



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

**CAREGIVERS' KNOWLEDGE, ATTITUDE AND HELP SEEKING BEHAVIOR
TOWARDS MENTAL ILLNESS, AT ST. AMANUEL MENTAL SPECIALIZED
HOSPITAL, ADDIS ABABA, ETHIOPIA**

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ADVISOR:
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JUNE, 2026

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DECLARATION

I, Julia Wondemu, conducted this study independently with the assistance and direction of the research advisor, Mr. Nimona Shaka, in partial fulfillment of the requirement for the degree of Master of Art in Counseling Psychology on the topic of “Caregivers’ Knowledge, Attitude and Help Seeking Behavior Towards Mental Illness, At St. Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia”

This research is entirely original to me and has not been submitted to any school, here or elsewhere, for a degree of master’s program.

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TOWARDS MENTAL ILLNESS, AT ST. AMANUEL MENTAL SPECIALIZED
HOSPITAL, ADDIS ABABA, ETHIOPIA: A QUALITATIVE STUDY**

APPROVAL OF THE BOARD OF EXAMINERS

**WE, THE EXAMINERS' BOARD, APPROVE THAT THIS THESIS HAS PASSED
THROUGH THE DEFENSE AND REVIEW PROCESS.**

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ABSTRACT

Caregivers play a vital role in the care and recovery of individuals with mental illness, making their knowledge, attitudes, and help-seeking behaviors important factors influencing treatment outcomes. This study explored caregivers' knowledge, attitudes, and help-seeking behaviors toward mental illness using a qualitative descriptive design. Participants were purposively selected based on caregiving experience and willingness to participate in Amharic-language interviews. A total of thirteen caregivers of patients admitted to St. Amanuel Mental Specialized Hospital participated in the study. Data were collected through in-depth interviews, which were audio-recorded, transcribed verbatim, translated into English, and analyzed thematically using Braun and Clarke's six-step approach with the support of Open Code version 4.03. Three themes emerged from the analysis: caregivers' conceptualization of mental illness, caregivers' perceptions of people with mental illness and their future prospects, and caregivers' help-seeking experiences and treatment decision-making. Across these themes, nine subthemes were identified. Findings indicated that caregivers generally demonstrated an understanding of mental illness and its perceived causes; however, gaps were evident in recognizing less visible symptoms, identifying specific diagnoses, and understanding medication side effects. Regarding attitude towards MI, the finding indicates promising positive attitude towards possibility of recovery and capability of PWMI. Whereas negative attitude is seen about their perception towards People with Mental illness, perceiving Mental illness as illegitimate illness and detectability of mental illness through physical attribute Help-seeking experiences were initially shaped by traditional and faith-based practices, while subsequent experiences with modern mental health services contributed to a growing preference for biomedical treatment pathways.

The study concludes that, despite a general understanding of mental illness, important knowledge gaps and stigmatizing beliefs remain among present among caregiver's participant. As a recommendation, the findings highlight the need for caregiver-focused psychoeducation, community mental health awareness initiatives, and collaboration with religious leaders to promote early recognition of mental illness and timely access to appropriate mental health care.

Table of Contents

DECLARATION	I
ACKNOWLEDGEMENT	III
ABSTRACT	IV
ACRONYMS	1
LIST OF TABLE	2
LIST OF FIGURE	3
CHAPTER 1: INTRODUCTION	4
1.1. BACKGROUND OF THE STUDY.....	4
1.2. STATEMENT OF THE PROBLEM	6
1.3. OBJECTIVE OF THE STUDY.....	8
1.3.1. General Objective of the Study.....	8
1.3.2. Specific Objective of the Study	8
1.4. SIGNIFICANCE OF THE STUDY	8
1.5. SCOPE OF THE STUDY	9
1.6. OPERATIONAL DEFINITION.....	10
CHAPTER 2: REVIEW OF RELATED LITERATURE	11
2.1. MENTAL ILLNESS.....	11
2.2. CAREGIVERS OF PEOPLE WITH MENTAL ILLNESS.....	12
2.3. EXPLANATORY MODEL OF MENTAL ILLNESS IN ETHIOPIA	13
2.4. CAREGIVERS' KNOWLEDGE, ATTITUDE AND HELP-SEEKING BEHAVIOR TOWARDS MENTAL ILLNESS.....	15
2.4.1. Caregivers' Knowledge towards Mental Illness	15
2.4.2. Caregivers' Attitude towards Mental illness	17
2.4.3. Caregivers' Help – seeking behavior towards Mental illness	18
2.5. THEORETICAL FRAMEWORK.....	20
CHAPTER 3: RESEARCH METHODOLOGY	21
3.1. STUDY APPROACH.....	21
3.2. STUDY DESIGN	21
3.3. STUDY AREA AND TARGET POPULATION	21
3.4. SAMPLE AND SAMPLING DESIGN	22
3.5. METHOD OF DATA COLLECTION	22
3.6. PROCEDURE OF DATA COLLECTION.....	23
3.7. ELIGIBILITY CRITERIA.....	23
INCLUSION CRITERIA	23
Exclusion Criteria.....	23
3.8. METHOD OF DATA ANALYSIS.....	24
3.9. ETHICAL CONSIDERATION.....	24
CHAPTER 4: RESULT	25
4.1. PARTICIPANTS SOCIODEMOGRAPHIC DATA.....	25
4.2. CAREGIVERS' CONCEPTUALIZATION OF MENTAL ILLNESS.....	28
4.3. CAREGIVERS' PERCEPTIONS OF PEOPLE WITH MENTAL ILLNESS AND THEIR LIFE PROSPECTS.....	35
4.4. CAREGIVERS HELP-SEEKING EXPERIENCES AND TREATMENT DECISION.....	44
CHAPTER 5: DISCUSSION.....	48
CHAPTER 6: CONCLUSION, LIMITATION AND RECOMMENDATION	56

