, 2007). Persons with BD have been reported to have a higher risk of suicide than patients with any other psychiatric or medical illness (Woods, 2000).

**Career Challenges:** By definition (Diagnostic and Statistical Manual IV criteria) the mood disturbance must be severe enough to cause marked impairment in social activities, occupational functioning, and interpersonal relationships and/or require hospitalization to prevent harm to self (American Psychiatric Association, 1994). Results from the National Depressive and Manic Depressive Association (NDMDA) stated that BD illness is not only common, but for those affected, it is a significant source of distress, disability, loss of life through suicide, and burden on relatives.

A survey of bipolar members of the NDMDA found that 88% had been hospitalized psychiatrically at least once and that 66% had been hospitalized two or more times. It also found that 88% of those with BD felt that their illness affected their ability to perform on their job, with only 40% reporting that they were employed at the time of the survey (Hirschfeld, Lewise & Vornik, 2003). Murray & Michalak (2007) stated that as a consequence of the illness, the quality of life for individuals with BD is characterized by lower wages, higher unemployment, work absenteeism and disability, marked interpersonal relationship instability and higher divorce rates, lower levels of educational attainment, and higher rates of arrest, hospitalization, and premature death compared to the general population. Occupational functioning frequently declines: About one in every three patients cannot work in the 6 months after a manic episode, and only about 20% work at their expected level (Dion et al., 1988). Bipolar disorder is also associated with high rates of separation and divorce and problems in the adjustment of patients' offspring (e.g., Coryell et al., 1993).

Major life challenges reported by high percentages of those with BD diagnosis include financial difficulties, divorce or relationship difficulties, losing jobs or dropping out of school, and injury to self or others (Lish, et al., 1994). Moreover, the functional impairment associated with BD may commonly persist, even despite resolution of symptoms when patients are in remission (Coryell,et al., 1993).

WHO (1996) in a landmark publication has estimated the global burden of varies illness to human population. One unit of measurement utilized is disability –adjusted life year (DALY). Bipolar disorder was ranked six in worldwide causes of DALYs in 1990 among person’s ages

15-44 years. Moreover, loss of employment, difficulty regaining employment and days lost from work all contribute to disability associated with bipolar disorder. The NDMDA survey found that 37%of bipolar patients were unemployed (Lish J, et al., 1994). A group of patients hospitalized for BD in New Zealand had been employed in only 34% of cases, compared with 75% for the general population. A study in patients in the United States found that43% of bipolar patients discharged from a psychiatric hospitalization were employed after discharge, and only 21% were functioning at their level of employment(Dion,1988)

**Diagnosis and Treatment as a Challenge:** BD is a complex disability that presents substantial challenges for diagnosis and treatment Andrea & Jane (2009). This complexity often makes it difficult to diagnose and treat, and the chronic experienced by individuals with the disorder significantly impacts their physical health and overall quality of life (Culver, Amow, & Ketter, 2007) According to Culver, Amow, and Ketter (2007), medications used to treat BD have been inadequate for a large proportion of these patients, who report persisting depressive or manic symptoms after a year on medications. The primary treatment challenge is none-adherence to medication regimens: approximately 60% of bipolar clients take less than 30% of their medication as prescribed (Culver, Amow, and Ketter, 2007; Rizvi & Zaretsky, 2007).

Interpersonal problems, life events, and lack of stress management skills are characteristics of BD, and these stressors worsen the course and outcomes of the illness (Basco, Ladd, Myers, & Tyler, 2007). Typically, pharmacological treatments are essential for managing BD (Miklowitz & Ofto, 2006); however, medication alone is often inadequate to restore and maintain physical health and quality of life. One study found that because of lack of an integrative therapy, as many as 60% of patients never regains full occupational and social functioning (MacQueen, Young, & Joffe, 2001). Regarding to this Andrea and Jane, (2009) stated that BD is a devastating illness for patients and their families and due to the complex and pervasive physiological, psychological, and social dimensions of the disorder, it remains a diagnostic and treatment challenge for the entire spectrum of professionals who work with this population.

## 2.6. Coping Strategies for Persons with BD

The term coping has several definitions ranging from the ability to deal with problems to, as Lazarus and Folkman (1984) defined it, a transactional process, which changes over time and within its situational contexts  Pearlin and Schooler (1978, pp.30), defined coping as "any response to external life strains that serves to prevent, avoid, or control emotional distress". They recognized that the act of coping is related to both the life strains and the state of one's inner emotional life. Lazarus & Folkman (1984) view that even though stress is inevitable; it is the coping that makes the difference in adaptation outcomes. According to them, coping has two major functions (a) regulating stressful emotions or emotion-focused coping and (b) altering the distressed person-environment relation or problem-focused coping.

Emotion-focused coping refers to efforts to manage the negative emotions associated with the stressful situation which is used when events are perceived as uncontrollable, such as health situations. These coping strategies include cognitive distraction, seeking emotional support, emotional regulation and expression, selective attention, communicating with family members about the illness and cognitive restructuring ( Phyllis et al. 2011).The other coping style is problem-focused coping which is referred to as the efforts used to change the basis of stress directly. This type of coping focuses on altering the environment, changing the external pressures, or seeking resources to help make the situation less threatening. Problem-focused coping strategies usually are used by adult individuals in work contexts (Lazarus & Folkman, 1984).

Coping strategies can also be classified as being positive or negative. Some patients and family members use positive coping strategies to manage and to help them manage their situation, such as positive thinking and the utilization of appropriate social supports, which include family, friends, and holy places (Perkins, et al., 2004). Others may also use negative coping strategies, such as the use of avoidance behaviors, negative thinking, and substance abuse (Greeff, et al., 2006; Nehra, et al., 2005].

**Communication:** It is a coping strategy that family members and patients use to share information about their thoughts and feelings but the social stigma of mental illness is seen as a restraint to sharing information about their mentally ill relative outside the family (Phyllis et al. 2011).Suppression of the illness has been viewed as preferable to disclosure due to the risk of negative reaction from others (Stengler-Wenzke, et al, 2004). Communicating with family members is considered to be an emotion-focused coping strategy and may be done through verbal or written contact (Lazarus and Folkman, 1984). They also stated that some patients and many family members cope with their situation by sharing their feelings only with their immediate family, and through this, receive support and understanding

**Acceptance:** Acceptance is a form of cognitive restructuring where individuals appraise their thinking reactions to situations and change negative reactions to positive, or at least neutral ones (Lazarus and Folkman,1984). Getting correct diagnosis and acceptance of the illness is a first step in learning to stay well so families and patients may use acceptance as a strategy to get an accurate and beneficial view of their situation (PatriK, 2010). Incorporating acceptance in their life helps patients to reduce stress and improve their relationship with family members (McCubbin, et al., 1991). A 47 year old librarian who accepted his illness diagnosis and educated himself about his BD said that Knowing the diagnosis and accepting it can help persons with BD to deal with the disorder so educating oneself about the illness could help the individual to adjust one's life accordingly (Sarah & Jan, 2005). According to Pollack and Aponte (2001) the identification with or acceptance of BD is a lengthy process. Acceptance promotes compliance and self-management, which is a foundation for persons with BD being able to take more responsibility for their own care. However, denial and despair in relation to the illness, common in persons with BD, can be obstacles in this process. The acceptance of the illness and increased knowledge about BD was a foundation on which those affected could develop individual and context-adjusted strategies, e.g. managing stress and having a supportive network, in order to stay well and avoid new episodes (Russel & Browne 2005).

**Cognitive Distraction:** The use of cognitive distraction is also noted to be an emotion-focused coping strategy which includes passive appraisal Phyllis et al., 2011) It may be something that limits attention or prevents concentration, distracts the mind from thinking about stressful situations and limit reactivity and allows the individual to accept and minimize reaction to difficult situations. Family members are able to minimize their reaction by utilizing passive appraisal activities, such as watching television, relying on luck, feeling helpless about the problem, and believing that time will solve the problem (Lazarus & Folkman, 1984]).

**Avoidance:** Avoidance is an emotion-focused coping strategy that some families and patients use when they overestimate the threat of the illness or underestimate their own coping ability (McCubbin, et al., 1991). Avoidant strategies may include ignoring the family member/the patient by decreasing physical and emotional contact, such as not communicating and visiting them regularly and limiting their affection. Families may also totally avoid their mentally ill relative and cut off any type of contact (Nehra, et al., 2005). According to Lesley (200-) said that 'some members of the family able to understand and listen to others but they wouldn't be able to talk to others who don't know much about it. People are frightened of the unknown. They show things on TV – sensationalize them. It's not so good so persons with BD avoid contact disclosure for those who have no understanding about the illnesses**.**

**Religiosity and Spirituality:** The National Alliance on Mental Illness (2010) stated that some families and patients use religious and spiritual support as a means for coping with the illness and/or coping with caring for a mentally ill relative. The use of spirituality is seen as a positive emotion-focused coping strategy (Phyllis et al., 2011). Spirituality may mean different things to different individuals, but has been seen to increase levels of well-being and decrease the level of stress in one's life (Rammohan, et al., 2002). It can be both intra-physical, such as through values and beliefs, and institutional, such as through church attendance and performing rituals. Spirituality includes seeking advice from a minister, attending and participating in church services, and having faith in God. Spirituality may also include prayer, privately and with a community (Phyllis et al., 2011).With regard to spirituality as coping mechanism, Jan had developed a deep sense of spirituality and he described that "I came to accept the serenity prayer, to let God grant me the serenity to accept the thing I cannot change and my partner Eileen has also helped me just being there. Her support makes me feel I am not a burden or a failure" (DBSA & FDA, 2002, P7.)

**Joining a Support Group:** The coping strategies of a family member may influence the treatment outcomes of their relative positively or negatively (Enns et al., 1999). Accessing social support is an adaptive problem-focused strategy (Lazarus and Folkman, 1984). Social supports may be social networks such as churches, friends, and extended family, or they may be more formal networks such as health care or educational institutes (McCubbin, et al., 1991). For example a person with BD noted the importance of social support as "being with people who understand what it's like to have this illness and sharing my experiences with others have been extremely helpful. He also believed in sharing experience, creating hope, inspiring people and makes them believe they can get better (Depression and Bipolar Support Alliance and Families for Depression Awareness [DBSA & FDA], 2002, p 6.)

**Being an Expert on the Disorder:** As mental health treatment options decrease, families are being given the responsibility of transitioning their mentally ill relative from inpatient psychiatric treatment to outpatient treatment (Enns, et al., 1999]. Not only families but also patients are responsible for their treatment; so being an expert or being well informed on the disorder is an important one (NAMI, 2008). In addition, information needs to flow both ways (consumer/patient and provider/health care professionals), ask questions, and write them down before appointments. You and your health care provider should ideally work as a team to fine-tune doses, schedule appointments for monitoring, or make any other helpful changes (Ken Duckworth, 2008). Zake, age 19, said that things are good when he stay on his medication. At first he would not - he was afraid it would change his personality and he did not want to accept that he had an illness. Then he was hospitalized several times after stopping the medication and he hated being in the hospital. He also lost two girlfriends that he really cared about because of things he said when he was manic, so he need medication (DBSA & FDA, 2002)

In addition, **Become aware of the earliest symptoms** is the other important coping mechanism in which patients should notice the pattern of symptom development which is a key to prevention (Ken Duckworth, 2008). In other words, if the person with the diagnosis is able to recognize the early triggers or warning signals of an impending episode and respond with the right 'coping strategy', they gain control over their mood swings (NCCMH, 2006). Be aware that the people closest to you may be the first to see signs so develop a plan for emergencies with people you trust know what to do in a crisis, no matter where or when it occurs—this will reduce uncertainty and stress (Ken Duckworth, 2008).

**Adjusting Life Style:** According to Ken Duckworth (2008, p.22-24) "adjusting life style is one of the coping mechanisms of patients with BD". Persons with BD identified a number of lifestyle factors that helped them to stay well. They included eating healthy food, regular exercising, drinking less alcohol/caffeine, having regular schedule, sleeping well, spending time with loved ones, having quiet times, managing stress, and laughing (DBSA & FDA, 2002). For example, a 42-year-old chief executive officer learnt to manage his work stress (Sarah et al., 2005) as a result, he also managed his illness. He said stress is a big trigger for him. To a large extent, managing his illness was about managing his stress. Mindfulness' is a coping strategy which mean being aware of themselves and how they were responding to their physical, mental, emotional, social and physical environment (DBSA & FDA, 2002).

Regarding to this a 52-year-old school teacher and a 57-year-old parks and gardens superintendent benefited with mindfulness to control the illness and minimize its impact on their life. The teacher says “I now understand the illness and its impact on my body. I move swiftly to intercept a mood swing” and the superintendent also says that “I am able to assist in my wellness by being aware and observing what is happening to me” (Quoted Sarah et al., 2005, p190). Sometimes patients need to make changes to stay well, develop a personal support system, consider volunteer work or hobbies and continue with life (don’t let your illness take control, but recognize that as with any chronic illness some plans may have to be changed, canceled, or postpone, Sarah et al., 2005).

