

ADDIS ABABA UNIVERSITY
COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES
SCHOOL OF PSYCHOLOGY

**PSYCHOSOCIAL PROBLEMS OF FAMILIES CARING FOR RELATIVES WITH
MENTAL ILLNESS AND THEIR COPING STRATEGIES AT AMANUEL MENTAL
SPECIAIZED HOSPITAL**

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and Their Coping Strategies at Amanuel Mental Specialized Hospital**

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Acronyms

EUFAMI: European Federation of Associations of Families of People with Mental Illness

DSM: Diagnostic and Statistical Manual of Mental Disorder

HIC: High Income Countries

LOS: Length of Stay

MHF: Mental Health Foundation

NAMI: National Alliance on Mental Illness

NIMH: National Institute of Mental Health

OCD: Obsessive-Compulsive Disorder

PWMI: People with Mental Illness

SPSS: Statistical Package for Social Science Research

WHO: World Health Organization

Abstract

Family members play a major role in providing care-giving assistance to patients with mental illness and while providing care they may experience considerable amount of distress and poor quality of life, especially when they are not able to cope with the stress associated with the process of care giving. The study assessed the psychosocial experience and the coping strategies of caregivers of patients with mental illness in Amanuel Mental Specialized Hospital. Mixed study designs were used. Data were entered into SPSS versions 21 for analysis. Descriptive statistics including, frequencies, proportion and mean was demonstrated by using tables, graphs and texts. Bivariate and multi-variate logistic regression analysis was computed considering $p < 0.05$ to be statistically significant. The data were collected among 327 caregivers of mentally ill patients and source of data was selected by using convenient sampling technique. The questionnaire has three parts: Socio-demographic, Psychosocial problem and Coping mechanism. Among the participants, 110 (33.6 %) and 217 (66.4%) reported having high and no psychosocial problem respectively. The caregivers age range between 35 and 44 were 2.56 times more likely to have psychosocial problem **{(AOR=2.56; (1.24, 5.25))}** compared to those age between 25 and 34. In addition, caregivers of patients who were divorced were 4.3 times more likely to have psychosocial problem **{(AOR=4.3; (1.23, 15.05))}** compared to care givers of patients with mental illness those their marital status was unmarried. The study found that there were a relatively high number of psychosocial problems among caregivers of mentally ill patients. Most of the study participants 199(60.9%) have no experienced venting to escape the problem whereas few 8 (2.4%) of the study participants have.

Chapter one

I. Introduction

1.1 Background

Mental health is the central key of every forms of a person's livelihood. Mental health problems are associated with different kinds of psychological and neurological disorders. There are different types of mental illnesses in nature and degree of spread as well as their impacts. The most prominent of them include Schizophrenia, Bipolar disorder, schizoaffective disorder and depression (Mark, 2013). Schizophrenia is a severe and chronic mental illness affecting approximately 1.5% in the general population. It is a psychiatric disorder that causes individuals to struggle with their ability to think, manage emotions, or maintain relationships and hence leads to hallucinations, delusions, issues with thought patterns, as well as flat affect, problems with memory, or poor decision making skills.

Bipolar disorder is a psychiatric illness characterized by frequent oscillation between manic and depressive symptoms. It can be identified by "extreme irritability and/or euphoria, agitation, surges of energy, reduced need for sleep, talkativeness and pleasure seeking and risk taking behaviors" (Smith, & Segal, 2012). Schizoaffective is the other form of mental illness that shares some characteristics and symptoms from both schizophrenia and bipolar disorder and strongly affects the psychological and socioeconomic wellbeing of the patient (NAMI, 2010).

Depression is a psychiatric illness wherein a patient experiences profound sadness, lack of motivation and energy, poor concentration, insomnia, fatigue, appetite changes, guilt and thoughts of suicide. All of these disorders have a profound impact on the patient's psychological states, affecting their social and daily functioning (Mark, 2013;MHF, 2016) referring to the 2010

Global Burden of Disease Study, stresses that the most predominant mental health problems worldwide are depression and anxiety. The degree and nature of spread of the problem varies from place to place. Initial estimates suggest that about 400 million people alive today suffer from mental or neurological disorders or from psychosocial problems such as those related to alcohol and drug abuse (WHO, 2001). Depression is now the leading cause of disability globally and ranks fourth in the ten leading causes of the global burden of disease. In sub-Saharan Africa, researches shows that mental illness and substance use disorder are considerably prevalent and interwoven. The figure is expected to be much higher in the future, because the global population is aging and some mental problems like Alzheimer's disease are to increase due to their direct relation with age (Harnois, 2000).

In Ethiopia, mental illness is one of the leading non-communicable disorders in terms of burden. Indeed, in a predominantly rural area of Ethiopia, mental illness comprises 11% of the total burden of disease, with schizophrenia and depression included in the top ten most burdensome conditions (Oshodi, 2012). Substance misuse and abuse are identified to be one of the major factors (Zenebe, 2015). The problem people with such and the like mental and psychological disorders face are not limited only to the unhealthy personal conditions they face. Many of them suffer silently, and alone. They are also made to lose almost all socially set values, trust, economic benefits, care etc (Harnois, 2000).

Beyond the suffering and the absence of care lie the frontiers of stigma, shame, exclusion, and more often death. More seriously than that, they are forced to lose the right to decide on buying, selling, exchanging, and investing on the properties that are clearly known to be their possession. They are even forced to undertake physical activities and movements only under the will and decision of their caregivers or doctors leaving their interests aside. The psychological

and socioeconomic problems are not limited only to the patients. However, the intimate family members and caregivers are bound to pass through multifaceted problems (Oshodi et al, 2012).

1.2. Statement of the problem

The majority of seriously ill psychiatric patients have been diagnosed with four major disorders: schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder (DSM-IV TR, 2000). All of these disorders have a profound impact on the patient's psychological states, affecting their social and daily functioning. It is important to understand not only how these illnesses affects the patient, but also what family caregivers face as they assume responsibility for these patients (Mark, 2013).

Usually family members of the patients with mental illness are seen working very hard to restore the normal health status of the patients. The more serious and prolonged the mental problem is the more that caregivers burden would be. They usually try to find traditional, spiritual and modern forms of medical services; maintaining their personal hygiene; they take the responsibility to look after the patient's properties and families; they keep themselves busy waiting the patient, moving him from one place (medical service center) to the other collecting money and necessary materials for the services and materials he/she needs; etc. leaving most of their own personal, work and family affairs. These and the like issues of shouldering additional responsibilities make caregivers to be psychologically burdened (Sintayehu et al, 2015). In addition to this, they face different social and economic problems that are directly linked to their care giving roles (Oshodi et al, 2012). For example, in Ethiopia, 56.7% of the caregivers of patients with severe mental illnesses are found to be facing psychological distress (Sintayehu et al, 2015). Different studies have been undertaken to identify the problems faced by caregivers of patients with mental illness and related concerns in different places. For example, Oshodi et al,

(2012) conducted a research on the prevalence of psychological distress and experience of burden of care among the caregivers of mentally ill patients in Lagos, Nigeria employing cross sectional descriptive study and finally came up with the result that there is a significant level of burden and psychological distress experienced by caregivers. Accordingly, caregiver burdens were complex and have been found to include several areas such as activities in daily life, worry and social strain (Oshodi et al, 2012).

Majority of relatives of patients with bipolar disorder experience subjective distress in relation to the patient's symptoms, role dysfunction and the adverse effect of the patient's illness on the relatives own work and leisure time. Stigmatization and discrimination are directed at both the family and friends of the people of mental illnesses as well as helping professions (Schulze, 2000). Stigmatization of mental illness in general and stigma associated with schizophrenia in particular represent main obstacles to successful treatment.

Interpersonal and psychological distress has been reported to be associated with higher levels of loss due to mental illness (Stein et al, 2005). Studies in HIC have revealed that personal loss attributed to mental illness includes changes in current roles and routine, self-identity and previous relationships (Stein & Wemmeru, 2001). Parents, spouses and siblings more often focus on the mentally ill relative and as a result are often unable to deal with their own individual or family developmental needs. Some studies in the USA have found a relationship between negative family environments and relapse (Holey & Campbell, 2002; Weisman et al., 2000) while only one study by (King, 2000) did not support those findings.

In many societies around the world, stigma is associated with mental illness (Thornicroft, 2006). Relationships with neighbours and the community at large can be strained. At times, the

family can be socially isolated due to the patients' behavior during the episode as some patients may become either physically or verbally aggressive (Struening et.al, 2001). This makes it difficult for neighbours to understand the condition. Studies in USA have also shown that 43% to 92% of caregivers of people with mental illness report having been stigmatized (Struening et.al, 2001).

Family members, who provide care for a family member with mental illness, are at increased risk of mental and physical health problems (Berg-Weger, 2000). In USA, caregivers of family members with a higher number of symptoms and level of cognitive impairment experience more depression. Rates of caregiver depression have been estimated to range between 38% and 60% (Berg-Weger, 2000).

In another USA study that set out to examine the experiences of living with a family member with bipolar disorder, the findings showed that family members felt alone, struggled to make sense of their experiences, and found it difficult to maintain a sense of normality, as their life was encroached on by the effects of the condition (Jonsson et al, 2011).

Discrimination in the form of social avoidance has also been found to be a result of blame and shame by the extended family. Three large studies in the USA reported that about a fifth to a third of family members reported strained and distant relationships with extended family or friends or both because of a relative with mental illness (Oestman & Kjellin, 2002).

Individuals with schizophrenia experience lifetime emotional, financial and social challenges that have significant effects in their families. Family reactions to having a family member with schizophrenia manifest as care burden, fear and humiliation about illness signs and symptoms, insecurity about cause of the disease, lack of social support and stigma (Czuchta et al,

2001). The experience of caring for a family member with schizophrenia has often resulted in psychological distress and an aspiration to control behavior problems (Shibre et al, 2001).