6.1. CONCLUSION.....	56
6.2. LIMITATION OF THE STUDY.....	56
6.3. RECOMMENDATION	57
REFERENCES.....	58
ANNEXES	66
ANNEX I - INFORMATION SHEET	66
ANNEX II - INFORMED CONSENT FORM.....	68
ANNEX III - DATA COLLECTION FORM	69
ANNEX IV - INTERVIEW TOPIC GUIDE	70
ANNEX V - SAMPLE INTERVIEW TRANSLATIONS	71

ACRONYMS

AMSH – St. Amanuel Mental Specialized Hospital

EM – Explanatory Model of illness

CMD – Common Mental Disorder

LMIC – Low- & Middle-Income Countries

MI – Mental Illness

PWMI – People with Mental Illness

WHO – World Health Organization

List of Table

Table 1 Caregiver participants' sociodemographic characteristics, Addis Ababa, 2026	26
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List of Figure

Figure 1 Thematic Analysis of Participants' Interview, Addis Ababa, 2026	27
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Chapter 1: Introduction

1.1. Background of the Study

Mental health is a critical state of well-being that empowers individuals to manage life's stresses, realize their potential and contribute to their communities (World Health Organization, 2024). Whereas, Mental illness is characterized by clinically significant disturbances in cognition, emotional regulation, or behavior, often causing profound distress and functional impairment (Association, 2022; World Health Organization, 2022). The global burden of these disorders is significantly high, as reported by the World Health Organization (WHO), nearly one billion people, including one in eight individuals worldwide, were living with a mental disorder in 2019, with anxiety and depression being the most prevalent (World Health Organization, 2022).

The distribution of the global mental health burden is highly inequitable, disproportionately impacting low- and middle-income countries (LMICs) like Ethiopia. The elevated prevalence of mental illness is driven by a complex set of risk factors, including socioeconomic determinants such as poverty, food insecurity, and unemployment, alongside trauma-inducing events like internal displacement, conflict, and natural disasters (Jebena et al., 2016; Rathod et al., 2019). Furthermore, inadequate healthcare systems and resources place significant additional strain on Low- and Middle-Income Countries (LMICs), making it difficult to address this growing crisis.

As the Ministry of Health of Ethiopia reports, Mental illnesses are the leading non-communicable disorders (Federal Democratic Republic of Ethiopia Ministry of Health, 2012). According to the World Health Organization (WHO) about 4.48 million people in Ethiopia (4.7%) live with depression, while around 3.14 million (3.3%) experience anxiety. These mental health issues lead to a significant number of years lived with disability, with depression accounting for approximately 837,683 years (10.1%) and anxiety contributing about 292,650 years (3.6%) (World Health Organization, 2017).

As the Diagnostic and Statistical Manual (DSM) of Mental Disorders describes, almost all mental illnesses cause significant distress and impairment in the social, occupational, and other important areas of functioning of the patient's life (Association, 2022). This impairment is often compounded by overwhelming feelings of worry, anxiety, and hopelessness regarding their condition (Cham et al., 2022; ÜSTÜN & KENNEDY, 2009). Consequently, individuals often struggle with daily

activities while experiencing social isolation, and inability to work, resulting in partial or full dependence on others for support.

These supporters known as, Caregivers, are individuals who provide support and assistance to persons who are unable to fully care for themselves. Depending on the socioeconomic context, caregivers may be paid professionals or family members. While formal caregiving services are more common in high-income countries, caregiving for individuals with mental illness in developing countries such as Ethiopia is predominantly provided by family members, including parents, spouses, children, and other relatives(Alem 2000; Baheretibeb et al., 2025)

The specific responsibilities of caregivers depend on the severity and functional limitations associated with the patient's condition. These duties may include assisting with activities of daily living and self-care, supervising medication adherence, accompanying patients to healthcare appointments, and managing financial matters(Chadda, 2014; Cham et al., 2022).

Study indicates that the role of caregivers in Ethiopia include providing a comprehensive support including meeting patients' daily living needs, facilitating access to spiritual and traditional treatment services, supervising care, ensuring physical safety and security, and monitoring for signs of aggressive or violent behavior(Baheretibeb et al., 2025).

The quality of this essential care is influenced by the caregivers' understanding and beliefs about mental health. In Ethiopia, societal knowledge, attitudes, and perceptions toward mental illness are significantly influenced by the country's diverse backgrounds. Moreover, general population awareness greatly influences caregivers' perceptions, as they are part of the community. Thus, the prevailing misconceptions and biases of society directly shape their understanding, perceptions, and caregiving decisions. Consequently, a caregiver's lack of knowledge, negative attitude, and reluctance to seek support play a significant role in the recovery of People with Mental Illness (PWMI).

1.2.Statement of the problem

Caregivers play a vital role in supporting and empowering individuals with mental illness. Effective caregiving requires adequate mental health literacy, which influences caregivers' ability to recognize symptoms, make informed decisions, and seek appropriate care. Mental health Literacy is defined as Knowledge and beliefs about mental disorders which aid their recognition, management or prevention(Jorm, 2000). However, caregivers may have limited mental health literacy, which contribute to insufficient knowledge unfavorable attitudes toward mental illness, and inappropriate help-seeking behavior (Wei et al., 2015).