## 2.7. Lived Experiences Across their Mood Swings

According to Speziale and Carpenter (2007), lived experience gives meaning to an individual’s perception of a particular phenomenon. For the purpose of this study, the lived experience is how the person involved describes experiences in their world (Nieswiadomy, 2008). Highs and lows in mood are a feature of being human. But what about when people get changes in their mood and energy levels that are to such an extreme that they no longer feel like their normal selves? These kinds of mood swings are common in people who do not have bipolar disorder and who are not seeking help for them (BPS, 2010). For example, in a Swiss study of young adults who experienced highs in mood and energy that would be considered to be ‘hypomanic’ over half had no history of depression and therefore did not have bipolar disorder (Wiki & Angst, 1991).

Similarly, in a study of undergraduate psychology students in the UK, a quarter of the sample reported a period of time when they were not their normal selves and had a cluster of experiences such as euphoric or irritable mood, reduced need for sleep and racing thoughts (Udachina & Mansell, 2007). High energy states and mood swings have also been reported in a wide range of individuals who do not have formal diagnoses of depression such as: naturally short sleepers (Monk et al., 2001), creative individuals (Furnham et al., 2008), and people with an anxiety disorder (Bowen et al., 2004).

**Lived Experiences in Manic Episode:** People may experience episodes of mania which is a very intense episode often associated with increased well-being, energy and optimism. People in a manic episode can feel very happy and excited and find their thoughts full of new and exciting ideas. When a 19-year-old with mania was advised that he was indeed ill, he replied; *‘If I’m ill, this is the most wonderful illness I’ve ever had’ (Campbell, 1953 Quoted in BPS, 2010).*

Regarding to the lived experiences of persons with BD especially in manic states BPS (2010) explained that although sometimes subjectively enjoyable other aspects of mania may prove problematic for the individual. People in a manic episode can easily become irritated with other people who don’t share their optimistic outlook or when other people find it hard to understand what they are talking about. People may also make plans that are grandiose and unrealistic, make odd decisions on the spur of the moment, sometimes with disastrous consequences such as recklessly spending money or getting involved in unwise sexual adventures. A period of mania can also affect both relationships and work (BPS, 2010). When these experiences are intense – so intense that a person's life is very seriously affected, if a person loses touch with reality or needs admission to hospital, for example – then this is called mania.

> *'My early warning signs are that colures seem very bright, particularly reds and yellows, they take on neon characteristics and I believe they have magical properties, I also start to talk much faster and more than is usual for me. If I do nothing about these signs, within a day or two I am highly excited, very active, wanting to run, dance and climb things. At this stage everything seems wonderful and I feel like I am a genius! The next stage is more worrying (though not to me at the time) I become dis inhibited and take off all my clothes in public. Also, I believe I can fly and try to get to high places so that I can launch myself into the air. What seems such a wonderful feeling quickly becomes very dangerous?'* Debbie Mayes – service user (Quoted in BPS, 2010)

People who report more problems with their high moods often report that they feel that their moods are outside their own control (Mansell et al., 2008). This feeling can be compounded by the experience of psychotic symptoms in mania or depression. Understandably, feeling that one's own thoughts and feelings are out of control can be very frightening and lead to worry about what one might do as a result. This can be especially concerning for people if mood changes have led to risky behaviors in the past. Conversely, people who manage to have hypomanic experiences and do not develop bipolar disorder report greater awareness of and control over their high moods (Seal et al., 2008).

Many people with bipolar disorder are admitted to hospital at the peak of their high moods. Although the admission is usually designed to minimize risk and provide a place for effective treatment, many people find this a distressing experience. For example, some people were admitted against their wishes because clinicians see them as being at risk. Whether people enter hospital voluntarily or against their wishes, many reported that some hospital staff treats them in ways that feel patronizing or belittling (BPS, 2010). This quote illustrates some of the stressors of going into hospital:

> *‘The experience of being sectioned felt like social control rather than treatment for illness. My aim was to convince the staff that I was fine so that I could get out of hospital. It was nothing to do with getting better. ‘The staff just would not listen. I found it so frustrating to be in a situation where I was suddenly so patronized. I was being spoken to by nurses in the way I might address a two-year old. This increasingly fed my frustration. How do you make yourself heard when no-one will listen and you have been put in hospital against your will? You may or may not have any time to pack. You may or may not have a comb- toothbrush, shampoo, never mind the collection of cosmetics you may be used to which help you feel "right" to face the world. What would you do if faced with that sort of loss of dignity? How would you make yourself heard? I'm not that proud of the ways I tried but through the experience of depot (injected medication against one's will), I felt like they broke my will if not my spirit. Depot was one of my most humiliating experiences of my life and they wonder why people are depressed after a spell in hospital? Might it be posttraumatic stress?'* Joanne Hemming-field service user

**Lived Experiences in Hypomania Episode**: Less extreme episodes (where a person's personal life is clearly affected, but not so seriously) this is called 'hypomania' (hypo means 'under' in Greek). The reason why the 'hypo-manic' experiences are so prevalent is that many people who experience them want to have them because they see them positively. For example, high moods can help them to perform at work and deal with other people (Seal et al., 2008). Here is one example from a female professional who has had four hypo-manic episodes but has never had depression nor sought psychological treatment:

> *'I enjoy that feeling of being able to give out more – it's almost like a special offer at the supermarket, 10 percent extra with your washing powder! I feel bigger and better. I think my husband finds it quite a positive thing really because I'm much easier to be with and I am I think probably entertaining and interesting too.'* Quoted in Seal et al., 2008

**Lived Experiences in Depression Episode**: The criteria for identifying an episode of depression in bipolar disorder are no different from identifying episodes of depression in 'uni-polar depression' ('uni-polar' referring to cases when people experience episodes of depression but without the 'highs') (BPS, 2010). Most people experiencing depression do not have the highs associated with bipolar disorder. What that means is that if a person experiences their first episode of mania, they be given a diagnosis of bipolar disorder, but if they experience a first episode of depression, they will be diagnosed with 'major depressive episode' or 'uni-polar depression'. If, at a later time, they then have an episode of mania or hypomania, then a diagnosis of bipolar disorder will be used. Here is an example that illustrated the above idea;

> *'My experience of depression tends to follow the same pattern each time. It comes on quite quickly, the first sign is that my sleep gets interrupted, I wake early in the morning and can't get back to sleep, then my appetite goes, I no longer feel hungry. Alongside these things is a worsening of my mood, I feel bleak and lonely, even when I am around people who I love and am loved by. I feel an intense ache deep inside my chest and a sense that I am a horrible person that no-one can possibly like. I feel useless and guilty and as though I have done something dreadful and it is only a matter of time before I am found out. As time goes by I start to feel suicidal, that the world and especially those close to me would be better off without me.' (*Debbie Mayes – service user Quoted in BPS, 2010)

**Lived Experiences in Mixed Episode**: Some people experience so-called 'mixed episodes' during which they experience some of the aspects of mania (for example, excitement a rush of new and exciting ideas) and with some of the aspects of depression (perhaps restlessness, agitation, anxiety, irritability or even suicidal thoughts). If a person is experiencing a manic, hypo-manic or mixed affective episode, or has done recently, then a diagnosis of bipolar disorder often follows (BPS, 2010).

Mania and hypomania can become problematic in bipolar disorder. Several studies have investigated the experiences reported by people in mania and found the most common symptom pattern is not euphoria/high mood but rather dysphoria (an unpleasant combination of depressed mood, anxiety and guilt) (Mansell & Pedley, 2008). When individuals experience a mixed state in which high and low moods combine there is particularly high risk of self-harming and suicidal ideation (Mansell & Pedley, 2008). Even when mania is perceived positively by the individual it can have a negative impact on relationships with others. This can be at more subtle levels such as becoming more dominant in conversation but can also include getting into unnecessary arguments with others and even being physically confrontational. People can also act out of character in other ways during mania such as being sexually promiscuous, spending excessively or using large amounts of drugs or alcohol. This can be very challenging for other people and can lead to separation or divorce (Dore & Romans, 2001).

Often when the person's mood drops again, they may experience feelings of shame for what they have said or done that was out of character (Lam et al., 1999). Some people may have unusual experiences (psychotic symptoms) during their highs such as hearing voices or they may develop strong beliefs that are not accepted by other people. For example, they may believe that they are a religious prophet or that they are fighting with the devil. These experiences can be very distressing and lead the person to worry that they will go 'crazy'. When the experience has passed it takes time to try to make sense of more unusual experiences (Bonney & Stickley, 2008).

One of the most common problems people with bipolar disorder experience is sleep disturbance. During periods of hypomania and mania, people are much more active and typically sleep less. At the end of this period, they may feel exhausted and low in energy, which can herald a period of low mood. A change in sleep may be one of the early warning signs of the beginning of an episode of mania or depression (Wehr et al., 1987; Hudson et al., 1992).

*‘I can’t sleep too much or too little, there has to be a balance. If I sleep too much it is an indication of low mood, and if I sleep too little it is an indication of high mood or mixed state. I have learnt to not ignore sleeping problems and force myself to follow a strict routine, hard as it may be. If I can’t sleep I go to the doctor who gives me a short-term prescription for sleeping tablets.’* Karin Falk – service use (Quoted in BPS, 2010)

# CHAPTER THREE

# 3. RESEARCH METHODS

## 3.1. Research Design

In this study, qualitative research was done as it allows the researcher to conduct an in-depth investigation of the lived experiences of adults with BD. As Creswell (1998) pointed out, based on detailed accounts from informants and other sources of information, qualitative researchers attempt to develop a complex and holistic, yet multifaceted, conceptual picture of the phenomenon under study. Qualitative researchers typically seek to explore, understand, and represent the subjective experiences of people and make sense of and interpret their actions, experiences, and other social phenomena in terms of the meanings associated with them (Ward, 2008). Specifically, this study was conducted employing a descriptive phenomenological approach. In phenomenological studies, one strives to present a description and possibly an interpretation of the meaning of an experience with a specific phenomenon (Thomas, 2004).

Phenomenology is a way to investigate subjective phenomena, and is based on the belief that essential truths about reality are grounded in everyday experience (Spiegelberg, 1975; cited in Ward, 2008). Two Phenomenological approaches (descriptive and interpretative) were used in the study. The aim of interpretative phenomenological approach is to explore in detail how participants are making sense of their personal and social world. According to Creswell (2007), this approach describes research as oriented toward lived experience of persons with BD (phenomenology) and interpreting the texts of life (hermeneutics).

## 3.2. Study Area

This study was carried out in AMSH. It is the only referral psychiatric hospital in Ethiopia located in the capital city of the country (i.e. Addis Ababa) with 260 beds. The clinical services of the hospital are organized under case teams, which include psychoses case team, mood case team, addiction case team, forensic case team, emergency case team, non-psychoses case team, neuropsychiatry case team and geriatric case team. Most of the inpatients were diagnosed with schizophrenia (56.1%), major depressive disorder (11.4%) and BD (20.6%) of which some are induced by substance use disorder (Abebaw et al., 2007).

A study conducted by Fekadu, et.al (2007) on the patterns of admission to the hospital showed that the hospital annual admission rate is 0.004% person(4 per 100 000 (n=1564)) of which 61.1% were admitted for the first time, 72.4% were males, 69% were aged 30 year and under, the age of patients ranged from 12-90 years. Patients under the age of 16 years account 1.8% while those patients who were above 60 years constitute 0.7%. With regard to regional contribution for the admission rate, Addis Ababa took the greatest share (42 per 100,000 and 2 per 100,000 for the rest of the regions of the country). Moreover, this study showed schizophrenia and BD were the top disorders treated in the hospital which accounts 56.1% and 20.6% respectively the average length of hospital stay was 63 days

## 3.3. Participants of the Study

Participants of this study were those who have diagnosed and lived with BD at least for one year. This helped to get more information about the situation and experience of bipolar phenomenon. The following criteria were applied to select the participants.

**Table-2:** Inclusion and exclusion criteria for selecting participants

| Inclusion criteria | Exclusion criteria |
|---|---|
| • The respondent should be on treatment of BD at AMSH | • Who are not on treatment of BD and who are in treatment of BD for less than one year |
| • Should be18 years of age and above | • Individuals under 18 years of age. |
| • Able to participate in an interview and who were not in a significant emotional distress at the time of the interview | • Who are not able to participate in an interview and individuals in significant emotional distress |
| • Meet DSM-IV criteria for BD | • Did not fulfill DSM-IV criteria of BD |
| • Participants who are able to respond | • Participants who are not able to respond |

## 3.4. Sampling Technique

Purposive sampling technique was used to select participants for this study. “Obviously qualitative researchers use purposive sampling, deliberately selecting respondents based on their ability to provide the needed information (Padgett, 2008 P.53).” Ten interviewees were selected using purposive sampling and eleven participants were selected using Snow-ball technique in which interviewees were given the mandate to select their primary care giver or family who well aware of about their lived experiences. The qualitative research usually relies on small numbers with the aim of studying in depth (Miles & Huberman 1984). Seeking a richness of data about a particular phenomenon, the sample is derived purposefully rather than randomly (Ezzy, 2002). In this study, the sample size was increased until saturation is reached.

### 3.5. Instruments of Data Collection

In-depth interview was used to collect data in this study. In-depth interview is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular situation (Thomas, 2004). It is useful when we want to get detail information about a person's thoughts and behaviors or want to explore new issues in-depth (Carolyn & Palena, 2006).

The second method of data collection used in this study is focus group discussion (FGD). I conducted two FGDs with eleven caregivers. They were selected using snow-ball technique in which I have given a chance for persons with BD to select their primary care giver who gave support and well understand about them. In order to increase the reliability and trustworthiness of the data collected for in-depth interview, the researcher used FGDs for triangulation.