The other group of researchers, (Ong et al, 2016), who have conducted a cross-sectional study to assess the correlation between perceived stigma and coping, and psychological distress as well as to determine the predictors of psychological distress among 200 caregivers of schizophrenic outpatients from the Counselor Tuanku Muhriz Psychiatric Clinic of Hospital in Malaysia finally found that almost one-third of the caregivers experienced psychological distress and stigma.

In Ethiopia researches related to mental illness have given greater emphasis to communities' perception towards mental disorder (Shibire, 2001; Alem, 1999), traditional and modern forms of treatment to mental illness (Kasaye et al, 2006), health behaviors of the mentally ill patients (Kloss et al, 1987), etc. Studies have exerted less effort to divulge the issue of caregivers to the mentally ill. In fact, some researchers like (Shibire et al, 2003) and (Sintayehu et al, 2015) have tried to assess the issue but there are several gaps in this regards. One of the gaps is that they analyzed the overall impacts than deep-rooted psychological burdens the caregivers shoulder. They addressed prevalence of psychological distress among caregivers of patients with severe mental illnesses leaving others aside. The coping mechanisms of the caregivers to escape the burden and their effectiveness are also lacking in the literatures. (Fikadu et al, 2007) indicated that the annual age-sex standardized admission rate at Amanuel Mental Specialized Hospital was 4 per 100,000 where two-thirds of the patients came from Addis Ababa and the immediate surroundings and nearly three-quarters were found to be men, and aged 30 years or younger. Accordingly, schizophrenia and bipolar disorder were the top two discharge diagnoses. The median length of hospital stay (LOS) was 63 days.

Hence, this study has tried to analyze the psychosocial experience and the coping strategies of caregivers of patients with mental illness in Amanuel Mental Specialized Hospital.

1.3 Research Questions

1. How many percent of the caregiver's experience psychosocial problems at Amanuel Mental Specialized Hospital?
2. How do caregivers cope the psychosocial problems they face while giving care at Amanuel Mental Specialized Hospital?

1.4. Objectives

1.4.1. General objectives: -

The general objective of this research was to assess the prevalence of psychosocial problems and the coping strategies of caregivers of patients with mental illness in Amanuel Mental Specialized Hospital

1.4.2. Specific objectives: -

The research, specifically attempted

1. To determine prevalence of psychosocial problems among caregivers of mentally ill individual at Amanuel Mental Specialized Hospital
2. To examine the coping strategies employed by caregivers of mentally ill individual at Amanuel Mental Specialized Hospital
3. To explore the main psychosocial problems among caregivers of mentally ill individual using interview guide at Amanuel Mental Specialized Hospital

1.5. Significance of the study

The primary care givers in particular and the family of mentally ill patients as a whole bear the psychosocial problems and responsibilities of providing care for patients at different stages. It is bogus to think of devising clear and effective mechanisms of maintaining wellbeing of both the patients and the caregivers without research based concrete findings on the matter. Therefore, the successful completion of this study is important as it bridges the literature gap on the subject of study. Besides, it will serve as a one ingredient of the greater base for decision makers to devise policies and lower level in relation to taking care of mental health problems. The final document of the research work will also serve as a reference literature material for readers and researchers who will be interested to conduct their research on related issues. It also helps to oversee its role as a self-reflection mirror for patient's caregivers.

1.6. Delimitation

The issues related to mental health problems are many in number, complex, and interwoven in nature. However, this research work is delimited in scope to analyze psychosocial experiences and the coping strategies of caregivers of patients with mental illness. Even though the problem and its impacts are prevalent all across the country and the globe, this research was delimited to Amanuel Mental Specialized Hospital for the sake of convenience.

1.7. Operational definition of terms

Psychological problems of families: -In this study, psychological problems of families refer to guilty feeling, depression, emotional disturbance, sleep disturbance and fatigue, feeling of loss, sadness, and embarrassment in social situations.

Psychological problem of patients: - In this study, psychological problems of patients refers to schizophrenia, depression, bipolar, and schizoaffective disorder.

Social problems of families: - In this study, social problems of families refer to stigma (disqualify one from full social acceptance), discriminations (social distancing, exclusion and being disadvantaged), unable to do day-to-day activities, loss of work & decreased functionality.

Family: - refers to a fundamental social group in society typically consisting of one or two parents and children.

Mental illness: - refers to health condition involving maladaptive thinking, emotion or behavior (or a combination of these).

Coping strategies: - In this study, coping strategies refers to reinterpretation, denial, humor, behavioral disengagement, positive reframing, social support, usage of religion or spirituality, active coping & acceptance. The responses were measured using Likert scale.

Relatives: - refers to a person who is connected with the patient by blood or marriage.

Caregivers: -refers to a person who provides care for mentally ill patients

1.8. Limitation

The study was aimed at gathering information, which could characterize specific person by identifying psychosocial problem and its coping mechanism. The limitation of the current study was:-

- Inadequacy of literatures hinders further discussion and comparison
- The cross-sectional nature of the study also prevented us from drawing definitive causal conclusions about the relationships between caregiver situations and psychosocial factors examined. For instance, several factors not examined could have accounted for the variation in coping strategies used or differences in psychological health outcomes. In relation to the point raised, it will be impossible to predict whether caregivers' experiences might change over a period of time because of the lack of follow-up data.
- Another limitation of the present study is that our population consisted of exclusively caregivers of mental problem patients, thus our findings may not necessarily be representative of caregivers of patients with other physical health conditions.
- Narrow scope of the study setting and population being only one hospital set up and population from specific area.
- And also the present study is that it was carried out in only one hospital in an urban setting and hence the results cannot be generalized to the population at a large

Chapter two

Literature review

This chapter explains about overview of different research studies of psychological and social problems of caregivers of mentally ill patients, theories of psychological problems of caregivers, coping strategies of relatives and review of the summary.

2.1. Psychosocial problem: overview

The term psychosocial refers to the psychological and social factors that influence mental health (Epperly, 2000).

Social influences such as peer pressure, parental support, cultural and religious background, socioeconomic status, and interpersonal relationships all help to shape personality and influence psychological makeup. Individuals with psychosocial disorders frequently have difficulty functioning in social situations and may have problems effectively communicating with others (Epperly, 2000).

The stigma and stress of mental illness can make it difficult for families to maintain relationships. Additionally, their personal lives may be restricted due to their responsibilities. “Neglecting friends or other family members, disagreement within the family, reduced leisure time, and missed days at work or school” were the problems identified (McFarlane, 1983; Tan, 2012). Ong, (2016) found that 31.5% of the caregivers experienced psychological distress along with “Community rejection”. The main psychological sufferings the caregivers experienced were depression, hatred, uncertainty, guilt, shame, embarrassment. Subjective psychological problem is emotional impact, feeling of grief, a feeling of loss, sadness, anxiety, and embarrassment in social situations, and worry on family members or on caregivers (Epperly, 2000).

2.2. Psychological problems

Psychological problems are diverse and cause not only personal suffering but also loss of workdays and heavy burden to health care systems.

DSM IV- TR describes different types of major psychological problems: Organic mental disorder, Mental disorder due to General Medical Condition, Substance related disorder, Schizophrenia, Mood disorder, Anxiety disorder, Somatoform disorder, Factitious disorder, Dissociative disorder, Sexual and gender identity disorder, Eating disorder, Sleep disorder, Impulse control disorder, Adjustment disorder, and Personality disorder.

The most prominent problems include Schizophrenia, Bipolar disorder, schizoaffective disorder and Depression (Mark, 2013). All these disorders have a profound impact on the patient's psychological states, affecting their social and daily functioning. It is important to understand not only how these illnesses affects the patient, but also what family caregivers face as they assume responsibility for these patients (Mark, 2013).

Schizophrenia is a severe and chronic mental illness affecting approximately 1.5% of the general population. It is one of major psychological disorders that causes individuals to affect their ability to think, manage emotions, or maintain relationships.

Bipolar disorder is characterized by frequent oscillation between manic and depressive symptoms. It can be identified by "extreme irritability and/or euphoria, agitation, surges of energy, reduced need for sleep, talkativeness and pleasure seeking and risk taking behaviors" and lifetime prevalence is 0.4% to 1.6% (Smith & Segal, 2012). Schizoaffective is the other form of mental illness that shares some characteristics and symptoms from both schizophrenia and bipolar disorder and strongly affects the psychological and socioeconomic wellbeing of the

patient and it appears to be about one-third as common as schizophrenia. The lifetime prevalence of schizoaffective disorder is uncertain, but probably less than 1%, in range of 0.5 to 0.8% (NAMI, 2010).

Depression is characterized by profound sadness, lack of motivation and energy, poor concentration, insomnia, fatigue, appetite changes, guilt, and thoughts of suicide and lifetime prevalence is 10-25% and 5-12% among women and men. All these disorders have a profound impact on the patient's psychological states, affecting their social and daily function (Mark, 2013).

The psychological overstrain of families: The psychological overstrain of families who provide long-term care to a family member who suffers from schizophrenia include a great number of hindrances and difficulties that result from the very care benefit. The degree of psychological overstrain depends on the available resources of the family, the age of the individuals who provide care, the sex, the financial status, the social supporting frame, the psychological resistances, the type of related relation with the suffering and the previous role of the mentally suffering within the family (Atkinson, 1995).