This challenge is vastly present in Ethiopia, where cultural and religious beliefs significantly shape public perceptions about mental health disorders. Studies indicate that the cause of mental illness is often attributed to supernatural causes, such as demonic possession or the evil eye (Alem, 2000, 2004; Bishaw, 1991; Jacobsson & Merdasa, 1991).Subsequently, caregivers frequently choose traditional and spiritual healing methods, including wearing amulets, consuming holy water or herbal drinks, and performing rituals or exorcisms(Alem, 2000; Jacobsson & Merdasa, 1991). These practices often take place against the patient's will, involving physical restraint and subsequent confinement at home until aggressive or violent behavior subsides (Alem, 2004). This reliance on and prolonged trial of traditional approaches creates a critical barrier, delaying or entirely preventing access to timely and effective psychiatric and psychological intervention.

The widespread lack of accurate knowledge about mental illness contributes to the underutilization of modern treatment options such as medication and counseling. Caregivers may fail to recognize the importance of treatment adherence, leading to poor health outcomes and increased relapse rates. Moreover, caregivers with limited understanding may neglect the emotional and psychosocial needs of individuals with mental illness, focusing solely on physical care.

Furthermore, caregivers with poor mental health literacy may misinterpret symptoms, fail to recognize early signs of relapse, or view mental illness as a moral or personal failing rather than an actual disorder or condition. Such misunderstandings compromise the quality of care and deepen the stigma surrounding mental health. In extreme cases, families may choose to hide mentally ill relatives due to fear of societal judgment, further isolating the affected individuals and exacerbating their condition.

Compounding the issue of knowledge gaps are pervasive negative attitudes and stigma. Research indicates that stigmatizing beliefs hinder rehabilitation, perpetuate social exclusion, decrease self-esteem, and prevent help-seeking behavior (Abi Doumit et al., 2019; Birkie & Anbesaw, 2021; Consortium, 2004; Jorm, 2000). For the individual with mental illness, this can lead to discrimination, loss of dignity, and profound feelings of shame and worthlessness.

In addition to caregivers own mental health literacy, the community they live in also shape their perception in a great way. Caregivers frequently perceive significant stigma from their broader community, an experience that profoundly impacts their psychological well attitudes and help-seeking behaviors. As evidenced by the study conducted in rural Ethiopia (Shibre et al., 2001) indicates 75% of caregivers reported experiencing stigma directly due to their relative's condition. This pervasive fear of societal judgment manifests as a constant anxiety, with 42% of caregivers specifically worried about being treated differently, and 37% feeling compelled to conceal their family member's illness altogether. This external pressure to hide the diagnosis, driven by the anticipation of prejudice, actively discourages caregivers from seeking crucial support services, as reaching out is perceived as publicly affirming the stigmatized condition. Consequently, this cycle of perceived and anticipated stigma not only fosters isolation but also cultivates an internalized sense of shame, thereby reinforcing unfavorable attitudes towards mental illness within the very families who need compassion and understanding the most.

While studies in other contexts have documented gap in mental health literacy of caregivers (Gabra et al., 2020; Nabi & Rizvi, 2022; Neupane et al., 2016; O. Jack-Ide & E. Amegheme, 2016) there is a notable absence of such studies in the context of caregivers in Ethiopia. Understanding the specific knowledge, attitudes, and help-seeking behaviors of caregivers is essential to developing targeted interventions that can break the cycle of stigma, improve literacy, and ultimately enhance care outcomes. Therefore, this study aims to fill this gap by assessing the mental health literacy of caregivers of individuals with mental illness in Addis Ababa, Ethiopia.

Consequently, this study aims to answer the following research questions.

1. How do caregivers understand of mental illness?
2. How do caregivers perceive and express their attitudes toward mental illness?
3. How do caregivers navigate help-seeking pathways for mental illness from its onset to future care planning?

1.3. Objective of the Study

1.3.1. General Objective of the Study

- ❖ To explore caregivers' knowledge, attitudes, and help-seeking behaviors towards mental illness attending at St. Amanuel Mental Specialized Hospital in Addis Ababa, Ethiopia, 2025

1.3.2. Specific Objective of the Study

1. To understand caregivers' knowledge about mental illness
2. To explore caregivers' attitudes towards with mental illness.
3. To identify caregivers' help-seeking behaviors, at the onset of the illness and currently time.

1.4. Significance of the Study

The significance of this study lies in both its theoretical and practical contributions to the field of mental health care, particularly in the context of Ethiopia. By assessing and understanding caregivers' knowledge, attitudes, and help-seeking behaviors towards mental illness, this research aims to address a critical gap in the existing literature. While much has been explored regarding patient care and treatment, general community members knowledge and attitude of mental illness, limited research has focused on the caregivers who play an essential role in the rehabilitation and recovery process. Understanding caregivers' perceptions and practices is crucial for developing a comprehensive approach to mental health care.

Theoretically, this study seeks to expand the knowledge base by examining gaps in caregivers' understanding that affect the quality of care they provide, exploring their attitudes toward mental illness and toward people with mental illness (PWMI), and analyzing their help-seeking behaviors—which directly impact patients' mental health outcomes. Practically, the findings of the study are instrumental for health sectors and mental health professionals in Ethiopia. By identifying gaps in caregivers' knowledge and attitudes, this research lays the foundation for targeted psychoeducation programs and awareness campaigns aimed at enhancing caregivers' understanding of mental illness and attitude towards mental illness. Such initiatives help to equip caregivers with the tools they need to better support patients, improve recovery outcomes, and reduce the stigma surrounding mental health in the community. Therefore, the findings of this study are beneficial for individuals with mental illness, caregivers, and mental health professionals.