### 3.6. Data Collection Procedures

Before conducting the interviews, I selected BD patients who were in treatment for one year and above, given them the informed consent form to request their willingness for the research and then we adjusted time and place for interview session. The data were collected in the months of January and February from patients admitted in AMSH. Regarding the FGDs data collection procedure, first the patients given the mandate to select their primary care givers who can better understand their illness. Eleven participants of FGD were selected, the informed consent paper given and/or read for all participants. The researcher clearly presented the objective of the research and the research ethics. The two FGDs were conducted with five and six participants. Finally, the researcher thanks all the participants for their active participation, giving their time and their cooperation.

## 3.7. Data Analysis

Thematic analysis was used, which is one of the data analysis strategies in qualitative research. The data analyses were carried out soon after the data collection, which is common in qualitative research (Padgett, 2008). Data analysis procedure which is specific to interpretive phenomenology was applied. According to Victoria Heather (2005) there is no universally accepted method for data analysis for interpretive phenomenology. However, it should be in line with the philosophical position of phenomenology. Since there are no uniform procedures to follow in transcribing and generating themes, the researcher used the following five ‘steps’ or phases of Hycner’s (1999) data analyses process. These are:

1) Bracketing and phenomenological reduction
2) Delineating (outline) units of meaning
3) Clustering of units of meaning to form themes
4) Summarizing each interview, validating it and where necessary modifying it
5) Extracting general and unique themes from all the interviews and making a composite summary

**Bracketing and phenomenological reduction:** Phenomenological reduction is "to pure subjectivity" (Lauer, 1958, p. 50), a deliberate and purposeful opening by the researcher to the phenomenon "in its own right with its own meaning" (Hycner, 1999). Here phenomenological reduction refers to the bracketing of the researcher's personal views or preconceptions (Miller & Crabtree, 1992).

**Delineating units of meaning:** This is a critical phase of explicating the data, in that those statements that are seen to illuminate the researched phenomenon are extracted or 'isolated' (Creswell, 1998; Hycner, 1999). The researcher is required to make a substantial amount of judgment calls while consciously bracketing her/his own presuppositions in order to avoid inappropriate subjective judgments.

**Clustering of units of meaning to form themes:** With the list of none-redundant units of meaning in hand of the researcher must again bracket hers or his presuppositions in order to remain true to the phenomenon. By rigorously examining the list of units of meaning the researcher tries to elicit the essence of meaning of units within the holistic context. Clusters of themes are typically formed by grouping units of meaning together (Creswell, 1998) and the researcher identifies significant topics, also called units of significance (Sadala & Adorno, 2001).

**Summarize each interview, validate and modify:** A summary that incorporates all the themes elicited from the data gives a holistic context. At this Point the researcher conducts a 'validity check' by returning to the informant to determine if the essence of the interview has been correctly 'captured' (Hycner, 1999, p. 154). Any modification necessary is done as result of this 'validity check'this point.

**General and unique themes for all the interviews and composite summary:** Once the process outlined in points 1 through 4 has been done fo*r* all the interviews, the researcher looks "for the themes common to most or all of the interviews as well as the individual variations" (Hycner, 1999, p. 154). The researcher concludes the analyses by writing a composite summary, which must reflect the context from which the themes emerged (Hycner, 1999; Moustakas, 1994).

## 3.8. Ethical Consideration

According to Kellehear (1993), ethical concerns include the principles of privacy, informed consent, confidentiality, protection from harm, and avoiding deception. These broad principles were applied while undertaking the present study. To protect participants, names of people and places were alter to pseudonyms during transcription and analysis, and all data would not be identified: no participant details were stored with transcripts. Thus confidentiality applied to the presentation of the data, as well as recruitment. All electronic data were stored in password-protected computer files. The researcher was also concerned with participants experiencing distress due to the personal and sensitive nature of talking about BD. A letter of support from AMSH was requested to provide counseling for the participants in time of need and included in the ethical applications. There is a personal and moral obligation on the researcher to treat participants with respect for their knowledge, experience and human rights. To this extent, phenomenological inter subjectivity enriched the ethical research relationship. Moreover, ethical clearance was obtained from Ethical Committees of AMSH.

# CHAPTER FOUR

# 4. RESULTS

This chapter presents the major findings of the study. From the analysis of the qualitative data, four major themes were emerged. Perception to their illness, the negative and positive experience, challenge of Persons living with BD, and coping mechanisms of persons lived with BD. The first part of the chapter presents socio-demographic characteristics' of the interview and FGD participants. The second part presents the four themes one by one and their sub themes or categories. The researcher used pseudonyms to present each participant's lived experience.

## 4.1. Demographic Characteristics of the Participants

In the study, 10 participants were interviewed and two focused group discussions were conducted to find out the subjective experiences of adults living with BD. Except three, all the other participants of the interview were women who are diagnosed as having BD for at least one year. The age of the participants ranged from 24-44 years. The educational level of the participants varied from 8th grade to higher education student. That is three grade eight, four grade ten, two grade twelve and one of the participants was second year college student.

Regarding the participants' occupation, three of them were daily laborer; one domestic (household) worker, one runner, one seller, one college student and the rest three have no any job/occupation. All of the women participants and one male participant were unmarried and only two male participants were married and have children. The participants labeled themselves as having low socio-economic status.

**Table-3:** Interview Participants' Demographic Characteristics

| Pseudo Name | Illness duration in years | Age | Marital status | Occupation | Educational level |
|---|---|---|---|---|---|
| Sitra | 8 | 28 | Single | - | 10th |
| Shakiso | 7 | 35 | Married | Daily worker | 8th |
| Selam | 5 | 30 | Single | Sealer | 12th |
| Halima | 4 | 25 | Divorced | Domestic worker | 8th |
| Meti | 5 | 28 | Single | Runner | 10th |
| Fuad | 11 | 30 | Married | Dailey laborer | 10th |
| Abebe | 3 | 24 | Single | Student | 2ndyear student |
| Hikma | 8 | 25 | Single | Daily laborer | 8th |
| Meseret | 3 | 25 | Single | - | 10th |
| Abeba | 24 | 44 | Single | - | 12th |

As it is shown in table-4 below, the socio-demographic characteristics' of the FGD participants are as below. Their age ranged 25-60 years; regarding sex, five of them are female and the rest of the participants are male. With regard to their relationship to the patients, two of them are mother, two fathers, four of them are brothers and the rest three are sisters. Regarding their marital status five of them are married, two of them are windowed, two divorced and two single. The occupational statuses of them were two teachers, two merchant, one seller, four farmers, one student and one counselor.

**Table-4:** FGD participants' Demographic Characteristics

| Code-No. | sex | Age | Relationship to the patient | Marital status | Occupation |
|---|---|---|---|---|---|
| **Group-1** | | | | | |
| 001 | F | 56 | Mother | Married | teacher |
| 002 | F | 60 | Mother | Divorced | farmer |
| 003 | M | 26 | Brother | Single | farmer |
| 004 | M | 60 | Father | Windowed | Farmer |
| 005 | F | 50 | Sister | Married | Merchant |
| **Group-2** | | | | | |
| 006 | M | 42 | Brother | Married | Merchant |
| 007 | M | 47 | Father | Divorced | Farmer |
| 008 | F | 25 | Sister | Single | Student |
| 009 | M | 30 | Brother | Windowed | Teacher |
| 010 | F | 47 | Sister | Married | Sealer |
| 011 | M | 36 | Brother | Married | Counselor |

### 4.2. Perception of Persons with BD to their Illness

In this part of the study ten participants were interviewed about their perception of mental illness (their particular illness). They described their perception with regard to the illness by comparing it after and before their illness. They explained that their perception towards mental illness as follows.

### 4.2.1. Perception towards Mental Illness before the Illness

Before the participants got their illness, they have almost the same perception about the illness. Nearly all participants believed that mental illness is caused by evil spirit, witchcraft and some sort of substance added to what they drink or eat "*መድሃኒት አብልተውኝ / አጠጥተውኝ ነው/* (which is made from various plants roots and leafs).They also had stereotyped attitude towards mentally ill individuals. For instance, they used some words to describe the characteristics of mentally ill individuals "walking naked", "sleeping on street", "dangerous/aggressive", "have no feelings", "could not control themselves", "insult and hit any person without any reason".

Regarding to this Sitra described her perception to mental illness as follows:

> *According to my perception mentally ill people are those who wander naked, who always run, sit, sleep and live on a street. I am not afraid of mentally ill individuals rather am afraid of mental illness and feel bad when I see mentally ill individuals on the street.I follow my treatment under cover (nobody knows that I'm treated here except my family).*

The FGD participants' believed that mental illness comes with evil sprite which comes because of their sin so every participants of a group took the patient to the holy water or Holy places. Even there are few families till now argued if the patient waited a lot in a Holy place, He/she might be cured, They also justify by giving example as there are a lot of persons recover even from HIV/AIDS and given their witness.

Most participants believed that, mentally ill individuals are unable to work and live without the help of others. They perceived that mentally ill individuals are not capable of taking care of themselves and others. Moreover, all participants considered that all mental illnesses are one and the same; they do not know the presence of various mental disorders and reported that mental illness cannot be managed and cured medically. With regard to this Meti explain her perception that:

> *I see mental illness can be caused by stress and consider mentally ill people as those who have no control of themselves, collect dusts and are not in touch with reality…I thought that mental illness is one and the same, and cannot be cured medically. Even, I didn’t know whether there is mental hospital or not.*

In addition to patients, most of the family members in FGD said that we have no clear information about mental illness, different people told you different things, some people said please take her to traditional healers or holy place since they believed that it is sin or Satan work or “•••••” but few persons said to take to hospital. In the middle we the family becomes confused and tried to taste everything and finally came to the Hospital when they are hopeless with other treatment trials.

### 4.2.2. Perception towards Mental Illness after the Illness

A number of participants reported many changes in perception after they become mentally ill. For instance, they described that mental illness is not total loss of the self and believed that individuals could function in between period of relapse and recovery (inter episode functioning). In addition, the participants reported changes in their perception about types of mental illness; currently almost all of the participants observe and understand the existence of different mental illnesses with different symptoms.

Majority of the participants told that after their recovery from the illness, they have better understanding of the factors that aggravate their problem and believed that medical treatment is important in reducing symptoms of BD. However, still a few patients and family members felt that, mental illness is related to bad spirits and inflicted by third party (i.e., friends, step parents, neighbors that are jealous of them/wants to hurt them) without their knowledge through some sort of substance “• • • • •” is given to them. Regarding to this Hikma had the following to say:

> *The illness began after my step-mother gave us (me and my mother) substance or* “• • • • •” *with food since she wanted to kill us and hold everything that we had in the house. We shout in the holly water site and the spirit called her name. Before I start medication, my mother came here and took medication but she can’t recover from her illness and after some week she died here in AMSH.*

Participants were also asked whether they see themselves as mentally ill or not. Regarding to this participant’s description can be grouped in to three. Those who accept their illness, those who didn’t accept their illness and those who are in between (confused).

Those participants who believed as they are mentally ill have different justification. Half of the participants believed that they are mentally ill because they are taking medication to manage the symptoms of BD and others believed as they are mentally ill because the doctor prescribed medicine for their illness.

> *When you are normal / healthy, you did not take medication. I know I am taking medication because I am ill and I am suffering with some symptoms of bipolar….*

> *Therefore, I see myself as mentally ill (Mseret). Shakiso Meseret, Meti and Selam also share meseret's idea.*

In addition to the above participants one participants of the study accepted his illness since doctors prescribed medicine for his illness:

> *I see myself as mentally ill because if I am well and healthy why the doctors prescribe medication for me. I take the medication properly and constantly as the doctor told me after that I can study like others and I can help needy people. There is nothing I can't do. It is clear that, external feedback affects the way you see yourself but I do not worry much about what people say. (Abebe)*

Some participants believed that they are mentally ill when they are not treated equally with their siblings (in job, social activities and parenting):

> *I see myself as mentally ill when my parents treat me differently from my sister within the same activities. For example, when I come home late from church and friend's home, my parents ask me where were you been and why you are late but if my sisters do the same thing, nobody asks them. When I see this, I think that it is because of my illness. (Selam)*

In contrary to the above participants, two of the participants of the study considered as they are not mentally ill because they are carrying out their responsibilities properly and well functioned, and the other justification pointed out by the participants was the absence of symptoms of the illness they previously had:

> *Am not mentally ill, because I have no any symptom of the illness and am not “• • •” and “• • • •  • • • • • •”. If I’m mad, how can I have family and manage or lead my family (am married and I have one child). I am taking the medication properly and doing my job very well. (Fuad)*

Halima also said the following on her part:

> *I am not considering myself us mentally ill because I am not wondering here and there, necked and sleep on the street.*

One of the participants felt ambivalent towards their status as mentally ill (they are confused whether they are mentally ill or not). For instance, they do not think that they are mentally ill due to the absence of functional impairment in various areas of their lives, such as, work, self-care, and participation in social life. Regarding to this Metie said as follow:

> *Thanks to God! Since I can carry out my responsibilities properly, I do not think that I am mentally ill. Someone is considered mentally ill when he/she is no more live independently. I take care of myself and my family no body guides me. However; I think of myself as mentally ill especially when other people say that you are “• • •” or “• • •”, and when the society /friends reject my idea in Edir and other social settings. (Metie)*

In relation to the above idea, the data obtained from the FGDs showed that most of the time patients denied their illness but sometimes they accept their illness and complained on the family or others. They said that you have done this and that because you consider me as mentally ill so I will not take medication from now onwards.