2.2.1. Nature of psychological problems

Mental illness, as it turns out, has some of the highest genetic loading of any common illness. Of course, there are some rather famous single-gene disorders (like Huntington's or cystic fibrosis) whose risk seems to be almost entirely genetic, but right up there is schizophrenia, where 80% of the risk is genetic. That means if you have no relatives with schizophrenia, it is unlikely you will develop it. Genetic loading counts for a large portion of the risk for bipolar disorder and major depressive disorder as well (Emily, 2011). There are significant ranges of

mental illnesses with varying degrees of severity. Examples include anxiety, depression, bipolar disorders schizophrenia and Obsessive Compulsive Disorder (OCD.) We all experience emotions such as being excited or happy. These are examples of positive mental health. At other times, we also come across things we struggle with, i.e., anxiety, worry or stress. These emotions are all part of our mental health. There are many possible causes of Poor Mental Health Conditions; these can range from childhood, significant events, anything such as a relationship breakdown, a bereavement, a sudden shock or trauma. General anxiety spiraling out of control and leading to depression. Genetics – certain mental health problems can skip generations and be passed down families. Some disorders can be biological. Certain ones are congenital however remain dormant until a person's late teens. The majority of people who experience mental health problems can get over them or learn to live with them especially if they seek help early on (Annabel, 2015).

2.2.2. Types of psychological problems: From the mentally ill patient's perspective

According to DSM IV- TR, there are different types of mental illnesses. These are Delirium, characterized by clouding of consciousness, disorientation to time, place and person, and distractibility. Dementia is characterized by impairment of intellectual function, impairment of memory, deterioration of personality and lack of personal care. Amnestic disorder is characterized by a disturbance in memory that is either due to the direct physiological effects of a general medical condition or due to the persisting effects of a substance. Mental disorder due to General Medical Condition must be supported by evidences from history, physical examination, or laboratory findings that the delusions or hallucinations are the direct physiological consequence of a general medical condition. Substance related disorders are related to Caffeine, Cannabis, and mixed and smoked with opioids, phencyclidine (PCP), or hallucinogenic drugs. Schizophrenia is characterized by hallucination, delusion and lacks of insight other psychotic

disorder like having schizophrenic feature. Mood disorder (mania & depression) is characterized by multiple persistent physical symptoms with no clear cause, low energy, fatigue, sleep problems, persistent sadness or depressed mood, loss of interest or pleasure in activities that are normally pleasurable & expansive or irritable mood & grandiose delusion. Anxiety disorder is expressed by palpitation, numbness, breathlessness, chest pain, discomfort, dizziness, sweating and shaking or tremor. Somatoform disorder is characterized by presence of recurrent and multiple somatic complaints of several years. Factitious disorder (i) with predominantly physical symptoms “Munchausen’s syndrome” e.g. fever, abdominal pain, anemia (ii) with predominantly psychological problems e.g. Depression, Anxiety, psychosis etc., and (iii) with symptoms from both categories. Dissociative disorder is expressed by partial or complete loss of normal integration between memory of past, awareness of identity, immediate sensation and control of body movements. Sexual and Gender identity disorder is characterized by persistent and intense distress about assigned sex along with a strong desire or instance to be of the other sex. Eating disorder (Anorexia Nervosa & Bulimia Nervosa) is deliberate weight loss induced & repeated bouts of overeating and an excessive preoccupation with control of body weight. Sleep disorder (Parasomnias it includes Insomnia, Hypersomnia and sleep wave schedule & Dyssomnias includes sleep waking, sleep terror, and Nightmare). Impulse control disorder the failure to resist an impulse, drive, or temptation to perform an act that is harmful to the person or to others. Adjustment disorder is a psychological response to an identifiable stressor or stressors that results in the development of clinically significant emotional or behavioral symptoms. Personality disorder significantly deviated from the accepted cultural norms.

2.3. Psychological problems of caregivers for mentally ill patients

Acting as the primary caregiver for a relative suffering from a severe and chronic mental illness is taxing in many ways. Many caregivers struggle emotionally to cope with the stress of supporting a relative suffering from mental illness. Caregivers generally grieve various aspects of their own and their relative's lives that are impacted by the diagnosis of a severe mental illness. Caregivers need to grieve the major changes in their mentally ill relatives (Erlingsson, 2012); (Milliken, 2001; Tan, 2012). Caregivers can also suffer from compassion fatigue, which has been defined in different ways.

Psychologically the family members of patients with mental illness face depression, anxiety, sleep problem, fatigue, hopelessness and thinking that God punished them. Socially they are exposed for stigma, unable to do day-to-day activities, loss of their works, unsustainable marriage, and restriction on relationships within and outside the family, lack of support and reduced quality of life (Mark, 2013; Ong et al, 2016; Cook, 1994 & Pickett, 1988).

2.3.1. Types of psychological problems experienced by caregivers

The family members of patients with mental illness face depression, anxiety, sleep problem, fatigue, hopelessness and thinking that God punished them. Socially they are exposed for stigma, unable to do day-to-day activities, loss of their works, unsustainable marriage, and restriction on relationships within and outside the family, lack of support and reduced quality of life (Mark, 2013; Ong et al, 2016; Cook, 1994 & Pickett, 1988). The caregivers may decide on several activities as a coping strategy some of which are exacerbating agents than solutions for the aforementioned problems (Ong et al, 2016). Undertaking researches on the multidimensional aspects of the problems faced by caregivers and the coping mechanisms they devise to withstand the problem will be very much important. The psychological and sociological wellbeing of the

caregivers will have direct and positive relationship with the degree of recovery of the patient and even serves as a strong agent of social stability around (Mark, 2013; Oshodi et al, 2012).

2.3.2. Caregiver psychological problems and relationship type with mentally ill patients

Family members play an important role in supporting the person who is suffering from mental illness. Beside pharmacological treatment for persons with mental illness, the quality of care given by the family members is directly related to the functioning of the patients. Family members of persons with schizophrenia experience more stress due to the nature of the symptoms as well as the prolonged duration of the illness. The prevalence rate of schizophrenia explains the magnitude of the problem as well as the magnitude of the issues involved in the process of care giving (Murthy, 1997). The caregivers' burden increases with more patient contact and when patients live with their families (Schulze, 2005). The psychological reactions which caregivers experience includes feeling of loss, sadness, anxiety, and embarrassment in social situations, the stress of coping with disturbing behaviors, and frustration caused by changing relationships (Ostman, 2004).

2.3.3. Duration of the mental illness and caregiver's psychological problems

These caregivers have been found to worry a lot about the display of difficult behavior's, negative symptoms, attempts of patients to harm themselves and concern if the caregiver had done anything that may have made the patient ill. Some studies have shown that approximately one third of caring relatives have elevated levels of anxiety or depression connected with the caring role (Oshodi et al, 2012). Caregiver burden is complex and has been found to include several areas such as activities in daily life, worry and social strain (Oshodi et al, 2012). Some of the roles and responsibilities identified are assessment, linking, monitoring, and assistance in

daily living, crisis intervention and advocacy. Accordingly, caregivers take the responsibility for many facets of a patient's life, not only in terms of daily living, but often financially as well (Harnois, 2000).

According to the survey conducted in a number of European countries, caregiver of adults with mental illness spends an average of 6–9 hours per day providing care (Magliano et al, 1998). Another survey carried out in the United Kingdom found that 95% of caregivers are members of service users' families and that 29% provide support and care for more than 50 hours per week (Jones, 2010). Apart from the pure emotional support given by caregivers, there are also many examples of practical support, such as cooking and other household chores, assisting in keeping medical appointments and giving financial support. Nearly 40% of caregivers provide support on a daily basis. A recent survey conducted by the European Federation of Associations on Families of People with Mental Illness (EUFAMI) shows that the typical caregiver has been caring for an illness ranged from 7 months to 27 years. All the caregivers were living with the patient in the same household and most of them were parents (Jones, 2010).

2.3.4. Gender of the caregiver and psychological problems

A notable statistics related to family caregivers shows that 82% are female (mothers, in 90% of cases), 70% are over 60 years of age and 33% are over 70 years (Jones, 2010). Moreover, the perception of problems may vary between different cultures in terms of being more or less accepting disability and seeing hope for the future (Rosenfarb et al, 2006). Hence, there is a clear need for support and training for such families (Jones, 2010).

Women caregivers, predominantly spouses and mothers, were reported to face financial problems or were more often forced to devote the shortage of resources they had to care for their

ill relatives than male caregivers. Hence, especially in Ethiopia most women have no adequate financial income and are prone to domestic burden, which contributes for this problem. There was also a significant association between separated, divorced and widowed relatives of both sexes and financial problem. Caregivers who are separated, divorced and widowed experienced a significantly heavier social burden. Stigma, Stereotypes, Prejudices Stigmatization, and discrimination are directed at both the family and friends of the people of mental illnesses as well as helping professions (Schulze, 2000).

Stigmatization of mental illness in general and stigma associated with schizophrenia in particular represent main obstacles to successful treatment. As a result of the stigma associated with mental illness, and with schizophrenia in particular, people suffering from mental illness often do not accept professional help until a late stage. The fear that they will be labeled simply because they have received psychiatric treatment is too great (Link et al, 1997). The cost that families incur in terms of economic hardships; social isolation and psychological strain are referred as family burden (Grad and Sainsbury, 1963). The caregivers of schizophrenic patients are exposed to high-level burden and distress. Mental illness causes disabilities which manifests in Patient daily life function. These disabilities lead to poor adaptability in One`s personal life, family and outside family life (Katsching et al, 1997).

2.4. Social problems of caregiver of mentally ill patients

Most studies in the area of caregiver problem have focused on caring for elderly patients with brain degenerating conditions like dementia. However, studies that are more recent have examined the problem experienced among caregivers of persons with severe mental disorders (Struening, 2001). Researchers have recommended that clinicians need to have an approach that focuses not only on the patient but also on the parents/caregivers, as care giving has significant

influence on the overall quality of life of the caregiver (Oshodi et al, 2012). According to Shibire, (2002), Female relatives had more experiences of difficulty in going to work or had to stop working because of the need to care for their relatives with schizophrenia. This fact applies to all female relatives in all relation groups and there was no significant difference as their mean occupational burden scores were compared. There were significant associations between being a spouse of a case with schizophrenia, caring for cases who had disorganized symptoms and work-related burden.

According to Cook, (1994), social problems include stigma, discrimination, economic burden, loss of work, social, and leisure activities, disruption of household routines, such as childcare, restriction on relationships within and outside the family.