1.5. Scope of the study

The conceptual scope of the study is limited to exploring caregivers' knowledge, attitudes, and help-seeking behaviors toward mental illness among caregivers of patients admitted to the inpatient ward at St. Amanuel Mental Specialized Hospital in Addis Ababa, Ethiopia. The study does not examine caregiver burden, patient clinical outcomes, or detailed treatment adherence, as these areas fall beyond the primary objectives of the study. This focus was chosen because caregivers play a central role in the recognition, treatment, and long-term management of people with mental illness, making their perspectives important for improving mental health care and support systems. Furthermore, understanding caregivers' knowledge, attitudes, and help-seeking patterns provides an important basis for developing context-specific psychoeducation, stigma reduction, and early intervention strategies.

Geographically, the study is confined to caregivers of patients receiving inpatient mental health services at St. Amanuel Mental Specialized Hospital in Addis Ababa, Ethiopia. Caregivers of patients attending outpatient services, private facilities, or other mental health institutions are not included. This geographic scope was chosen because caregivers of individuals receiving inpatient psychiatric care are more likely to have prolonged caregiving experiences and exposure to severe forms of mental illness, making their perspectives particularly relevant to the study objectives. In addition, as St. Amanuel Specialized Mental Hospital is one of the major specialized mental hospitals and a national referral center in Ethiopia, caregivers from different parts of the country attend the hospital, allowing the study to capture diverse caregiving perspectives and experiences.

1.6. Operational Definition

Knowledge: refers to the understanding of mental illness, which includes causes, symptoms (manifestation), management, and treatment related factors.

Attitude: refers to caregivers expressed positive, negative, or mixed evaluations toward people with mental illness regarding their perception towards MI, capabilities of PWMI, recovery potential, treatment effectiveness and physical detectability of mental illness.

Help-seeking behavior: refers to the actions individuals take to obtain assistance, support, or treatment when caring for people with mental illness (PWMI).

Caregivers of People with Mental Illness: Family members who currently live with and provide ongoing care and support to a person with mental illness.

Chapter 2: Review of Related Literature

2.1. Mental illness

Mental illnesses represent a substantial and growing public health challenge, ranking among the most common non-communicable diseases worldwide. To contextualize the present study on caregivers, it is first crucial to understand the scale and impact of mental illnesses, from a global perspective down to the specific national context of Ethiopia. According to The Institute for Health Metrics and Evaluation, mental illnesses are ranked among the top ten leading causes of health loss worldwide, contributing significantly to global morbidity and premature mortality, with anxiety and depressive disorders being the most prevalent across all age groups and geographic locations (Bloom, 2011; Fan et al., 2025). The 2021 Global Burden of Disease study indicates that this global burden has increased over the past decades, showing a marked elevation during the COVID-19 pandemic (Fan et al., 2025b).

In Ethiopia, a systematic analysis of the global burden of mental illness from 1990 to 2019 indicated that the most common forms of mental disorders were depressive disorders, anxiety disorders, bipolar disorders, and schizophrenia (Zergaw et al., 2023). This high prevalence is met with a significant treatment gap; in low- and middle-income countries like Ethiopia, more than 75% of individuals with mental illness do not receive care due to limited, disproportionately distributed, and ineffectively used resources (Bloom, 2011).

Studies across various regions of Ethiopia report a wide range in the prevalence of common mental disorders (CMDs), reflecting methodological and demographic differences. The prevalence of CMDs in the general adult population ranges from approximately 15% to 33%. Specific studies found a prevalence of 32.4% in Kombolcha (Yimam et al., 2014) 14.9% - 21.31% in the Harari Region (Abdeta et al., 2023; Hunduma et al., 2017), 24.7% in Addis Ababa (Y. Habtamu et al., 2022)

The aforementioned studies consistently indicate a core set of sociodemographic, psychological, and health-related characteristics linked to common mental disorders in Ethiopia. Female gender, advanced age, lower socioeconomic level and unemployment, lower level of educational attainment, marital status (particularly divorced, widowed, or single), family history of mental illness, poor health behaviors (chewing khat), living with a chronic physical condition and stressful life experiences have shown significant correlation with CMD (Abdeta et al., 2023; Habtamu et al., 2022; Hunduma et al., 2017b; Kassa & Abajobir, 2018; Yimam et al., 2014).

2.2. Caregivers of people with mental illness

The role of caregivers for individuals living with mental illness is one of the profound dedication and responsibility. Typically, family members—including parents, spouses, and adult children—provide this essential care informally, motivated by familial ties and affection rather than formal training. Balancing these intensive duties with other responsibilities—such as employment, child-rearing, and personal life—makes the caregiving role immensely challenging, frequently resulting in considerable emotional and practical strain. This phenomenon, termed caregiver burden, comprehensively affects a caregiver's physical health, psychological well-being, and overall quality of life (TREUDLEY M. B., 1946).

Caregiver burden is frequently categorized into two interconnected types (Chadda, 2014; TREUDLEY M. B., 1946). The objective burden involves tangible, quantifiable pressures such as financial strain from medical expenses and lost income, alongside the considerable time commitment that interrupts work and social life. Conversely, subjective burden describes the internal psychological experience, which includes persistent feelings of stress, shame, isolation, and hopelessness. The prevalence of this burden represents a pressing worldwide public health challenge. Studies indicate that approximately one-third of all mental health caregivers globally experience a substantial burden (Cham et al., 2022). The situation is particularly acute in low-resource nations like Ethiopia, where a meta-analysis found that 38% of caregivers report high objective burdens, and a striking 63% suffer from severe subjective (psychological) burdens (E. Tesfaye & Demelash, 2025).