In general those participants who perceive as they are mentally ill imply that they can take their medication properly, they have been functioning themselves and the families. But those who didn’t accept their illness, they have no good understand about their illness. If the patient did not accept their illness, it shows that it would be difficult to manage the illness using different coping strategies. For those participants who have ambivalent feeling regarding their illness indicates that they might suffer with quitting their medication in time of their well functioning.

### 4.2.3. Participants experiences to risk factors of their illness

Participants also asked about their illness risk factors and they replied that the risk factors related to their illness are multiple. Some of them were individual’s personality, stressful and negative life events. With regard to this, eight participants have common risk factors related to their illness. These are negative thought, quitting medication, economic problem, use of substance and alcohol, worrying too much, trying to live beyond ones capacity and inability to anticipate difficult circumstances.

With regard to negative life events, use of substance and alcohol Fuad said as follows:

> *Most of the time the risk factors for my illness relapse are stressful and negative life events like separation with family, and drinking alcohol and chewing khat to get relief from the symptoms of the illness that leads to quitting medication.*

With regard to risk factors for Shakiso's illness relapse was also negative life events like loss of his cattle which resulted in quitting his medication. Shakiso in his part has said

> *My life was based on cattle rearing but unfortunately I lost my cattle totally in a day. Hence I became hopeless and quite medication because I will not have any source of money for transportation fee for every 2 or 3 months of medical appointment.*

The nature of the person is also an important thing to aggravate or control relapse. That is the way an individual perceive life events, like how a person sees things/events as simple/ease or difficult/challenging. Some individuals have the habit to see things as difficult/ impossible and become easily worried whereas others perceive challenges as a means for change and could handle difficult circumstances as much as possible. If they cannot handle it, they are ready to accept it and couldn't worry a lot.

Stressful life events are the other issues raised by some of the adults in relation to risk factor to BD. Most adults felt that stressful life events have significant contribution to bipolar disorder. They mentioned events such as, failure in education; break up with boyfriend/girlfriend, loss of job, economic problem and overlapping family problem. For instance, one of the interview participants, Meti, stated that:

> *Thinking or worrying too much, lack of social support who might share your feeling and thought (*loneliness, *worrying about future life, family responsibility, and abusive relationship (rape) in time of my illness were some of my stressful life events.*

Another interviewee, Meseret, also stated:

> *The risk factor for my first relapse was my boyfriend's infidelity i.e. I saw him with other girl and he married her immediately whom makes me worry too much and become aggressive.*

Some stressful life events were serious which have observable impact on their emotion in time of the interview (i.e. negative life events that emerged as a concept from the interview). When participants requested to recall their negative life experience, they were upset and emotionally disturbed. These negative life events are rape; three women experienced rape and or forced sex at some point in their life, three women have abusive relationship with their partners and hence traumatic experience, Abeba lost her brother suddenly, Sitra and Meti lost their mothers, Fuad and Hikma lost both of their parents and unfortunately whole family members of Halima are mentally ill.

In relation to risk factors, the family members who participated in the FGDs complained that most of the relapse was related with taking substance or drinking alcohol. When they took the substance, he/she will not take the medication properly even if the family reminds them. They rather refused. Few family members said that after the illness they become over sensitive to all life stressors so their illness relapsed with minor events (conflict with family or girlfriend or boyfriends), loose of goals or financial lost and other triggering factors.

### 4.3. The Negative and Positive Experiences of Persons with BD

Participants have experienced both the negative and positive experiences related with their illness. But the negative experiences were common among participants. Some of the traumatic experiences of the participants were presented as follow.

**Negative Experiences;** Most of the participants experienced traumatic life experiences that left them with painful memories. They described the pain as an intense type of suffering, “you could feel it physically.” Participants spoke of the pain from the consequences they had suffered as the result of being an adult with BD. When their feelings tensed them in two extreme mood swings, they become aggressive and make crime or made suicidal attempt or suicidal ideation. The data also show that there were many risks on adults with BD (negative experiences) due to their illness.

Most of the female participants experienced rape and forced sex in time of their illness with unknown person on the street, with neighborhood and with their boy friend in which their consent is invalid. The following quotes best describes this issue.

> *Since the illness have symptoms of urge to go and being restless “• • • • • • •”, There were nobody around me who control me at that time, I am living alone, I went to the*

> *street, I do not remember where I am going, I could not get home and raped with unknown person on the street. With all this I suffer with suicidal Ideation.* (Meti*)*

One of the participants was also raped with neighborhood which is a big traumatic experience in the life of the participant which leads to worry a lot with fear of being HIV/AIDS positive. Regarding to this Abeba has said:

> *Before 2 years I was ill and my neighborhood raped me. I didn't tell for anybody because nobody believes me. After that I was worried about getting HIV/AIDS, I was very much stressed and after some days later I admit to Amanuel Hospital.*

The other traumatic experience of a participant which triggers for illness relapse is that infidelity (unfaithfulness) of their boyfriend. They suffer with frequent relationship break up; they cheated and suffered with psychological problems like guilty feeling and regression.

> *I made forced sex with my first boyfriend and he left me in pension. When I start boyfriend relationship for the second time, we discussed and decided not to have sexual relationship before marriage. However; he cheated me he took me to far place to relax and he forced me to make sex. I have guilty feeling and regression because I failed to have successful relationship. (Selam)*

Most of the FGD participants said that the family frequently quarreled with the patient. Families tried to restricted patients from outgoing; since families fear either the patients hurt others or to be hurt (quarrel or have sex with somebody else). We advised the patient not to have boyfriend or girlfriend, have any other external relationship and patients were also forced to spend the whole time in the house but they did not accept it. Hence; the patient becomes aggressive, run away from the house and comes with different problems that might affect their later life (like unwanted pregnancy, HIV/AIDS, injury, physical impairment and so on)

Regarding the negative experience mentioned above the experience of some participants below strengthened it. For example when participants get ill or when their illness relapsed, they might be harmed by others, They may be exposed for traffic accident, harm themselves(their bodies) or their family members or others, may attempt suicide, unconsciously may go long distance and unable to back and throw their medication. They may fail to control their emotion or anger in their interpersonal communication.

Some participants have been suffered with guilty feeling since they have no control over their emotion in time of their illness and harm their families or insulted their neighborhood with taboo words.

> *One day my grandmother insults me saying "mad (• • •)" and I have injured her with bottle and died after a week later. Till now I remember the event and feel guilty, blame myself why I did this on her? It is my big mistake that I had done in my life. The other negative experience is that I was on a marriage ceremony; everybody is dancing and singing in between I became aggressive. I quarreled with an invited guest and injured him* (Sitra)

The most devastating experiences of participants were suicidal ideation and suicidal attempt. The ten participants in this study had all experienced suicidal ideation and one of them had repeated suicidal attempt. Their suicide ideation and attempts were described as a way to escape from routine life stressor and to obtain relief from life problems. Findings in this study revealed factors associated with the participants' suicide risks were history of traumatic experiences (rape), failed life goals, unpredictable mood swings, and extreme depressive episodes. The participants have made repeated attempts of suicide to manage the painful feeling of depression and life stressors.

One of the participants of the study have repeated suicidal attempt because of basic life stressors (financial crises because of lose of his total cattle in a day) as a result the participant throws his medication to the toilet and hang with cable but fortunately his neighborhoods saved his life.

> *Since I have lost a lot of cattle which were a base for my life and health, I became hopeless, throw my medication, attempt suicide by hanging with cable. After a while the illness relapsed and my wife took me to Amanuel Hospital.* (Shakiso)

Sometimes the illness made the patients restless, lose their concentration, unconsciously may go long distance and unable to come back to their home. As a result participants worry a lot with fear of traffic accident or other harms. In relation to this Fuad has said the following:

> *At one time I get ill and became restless, I travel long distance unconsciously and unable to come back to my home. When I became conscious I didn't know where I am, how I*

> *cross the traffic road and I came back to my home after three days. Hence, I worry a lot in fear of traffic accident and other harms since I am not conscious at the episode.*

Other participants pointed out physical problems associated with bipolar disorder. When they felt depressed, they encountered problems of loss of appetite, fatigue, and over sleep. In addition to depression effect, medication side effect also has an observable impact on the body such as tremor, dry mouth, hand shaking, weight gain and dizziness.

> *One time a person hired me as a servant but I could not wake up early to undertake my responsibilities. Even if I tried to explain to her my reason (it is because of the medication side effect that I could not wake up early), she said me get out of my house, you are always sleeping and dizzy, you are not working your duty properly so I don't want you. (Halima)*

Abeba says in her part as follows:

> *Since the medication side effects always dry my mouth and tongue, and it is hard to talk so I hold water in my bag always.*

**positive Experiences:** Even if it is short lived, one participants described positive aspects of their bipolar experiences, including increased sense of independence, over confidence (grandiosity), being master of everything, and being highly sociable and over activities in job or spirituality. Since participants need the feeling at the hypo-manic state and that many would not like to change the relative distress caused by their mood difficulties for a life without the positive aspects, hence many patients tend to suffer with BD.

> *When my depression is at its worst, I can't make simple choice like what to wear, can't think and make decision, unable to make any conversation and have no motivation to work. So I extremely dislike my depression. 'But when my mood starts to be elated, at these times I don't feel miserable or unhappy, useless and worthless. In my episode of mania, I would have a great deal of positive energy and creativity in my life. For a great deal of my time I am blessed with full of energy – more than most people, I love to work hard and my thought becomes fast. I can also see what things mean quickly and clearly. I know my excess energy can be irritating to others, but my brain does all the things very efficiently so I want it and I am proud of it. I feel extremely engaged with, and part of my life.'* (Abeba)

According to the FGD data sometimes patients become over active even beyond us (the normal person); they work a lot of job without any exhaustions; they become energetic work day and night but as time goes they increase their motivation and tried to work all things at a time which cannot go side by side; they start many things but they did not accomplish them then they start to worry about their unfinished business which ends with great lose and relapse.

## 4.4. Challenges of Living with BD

According to the findings of the study, participants experienced different challenges due to mood swings. The description provided by participants' highlighted one major theme ("living with BD is challenging/hard") and five sub-themes. The sub themes are psychological, social, career related, medical/treatment side effects which all have impacts on the patients.

### 4.4.1. Psychological Challenges of the Illness

The findings of the study revealed that participants encountered psychological problems due to their illness. The psychological impacts are organized and described under the following categories, lack of attention and concentration, experiencing bad feelings and negative self-image.

**Lack of attention and concentration;** One of the psychological challenges of participants was the problem of attention and concentration. Participants described problems of forgetfulness of places and names, missing procedures of different activities in work place, unable to concentrate on activities such as education, unable to focus on issues at hand and distraction in time of conversation. The data from FGD also revealed that when family members meet, they talk and discuss different things; sometimes a patient participate actively and try to force all to listen him/her only and in another time his/her body is there with us but not their mind. They may not hear what we discuss or hear few of the discussion.

> *I worry a lot with different issue while people talking with me. It is my parents that remind me to involve in their conversation and help me to shift my thought. Most of the times my mother looks my face and says you are not with us, come back and be with us. After some conversation if you ask me about what we talked, I do not remember a lot.* (Selam)

**Bad feelings;** The second sub theme under psychological impacts was experiencing bad feelings which include anger, loss of interest or being over active in work, over joyfulness, fearfulness, suspiciousness, anxiety, being irritable, guilt feelings, shame about bipolar feelings and behaviors.

One of the study participants has a problem of suspiciousness, guilty feeling, hate himself and isolated from social activities because of his immoral activities or spoke taboo words in time of his illness. Regarding to this Shakiso says:

> *In time of my illness I wonder around me, bit peoples and insult my neighborhood with taboo words. When I became conscious and told me what I have done on my neighborhood, it makes me to feel guilty, shame, hate myself and avoid social contacts.*

In addition to Shakiso, Sitra also have traumatic experience related to lack of her emotional control or anger management and being easily irritable which exposed her in criminal activity like harming the family and others. She says

> *One time my grandmother insults me saying "mad (• • •)". Since I was very upset, I injured her with bottle and she died a week later. In another time, we were dancing and singing in a marriage ceremony, but in between I quarreled with a person and injured him. When I remember these two events, I feel shame, guilty and blame myself.*

Sometimes participants have changed their interest to any job and social activities because of the effects of depression episode. This in turn resulted in loneliness, hopelessness and helplessness which might lead to devastating consequence of the illness (suicidal attempt).

> *Previously I had an interest to do something (work, to get people, making friend and so on), but now I have no any interest to do something, to get friends and I have no feeling inside. Gradually I develop passivity for all things because of the illness effects. (Selam)*

Like Selam, Meti also told about her lost interest to everything as follow:

> *Previously I was very interested to do any job which had an income (labor work like carried barrel and soled "kolo") and learned my education. Moreover, while I was working in governmental organization, I soled vegetables in weekends and take care of five little siblings. But now I am not interested to do anything like to have friends even I have no interest (my feeling is already died) to change and wash my clothes. (Meti)*

The effect of torn relationships with their families and loved ones was the most difficult one for them to accept because they had damaged and ruined these relationships. Most women participants had lost their friendship or have no marriage. This was the most devastating consequence of living with bipolar disorder.