2.4.1. Types of Social Problems of Caregivers of Mentally Ill Patients

People with Mental Illness (PWMI) are stigmatized in most of the societies, the intensity being more profound in the Asia (Lauber, 2007). Disgrace to these people is so high that even their caregivers face its spillover effects—referred to as “courtesy stigma” (Goffman, 2009). The stigma contributes to negative consequences for both patient and caregivers perpetuating self-stigmatization and low self-esteem (Mehta, 2009; Ostman, 2002). PWMI are discriminated and isolated (Borke, 2011; WHO, 2002) whereas caregivers avoid social interactions and face social exclusion (Larson, 2008). When stigma exists, the caregiver may conceal their relationship with patient, fail to acknowledge the illness and avoid treatment of the patient.

Globally, both patients and their caregivers suffer stigma and are often deprived of their basic human rights (Drew, 2011). Consistent with the global experience, PWMI and their caregivers in Asia are treated unequally (Lauber, 2007; NGCH, 1997). Due to the stigma,

patients and their caregivers in Asia are hesitant to visit psychiatric facilities for treatment of mental illness (Campion, 1997). On the other hand, stigma tends to avoid or delay health seeking behavior increasing their vulnerability to violence, exploitation, malnutrition, drug abuse, and even suicide and death (Girma, 2013; WHO, 2009). Similarly, stigma leads to numerous detrimental consequences from economic and social perspective, and has tremendous impact on family relations and employment affecting the quality of life of PWMI and their caregivers (Borke, 2011; Link, 2001; Rusch n.d).

2.4.2. Relationship Type and Social Problems

Literatures indicates that Mark, (2013) psychological well-being indicators other than burden frequently indicate that spouses are worse off than adult children. (Pinquart and Sorensen's, 2011) meta-analysis of studies comparing care giving spouses, adult children, and children-in-law, came to the conclusion saying “spouse caregivers report more depression symptoms ... and lower levels of psychological well-being”. Based on such findings, (Litwin and colleagues, 2014) concluded that “long-term spousal care ...presents the greatest challenge to caregiver mental health among the respective relationship types”.

Less is known regarding how middle-aged and older spousal and adult child caregivers compared to parental caregivers of children are affected with long-term illnesses or disabilities. Poor psychological well-being has also been documented among middle-aged and older parent caregivers of children with mental health or developmental problems (Ha, Hong, Seltzer, & Greenberg, 2008).

For example, Litwin and colleagues, (2014) found that along with spousal caregivers, co resident caregivers of adult children experienced more depressive symptoms than those who

gave care to parents or others. Even less is known regarding how middle-aged and older spousal, parental and adult child caregivers compare to caregivers of siblings, friends, or other more distal care recipients. (Chen and Lukens, 2011) compared parent and sibling care giving for a family member with severe and persistent mental illness and found sibling status was associated with greater emotional well-being but had no impact on burden or depressive symptoms. Finally, (Marks, Lambert, and Choi's, 2002) study of transitions into care giving among primary kin (i.e., child, spouse, parent), parent-in-law, other kin and nonkin among adults of all ages, found evidence of negative implications for psychological well-being (depression, happiness) but primarily among caregivers of primary kin: "providing care to a parent-in-law was not associated with negative effects for women or men.... The care giving relationship type with the lowest level of normative obligation (and therefore, we would expect the greatest degree of voluntary effort), the care of a nonkin associate, was the ... type associated with the most beneficial effects...".

Women caregivers, predominantly spouses and mothers, reported significantly more financial problems or were more often forced to devote the shortage of resources they had to care for their ill relatives than male caregivers. There was also a significant association between separated, divorced and widowed relatives of both sexes and financial problem. The caregivers who were separated, divorced and widowed experienced a significantly heavier social burden. Stigma, Stereotypes, Prejudices Stigmatization, and discrimination are directed at both the family and friends of the people of mental illnesses as well as helping professions (Schulze, 2000).

2.4.3. Types of Mental Illness and Social Problems

Schizophrenia and bipolar disorder are two of the most serious and debilitating psychiatric disorders, for those living with a mental illness, especially in the developing world in which the

availability of community support service is limited, family members are the major, if not the exclusive, sources of support and care (WJKMiISARJ, 1994).

Family caregivers shoulder the vast majority of long-term care responsibilities worldwide without pay or compensation (Carter, 2008). Caregiver studies have documented numerous adverse effects of care giving for a mentally ill family member, impairing quality of life, causing time lost from work, financial stresses, limiting time for leisure and socializing, as well as causing adverse health effects such as elevated stress and depression, feelings of stigmatization, poorer self-rated health, chronic medical conditions, greater use of tranquilizers and antidepressants and increased risk of medical hospitalization (Perlick, 2007; Carreteros, 2009; Papastavrou, 2010).

Severe mental illness has been found to affect caregivers in complex ways. Disability, impaired functioning and symptom severity of the ill family member have all been identified as predictors of consequences for caregivers (Tang, 2008; Hjarthag, 2010). Moreover, the characteristics of caregivers themselves, and of their relationship to patients, are also important determinants. For instance, being older, being a parent, or spending increasing numbers of hours caring for the patient may increase burden (Hadrys, 2011). Ample social support and adaptive coping, in contrast, may be protective (e.g., problem solving seems more effective than avoidance or other emotional coping strategies) (Magliano, 1998). Finally, regarding the well-known association between caregiver burden and patient distress, the direction of causality remains a matter of debate (Hadrys, 2011; Magliano, 1998).

It is important to understand not only how these illnesses impact the patient, but also what family caregivers face as they assume responsibility for these patients (Oshodi et al, 2012);

(Mark, 2013). The caregivers' burden increases with more patient contact and when patients live with their families and the level of responsibility, they shoulder (Meeta, 2016). Families or relatives of patients with mental illness face many challenges that can be categorized broadly as objective and subjective. It is a widely accepted fact that the majority of caregivers for such patients are family members.

2.5. Theories of psychosocial problems of caregivers of mentally ill patients

There are many theories regarding families and mental illness. Over the years, theories regarding family systems have evolved. Once blaming and stigmatizing families, especially mothers, (so-called "schizophrenogenic mothers") the field has moved to a more accepting and strengths based perspective. Below is a brief discussion of family systems theory.

Bowen's Family Systems Theory: - Bowen was the pioneer of Family systems theory and he focused his interest on family relationships, particularly families in which a member was suffering from schizophrenia (Goldenberg and Goldenberg, 2008).” Bowen “believes that the driving force underlying all human behavior came from the submerged ebb and flow of family life, the simultaneous push and pull between family members for both distance and togetherness (Goldenberg and Goldenberg, 2008).

Although this theory discusses multilevel of assessing family organization, Bowlby emphasizes two main issues: "(1) the degree of their enmeshment versus the degree of their ability to differentiate, and (2) an analysis of emotional triangles in the presenting problem” (Kaplan et al, 1994). Triangulation refers to the way couples, especially when stressed, "one or both partners will involve a third person” (Goldberg & Goldenberg, 2008).

Family systems theory takes into consideration the various aspects of a family communication and relationships to understand their dynamics. The goal of family systems therapy is “changing the relational system including helping family members to manage their anxiety, helping them detriangulate from three person systems, and more importantly, aiding each family member to increase his or her basic differentiation of self” (Goldenberg and Goldenberg, 2008). However, this theory does still hold an aspect of blame on parents for children suffering from mental illness. Bowen and the family systems theorist hypothesized that schizophrenia is a manifestation of a process that involved the entire family and that the client is merely the person who displays the family psychosis. Bowen agreed that the child who has developed schizophrenia was intimately involved in stabilizing his or her parent’s marriage (Fallon, Boyd, & McGill, 1987).

The functioning of schizophrenic patients were related to the interactions of the other members of their families. Therefore, he pursued this hypothesis in a research project funded by the National Institute of Mental Health (NIMH) in which he hospitalized small numbers of schizophrenics along with their immediate family members. This allowed him to move from a conceptualization of schizophrenia as an individual problem (i.e. having its roots in one person) in to seeing schizophrenia as something to do with the mother-child relationship and he concluded that schizophrenia was related to the functioning of the whole family unit. Without blaming the family for the schizophrenia, he began to articulate a theory that described how the social existence of human beings, in family groups, affects the functioning of each individual member across the spectrum of healthy and symptomatic behavior.

2.6. Coping Strategies of Relatives of Patients

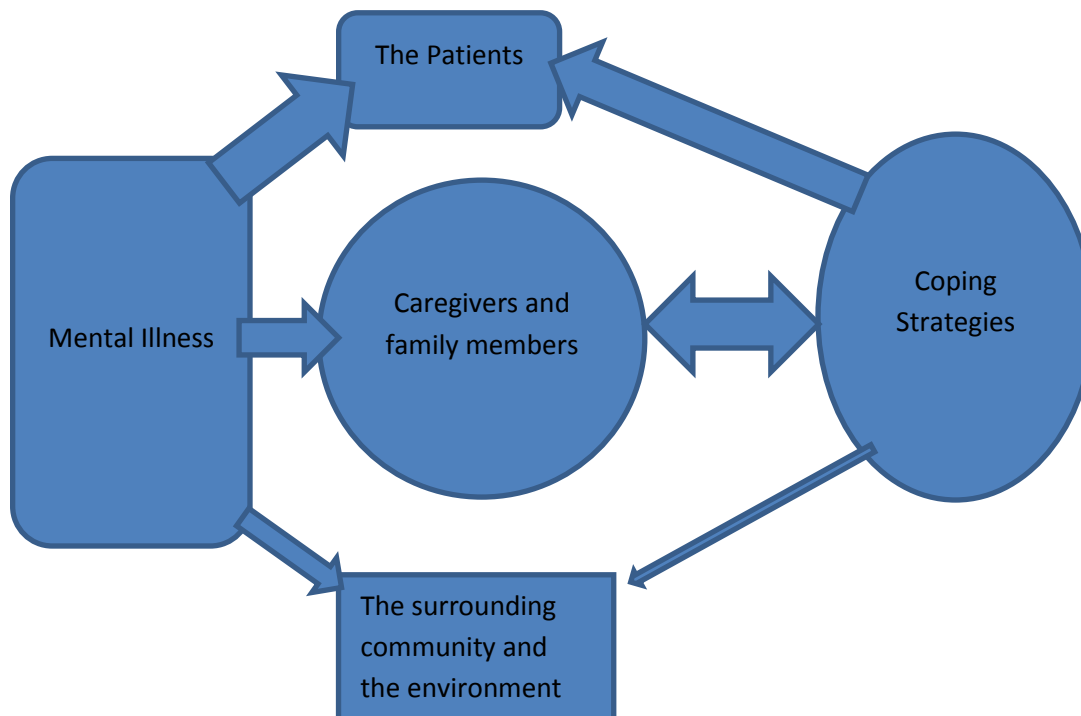
Coping differs from one family to another for a variety of reasons. In developed countries, some researchers have emphasized coping as a key concept for the study of adaptation and mental health (Doombos, 1996; Doherty, 2008). However, the effects of age, duration of illness, living arrangements and other contextual factors on the coping styles of family caregivers, and on the recovery or rehabilitation of persons with mental illness are important factors to be considered (Doherty, 2008).