On top of the burden they experience, caregivers are subjected to different kind of stigma. A study conducted in Ethiopia (Handebo et al., 2025) reported that more than half of caregivers experienced or perceived stigma, about half (49.3%) of the caregivers experienced that they were always treated differently. In addition to this, caregivers also experience self-stigma in a different manner, such as feeling shame, the need to hide the patient or the illness, experiencing grief or depression, anxiety and fearing of discrimination. Among the caregivers: around 30% felt ashamed about the patient. Furthermore, some caregivers worried other people would find out about the situation (23.7%) and be avoided (20.3%) (Derajew et al., 2017; Handebo et al., 2025; Siddiqui & Khalid, 2019)

While navigating these challenges, caregivers' knowledge, attitudes, and help-seeking behaviors are shaped by prevailing community beliefs and perceptions, as they are embedded within the broader social and cultural environment. Studies consistently report that communities possess inadequate knowledge, hold negative attitude, and maintain stigmatizing beliefs regarding mental illness (Benti et al., 2016; Birkie & Anbesaw, 2021b; Jarso et al., 2022).

Given the central role caregivers play in supporting individuals with mental illness, their knowledge, attitudes, and help-seeking behaviors are important factors that may influence the quality of care provided and engagement with mental health services. Understanding these factors is therefore essential for developing interventions that support caregivers and improve outcomes for people living with mental illness.

2.3. Explanatory Model of Mental illness in Ethiopia

Evidence from Ethiopia suggests that community understanding of mental illness remains inconsistent, with awareness coexisting alongside considerable misconceptions regarding its causes, manifestations, and treatment. A study conducted in Dessie Town found that more than half (55.3%) of community members demonstrated poor knowledge of mental illness, particularly in relation to its causes and available treatment options. Better knowledge was observed among individuals with higher educational attainment, previous exposure to mental health information, and greater access to information sources (Birkie & Anbesaw, 2021b). Consistent with these findings, a recent synthesis of Ethiopian studies reported that many communities continue to explain mental illness through a combination of biomedical and supernatural beliefs. Explanations involving spirit possession, evil spirits, curses, and divine punishment were frequently reported alongside psychosocial and medical explanations, reflecting the pluralistic nature of mental health beliefs in Ethiopia (Debela et al., 2024).

In addition to the above-mentioned studies, A qualitative study conducted in rural Ethiopia (Tekola et al., 2021) explored community members and patients' understandings of depression. The study found that although participants were generally able to recognize emotional distress and describe symptoms consistent with depression, most did not identify it as a distinct mental health condition. Instead, depressive symptoms were often understood through everyday experiences such as excessive worrying, poverty, interpersonal conflict, loss of loved ones, and other social adversities. Participants commonly attributed depression to psychosocial stressors rather than biomedical

causes and frequently described the condition using local concepts and expressions. These findings suggest that while community members possess some awareness of depressive symptoms, knowledge regarding depression as a recognizable mental disorder and its biomedical understanding remains limited (Tekola et al., 2021).

Attitudes toward people with mental illness also appear to be shaped by these beliefs. Evidence from different parts of the country indicates that stigmatizing perceptions remain common despite increasing awareness of mental health conditions. In Dessie Town, nearly half of the respondents expressed unfavorable attitudes toward mental illness (Birkie & Anbesaw, 2021b). Similarly, a study conducted in Jimma Zone revealed that many community members preferred to avoid individuals with mental health problems and viewed marriage to a person with a current or previous mental illness as foolishness (Y. Tesfaye et al., 2020). Comparable findings were reported in Southwest Ethiopia, where unfavorable perceptions of mental illness remained prevalent among community members. Across studies, recurring themes included fear, social distancing, stigma, and negative stereotypes toward people with mental illness, suggesting that mental illness continues to be associated with considerable social disadvantage in many Ethiopian communities (Debela et al., 2024).

Help-seeking behavior for mental illness in Ethiopia is likewise influenced by prevailing cultural beliefs and local understandings of illness. Research examining treatment pathways has shown that families often explore multiple sources of care before seeking psychiatric services. Religious institutions, traditional healers, holy water sites, and informal community networks frequently serve as initial points of contact, while professional mental health services are often sought later in the course of illness (Girma & Tesfaye, 2011). Similar patterns were observed in Jimma Zone, where many community members reported a preference for traditional and informal sources of support before considering formal mental health care (Y. Tesfaye et al., 2020). Furthermore, studies from Southwest Ethiopia indicate that a substantial proportion of community members remain reluctant to seek professional help for mental health problems, highlighting persistent barriers to formal service utilization (Debela et al., 2024).

National-level evidence further supports these observations. A recent systematic review and meta-analysis found that positive help-seeking behavior toward modern mental health services remains

relatively low in Ethiopia, with many individuals continuing to rely on traditional, religious, or informal treatment options (Asnakew et al., 2024). The review identified awareness of mental illness, perceived effectiveness of treatment, and knowledge of available services as important determinants of help-seeking behavior. Similarly, (Debela et al., 2024) concluded that culturally rooted beliefs about the causes of mental illness continue to influence treatment preferences and often contribute to delays in accessing professional mental health care.

Taken together, the Ethiopian literature suggests that although awareness of mental illness has improved over time, important gaps remain in community knowledge, attitudes, and help-seeking behavior. Misconceptions regarding the causes of mental illness, persistent stigma toward people with mental illness, and strong reliance on traditional and religious healing approaches continue to shape how mental illness is understood and managed within Ethiopian society.