> *All of my friendship (boyfriend) relation ends without marriage. They run away or broke the relationship suddenly as they heard about my illness or see in time of relapse. Hence; I become suspicious, socially isolated and avoid any social contact. This is because of my illness. (Halima).*

The data From FGD related with the bad feelings revealed that patients in time of their illness insulted people with taboo words, tried to have sexual play with opposite sex wherever, whenever and whoever. After their recovery people remind them what they have done or told during their illness, then they run away, isolated from people, worry a lot by their behavior, feel guilty, hate themselves and said it is better to die than behaving like this.

**Negative self - image.** The third psychological problems of the illness was negative self image which comprises over or low self-esteem, lack of confidence, hopelessness, inferiority, lack of motivation for change and viewing mental illness as master of their identity. All participants have negative self image about themselves, this is due to the fact that, they have low self-esteem when they think that they are mentally ill and they have unpredicted self. They view themselves as failure, useless, worthless, weak / incompetent, burden for others and fearful to describe their current self.

One of the self damaging behaviors in the family was stigmatization of persons with BD from any family issue and social activities. In relation to this Abeba says:

> *My entire family member doesn't include me in any aspect of discussion and not invited to participate on family matters. Particularly my sister ashamed with me and rejected me to accompany her when she comes with her friends /any guest. Moreover she told me to go to my bedroom until her friends out. Hence; I feel inferiority and hate myself.*

Some participants described themselves as unfortunate persons because of complex and stressful life events. Some of them have economic problem and others have social problem (unable to establish marital relationship and unable to have family in the future) because of their illness. These resulted in participants to have negative self image. Shakiso describe his self image from three interrelated and challenging life aspects. He says:

> *I am poor, being in distance from the hospital and quieting my medications which are a major factor for my frequent illness relapse. I insulted persons with taboo/immoral words which might not be expected from me so I become hopeless in my future life and see myself as unlucky person.*

One of the participants of the study described her as unfortunate persons who have no hope to have families in the future because of unpredictable nature of the illness relapse. She does not believe those mentally ill people have family (wife or husband) and she has low self esteem:

> *After I get ill, I do not think that I will have family (marriage and children) like others do. Even if I know there is somebody who loves me and requested me for marriage, I refused because I am ill, have unpredictable illness relapse and take medication. So I do not think that I am the right person for him and how could I have husband and children like other people do?* (Sitra*)*

There are also unfortunate participant who has no any family support because all of the families are mentally ill and no one wants to accompany the family as a whole. Not only the participant but also families are rejected or stigmatized by the society. So they have no hope, have low self esteem and have negative self-image:

> *All my family member are mentally ill because of this we don't have any supporter. Since nobody wants us and people hate us, we all are useless and hopeless…* (Halima)

The other challenging effect of the illness was unsuccessful relationship issue in which most women participants were suffered with broken relationship:

> *It is very stupid illness, it isolates you from people. For instance I breakup with my boyfriend at this moment because of my illness. Since I have no confidence in myself, I do not have boyfriends' in the future.* (meti)

With regard to negative self-Image, participants of the FGD stated that patients have negative self-image, they have feeling of inferiority compared with their peers/friends and have different complain like everybody hate me, no one consider me as person, do not want to eat with me, do not sit and play with me, laugh at, make fun and cheat me.

### 4.4.2. The Social Challenges of the Illness

Regarding to the impact of BD on the social aspects, participant's response categorized into four. These categories consisted of, stereotype and stigma, poor social lives, unable to fulfill roles and responsibilities and risks related to bipolar.

**Stereotype and stigma:** The participants described that they face a great deal of social stigmatization and negative judgment from family members and others especially in work place and in their neighborhoods if they know that they are mentally ill. They experienced prejudice and misunderstanding that surrounds their mental illness/BD. After their illness their identity became mentally ill, people view them as "dangerous", incapable of doing things, "mad", "crazy" and “sick”. Moreover, they misunderstood their interest and need even they may consider as they have lost their humanity as other “normal” human being have.

Some participants argued that they have been given over care from family member but they were not happy or comfortable with the special treatment they provided to them. In addition, if they do any mistake, it is associated with their illness.

> *My families over care and special treatment hurt me a lot inside. They should not see me like other family members (my sister…) and they did not perceive me as I am capable in doing my job/activities. Even if I want to work, they did not allow me to work any job in my home. I hate being dependent. When I make mistakes that anybody can do, it is associated with my illness. Simply they side that go to your bed and sleep, watch film or television as you want (Sitra).*

Like Sitra, Abeba and Metie have been suffering with families’ and neighbors’ misunderstanding and stigma. If the patient site idle or did not allow participating in any social activities and any work, they feel bad or dependency or rejection and they lose their confidence. In this regard Abeba says the following:

> *My family misunderstood me, they don’t think I am capable of doing things, thinks like other people think. When gusts or friends of my sister came to our home, my families ashamed on me and they do not want to accompany them.*

Some participants have been socially stigmatized; the society wrongly perceived patients who took psychiatric medication as dangerous person, they were backbitten as they are crazy person and they were not trusted by their neighborhood. Since the societies embarrassed the participants with their illness, they prefer to be alone*:*

> *My neighbors didn't allow me to participate in their social activity. Since they have no trust, they see all your activities from the perspective of the illness; you can't have fun or humor or talk facts ("ቁም-ነገር") with them. They also consider me as a dangerous person, gossip about me saying do not trust her she is taking medication from Amanuel. They also do not want me to join them so I do not want to participate in social activities.* (Meti)

Some participants negatively perceive the society's sympathetic understanding of the patient. Since the society believed that being mental ill mean losing everything so they visit and talk with them or with their families with broken heart. These hurt the patient and lead them to be hopeless.

> *When people talk sympathetically about my illness and education, I feel sad, I feel worthless, I feel as I have lost myself and it hurts me badly. I am also easily aggressive, people fear and perceived me as dangerous person.* (Meseret)

According to some participants unequal siblings' treatment leads patients to develop aggression. One of the participants negatively perceives the special restriction or special attention for the patient. Selam said special attention hurts the patient seriously.

> *My parent did not treat me and my sister equally. For instance when I came late to home, my parents ask me where I was but they did not ask my sisters. It makes me feel bad and ask them why they want to control only me. They told me that you are mentally ill and should get home early.*

In relation to stigmatization people knowingly or unknowingly stigmatized patients from social participation for example one of the FGDs participants said when neighbor women saw my daughter and say "••–•••••• ••••• •• •••• •••• •• •••." When she heard this, she cried a lot and isolated herself from any social participation. The other FGD member also says when my daughter went somewhere, grouped city boys star at her, gossip about her illness and they said that she looks normal but she is not. When she heard this, she return back to home and said I do not want to take any medication, I want to die. I do not like to live people joking and laughing at me. The stigma also starts in the family, there is stigma between siblings in treatment, child rearing or parenting style, in valuing, and sometimes they are rejected from any family issues.

**Poor social lives/Relationship:** the other social problems of BD reported by participants were poor social contact. Nearly all participants believed that the illness made them to have unpredictable social relationship. Sometimes their interest to social activities decreased and on the other time increased. The social interaction with their friends and colleagues decreased when their mood is down and increased when their libido increases. Their inconsistent social relationship creates mistrust on other people.

In order to get deeper understanding into the challenges individuals face in their social lives (social relationship and social interactions) participants were asked to compare their social life before and after the illness. The finding revealed that there were observable differences in their social lives. Most of the participants said that before the illness their social relationship was good and predictable. They said we were sociable, have interest to be with others keeping their personal boundaries and participate in social activities (like Edire and Marriage ceremony) in their community and neighborhood.

> *"Before the illness I'm very much sociable, I like to be with people and it make me relax and easily make friends. In addition, I like joke and I am joyful. I forget negative/bad things quickly and easily" (Selam). Like Selam, Metie also says "before the illness I am very sociable and I have a lot of friends who were customers in my shopping".*

However, only one participant believed that his social relationship was poor. This is because the participant drank alcohol and chewed khat to escape from his low mood in time of depression episode that lead to lose the social value but it is improved after his recovery of the illness:

> *He says that "I have poor social relationship (was less sociable, aggressive and silent in my nature) but after my recovery the behavior is changed, I become easily sociable and feel good to be with friends and others."* (Fuad)

After the illness all participants, except Fuad, described that they have poor social relationship with people. Most of the participants acknowledged that, they are less sociable than before the illness because of fear of stigmatization, fear of conflict, distrust, lack of interest to be with others, fear of mistakes or lack of self confidence and have poor social interaction with others.

Sometimes when the patient was in manic episode, their social interest and interaction becomes high but it is short lived and discouraged. The participants' social relationships were also discouraged with fear of mistakes and they intentionally avoid social contacts not to affect their relationship with others. Regarding to this Sitra described her social relationship as follows:

> *Most of the time, I have poor relationship with my friends and do not want to mix up with people. This is because when my illness starts to relapse; I become more talkative, I did not keep my turn and I believe that my idea is perfect which leads to conflict. Even if occasionally I want to join the social setting, I feel anxious because of fear of talking unrelated issues. Hence; I avoid social contacts not to affect my relationship with others".*

Shakiso also shared the above idea and the only difference between Shakiso and Sitra is that he can attend in the social setting but he intentionally prefer to be silent not to affect others feeling:

> *When I compare my social relationship before and after the illness, the difference is observable. After the illness, most of the time I find silent place and isolate from people, but rarely I need people to have fun with them. When I attend coffee ceremony or other social settings, I prefer to be silent. This is because if once I start to give idea/to talk, I can't stop and give chance for others.*

Some participants also have visible difference in their interpersonal relationship. Before their illness they have friends and enjoy social activities but after their illness their social relationship completely changed from sociable behavior to loneliness. One of the participants avoids social contact due to unsuccessful friendship in her previous relationship.

> *After the illness I become suspicious to join people and make friends. I am afraid of relationship breakup because of my illness (when they know about my illness and/or see the illness relapse, they feel discomfort and runaway). So I prefer my loneliness. (Halima)*

The other participant avoids social relationship due to distrust of friends. The participant over generalized his friends' mistake (disclosing his secrete to his dormitories) and avoid friendship.

> *Before my illness I have a lot of friends, I had also good communication with people and my colleagues. But now I don't want to have any friends because of my illness. This is because I don't trust people (two years ago I had close friend and I told him a secret but he disclosed the secret to our friends and dormitories). After that I become stressed with the issues and I become mentally ill. Therefore, I don't trust anybody and I don't want to have friends any more.* (Abebe*)*

One of the reasons for self stigmatization was suspiciousness and feeling anxious when they join social activities/environments. One of the participants of the study avoids visiting their relatives and even did not participate in mourning/ funeral ceremony of their families:

> *When I mix with people, I feel anxious and become suspicious about what they talk. Even I did not go to my sister mourning (when I was in the hospital my sisters' child was died)*

> *and did not visit my relatives too. So I like to sleep, to be alone and think about how the illness comes to me.* (Abeba)

In relation to social relationship, the FGD participants stated that sometimes they do not want to have any social contact, they sleep day and night, sometimes simply they may cry, they may lost motivation for work. In another time, they become easy going, sociable, have no time and place limit, have no criteria for their sexual afflation and they may become generous in what they have.

### 4.4.3. Career challenges

The third challenge of participants was problem of carrying out roles and responsibilities. Like any other normal people, all participants stated that they have no difficulty in fulfilling their roles and responsibilities before the illness; they can take care of children, help their family in household activities and properly undertake responsibilities at work place. However, after the illness, most of the participants especially in their depressive episode, they cannot function properly (they lose their motivation to work) and they cannot make simple decision. On the other time, when their mood elated, they took a lot of responsibilities and start different activities but they did not accomplish, they lose focuses and become over busy day and night. They described having periods of extreme lows times when they would “just sit alone and cry.”

One of the participants shared her experience of career challenge with regard to her depressive episode:

> *I am very negligent and unable to take care of myself and work. I don't have any motivation or interest to do something as previous. It is because of my illness. (Meti)*

Another participant has complained on medication on their lack of interest or motivation for job. Halima has said as follows:

> *I know I have the capacity and how to do it, but I can't work because of medication. The medication or the illness makes me dizzy. I'm not active in any work/job, sometimes in the middle of my work I get sleep and become so tired.*

Most of the time families and societies misjudge the patient's ability to work. If the patients are taking psychiatric medication, they have no trust in any activities. So they did not allow them to participate in any job and they simply forced to sit idle. This has been illustrated as follow:

> *Now I am almost 28 years old. Although I feel that I am capable and I can do anything like others do. But my family didn't give me chance to show them my capability. In addition, I don't have any roles and I am dependant on them because all things were done by them. These all makes me to feel shame, inferior and feel uncomfortable with their over care.* (Sitra)

In contrary to Metie, one participant said that there is no difference before and after the illness in fulfilling his roles and responsibilities:

> *He says there was no stigma and discrimination in work place: When I get ill, I request permission and they gave me. When I recovered from my illness, I return to work and took my roles and responsibilities properly.* (Shakiso)

The other surprising result regard to career challenge is that, one of the participants performs his daily activities better than the activities before he took medication for the illness. Here also mediation side effect is not a challenge to carry out his roles and responsibilities.