To withstand the grave burden they face, caregivers of the mentally ill patients devise and implement different coping strategies. Some of these strategies are positive and some are negative to the patients' recovery and the health of the caregiver. (Ong et al, 2016) conducted a research on some of such strategies and found that coping subscales, caregivers psychological burden had a positive correlation with substance use, use of emotional support, behavioral disengagement, venting, and self-blame, while it was negatively correlated with "positive reframing" (Ong et al, 2016). In India, the caregivers of patients suffering from schizophrenia were found using both adaptive and maladaptive coping strategies (Ong et al, 2016).

Coping strategies such as reinterpretation, positive life growth, and social support, usage of religion or spirituality, active coping, acceptance, positive reframing, self-blame, avoidance, and mental disengagement were positively correlated with higher distress (Ong et al, 2016). In the face of the psychological distress and societal problems, although some of these strategies help reduce their burden or stress, others are not particularly helpful. (Kausar, and Powell, 1999) found that the caregivers of patients with neurological disorders who used emotional coping experienced higher distress than those who used problem coping. Other studies have found that coping strategies such as greater positive reframing, acceptance and lesser self-blame can

mediate between the patient's illness identity and the caregivers' belief in the patient's level of personal control over the illness (Fortune et al, 2005). Avoidance was associated with higher distress, while acceptance and social and instrumental support were related to lower distress among caregivers of terminally ill patients (Ong et al, 2016).

2.7. Summary of the Review and Conceptual Framework



Mental health problem is a multifaceted problem that is caused by numerous factors. It affects the patient and the rest people in different degree, characters and patterns. Those affected by its impact could be categorized in to three broad categories namely the patient, the family/caregivers and the surrounding community along with the rest environment. Caregivers and family members who give care for mentally ill patients encounter psychological problems in the process of helping patients. As a result, caregivers use different strategies to cope the burden.

Chapter three

Method

This consists of study design, study setting, sample population and sampling procedures, instruments of data collection, procedures of data collection, method of data analysis and ethical considerations.

3.1. Design

The research was undertaken in a mixed approach which literally includes both quantitative and qualitative category (Creswel, 2009) and Cross sectional study design. A considerable inclination has gone to the quantitative portion and the qualitative part was used to further explain the results.

3.2. Study setting

Amanuel Mental Specialized Hospital is one of the oldest hospital in Ethiopia which was established in 1937 G.C during the Ethio-Italian war. It is located in the western part of Addis Ababa in Addis Ketema Sub-city, kebele 08. Rendering health treatment service was interrupted in the hospital in the early 1947s G.C. The hospital resumed its function by expatriate doctors from Russia, Bulgaria, and Cuba from 1953-1977 G.C (Hussein et al, 2015).

On average 46,520 people with schizophrenia, 20,953 people with depression, and 3,406 people with bipolar disorder are treated as outpatients each year and approximately 200 patients are admitted each month. The hospital has 300 beds including 11 beds in private wing which serves for all type of mental disorder patients. The hospital has 13 Outpatient departments. The hospital is working on increasing the efficiency & effectiveness of the serves to make itself the center of mental health care excellences by giving core mental clinical services, conducting

research and trainings and other administrative services (Hussein et al, 2015). Another general hospital with the same service was constructed in the other part of the city, kotebe area, as one chamber of the main hospital.

3.3. Population, Sample and Sampling

3.3.1. Target population

The target populations were all caregivers or relatives who have attended the outpatient department at Amanuel hospital during the study period

3.3.2. Sample size determination

A total of 2200 persons were registered as caregivers in a month and the number of Hospital staffs who were involved in providing treatment and care was 398.

Hence, the researcher has employed Krejcie & Morgan (1970), formulae to identify representative sample from the total population.

The formula $S = \frac{X^2NP(1-P)}{d^2(N-1) + X^2P(1-P)}$

S = Required Sample Size

X^2 = the table value of chi-square for 1 degree of freedom at the desired confidence level

N = the population size

P = the population proportion (assumed to be 0.50 since this would provide the maximum sample size)

d = the degree of accuracy expressed as a proportion (0.05)

Accordingly, the required sample size was calculated to be 327.

3.3.3. Sampling technique

Mainly primary data were collected from people of two categories, namely, the caregivers of mentally ill outpatients in the hospital and the staff members who were exposed to both patient's service and their caregivers. The number of the caregivers and the staffs included in the research were indicated in the sample frame.

3.4. Inclusion and Exclusion criteria

1. Caregiver living with relative who had been suffering from mental illness for more than 6 months and
2. Caregivers whose age is 18 years and above were included in the study.

3.5. Tools/instruments of data collections

3.5.1. Socio-demographic measure

The questionnaire was adopted from (Zarit, 1980); (Oshodi et al, 2012) after some modifications consisting 15 items. The questioner is originally prepared in English and then translated to Amharic by the translators in order to make it easy for the respondents. The instrument has strong validity.

3.5.2. Psychosocial problem measure

The questionnaire/scale was adopted from Oshodi et al, (2012) and has 22 items, which is modified to suit the specific study context. The questionnaire was originally prepared in English and then translated in to Amharic by the translators in order to make it easy for the respondents.

The validity of the burden of care schedule (BOC) was found to be good. The internal consistency of the instrument was determined using Nigerian Sample Cronbach alpha & split-half reliabilities were computed. The Cronbach alpha of 0.91 & Split-half coefficient of 0.82 were obtained. The instrument has a strong internal consistency thereby suggesting that it is highly reliable. The prepared questionnaires were distributed for 30 caregivers for pilot testing in order to check the reliability of the study and it is 0.91.

3.5.3. Coping mechanism measure

The questionnaire/scale was adopted from Ong et al, (2016) 16 items which is modified to suit the specific study context. The questioner was originally prepared in English and then translated to Amharic by the translators in order to make it easy for the respondents. It has internal consistency and Conner-Davidson Resilience Scale (CD-RISC) had a Cronbach alpha of 0.94. The prepared questionnaires were distributed for 30 caregivers for pilot testing in order to check the reliability of the study and it is 0.91.

3.5.4. Interview guide

Seven items were prepared for health professionals who give care for mentally ill patients by counting them as the caregiver for mentally ill patients at Amanuel Mental Specialized Hospital. There were around 398 health professionals that give care for patients. The researcher used convenient sampling in order to select them.

3.6. Procedure of data collection

Orally permission and management approval was obtained for the study from Amanuel Mental Specialized Hospital. Official letter was written from the School of Psychology to the Hospital higher official's in order to conduct the study. The prepared questionnaires were

distributed for 30 caregivers for pilot testing in order to check the reliability of the study (0.91). After checking the reliability, the required data were collected, and analyzed accordingly.

3.7. Method of data analysis

The findings of the research were analyzed using SPSS and summarized in the forms of descriptive statistics and inferential statistics. The descriptive findings were expressed using frequencies, percentages, and means. Odd ratio was used to analyze the relationship between factors and psychological experience, and coping strategy of the caregivers. These were then put in tables, figures and graphs. The interpretations include both qualitative and quantitative modalities.

3.8. Ethical considerations

Ethical approval was obtained from the Ethical Review Committee of the School of Psychology at Addis Ababa University. Official letter was written for Amanuel Mental Specialized Hospital from the School of Psychology. The study participants were informed to sign a written informed consent form before commencing the study. Information was provided to all the study subjects regarding the purpose of the study. Participants who are not able to read and write were requested to give a verbal consent. The collected data were only used for research purpose. Confidentiality was guaranteed by maintaining anonymity of all caregivers who were participated in the study. Freedom to withdraw from the study was ensured as well.

Chapter four

Result

4.1 Socio demographic characteristics of the study participants

The study involved a total of 327 participants with response rate of 100%. Out of the 327 participants, 144 (44%) were female and 183 (56%) male. One-third 108 (33%) of the participants were in the age group of 25-34 followed by the age group 35-44 (23.2%). Regarding their religion, majority 168 (51.4%) were orthodox Christian followers.

The percentage distribution of participants according to the educational level of the mother indicates that 75 (22.9%) have attended higher education and 17.1 % of them are able to read and write. The finding further revealed that 64.2% of the patients had more than two years treatment follow up (Table 1).

Table 1: Distribution of socio demographic characteristics of the respondents in Amanuel Hospital, 2018 (n=327).