2.4. Caregivers' Knowledge, Attitude and Help-seeking behavior towards Mental Illness

2.4.1. Caregivers' Knowledge towards Mental Illness

A systematic review conducted in mainland China assessed the knowledge and beliefs of patients and caregivers regarding mental illness (Li & Reavley, 2020) and revealed varying levels of knowledge among caregivers. While the majority of caregivers (65%) were aware of the specific name of their relative's disorder, far fewer could identify its signs and symptoms (between 10.2% and 36.7%) or recognize them (between 11.7% and 13.2%). Understanding of causes was limited, with only one-third participant (33.3%) knowing the causes of severe mental illnesses. Most patients and caregivers favored psychosocial explanations, attributing mental illness to factors such as exposure to negative life events, morally inappropriate thinking, a combination of various factors, or financial problems. Regarding treatment, most caregivers believed that patients required both counseling and regular medication. However, specific knowledge was low: although 41% knew the names of the medications, only 18.1% were aware of the required treatment duration. Knowledge of therapeutic and side effects was very poor (ranging from 2.9% to 35.8%), and only 24.7% knew how to manage these side effects.

In addition to these findings, (Li & Reavley, 2020) reported that although nearly half (46%) of caregivers stated they knew the signs of relapse, very few understood how to prevent it. Similarly,

while over half agreed on the importance of family involvement, only a small minority (17.5% for schizophrenia and 18% for other severe mental illnesses) knew how to provide actual care at home. The theme of knowledge gaps is further explored in India. A study in North East India (Ahmed & Baruah, 2017) reported a considerably higher knowledge mean score of 32.2 ± 6.93 . However, this strong performance was not uniform, as caregivers demonstrated notably poor knowledge in critical domains, particularly regarding medication side effects and their management.

In accordance with these findings, a study focused specifically on caregivers of individuals with alcoholism in the Karda region revealed a more moderate knowledge base overall, with the vast majority (68.3%) possessing only an average level of understanding and a significant portion (18.3%) having poor knowledge (Desai et al., 2014).

Beyond quantitative scores, qualitative research from the Kashmir region of India (Nabi & Rizvi, 2022) provides depth to these statistics by revealing caregivers' lived experiences behind the knowledge gaps. The findings indicate that caregivers struggled with poor knowledge about their relative's mental illness and causative factors and were often perplexed by their relative's constantly changing behaviors, sometimes perceiving them as "pretending to be ill."

Similar knowledge gaps have also been documented in African countries. A cross-sectional study conducted at a public mental health outpatient clinic in the Niger Delta Region of Nigeria (O. Jack-Ide & E. Amegheme, 2016) indicated that caregivers had poor knowledge regarding the type of mental illness affecting their relatives, difficulty recognizing early signs of relapse, poor information concerning the action, dosage, and side effects of medications, and limited knowledge about managing medication-related adverse effects. Despite these gaps in knowledge, the majority of participants believed that their relatives' conditions would improve with treatment and expressed satisfaction with the care provided by mental health professionals.

Similarly, a cross-sectional study conducted at Assuit University in Egypt involving 425 family caregivers of individuals with mental illness found that caregivers had poor knowledge regarding mental illness, with a mean knowledge score of 16.90 ± 4.22 (Gabra et al., 2020). In contrast to the above findings, a quantitative study conducted in South Africa indicated that 63.23% of participants demonstrated good knowledge about mental health (Mokwena, 2025)

2.4.2. Caregivers' Attitude towards Mental illness

Regarding caregivers' attitudes towards mental illness, a cross-sectional study conducted in Kathmandu, Nepal, (Neupane et al., 2016) among 170 caregivers reported an overall median attitude score of 42 (IQR = 8) out of a maximum of 60. Analysis of individual items revealed that the highest median scores were linked to beliefs that individuals with mental illness are violent, require control similar to young children, and need hospitalization at the first sign of illness. In contrast, the lowest median score was associated with the statement that “it is our responsibility to provide the best care for PWMI.”

Another descriptive study conducted in Nepal among caregivers of mental illness patient (Pandey, 2019) reported that people with mental illness are dangerous (64%), mentally ill people are violent (70%) and 72% feel that health organizations are giving less priority to mental illness as compared to other disorder.

Similarly, a study conducted in Egypt using the Modified Attitudes toward Mental Illness Questionnaire reported the presence of negative attitudes toward people with mental illness among caregivers (Gabra et al., 2020). Many caregivers believed that individuals with mental illness were unable to distinguish between right and wrong, and a considerable proportion supported restrictions on their social freedoms, including limitations on marriage and movement in public places. Nevertheless, positive attitudes were observed in some areas. Most caregivers rejected the notion that people with mental illness should be segregated from the community and believed that recovery from mental illness was possible.

These findings suggest that caregivers may hold both stigmatizing and supportive attitudes simultaneously, reflecting the complex nature of attitudes toward mental illness. An in-depth qualitative study conducted in Zambia on family caregivers' perspectives regarding cultural beliefs and practices towards mental illness (Sichimba et al., 2022) found that many caregivers attributed mental illness to supernatural causes such as witchcraft, ancestral curses, or spiritual possession. In addition, many caregivers experienced stigma and social exclusion from community members due to these beliefs, creating further challenges in caregiving.

In contrast, the South African study reported that 65.61% of participants demonstrated supportive and accepting attitudes toward individuals with mental illness. Furthermore, place of residence and duration of caregiving remained significant predictors of attitude, while a patient's history of substance use and caregivers' knowledge of mental illness were significantly associated with attitudes toward mental illness(Mokwena, 2025).

2.4.3. Caregivers' Help – seeking behavior towards Mental illness

Regarding help-seeking behavior,(Li & Reavley, 2020) reported that a very high proportion of caregivers in China (over 80%) agreed on the necessity of seeking professional help and stated that they would accompany their relatives to access mental health services. Whereas, In Africa, a study conducted in Egypt found that the majority of caregivers (80.2%) initially sought advice from traditional healers for the care of their mentally ill relatives, while only 17.4% pursued psychiatric care as their first option. Among those who consulted traditional healers, only a small percentage (16.4%) subsequently referred patients to psychiatric services(Gabra et al., 2020).