> *One participants said that, when I compare the ability of fulfilling my responsibility and roles before and after the illness , after the illness I fulfill very well because before my illness I used to take substance (addiction) so I was dependant on family. But after I get ill and start medication everything was changed. Like I get married, have a child and I have also job.* (Fuad)

With regard to career challenge, one of the FGD participants says that her daughter was trained in day care and she was working in it. After her illness, no one trusts her to employ. In addition, not only external body or organization but also the family has no trust on them to give responsibility in the home. They simply said them to watch television, film and to work house chores.

### 4.4.4. Medication/treatment/ Side Effect as a challenge

The participants pointed out, physical complain associated with illness. When they felt depressed, they encountered problems of loss of appetite, fatigue and so on. The other physical impact participant talked about was related to medication side effects such as dry mouth, hand shaking, weight gain and dizziness.

> *One time I get work and household employer hired me as a servant but I could not wake up early to undertake my responsibilities. I have tried to explain to her it is because of the side effect of the medication that I could not wake up early, however, she said get out from my house, you are not working properly. You always sleep and dizzy so I don't want you. (Halima)*

In addition to Halima, Ababa has her own challenge related with medication side-effects.she says:

> *Since the medication side effects always made my mouth and tongue dry, it is hard to talk. So wherever I go, I always hold water in my bag.*

In relation to treatment challenges as the patient said, the data from FGDs show that since the medication has side effects which makes them dizzy, over weighted, have clumsy movement, muscle agitation and dry mouth, they refused to take medication properly. In addition, people use abusive words for those who take the medication so not to be insulted with the community some participants tried to take it in cover.

## 4.5. Coping with challenges

In this study coping strategies are ways of dealing with their illness and in a situation more competently. Coping strategies can be regarded as skills, activities or ways of thinking about things that can be used to help a person cope more effectively (Phyllis, 2011). From the collected data the researcher categorized the different coping mechanisms into eight categories which merged in to two major themes (Emotion focused & Problem Focused Coping strategies)

### 4.5.1. Emotion Focused coping strategies

Emotion-focused coping refers to efforts to manage the negative emotions associated with the stressful situation or related with their illness. With regard to this most patients cope the stressful situation and their challenges using various emotion focused coping mechanisms like searching for people to talk/communicate, using cognitive distraction and avoidant coping.

**Communication/talk to people**: some participants use Communication as a coping strategy in which they share information about their illness thoughts and feelings. Especially the social stigma of mental illness is seen as a restriction to share information about their illness outside the family.

Most adults discuss and share their feeling with their family or significant others or for those people who approached and helped them. In previous time shakiso and Sitra were not much interested to share their feeling so they refused social settings and isolated themselves from people. But now they try to socialize themselves and they feel better when they are with people, talk and discuss with people. With regard to this Sitra says: "*When I share my feeling with people, I get relief*"

In contrary to the above idea, Four of the participants were not comfortable to talk or share their feeling with friends, families or any significant others. According to them, sharing feelings or ideas resulted in back biting, when secrete is disclosed for other people and make fun on you/exposed you for stigma. Hence; they were not interested to talk with people about their illness or feelings. As a result their relationship with other people/close relatives was declining from time to time. For instance Halima has said the following:

> *Since I have bad experience with regard to friendship (people requested me for friendship and entered with the relationship but suddenly they break up the relationship when they heard about my illness/or see the illness relapse). Hence I am socially isolated and I become suspicious when I meet somebody since I anticipated that when they know my illness they runaway/ did not stay with me.*

**Cognitive distraction:** Some Patient's use of cognitive distraction which includes passive appraisal (utilizing passive appraisal activities, such as watching television, relying on luck, feeling helpless about the problem, and believing that time will solve the problem) to limit their attention or prevent concentration on stressful events distracts the mind from thinking about stressful situations and limit/minimize reactivity. With regard to this Metie and Abeba utilize reading books as passive appraisal.

> *Back to school learning and Reading book are the other new coping strategies experienced currently. Two of the participants read books to cope with depressive feelings;*

> *I am back to school after a long time. I read book, I study hard and I hide myself inside the book. (Metie).*

With regard to reading books to shift their mind from thinking negative things, Abeba says on her part as follow:

> *I started to read different books and I try to make my mind busy so it helps me not to think so many things (about my illness, futurity and so on). I didn't think so much as pervious when I am concentrating on the book.*

One participant used work or undertaking various activities to distract depressive feelings, engaging in activities reduces the chance to listen what happened and resorting to self and ruminate. Regarding to this, Selam says:

> *When I get myself busy it shifts my mind not to think negative thoughts and which reduces listening to my inner voice and worry too much.*

Positive cognition as coping strategy is used by one of the informants, changes in perspective about their problem such as, thinking positive things about their future and positive self- image. Abebe stated as follows:

> *Since I have hope and want to stay well (recovered) for the future, I took the medication properly. I do not want to upset but if I will upset, I tried to control it remembering the past which cost me a lot. In addition, I feel good with listening to God's word.*

**Avoidant.** Most of the participant's use sleeping and being alone as strategy during the worst feeling, most adults preferred to sleep and isolating themselves when they feel depressed.

> *"When my illness starts to relapse; I become more talkative, I did not keep my turn and I believe that my idea is the perfect one. Hence; I avoid social contacts not to affect my relationship with others". (Sitra)*

Some participants used suicide as an out let from suffering with depression or delusion at the manic episode. With regard to this Shakiso has said the following:

> *"When my illness relapses I insult people with taboo words. When I recover from the illness, my family tells me what I have insulted them or others. Hence; I feel guilty worry a lot when I see them as a result I have done suicidal attempt by hanging with cable and throw the whole medicine to toilet." (Shakiso)*

### 4.5.2. Problem Focused Coping Mechanisms

**Acceptance of diagnosis / the illness:** The first step in learning to stay well was receiving the correct diagnosis, and then accepting it. Unfortunately, some participants initially received misdiagnosis which leads to mistreatment. For them, the misdiagnosis of manic depression, and the subsequent mistreatment with incorrect medication, had serious implications for their quality of life. The most common misdiagnoses were clinical depression, schizophrenia, anxiety disorders, borderline personality disorder, and attention deficit disorder.

> *Public understanding of mental illness is very poor so that not only me but also most patients did not accept their illness because of stigmatization. I know that no one can escape from being bipolar once they are diagnosed/ labeled as BD patient. Hence; accepting the illness is mandatory for recovery. Having this in mind, I contribute positively to society and that I am a good parent. I always allow people to get to know me well before I tell them my mental health history so that I can be a model for recovery.*
>
> (Fuad)

**Access to support:** Four Participants (Shakiso, Selam, Halima and Sitra) believed on the importance of support networks to stay well. This included partners, parents, children, brothers, sisters, friends, colleagues, community and health care professionals. With assistance from their support networks, participants described learning to set limits and boundaries and set up harm minimization strategies. No one participant has personal support networks to help them to recognize early warning signs. Many participants felt that they had no consistent and proper support.

> *'No support really - had to adapt to looking after myself, I lost both of my parents. Since the community has no awareness about the illness, they hurt me when they tried to support me.* (Hikma*)*

Halima also shares Hikma’s idea and she says on her part as follows:

> *I had hardly any support. I wasn't told very much. There was no support because all my families are mentally ill. (Halima)*

In contrast to the above idea, tow participants (Shakiso and Sitra) have support from the organization and family respectively: regarding to this Sitra says*: “I had extensive support from my family and friends”.*

**Being an expert and partner to the treatment;** participants stressed the need for more information about the illness to be an expert to their illness and develop partnership to the treatment. Many participants need for information was paramount importance not only for patients but also to all care providers to cope with the illness. Some participants stated that even if the need for more information of all kinds to help themselves, understand the complexity and effects of BD to develop their coping strategies accordingly, there is no adequate information provision regarding their illness.

> *Even if 'Information and knowledge about the illness is vital, 'I wasn't told very much about the prognosis and warning signs of the illness'. But I will take my medication properly and constantly so that I study hard and work very well. When I compare myself with other mentally ill people who are on street, necked body, with dirty clothes and who are aggressive, I feel better and I told my mind as my problem is not overwhelming.* (Meti)

One of the participants told me that, he tried to be an expert to his illness and partner to his treatment. He critical observed the health change when he takes substance and alcohol, and does not take them. Finally come to stop taking substance and alcohol in order to be partner with his treatment. In relation to this Fuad has said the following:

> *Previously I use substance like khat and drink alcohol as a coping mechanism. When I took the substances, it seems I feel very good and happy but after some hours the feeling disappear and feel bad, become irritable, sleepless and then some days later my illness relapsed. When this happened repeatedly, I understand that taking substance is not good for my health and I decide not to take any substance. Instead I spent my spare time in the mosque reading Quran and praying. Now I'm taking my medication properly and constantly, doing my job very well and I am a good father.*

Abeba says in her part as follows:

> *I believe that my medication helps me to live my normal life but my medication have side effect (dry mouth and tongue, hard to talk)so in order to manage the side effect I always hold water in my bag.*

**Be aware of the earliest symptoms.** Participants described the importance of observing small changes in their physical, mental and emotional status. Two Participants (Fuad & Shakiso) were particularly mindful of small changes in sleep, mood, thoughts, and energy levels but they regret since they did not take appropriate measures to control their relapse. They felt it was important to take small changes seriously. However nearly all participants do not trust their close friends and family support in monitoring their moods and behavior.

> *My wife clearly understands the early warning signals of the illness so she follow my behavior and told me to wait in the house or motivated me to go to Hospital for treatment. Previously I was not cooperative but now I am aware of the truth and for the future I will accept her request. (*Shakiso)

If participants experienced early warning signals, they implemented interventions to ensure they avoided episodes of illness. Responses to early warning signs included canceling work and social engagements, exercise, sleep, and meditation. In some cases participants increased/changed medication and made appointment with a health care professional. However; participants do not utilizing such an important coping strategies.

**Religiosity/spirituality;** Most participants defined the perceived, personally supportive components of their relationship with God as spiritual support. They believed spiritual support was important to their recovery from BD. They felt this way because spirituality was a fundamental skill in controlling their disorders. Their connection with God offered relieve, help, understanding, unconditional love and forgiveness. Their personal relationship with the Almighty God contributed to their sense of well-being. Whenever they face challenges which are beyond their capacity, they go to Church/mosque request him his mercy, his support; talk to God their problems openly, by crying out to God in prayer. This helps to make catharsis/ to release their repressed emotion. They have hop and trust with God's support. During the interviews, the participants called God "higher power," "Lord and Savior" and "awesome."

One of the Participants believed that she and her family were alive because of God's omnipotence:

> *My higher power is God. I pray five times a day and thanks him when I wake up in the middle of the night. If I get hard to sleep, I stand up and make abolition to connect with my God every night. I'm constantly thanking God for just being here today because if it wasn't for God's help, I wouldn't be here. All my families are mentally ill so it is because of His mercy we live together. (Halima)*

The comfort the participants found in God was a component of spiritual support that helped them carry on whenever things were difficult. The relief they received from God eased the load to them:

> *When I get difficult/stressful events I go to mosque pray and read the holy Qur'an request his support by crying and raising my hand and it really helps me in easing my shoulder. I really believe that He is with me and looking after me. Anytime I get in a tense situation, I raise my hand to Allah. It helps me for some reason it calms me down where I can be able to function.* (Fuad)

The participants said they communicated with God through prayer. Most of them described having enthusiastic prayer lives. They felt their "constant" prayers to God were not only being heard, but were being answered:

> *Every morning, I go to church listen God's word and pray a lot. For me God is everything. I thank Him for waking me up in the morning and I pray every morning. Whenever I have suffered a lot with something, God erases it from my life.* (Abebe)

Hikma also says on her part as follows:

> *With all my sin (even if I take Alcohol), the most merciful God (Allah) is with me. In the future Allah will help me so that, I will not relapse again. I have faith and do not lose hope in Allah. I always try to pray.*

No matter what had happened in their lives, having a personal relationship with God helped them through it. Most of the participants identified God as a higher power in their lives and found comfort in knowing that the support and unconditional acceptance of God was available to them.

With regard to striving to cope with their challenges, the FGD data revealed that, most of their coping mechanisms are negative and emotion based coping mechanism, they refuse social participation to avoid conflict/or distrust, crying, want to die/make suicidal attempt or ideation, refuse to take medication to get what they want from the family, sometimes read books, watch televisions or films, used to go church or mosque, praying and singing a lot, listen music, sometimes tried to be busy with work and so on.

# CHAPTER FIVE

# 5. DISCUSSION OF THE FINDINGS

The discussion section attempts to relate the result of the analyses with the research questions forwarded at the beginning and/or to discuss the lived experience of adults (participants) in relation to various related research findings. The research result in relation to other related findings were briefly discussed as follow:

Ten adults were interviewed using a descriptive phenomenological approach. Participants' descriptions revealed Four major themes as discussed in the previous chapter (1)perception to mental illness(their illness); (2)*the negative and positive Experiences of persons with BD*; (3) *challenges of persons lived with BD; (4) coping strategies of persons with BD.* This chapter explores the meaning of the themes and discuss participant experiences in relation to past research findings. Finally, come to conclusions and forward recommendations for the problems and for further research.

## 5.1. Perception to their Illness

In the first theme the research investigates the change in participant's perception before and after their illness with regard to general mental illness and in particular to BD. The research findings discussed the participant's present perception towards their illness risk factors.