Variables	Category	Frequency	Percentage
Age	18-24	71	21.7
	25-34	108	33
	35-44	76	23.2
	45-54	41	12.5
	Above 55	31	9.5
Sex	Male	183	56
	Female	144	44
Religion	Orthodox	168	51.4
	Protestant	65	19.9
	Muslim	82	25.1
	Other	12	3.6
Marital status	Unmarried	125	38.2
	Married	183	56
	Other	19	5.8
Level of education	Non educated	46	14.1
	Reading and writing only	57	17.4
	Primary school	104	31.8
	Secondary school	45	13.8
	Higher education	75	22.9
Occupation	Employed	86	26.3
	Non employed	86	26.3
	Self employed	155	47.4
Monthly income	Below 1000	23	7.0
	1001-2500	90	27.5
	2501-3500	69	21.1
	3501-4500	21	6.4
	4501-5500	16	4.9
	Above 5501	22	6.7
What is your relation with the patient?	Supportive	86	26.3
	Father	23	7
	Mother	50	15.3
	Sister	88	26.9
	Brother	76	23.2
	Other	90	27.5
How long has it been since the patient started follow up here?	From a week to six months	80	24.5
	From six months to one year	14	4.3
	From one year to two years	23	7.0
	Above two years	210	64.2
How long have you been involved in giving care for a mentally ill person?	From one week to six months	161	49.2
	From six months to one year	17	5.2
	From one year to two years	10	3.1
	Above two years	139	42.5
The kind of mental disorder has the patient you give care has faced?	Schizophrenia	139	42.5
	Bipolar	66	20.2
	Depression	67	20.5
	Schizoid affective	20	6.1
	Other	35	10.7
How many hours a day in average you spend with the patient?	1-8 hours	140	42.8
	9-16 hours	45	13.8
	17-24 hours	142	43.4
Are you the only caregivers for the patient?	Yes	43	13.1
	No	284	86.9
Who else supports you in care giving activity?	Family member	260	79.6
	Relatives. Friend and colleague and Neighbors	24	7.3
What kinds of support have you got so far?	Part time care giving	217	66.4
	Financial support, Covering home/office work	67	20.4

4.2 Relation of the respondents with the patient

Regarding the relation of the respondents with the patients, 88 (26.9%), 50 (15.3%) and 76 (23.2%) were sister, mother and brother respectively. (Fig 1)

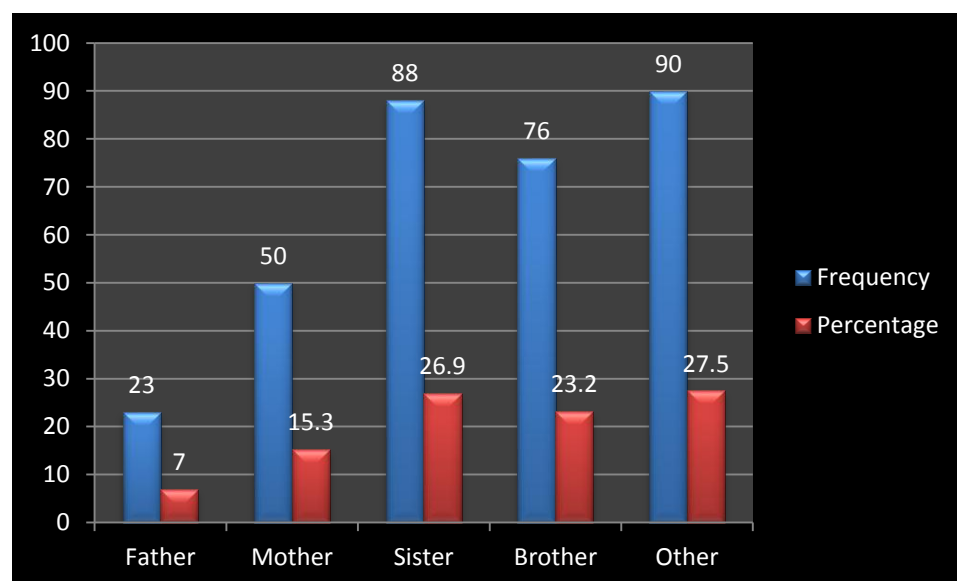


Fig 1:- Relation of the respondents with the patient in Amanuel Hospital, Ethiopia, 2018 (n=327).

4.3 Psychosocial problems of the caregivers

Out of the 327 study participants, 275 (84.1 %) reported that their privacy was not affected because of their relative. Whereas 10 (3.5%) of the participants said that they always do not have privacy as they would like because of their relative. Majority of the study participants 291 (89%) have reported as they do not avoid inviting friends and acquaintances home because of their relative's problem.

Of the total respondents, 17 (5.2%) have reported that they feel their relative is dependent upon them. Some of the study participants 89 (27.2 %) have reported that they have lost their job because of their relative's illness (Table 2).

Table 2:

Psychosocial problems of the caregivers in Amanuel Hospital Ethiopia, 2018 (n=327).

Variables	Not at all	To some extent	Frequently	Always
Do you feel that you don't have as much privacy as you would like because of your relative?	275(84.1%)	37(11.3%)	5(1.25%)	10(3.5%)
Do you feel that your relative is dependent upon you?	251(76.8%)	55(16.8%)	4(1.2%)	17(5.2%)
Have you a feeling that life has treated you unfairly?	277(84.7%)	33(10.1%)	13(4.0%)	4(1.2%)
Do you avoid inviting friends and acquaintances home because of your relative's problem?	291(89.0%)	24(7.3%)	6(1.8%)	6(1.8%)
I have faced loss of work	217(66.4%)	89(27.2%)	14(4.3%)	7(2.1%)
I have faced conflict with neighbor's by the patients uncontrolled behavior	238(72.8%)	75(22.9%)	11(3.4%)	3(0.9%)
My sleep is affected since the patient is ill	106(32.4%)	171(52.3%)	36(11.0%)	14(4.3%)
I fall sick	236(72.2%)	84(25.7%)	3(0.9%)	4(1.2%)
I have experience psychological problem	236(72.2%)	71(21.7%)	14(4.3%)	6(1.8%)
I am angry	252(77.1%)	56(17.1%)	14(4.3%)	5(1.5%)
I feel ashamed	274(83.8%)	38(11.6%)	6(1.8%)	9(2.8%)
I feel sad	244(74.6%)	65(19.9%)	11(3.4%)	7(2.1%)
I get worried	246(75.2%)	62(19.0%)	13(4.0%)	6(1.8%)
I feel embarrassed	258(78.9%)	51(15.6%)	7(2.1%)	11(3.4%)
I am very tired	143(43.7%)	98(30.0%)	32(9.8%)	54(16.5%)
I am afraid	231(70.6%)	78(23.9%)	10(3.1%)	8(2.4%)
I always feel guilty	281(85.9%)	38(11.6%)	4(1.2%)	4(1.2%)
I have no friends	276(84.4%)	41(12.5%)	8(2.4%)	2(0.6%)
I can't tell anyone my agonizing experience	251(76.8%)	47(14.4%)	23(7.0%)	6(1.8%)
I have faced social role restriction	277(84.7%)	41(12.5%)	5(1.5%)	4(1.2%)
I have faced friendship refusal	276(84.4%)	43(13.1%)	3(0.9%)	5(1.5%)
I faced a problem in my marriage life	285(87.2%)	33(10.1%)	8(2.4%)	1(0.3%)

4.4. Coping Mechanisms

In relation to coping mechanism, this study has revealed that 302 (92.4%) of the respondents have not used substance as a means to escape the problem while 2 (0.6%) of the respondents experienced substance use. Nearly 77(23.5%) have used religious and spiritual means to escape the problem. Of the total participants 227 (69.4%) did not experienced behavioral disengagement to escape the problem.

Regarding self-distraction, 231 (70.6%) have not, 78 (23.9%) to some extent, 11 (3.4%) frequently and 7 (2.1%) always experienced self-distraction to escape the problem. Most of the study participants 199 (60.9%) have not experienced venting to escape the problem whereas 8 (2.4%) of the study participants have (Table 3).

Table 3: Coping Mechanisms in Amanuel Hospital Ethiopia, 2018 (n=327).

Variables	Not at all	To some extent	Frequently	Always
I have experienced substance use as a means to escape the problem	302(92.4%)	21(6.4%)	2(0.6%)	2(0.6%)
I have experienced venting to escape the problem	199(60.9%)	105(32.1%)	15(4.6%)	8(2.4%)
I have experienced religion and spirituality to escape the problem	136(41.6%)	89(27.2%)	25(7.6%)	77(23.5%)
I have experienced reinterpretation to escape the problem	233(71.3%)	84(25.7%)	4(1.2%)	6(1.8%)
I have experienced denial to escape the problem	268(82.0%)	51(15.6%)	5(1.5%)	3(0.9%)
I have experienced humor to escape the problem	249(76.1%)	66(20.2%)	7(2.1%)	5(1.5%)
I have experienced behavioral disengagement to escape the problem	227(69.4%)	86(26.6%)	6(1.8%)	8(2.4%)
I have experienced positive reframing activities to escape the problem	172(52.6%)	79(24.2%)	35(10.7%)	41(12.5%)
I have experienced self-distraction to escape the problem	231(70.6%)	78(23.9%)	11(3.4%)	7(2.1%)
I have experienced total acceptance of the problem to escape the burden	165(50.5%)	111(33.9%)	21(6.4%)	30(9.2%)
I have experienced emotional support from others to escape the problem	180(55.0%)	133(40.7%)	7(2.1%)	7(2.1%)
I have experienced instrumental support from others to escape the problem	187(57.2%)	127(38.8%)	6(1.8%)	7(2.1%)
I have experienced social support to escape the problem	193(60.2%)	113(34.6%)	12(3.7%)	9(2.8%)
I have experienced active coping to escape the burden	173(52.9%)	115(35.2%)	21(6.4%)	18(5.5%)
I have experienced crying to escape the problem	261(79.8%)	41(12.5%)	20(6.1%)	5(1.5%)

4.5. Prevalence of psychosocial problem

Questions related to psychosocial problem were asked to magnify the burden of caregivers. The psychosocial problem was estimated by taking the mean score of all subscales. The responses were summed up and a total score was obtained for each respondent. The mean was calculated (mean = 29.3) and those who scored above the mean value had psychosocial problem and the one who scored less than the mean value had no psychosocial problem

Among the study participants 110 (33.6 %) were reported having psychosocial problem, and 217 (66.4%) have no psychosocial problem (fig 2).