Similarly, the Zambian study (Sichimba et al., 2022) reported that caregivers' beliefs regarding supernatural causes of mental illness strongly influenced help-seeking behavior, with many families first consulting traditional healers or religious leaders before seeking formal mental health care. These pathways often contributed to delays in treatment.

Comparable findings were reported in a qualitative study conducted in Uganda(Okello & Neema, 2007) which explored explanatory models and help-seeking behavior among individuals with mental illness and their families. The study found that caregivers attributed mental illness to psychosocial stressors, interpersonal difficulties, and supernatural influences. These explanatory beliefs played a significant role in determining help-seeking pathways, with many families moving through multiple sources of care before accessing psychiatric services. Differences in causal beliefs between patients and family members often influenced treatment decisions and delayed access to appropriate mental health care. Psychiatric treatment was frequently sought only after other alternatives had failed, highlighting the important role of family interpretations of illness in shaping help-seeking behavior.

In contrast, although the South African study reported relatively good knowledge and supportive attitudes, 60.05% of participants exhibited negative help-seeking behavior characterized by avoiding or delaying professional care and preferring informal support systems. Furthermore, 62.86% believed that combining different treatment modalities would promote recovery more effectively than relying solely on medical treatment(Mokwena, 2025).

In Ethiopia, existing caregiver research has largely focused on burden, stigma, and caregiving experiences, with limited attention given to caregivers' knowledge of mental illness, attitudes toward people with mental illness, and help-seeking behavior. This highlights the need for context-specific evidence to better understand how caregivers perceive mental illness and navigate treatment decisions.

2.5. Theoretical Framework

This study is grounded in the Explanatory Model of Illness (EM), originally developed by Arthur Kleinman in 1978. The EM focuses on how patients and their families make sense of an illness, including its nature, causes, course, consequences, and appropriate treatments, within their own cultural context (Dinos et al., 2017).

Kleinman's framework proposes a set of open-ended questions that can be used to explore the illness understandings of patients and caregivers. These questions are designed to capture people's perspectives in their own cultural terms, enabling researchers and clinicians to identify gaps between local understandings of illness and biomedical explanations. Identifying such gaps can inform the development of culturally appropriate psychoeducation and intervention strategies.

In the context of mental health, caregivers' explanatory models strongly influence how they recognize, label, and interpret symptoms; assess the severity of the condition; understand its causes; and determine which forms of treatment are most appropriate (Mathews et al., 2019). These understandings, in turn, shape help-seeking pathways and treatment-related decisions, including whether caregivers pursue biomedical, religious, traditional, or combined forms of care.

While the Explanatory Model served as the primary theoretical framework for understanding caregivers' knowledge, attitude and help-seeking behavior, the attitude component of the study was further interpreted through the Dimensions of Stigma framework proposed by Edward E. Jones and colleagues in 1984 (Ahmedani, 2011; Hilbert et al., 1985). According to this framework, conditions subjected to social stigma are evaluated across several dimensions, including peril (dangerousness), concealability (visibility), origin (perceived responsibility for the condition), pity, course and stability, disruptiveness, and aesthetics. These dimensions influence how individuals perceive and respond to people with conditions that are usually associated with stigma, including mental illness. The framework is particularly relevant to mental health research because it provides a structured approach for understanding how beliefs regarding dangerousness, visibility, responsibility, recovery, and social functioning shape attitudes toward people with mental illness. In the present study, the framework was used as an interpretive lens to better understand caregivers' attitudes and perceptions toward mental illness and people with mental illness, particularly where such attitudes reflected stigmatizing beliefs and assumptions.

Chapter 3: Research Methodology

3.1. Study Approach

This study employed a qualitative approach to gain an in-depth understanding of caregivers' perceptions and experiences regarding mental illness, including their knowledge, attitudes, and help-seeking pathways. A qualitative approach was considered appropriate because it enabled the exploration of participants' perspectives, meanings, and experiences in their own words, providing rich insights into how caregivers understand and respond to mental illness.

3.2. Study Design

Among qualitative research approaches, a qualitative descriptive design was employed to provide a comprehensive and straightforward understanding of the phenomenon as experienced and perceived by participants. This design was considered appropriate because it enabled the collection of rich, detailed information on caregivers' knowledge, attitudes, and help-seeking pathways regarding mental illness. By staying close to participants' perspectives and experiences, the qualitative descriptive design facilitated the generation of contextually grounded findings that reflected caregivers' understanding, perceptions, and help-seeking behaviors.

3.3. Study area and target population

This study was conducted in Addis Ababa, the capital city of Ethiopia, with an estimated population of 5,957,000 in 2025(Macrotrends.net., 2024). Addis Ababa is home to two major specialized public psychiatric hospitals: St. Amanuel Mental Specialized Hospital and Eka Kotebe Psychiatry Center. In addition to these major center, psychiatric and psychological care is offered across various levels of healthcare, from primary health services to general hospitals, by psychiatrists, psychiatric nurses, and psychologists. Furthermore, private psychiatric and psychological centers also provide services in the city.

Among these psychiatric centers, St. Amanuel Mental Specialized Hospital was selected because it is one of the major specialized mental hospitals, offering services to a diverse population from across the country, including individuals from both rural and urban areas.

St. Amanuel Mental Specialized Hospital was established in 1938 and has continued serving as the major public specialized Mental hospital in Addis Ababa, Ethiopia(*Amanuel Mental Sepecialized Hospital*, 2024). It provides inpatient and outpatient psychiatric and psychological service to thousands of patients from all over the country.