**Perception before the illness;** The finding with regard to Perception before the illness shows that almost all participants except one participant have no awareness about mental illness. As they are part of the community, they perceive mental illness wrongly/badly. They believed that mental illness is caused by evil spirit, witchcraft and some sort of substance added to what they drink or eat, “• • • • • • • • • • •/ • • • • • • • •” (which is made from various plants roots and leafs). Participants describe mental ill individuals are persons who walk naked, sleep in the street, aggressive, feeling less, insult or bit people without any reason and can’t keep their personal hygiene They also label all mental illness as the same illness and not treatable with medication so most of the participants have given priority for traditional healers or spiritual treatment than the modern hospital treatment/medication which is the last option due to stigma and lack of awareness. This finding is congruent with (SAMHSA, 2003) findings that stigma is also one of the major barriers that discourage adults with mental illnesses and the families of children and adolescents with serious emotional disorders from seeking treatment, lowered self-esteem, disrupted family relationships, and increased difficulty in building connections in the community, securing housing, and obtaining employment.

**Perception after the illness;** In relation to participant’s perception after their illness the data revealed that there is perception change towards mental illness among participants. They believe that all mental illness is not the same but almost all participants do not know the name of their illness, what care it needs. They have no complete trust on the medication. Some participants are confused whether they are mental ill or not since the symptoms are on and off. They have ambivalence feeling with regard to their illness (most adults thought that they are mentally ill because they are taking medication). In contrary to this some participants do not believe that they are mentally ill due to the absence of functional impairment in various areas of their lives, such as, career, self-care, and participation in social life. The other justification pointed out by the participants was the absence of symptoms or of the illness they previously had. Moreover, they stated that when compared with others who have serious mental illness, they do not see themselves as mentally ill.

**Perception to risk factors;** According to the participant's perception, the risk factors related to their illness are multiple. They emerged from participants description were individual's personality and life stressors. With regard to this eight participants have common and similar risk factors related to their illness. These are negative thought, quitting medication, economic problem, use of substance and alcohol, worrying too much, trying to live beyond ones capacity and inability to anticipate difficult circumstances. This result is consistent with Goodwin and Jamison (1990) they stated that BD affects each person differently; there are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder.

***The nature of the person;*** It *is* also an important issue to trigger relapse, some individuals have a tendency to see things from the positive aspects and the other from the negative side (the way an individual perceive life events affects their daily life. Other individuals have potential to see challenges as means for change and accept things as they are when it is difficult to change.

***Thinking styles;*** According Steven, et al., (2010) one of the psychological risk factor for BD is positive and negative thinking Styles: Some people with a diagnosis of BD appear to show certain characteristic patterns of thinking. These have been termed 'thinking styles' by psychologists and include both positive and negative styles. Zimmerman, et al., (1999) also strengthen the current and she stated that there are a range of personal, social and environmental factors that affect the individual impact of bipolar mood disorder. In a risk-protective model of resilience, a protective factor interacts with a risk factor to mitigate the occurrence of a negative outcome for example; high levels of sociopolitical control were found to limit the negative consequences of helplessness on mental health.

***Stressful life events;*** Most Participant's felt that stressful life events which have a major contribution to bipolar. The stressful life events includes, failure to education; break up with boy friend, loss of job, economic problem and overlapping family problem as risk factor to bipolar. But one participant believes that it is hereditary illness since the whole family is mentally ill. With regard to this finding Ellicott et al., 1990; Johnson & Miller, (1997) have said that stressful life events also influence people's outcomes after BD has been diagnosed. So, research has shown that higher levels of life stress are linked to higher rates of relapse and slower recovery from mood episodes in individuals with a bipolar diagnosis.

### 5.2. The Negative and Positive Experiences of Persons Lived with BD

The second theme focuses on the effects of being an adult with BD. The effects of their diseases were all encompassing, touching every aspect of their lives. For the participants, being an adult with BD meant living with the negative consequences of their illness. There was an extensive impacts associated with living with BD. The participants stated that they had engaged in risky behaviors, experience forced sex or rape which might lead to acquiring HIV/AIDS and other Sexual Transmitted Infections, and involved in a criminal activities. They had spoiled/damaged inter and/or intra relationships with the self, and family and friends respectively. Moreover, in time of manic episodes, participants lost their economic stability because of their highly financial extravagance.

My study findings are consistent with those of Lim, Nathan, O'Brien- Malone and Williams (2004) who found that bipolar patients perceived their lives as being characterized by loss and deficits. The Participants' responses revealed that the onset of BD is not only a life-changing experience in itself but also brings changes that could not be reserved throughout lifetime. These changes include the breakup of relationships, loss of job/ an employment and financial status, and isolation from friends, families, relatives and neighbors. Regarding to this findings, Basco& Rush, (1996) found that BD episode is mostly followed by mood liability, financial extravagance, fluctuations in levels of sociability, sexual indiscretions, or violent behavior, for which one may have to "pay later."

The finding was also supported by Bender et al., (2007) a study which shows that outpatients diagnosed with BD and substance use disorder experienced negative consequences of their illness including psychological, social, physical and economic issues. Psychological problems were associated with guilt, shame, impulse issues (foolish risks or accidents) and damage to their status. The social problems inculcated issues with family and close friends. Physical problems were appearance, weight change and physical illness.

The participants in this study had experienced family loss, deficits of support and others. These negative experiences affect the person socially, physically, and in their intrapersonal lives. The damage to their status resulted in them not being accepted by family, friends and society. They attributed negative consequences to BD. Violent/aggressive behaviors that resulted in crime activity were related to the irrational thoughts brought on by BD. The participants in this study described these negative consequences might be the impacts of BD.

## 5.3. Challenges of Persons Lived with BD

The third theme described how participants were challenged with external factors and their lives were consumed by the illness. Participants viewed their lives as unstable and full of difficulty. Their lives were difficult because of the negative impact their illness had on everyday challenges as well as other health problems.

**Psychosocial challenges**. It was one of the major life challenges of adults living with BD. Everyday participants faced with a number of psychosocial challenges which include life stressors, emotional instability and lack of concentration, negative self–image, ineffective socialization, and inability dealing with the signs and symptoms of their illnesses. Since mood disorder lies in a continuum, it has no clear cut to take reaction/measure (it vacillate from high to low mood, it is difficult to firm the mood pendulum when one disorder ends and the other begins/ends). When participants expressed their challenges to others, they faced difficulties, yet the ability for people to understand and pay attention to their concerns was missing. They did not believe people heard them when they spoke of the difficulties they faced. Thus, they identified all these feeling as life is challenging.

The above finding is consistent with those of Basco & Rush, (1996) findings that BD episode is mostly followed by mood liability, financial extravagance, fluctuations in levels of sociability, sexual indiscretions, or violent behavior, for which one may have to “pay in their later life. In addition to this, the research findings related with major life consequence during BD’s episode is interrelated and difficult which is similar with Lish, et al., (1994) findings in which the major life consequences reported by high percentages of those with the diagnosis include financial difficulties, divorce or relationship difficulties, losing jobs or dropping out of school, and injury to self or others.

Moreover the study shows that most of the female participants have suffered with abusive relationship, rape, forced sex, ineffective social relationship hurt them badly and most of them made suicidal attempt or have suicidal ideation. Since participants hate their life, they suffer with feeling of uselessness, worthlessness and hopelessness in time of their depression….. This finding is also consistent with Dilsaver, (1996) and Kass et al., ( 1999) in which two-third of the patients with BD are at substantial risk for suicide and among patients with BD, 42% reported that their work is markedly affected by their symptoms, and social activities were at least markedly affected in 37% (Paul, et. al, 2007).

**Career as a challenge;** The other challenging aspect the participants' life is related with ***career***. As the finding shows that almost all participants of the research, they are not fully functioning not only outside job but also in home activities. As a result they feel depressed become hopeless or they might be easily irritable, aggressive, made impaired decision which in turn affects their life for example, they may do reckless/unsafe sex; try to hurt themselves or others. In favor of these results, the National Depressive and Manic Depressive Association surveys conducted in America suggested that 88% of those with BD felt that their illness affected their ability to perform on their job, with only 40% reporting that they were employed at the time of the survey (Hirschfeld, Lewise, Vornik. 2003). In addition, almost every participants of this study either they tried to hurt others or made an attempt to hurt themselves. In relation to this finding Murray &Michalak, (2007) found similar results with the current study. they states that as a consequence of the illness, the quality of life for individuals with BD is characterized by lower wages, higher unemployment, work absenteeism and disability, marked instability in their interpersonal relationship and higher divorce rates, lower levels of educational attainment, and higher rates of arrest, hospitalization, and premature death compared to the general population.

**Diagnosis and treatment challenges;** The other tangible challenge as they live with BD is related with their. As it shown in the finding every participants came to hospital after they are deteriorated/developed chronic illness. They spent a lot of time in traditional and religious or spiritual treatment. In addition, when they came to the hospital they may not come with full information about their illness symptom and onset time which leads to misdiagnosis. In addition, the participants were not given comprehensive therapeutic treatment only they took pharmacotherapy, they did not get psychotherapy. That might result in frequent relapse and then participants are suffering with higher dose medication side effects. With regard to this, researchers Miklowitz & Otto, (2006); found supportive results that pharmacological treatments are essential for managing BD however, medication alone is often inadequate to restore and maintain physical health and quality of life.

Other MacQueen, Young, & Joffe (2001) study findings also strengthen the current research findings stated that as many as 60% of patients never regains full occupational and social functioning. Research increasingly supports the theory that a combination of pharmacotherapy and psychotherapy significantly improves long-term outcomes for these individuals (Culver et al., 2007; Leahy, 2007; Miklowitz& Otto, 2006; Rizvi&Zaretsky, 2007); therefore, an integrated care approach to managing BD gives therapists an opportunity to significantly improve functioning and quality of life for clients and their families.

## 5.4. Coping Strategies for their Challenges

Coping strategies can be regarded as skills, activities or ways of thinking about things that can be used to help a person cope more effectively in their day to day activities. The collected data are categorized the different coping mechanisms merged in two major categories which is Emotion focused & Problem Focused Coping strategies.

The study found that participants were striving to cope with their challenges in their day to day activities. Their coping strategies are immature, weak, and inconsistent. Most of the coping strategies are emotion focused strategies which includes crying, avoidance, search people to talk (communication) and cognitive distraction, and the problem focused coping strategies which are access to support, accept diagnosis and treatment, being try to be an expert on the illness and spiritual support. Supporting the above idea educators (Perkins, et al., 2004) found that some patients and family members use positive coping strategies to manage and to help them manage their situation, such as positive thinking and the utilization of appropriate social supports, which include family, friends, and holy places.

Participants used their coping strategies when they face external life challenges or suffer with psychological problems like stress, repetitive negative thoughts and so on. With regard to this scholars like Pearlin and Schooler (1978, pp.30), said coping as “any response to external life strains that serves to prevent, avoid, or control emotional distress”. In relation to the above idea

Lazarus & Folkman (1984) view that even though stress is inevitable; it is the coping that makes the difference in adaptation outcomes.

The study identified the above coping mechanisms which are supported by different literature review but the patients did not cope effectively. Since their coping mechanism is not supported by professionals, they did not use them properly; their coping mechanisms did not save them from frequent relapse. On the other hand some participants use negative coping mechanism like isolation, crying and attempt suicide when the situation is beyond their capacity.

One of the emotion focused coping strategies of participants was ***search people to talk or to communicate*** with people and share their feelings when they face challenges. Although they have challenges to get people who can listen and understand their problems, they want to talk/share their challenges. This finding is supported by the work of Lazarus and Folkman (1984), they stated that some patients and many family members cope with their situation by sharing their feelings only with their immediate family, and through this, receive support and understanding. In contrast to this some participants used avoidance (prefer to be alone, decrease communication, limit their social interpersonal reactions) as coping strategies. This coping strategy is also supported by Nehra, et al., (2005) they said that avoidant strategies may include ignoring the family member/the patient by decreasing physical and emotional contact, such as not communicating and visiting them regularly and limiting their affection. Families may also totally avoid their mentally ill relative and cut off any type of contact.

Sometimes a few participants used ***acceptance*** in the form of cognitive appraisal and which helps them to manage or save their interpersonal relationship. They use it for one or two events, if the events become repeated they can't control themselves or they failed to cope with this strategies. With respect to acceptance McCubbin, et al., (1991) found that incorporating acceptance in their life helps to reduce stress and improve their relationship with family members. They also said that correct diagnosis and acceptance is a first step in learning to stay well.

Problem focused coping strategy was the second major category under the themes of striving to cope with challenges. Almost all participants have limited problem focused coping mechanisms. These mechanisms are joining support group, being an expert of their illness or become aware of the earliest symptoms of their illness, adjusting life styles and searching spiritual support.

As the participants said, they have no information whether there is legally organized support group for mental illness but they use spiritual support group, they frequently went to church or mosque when they face difficult situation. They have strong believe and hope on God's help so they have strong contact (they pray, listen preaching or religious songs) with God. They are comfortable and feel good when they are in holy places. They also said that it is the only place where no difference among the patient and the community. In favor of the above findings Rammohan, et al., (2002) and the National Alliance on Mental Illness, (2010) said that the use of spirituality is seen as a positive emotion-focused coping strategy. Spirituality may mean different things to different individuals, but has been seen to increase levels of well-being and decrease the level of stress in one’s life.