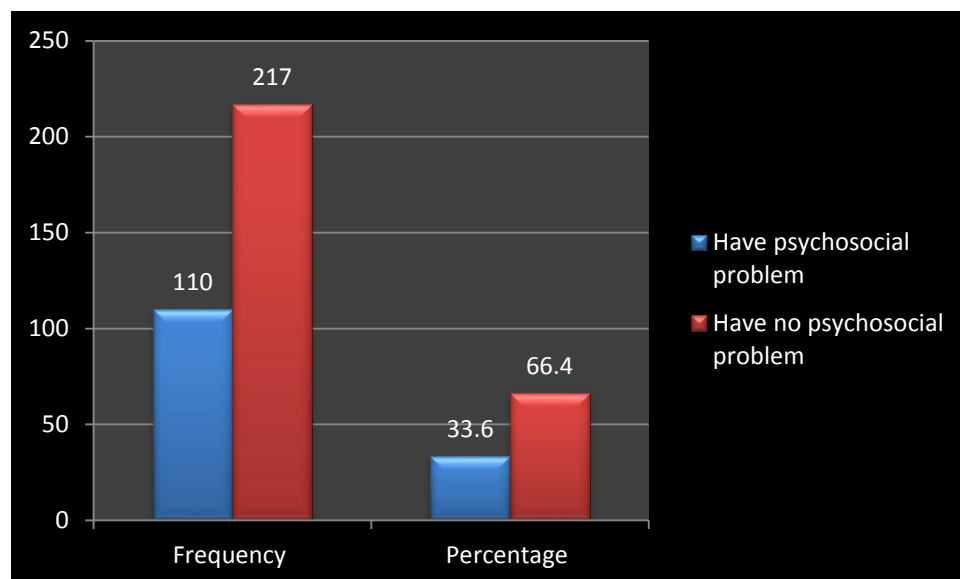


Fig 2:- Prevalence of Psychosocial problem in Amanuel Hospital, Ethiopia, 2018 (n=327).

Among the total population those participated in the current study, the percentage of psychosocial problem according to sex was calculated as follows: -

Among the male respondents: -

$$M = n_1 / \text{total male}$$

$$M = 42 / 183 \times 100$$

$$M = 22.9\%$$

Among the female respondents: -

$$F = n_2 / \text{total female}$$

$$F = 68 / 144 \times 100$$

$$F = 47.2\%$$

The total percentage of psychosocial problem was:-

$$\text{Total psychosocial problem} = n_1 + n_2 / \text{total population}$$

$$\text{Total psychosocial problem} = 110 / 327 \times 100$$

$$\text{Total psychosocial problem} = 33.6\%$$

4.6 Factors associated with prevalence of psychological problems

Bivariate and multivariate analysis was performed between psychological problems (dependent variable) and socio demographic status of caregivers (independent variable). Binary Logistic regression was performed to assess the association of each independent variable with psychological problems. The variables that showed a p-value of 0.2 and less were added to multivariate regression model. In the multiple logistic regression analysis: age, marital status, duration in giving care and being the only care giver remains significantly associated with psychological problems.

The caregivers whose age between 35 and 44 were 2.56 times more likely to have psychosocial problem **{(AOR=2.56; (1.24, 5.25))}** as compared to those age between 25 and 34. Caregivers of patients with mental illness who were divorced were 4.3 times more likely to have psychosocial problem **{(AOR=4.3; (1.23, 15.05))}** as compared to caregivers of patients with mental illness who were unmarried.

Table 4:

Factors associated with prevalence of psychological problems, 2018 (n=327).

Variables	Category	COR. 95%CI	AOR, 95%CI
Age	18-24	1.93 (1.009, 3.71)	1.663 (.789, 3.502)
	25-34	1	1
	35-44	2.55(1.35,4.8)	2.561 (1.248, 5.255)
	45-54	1.3(0.58,2.91)	1.353 (.541, 3.386)
	Above 55	1.73(0.73,4.09)	1.628(.579, 4.580)
Marital status	Unmarried	1	1
	Married	0.88(0.54,1.43)	.630(.319, 1.245)
	Divorced	4.5(1.46,13.83)	4.316(1.237, 15.053)
	Widowed	-	-
How long have been involved in giving care for a mentally ill person	From one week to six months	1	1
	From six months to one year	3.6(1.3,10.26)	4.601(1.514, 13.977)
	From one year to two years	2.57(0.7,9.33)	2.981(.712, 12.485)
	Above two years	1.44(0.88,2.36)	1.625(.920, 2.870)
the only caregivers for the patient	Yes	5.88(2.92, 11.85)	5.410(2.567, 11.400)
	No	1	1

4.7 Qualitative Result

After interviewing the professionals in Amanuel Hospital on psychosocial problem of caregivers and the solution, the following findings were narrated.

Table 5. Socio-demographic characteristic of the respondents for interview in Amanuel Hospital in Addis Ababa, Ethiopia, 2018

Respondent	Age	Sex	Position	Level of education
R1	35	F	Case team coordinator	Psychiatry Nurse
R2	50	M	Expert psychiatry profession	Expert Ps Profession
R3	36	M	Coordinator	Expert Ps Profession
R4	25	M	Social worker	Masters
R5	27	F	Nurse coordinator	Degree
R6	37	M	Inpatient vice director	Masters
R7	25	F	Psychologist	Degree

Analysis of qualitative data

Regarding the assessment of the psychosocial problem and its solution, majority of the interviewed respondents have figured out some common problems. After analysis, the following themes emerged from the data.

Anxiety due to poor prognosis

For example, 35 years old female case team coordinator said that:

R1 *“the care givers of mentally ill patients may encounter different problems. Anxiety is one of the problem they face because they worry about the future due to poor prognosis of the disease. They fear to live with the society as before because their income will be deprived day to day and their economy will be low. To solve the problem, they attempt activities that they believe will improve the*

disease, like by locking the patients in isolated room, by taking into traditional healer and by taking into spiritual places.

Poor societal awareness

A 50 years old expert psychiatry professional mentioned that

R2 “the care givers have many problems related to mentally ill patients. The main thing is the one that comes from the society. The societies have low awareness about psychiatric illnesses and they discriminate the family. They do not understand the pain or burden that comes because of the patients. The societies believe that the disease comes from evil spirit or from curses. So in order to overcome this problem the government should increase the awareness by educating the society. Social workers should work closely with the society and establishing rehabilitation centers can improve the problem.”

Societal discrimination

Another 36 years old male coordinator also mentioned that

R3 “.....they are discriminated from the society. This discrimination is not only because of societal impact but it is mainly by the patients themselves. Because of themselves and the societal reason, patients are being isolated. The caregivers try to overcome this problem by hiding the patient in room and by acting, as he/she does not have the illness. On the other hand, the other caregivers bring the patients to the clinic by understanding the problem as like other treated disease. The government has to work on increasing community’s awareness whether in school or using media.”

Economic crisis and poor societal interaction

A 25 years social worker explained that

R4 *“the caregivers face both self and social stigma. The society believes that the families are cursed and God has punished them by saying ‘Yegzerkuta ‘. Patient’s families believe, as the patient is useless after all. They worry about economy and decreased activity in the society. The government should give more attention and work on awareness creation campaign”*.

Patient inflicted injury

A 27 years female nurse coordinator mentioned that

R5 *“the caregivers fear the patient perceiving that he/she can injure them and because of this they develop depression. They want them to be admitted in the clinic and they do not want to go home with the patient.”*

Anxiety because of disease recurrence

A 37 years old inpatient vice director explained that

R6 *“the caregivers of the patient develop anxiety because of disease recurrence and prolonged treatment duration”. To solve the problem, they need encouragement and detailed information about the disease progress and probability of cure from professionals”*.

Wrong believe

A 25 years psychologist mentioned that

R7“they took as it is the only problem the family is facing and it is a curse that came from God to punish us. They got depressed because of absence from work and the time they spent with the patient. To be sure about the prognosis they need to share experience from others who have encountered similar problem.”

Chapter five

Discussion

The study employed has attempted to assess the magnitude of Psychosocial Problems among Families Caring for Relatives with Mental Illness and their Coping Strategies in Amanuel Mental Specialized Hospital, Ethiopia.

5.1 The prevalence of psychosocial problems

The current study found that almost one-third (33%) of the study participants had Psychosocial problem. This study was consistent with the study conducted in Malaysia. In Malaysia, 31.5% of the caregivers had psychosocial problem and more than half the sample of respondents did not exhibit any psychosocial problem (Tan, Yeoh, choo, 2012).

In the current study, some of the participants mentioned that they have faced conflict with neighbors due to the patient's uncontrolled behavior. This finding was consistent with the finding of the research conducted in Tanzania where the caregivers revealed that their relatives' uncontrolled behavior such as temper tantrums, shouting in public, insulting people and neighbors and hitting people had caused them to have difficulty in forming and maintaining good social relationships. Some caregivers were blamed for their relative's behavior in court of law causing endless misunderstanding between family with the ill relative and the neighborhood (Masunga et al, 2016).

5.2 Factors associated with prevalence of psychosocial problem

In the regression model the factors that were significantly associated with psychosocial problem was age. The caregivers whose age was between 35 and 44 were 2.56 times more likely to have psychosocial problem {(AOR=2.56; (1.24, 5.25)} as compared to those whose age was between 25 and 34. This finding was consistent with the finding of the study conducted in west India where there was a statistically significant positive correlation between the age of caregivers and the level of psychological problem. It implies that the level of problem increases with the age of caregivers (Aditya et al, 2015).