The other problem- focused coping strategies were ***being an expert for their illness***. As they become more aware of the warning sign and symptoms of their illness, they can manage their relapse frequency and can live their normal life. In contrast to this, except one participant, all of the participants they know the warning signs of their illness but they did not know what they do. As a result they are victims of frequent relapse. Some of the participants also said that the sign and symptom when they are in the process of manic (elated mood and increased energy), they need the feeling so that they did want to take reaction for the symptoms. Moreover; they are not cooperative for their close families when they told them as they are in process of relapse. Because of this most of the participants have no good relationship with family, close friends and relatives.

In contrast to the above findings, researchers advised that being aware of the earliest symptoms is the other important coping mechanism in which patients should notice the pattern of symptom development which is a key to prevention (*Ken Duckworth,* 2008). In other words, if the person with the diagnosis is able to recognize the early triggers or warning signals of an impending episode and respond with the right ‘coping strategy’, they gain control over their mood swings (National Collaborating Centre for Mental Health, 2006). Patients should be aware that the people closest to them may be the first to see signs so develop a plan for emergencies with people you trust and know what to do in a crisis, no matter where or when it occurs—this will reduce uncertainty and stress(*Ken Duckworth,* 2008).

***Adjusting life style***; It was also one of the problem focused coping mechanism and few participants used to cope in their day to day activities. As the findings show that no one use adjusting life style as a coping mechanism even if it is one of the most effective mechanisms in managing their relapse. In contrary to this Ken *Duckworth (*2008, p.22-24) “adjusting life style is one of the coping mechanisms of patients with BD”. Persons with BD identified a number of lifestyle factors that helped them to stay well. They included eating healthy foods, regular exercising, drinking less alcohol/caffeine, having regular schedule, sleeping well, spending time with loved ones, having quiet times, managing stress, and laughing.

# CHAPTER-SIX

# 6. CONCLUSIONS AND RECOMMENDATION

## 6.1. Conclusions

This study captured the experiences of ten adults diagnosed with BD. Study participants explained about the detail and complexities of their experiences. Participants have ambivalence feelings on their illness. Not only the patients but also the families have poor perception towards mental illness and medical treatment. Hence; they gave priorities for traditional healer and spiritual treatments.

Participants are losing their ability to function and they are dependent on the family at their productive age because they were striving to manage the impacts of their illness. The participants were also trying to overcome the consequences of their negative experiences and poorly managed health issues. The stigmas associated with their disorders also made them feel like they were not valued and challenged them not take their treatment properly. Participants sought comfort, acceptance and forgiveness in spiritual settings. The participants need to be heard, accepted and forgiven by society since they are devalued, rejected and stigmatized because of poor perception for mental illness and misunderstanding of the patients. Acceptance, forgiveness, listening and understanding would allow them to move forward and maintain a successful recovery.

Participants need comprehensive or an integrated treatment or holistic approach which address their Bio-psycho-social aspects. So patients, health care professionals (psychologists, nurses, psychiatrists, occupational therapists and social workers), families and the community should work together for better improvement of patients' health status and give them the opportunities to be productive society.

## 6.2. Recommendations

Several important questions have raised from the study findings. All participants have no full information about their disorder. There is a need for improvement in providing necessary information about mental illness (in particular with BD). A study looking at the perceptions, the negative and positive experiences, the challenges of the illness, and their copping strategies was addressed. As it shown in the finding some participants have no trust on the treatment and give priority for traditional or spiritual treatment so they need psycho-education to understand their illness, and to have an initiation for psycho and pharmacotherapy (integrative therapy) and taste the benefits of modern treatments. The research also identified compliance on treatment side effects and they quit their medication without consulting their physician, so health care providers should improves identification of crises related with the treatment compliance to increase earlier intervention in these individuals.

Each woman participant in this study identified experiencing either an abusive relationship, rape or both which occurred prior to and after the participant being diagnosed with BD. Detail research is needed to determine the relationship between BD and a history of sexual, physical abuse. Conducting research in this area may help to reduce the frequency of illness relapse and may improve coping mechanisms to manage the pain of experiences of sexual or physical abuse.

Research focusing on a larger scale, including nationwide will have a statistical meaning, to generalize the study's findings for population so diversity of the research sample will be enhanced. The experiences of adults with BD who live independently in their homes or independent living communities also should be included with a representative sample.

Every participants of the study have either frequent suicidal ideation or attempt so professionals should improve assessment techniques for suicide risk in the population is needed to decrease the number of suicide attempts. Health Professionals, the family and the community should work in identifying resource needs of individuals with BD and an effort to provide support before suicide attempts occur is indicated evidence-based suicide prevention programs so that crises can be managed without suicide attempts must also be developed. Both qualitative and quantitative research addressing these questions might further enhance the body of knowledge available to practitioners working with individuals who are diagnosed with BD.

One of the major accomplishments of this study was providing the participants with a voice. Outside of the connection with their higher power, participants described feeling as if they were not heard. This was evidenced by their behaviors and feelings of devaluation. It is imperative that nurses, health care professionals and society recognize that people with BD need to be heard in their voices are requests for help and support. These individuals are demanding for forgiveness and acceptance by society so responding to their need for support can improve the treatment outcomes. Ultimately, it will lead to a decrease in suicide attempts and may save lives.

It is important that mental healthcare services is organized in a way that gives possibility to work health-promoting by strengthening self-management ability and social functions of persons with BD, and that also includes the whole family. A collaborative approach is necessary both between the professionals and the person affected together with his/her family, and also between different mental healthcare professionals.

More knowledge and understanding are needed about what living with BD means for those affected and their families in order to combat the prejudiced attitudes to BD that still exist in society. Efforts made by society are needed to help or give this people possibility of regaining a place in and feel part of society, *e.g*. through offering them the opportunity to participate in emotional support and self-help groups, meeting others in similar situations, but also through adjusting work to reduce stress and relapse.

Participants are better to employ their coping strategies during times of stress, when early warning signs appear and during an episode. Working out good coping strategies when you are well is an individual process and can be helped by taking advice from those closest to you and your healthcare professionals. You may need their help to implement your strategies. Examples include getting more rest, minimizing social contact during a high, arranging to have regular healthy meals during a depression and so on.

Avoid using alcohol or other substances as a coping strategy. They will only make things worse. Avoid making major decisions during times when you are unwell. Keep a record of all your triggers, warning signs and coping strategies for both mania and depression and refer to it as you need it. Planning ahead when you are well for the times when you are unwell is an important way to keep well for longer and reduce the impact of episodes. Ask your health professionals for assistance and include your family and friends in the process.

The overall support from mental health professionals (nurses, psychiatrist nurses & physicians), psychologists (clinical and counseling) and clinical social workers have to be further developed and designed to provide a comprehensive health care in order to best meet all the different needs of persons with BD and their families.

More research is also required to identify the specific meanings and needs of experienced by youth adults with BD and their families as those have to struggle really hard to maintain some structure to their daily life and to manage remain hopes for the future. It should be evaluated what kind of support that best meet their needs and are most beneficial for their self-management under different stages of illness.

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# APPENDICES

## APPENDIX-A

## CONSENT FORM

Thesis Title: The Lived Experience of Adults with BD

Researcher name: Sewbesew Getnet

Participant's Name: ________________________________________________

**Description and explanation of procedures**: My name is Sewbesew Getnet, I am graduating student of counseling psychology. I am conducting a study for master's thesis on the Lived experience of adults with BD. The objective of the research to gain deeper understanding about how do adults with BD perceive their illness and explore the various challenges they encounter when they live as bipolar patients, how they cope with the challenges and to assess what are the positive and negative experience of adults with BD. Therefore, if you are willing, I am going to ask you about your experience of the illness. The purpose of this study is primarily to fulfill the requirement of Masters Program in counseling psychology; the result of study will be used only for educational purposes. It also contributes for further, research and intervention to improve the services provided to adults with BD.

To appropriately understand your experience I will use tape recorder during the interview if you are comfortable with it and I will keep all the recording in safe place until I finish the transcription. When the study is finished I will remove the recordings from the cassette. Therefore, I assure you that all the information you provide me will not be disclosed to a third person and the study do not have any relation with your service provision. You may talk about things that become stressful for you and if you feel the conversation is too stressful you may ask that the tape recorder be turned off and the interview be stopped.

By signing this form, you are agreeing to participate in the research described to you by the researcher.

___________________________________ ____________________________

Participant's Signature Date

# APPENDIX-B

## [illegible]

[illegible]

[illegible]

[illegible]

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[illegible] [illegible]

# APPENDIX-C

## Interview Guiding Items

Q1, how do adults with BD perceive their illness?

- What is your perception about mental illness before the illness?

### Past Experience

- Could you please tell me a brief history of your illness problem?
- How do you feel about having BD?
- Do you see yourself as mentally ill? Why?

*(Probe, can you elaborate it with example*)

### Present Experience

- What do you think is currently changed about your illness?

*(Probe changes in perception, feeling and understanding of the illness experience)*

Q2, what are the positive and negative experiences of persons with BD?

- What are your experiences in general as you live with BD?

(Probe, explain the negative and the positive experience with example)

Q3, what are the challenges adults with BD faces because of the illness

### Past Experience

- Would you tell me the problem you face because of the illness?
- How BD affects your daily life?

*(Probe, psychosocial, career and treatment)*

- Has having BD made a difference to how you see yourself?

- Did it change the way other people see you?

  *(Probe, members of your family, friends)*

- How do you describe your social relationship before and after the illness?
- How do you compare fulfilling your responsibilities before and after the illness?

**Present experience**

- What are the challenges you are currently experiencing due to the illness? Any changes from the past?

  (Probe *recent challenges regarding psychosocial career and Treatment)*

Q4, How persons with BD cope with their illness?

- On day to day basis how you deal with having BD (the illness)?
- Do you have particular strategies for helping yourself? Ways of coping?

  (*Probe, Could you describe your strategies/ways of coping with example*?)

**Present Experience**

- Could you please tell me the changes in the way you cope with the illness?

  *(Probe, how and in what ways the coping strategies changed now*?*)*

## APPENDIX-D

## FOCUSED GROUP DISCUSSION GUIDE

1. Facilitator Name ------------------------------------------------------------------------------------
2. Place of Meeting------------------ Date --------------------Time Allowed ----------------------
3. Before the FGD is started, the facilitator should follow /apply the following guidelines
4. Should get the informed consent of each participants
5. Be sure every participant is sited comfortably and the meeting room has enough light and fresh air.
6. Please introduce each other, informed them how they are selected
7. Inform them as they have the right to omit the discussion at any time and do not obliged to respond on the issue which creates any discomfort on you
8. Informed them how their participation is necessary for the research and read the objective of the Research and its significance as follow:
    - ❖ **General Objective:** The overall objective of this study is to explore and describe the lived experiences of adults with BD (BD).
    - ❖ **The Specific Objectives are:**
        - o To understand what does mean living with BD for adults with BD.
        - o To describe the positive and negative experiences of persons with BD.
        - o To investigate the challenges that persons with BD face due to their illness.
        - o To find out how persons with BD cope with challenges related to their illness.
    - ❖ **Significance of the study:** It will have implication for

A. persons with BD and their primary care Giver

- The persons with BD will learn how the illness perceived by different individuals, what challenges they faced, in what way they manage, the negative and positive impact of the illness and manage their illness according to their context.
- The primary care giver can also learn how to provide care and support for persons with BD and how can manage their challenges.

**B.** Health Service Provider(Nurses and Psychiatrist)

- The study will filling the gap in perception between the service provider, services users and care givers which will decrees relapse rate and burden of both Service provider and service users since the study address how persons with BD perceive their illness.
- They will have common understanding on the real challenges and coping strategies of the persons with BD.

C. The clinical psychologists will also benefit from the study by identifying the subjective perception of the psychosocial factors and will give an insight how the person with BD cope with from their challenges.

D. The mental health society-Ethiopia will benefited from the research to develop their strategies from the perspective of the person with BD

9. Ask them their readiness for participation and write the participants coded name and their sex
10. Raise FGD items for discussion, facilitate the FGD, and finally summarized the issue and thanks the participants.

# APPENDEX-E

## FGD Guiding Items

Q1, how do adults with BD perceive their illness?

- Can you discuses about the brief history of their illness

  (Probe; related with their feeling, self understanding and perception change, can you elaborate it with example)

Q2, what are the positive and negative experiences of persons with BD?

- What experiences do they have when they live with BD?

  (Probe, explain the negative and the positive experience with example)

Q3, what are the challenges adults with BD faces because of the illness

- Would you explain the problem they face in their daily life because of their illness?
- What triggering factors make them ill repeatedly?

  *(Probe, psychosocial, career and treatment, and any change with their challenges)*

Q4, How persons with BD cope with their illness?

- On day to day basis how they deal with having BD (the illness)?
- Do they have particular strategies to help themselves? Ways of coping?

  (*Probe, Could you describe their strategies/ways of coping with example*?)

# Declaration

**Sewbesew Gtnet;** the first author of this thesis is a MA candidate who is responsible for the conception, design, analysis and interpretation of the study data. She had collected original data, thus, she had full access to all the data in the study, and responsible for the integrity of the data and the accuracy of the data analysis. I, the under signed, declare that this thesis is my work, and that all sources of materials used for these thesis were acknowledged.

**Kassahun** he was the first advisor of the candidate. He had contributed in the designing stage of the study and critical review of the document. He approved the final one.

**Name: SewbesewGetnet**

Signature ___________________________________

A.A.U Jun 2013

This thesis has been submitted for examination with my approvals thesis advisor

**Name: Kassahun ( )**

Signature: ___________________

Date: ___________________