It is also comparable with the Indian study in which when caregivers become older; they are worried about who will take care of their ill family member in the future. (Rammohan et al, 2012). The effects of age on the coping styles of family caregivers, and on the recovery or rehabilitation of persons with mental illness is important factors to be considered (Doherty et al, 2008).

5.3 Coping strategies

In relation to coping mechanism, the present study revealed that almost half of the participants have totally accepted the problem to escape the burden. This was comparable with the finding of the study conducted in Tanzania where the caregivers had learned to accept and reconcile the disability or deviant behavior in the mentally ill relative so as to avoid the dissatisfaction and disappointment that could have resulted from the patient's bizarre behavior (Masunga et al. 2016).

The study further revealed that the caregivers of mentally ill patients experienced some coping strategies such as substance use, use of emotional support and behavioral disengagement

as a means to escape the problem. This study was comparable with the study conducted in Malaysia where some coping strategies such as substance use, use of emotional support, behavioral disengagement were experienced Tan, (Yeoh, choo, 2012)

Chapter six

Summary, Conclusion and Recommendation

6.1. Summary

The current study was conducted on the psychosocial experience and the coping strategies of caregivers of patients with mental illness in Amanuel Mental Specialized Hospital. The study specifically examined the prevalence, coping strategies and factors associated with psychosocial problem.

The study was directed by two research questions. The research questions were

1. How many percent of the caregiver's experience psychological problems at Amanuel Mental Specialized Hospital?
2. How do caregivers cope the psychological problems they face while giving care at Amanuel Mental Specialized Hospital

The study design was cross sectional study and some portion of the research questions were addressed using qualitative interview. All caregivers or relatives who have attained the outpatient department at Amanuel hospital with in the study period were the target population. The questionnaire divided into three sections was used to collect data from the respondents. Section one was socio demography, section two was about psychosocial issues/problems and section three was about coping mechanism.

The quantitative questionnaire consisted closed-ended and the qualitative one contained open-ended questions. The collected data were analyzed using the Statistical Package for Service Solution (SPSS) version 21.

Key Findings

The main findings of the study were organized in line with the research questions

- The percentage distribution of participants according to the educational level of the mother indicates that majority of the respondents have attended higher education.
- Majority of the participants were in the age group of 25-34.
- Majority of the study participants have reported as they do not avoid inviting friends and acquaintances home because of their relative's problem.
- Some of the study participants have reported as they faced loss of work because of their relative's illness.
- A number of participants have used religious and spiritual means to escape the problem.
- Almost one third of the study participants had psychosocial problem.

6.2. Conclusion

The study found that there was a relatively high number of psychosocial problems among the study subjects. In addition, age, marital status, duration of giving care and being the only caregiver for the patients had significantly associated with high psychosocial problem. Older caregivers were more likely to have psychosocial problems. Divorced were more likely to have psychosocial problems compared to single caregivers. Those caregivers who provide care for long period of time were likely to develop psychosocial problems as compared to those who provide care for less duration. Being the only caregiver was positively associated with psychosocial problems. The major reasons that were mentioned by health care providers on the development of caregivers psychosocial were poor disease prognosis, extended follow up, self and social stigma, taking as it is the only problem of their family and thinking that it is a curse

that was came from God to punish. As a result, they lock patients in isolated room and hide them to overcome the discrimination that exists in the society. A number of participants have used religious and spiritual means to escape the problem. Most of the study participants have experienced venting to escape the problem

There is a need to design and implement important interventions in order to tackle the identified psychosocial problems early.

6.3. Recommendation

Based on the finding of the study, the following recommendations were forwarded for all concerned bodies/stakeholders and other researchers:

6.3.1. Hospital decision makers

- The hospital decision makers should focus on the availability of services to meet the psychological needs of mentally ill patient's caregivers.
- The Amanuel hospital should adopt a holistic approach (all-inclusive like the problems of caregivers) in the treatment of mentally ill patients and family caregivers.

6.3.2. Health care providers

- The health care professionals have to address the emotional needs of caregivers by teaching them most effective coping strategies

6.3.3. Other researchers

- Other researchers should focus on the care giving role and patient characteristics (behaviors that are being reflected by the illness) which can affect caregiver's outcomes.

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Appendix I

Questionnaire

Dear Sir/Madam

I, Ms. Serkalem Getaneh, am MA student at Addis Ababa University, School of Psychology. Currently, I am conducting my Master's thesis research on "the Psychosocial Experience and the Coping Strategies of Caregivers of Patients with Mental Illness in Amanuel Mental Specialized Hospital". This questionnaire is prepared to collect data in order to meet this endeavor. Assuring you that the data is required only for an academic research and will be confidential from any third party, I ask you to fill the questionnaire.

In case you want to contact me for any clarification or information regarding this questionnaire, please do not hesitate to reach me via the following addresses

Serkalem Getaneh

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Part I. Background Information

1. Your Age:-18-24 years, 25-34 years,35-44 years,45-54 years, 55 & Above
2. Sex Male ☐ Female ☐
3. Religion: Orthodox ☐ Protestant ☐ Muslim ☐ catholic ☐ others_____
4. Marital status Unmarried ☐ Married ☐ Divorced ☐ Widowed ☐
5. Level of education: -Non educated, Reading & Writing, Primary school, Secondary school, higher education, other.....
6. Occupation: -employed, Non employed, self employed
7. Monthly income: - Below 1000 ☐ 1001-2500 ☐ 2501-3500 ☐ 3501-4500 ☐
4501-5500 ☐ Above 5501 supportive ☐
8. What is your relation with the patient: -father, mother, sister, brother, other.....
9. How long has it been since the patient start follow-up here?from 1 weak-6 month ☐
from 6 month-1 years ☐ 1 year-2 years ☐ Above 2 years ☐
10. How long have you been involved in giving care for a mentally ill person? from 1 weak-6 month ☐ from 6 month-1 years ☐ 1 year-2 years ☐ Above 2 years ☐

11. The kind of mental disorder has the patient you give care has faced? Schizophrenia ☐
 Bipolar ☐ Depression ☐ Schizoaffective ☐ Other ☐
12. How many hours a day in average you spend with the patient? 1-8 hours ☐ 9-16 hours ☐
 17-24 hours ☐
13. Are you the only caregivers for the patient? Yes ☐ No ☐ if ☐ answer the next No, 14
 & 15
14. Who else supports you in care giving activity?
- Family members, ☐ relatives, ☐ friends and staffs, ☐ neighbors, ☐
15. What kinds of support have you got so far
- Part-time care giving ☐ financial support ☐ covering home/office works ☐

Part II. Psychosocial problems face by the caregivers

Please tick one box in each row for the following items to show the degree of psychosocial problems you experienced due to your care-giving role.

According to the given choice, if you did not have any psychosocial problem you can tick No, 1 if you face a little problem you can tick No 2, if you face the problem regularly you can tick No 3, & if you face the problem at all time you can tick No 4.

1=Not at all 2= to some extent 3=frequently 4=Always

N	Item questions/issues	1	2	3	4
1.	Do you feel that you do not have as much privacy as you would like, because of your relative?				
2.	Do you feel that your relative is dependent upon you?				
3.	Have you a feeling that life has treated you unfairly?				
4.	Do you avoid inviting friends and acquaintances home because of your relative's problem?				
5.	I have faced loss of work				
6.	I have faced conflict with neighbor's by the patients uncontrolled behavior				
7.	My sleep is affected since the patient is ill				
8.	I fall sick				
9.	I have experience psychological problem				
10.	I am angry				
11.	I feel ashamed				
12.	I feel sad				

N	Item questions/issues	1	2	3	4
13.	I get worried				
14.	I feel embarrassed				
15.	I am very tired				
16.	I am afraid				
17.	I always feel guilty				
18.	I have no friends				
19.	I can't tell anyone my agonizing experience				
20.	I have faced social role restriction				
21.	I have faced friendship refusal				
22.	I have faced a problem in My Marriage life				

Part III. Coping Mechanisms

How often have you experienced the following coping strategies as a means to escape the problem associated to your care-giving role by ticking on one box of each rows

According to the given choice if you didn't use any coping strategy you can tick No 1, if you use a little coping strategies you can tick No 2, if you use coping strategies regularly you can tick No 3, & if you use coping strategies at all time you can tick No 4.

1=Not at all 2 = to some extent 3= frequently 4= Always

N	Item questions/issues	1	2	3	4
23	I have experienced substance use as a means to escape the problem				
24	I have experienced venting to escape the problem				
25	I have experienced religion and spirituality to escape the problem				
26	I have experienced reinterpretation to escape the problem				
27	I have experienced denial to escape the problem				
28	I have experienced humor to escape the problem				
29	I have experienced behavioral disengagement to escape the problem				
30	I have experienced positive reframing activities to escape the problem				

N	Item questions/issues	1	2	3	4
31	I have experienced self-distraction to escape the problem				
32	I have experienced self-blame to escape the problem				
33	I have experienced total acceptance of the problem to escape the burden				
34	I have experienced emotional support from others to escape the problem				
35	I have experienced instrumental support from others to escape the problem				
36	I have experienced social support to escape the problem				
37	I have experienced active coping to escape the burden				
38	I have experienced crying to escape the problem				

These interviews are prepared for Amanuel Hospital Health professional who give care for mentally ill patients at outpatient department to measure the psychosocial problem and coping strategies of mentally ill patient's relatives or caregivers.

Interview index (for key informants)

1. Your position/ role in this institution
2. How long have you been working here
3. What are the major psychological problems the caregivers of the patients here face?
4. What are the major social problems the caregivers of the patients here face?
5. What are the major problems that the caregivers of the patients here face?
6. What actions do they take as coping strategy to escape the psychosocial burden?
7. What do you advise the caregivers, the government, this institution and the community to do to reduce the problem?

Appendix II: Amharic version questionnaire