The target populations were caregivers of individuals with mental illness. The study population was caregivers of individuals with mental illness who are attending an inpatient unit of St. Amanuel Mental specialized hospital, who meet the eligibility criteria. The study was conducted starting from September 2025 – October 2025.

3.4. Sample and Sampling design

Purposive sampling was employed to select participants for this study. This sampling technique is widely employed in qualitative research, because it allows the selection of caregivers who were directly involved in the care of people with mental illness and were therefore able to provide rich, relevant, and experience-based information related to the study objectives (Palinkas et al., 2015). Since the study aimed to gain an in-depth understanding of caregivers' knowledge, attitudes, and help-seeking behaviors toward mental illness, participants were purposely selected based on their ability to provide detailed insights into these areas.

Initially a sample size of approximately fifteen caregivers was planned for this study. However, participant recruitment and data collection were guided by the principle of data saturation, whereby interviews continued until no new relevant information, perspectives, or themes emerged from participants' responses. Saturation was reached after interviewing thirteen caregivers; therefore, data collection was finalized, as additional interviews were unlikely to contribute substantially new insights relevant to the study objectives.

3.5. Method of Data Collection

To conduct this study, in-depth interviews were employed to obtain detailed accounts of caregivers' perspectives, experiences, and understandings regarding mental illness. A semi-structured interview guide was developed based on the study objectives, relevant literature, open-ended questions adapted from Kleinman's Explanatory Model Questions, and domains drawn from previously validated mental health instruments, including the Community Attitudes toward the Mentally Ill (CAMI) scale (Taylor & Dear, 1981) and the Mental Health Literacy Scale (O'Connor & Casey, 2015).

These sources were used to inform key areas of inquiry related to caregivers' knowledge, attitudes, and help-seeking behaviors toward mental illness. However, rather than administering these tools

as standardized measures, relevant domains were adapted into semi-structured, open-ended interview questions to facilitate an in-depth exploration of caregivers' perspectives while allowing flexibility to ask probing questions and explore emerging issues during the interview process.

The interview guide was first prepared in English and translated into Amharic. To ensure linguistic accuracy and clarity, the Amharic version was reviewed by individuals fluent in both languages and with linguistic expertise.

Regarding ethical considerations, oral and written informed consent was obtained from each participant before data collection. Face-to-face interviews were conducted in the Amharic language and audio-recorded with participants' permission to ensure accurate capture of the information shared.

3.6. Procedure of Data Collection

Each in-depth interview lasted approximately 20 to 40 minutes. Variations in interview duration were influenced by caregivers' caregiving experience and duration, depth of information shared, willingness to elaborate, and the extent to which probing questions were required. Despite differences in length, interviews provided sufficiently rich and relevant information related to caregivers' knowledge, attitudes, and help-seeking behaviors toward mental illness.

3.7. Eligibility criteria

Inclusion Criteria

- ❖ Adult Participants (above the age of 18) and can give informed consent
- ❖ Participants who has been living with of people with mental illness for at least the past 3 month and currently serving as primary caregiver of the Patient
- ❖ Participants who can sufficiently listen and communicate in Amharic language.
- ❖ Participants who are residing in Addis Ababa at the time of data collection: either as their permanent place of residence or temporarily for treatment purposes, including those who had traveled from other regions.

Exclusion Criteria

- ❖ Participants who are not willing for their voice to be audio recorderd
- ❖ Individuals who did not meet the definition of a caregiver used in the study

3.8. Method of Data analysis

At the end of the data collection process, the gathered information was transcribed verbatim and translated into English. Subsequently, data analysis was conducted using thematic analysis by “Open code software version 4.03” to manage the collected data. Thematic analysis was used in this research to extract common themes and tendencies from the semi-structured interview transcript files, which were created solely for this work. The analysis consisted of Braun and Clarke's six-step process (Braun & Clarke, 2006). These steps are familiarization with the data, generating initial codes, searching for theme, reviewing theme, defining and naming theme and finally producing the report.

3.9. Ethical consideration

Throughout the study, ethical principles such as informed consent, confidentiality, and protection from harm were strictly followed. Participants were clearly informed about the study's purpose, the voluntary nature of their involvement, and their right to withdraw at any time. Informed consent was obtained from all participants before the interviews. Ethical approval was secured from the Institutional Review Board (IRB) at St. Amanuel Mental Specialized Hospital. The collected data was managed and stored securely.

Chapter 4: Result

4.1. Participants sociodemographic data

The result of this study was obtained from 13 participants. among the participants, five of them were male and eight were female. Participants are found in different age group ranging from 20 – 72, and most of the participants are married. Majority of the participant was caring for their children. All participants are currently residing in Addis Ababa, however only four participants are permanently residents of Addis Ababa, the rest participant came from different part of Ethiopia for treatment purpose; including from Illibbor, Fiche, Adama, Lalibela and Silte zone. The highest education level of the participant is 10+3 or TVET. Majority of the caregivers are solo caregivers of the patient.

Sociodemographic characteristics	of	Number of Participants	Percentile (%)
Participants		(N= 13)	
Sex	Female	8	61.5%
	Male	5	38.5%
Age	20 – 30	4	30.8%
	31 – 41	3	23%
	42 - 52	4	30.8%
	53 – 72	2	15.3%
Educational Status	No formal education	3	23.1%
	Grade 1 – 8	4	30.8%
	Grade 9 – 12	3	23.1%
	10+3 / TVET	2	15.4%
	Other (Abenet school)	1	7.7%
Marital Status	Married	5	38.4%
	Unmarried	4	30.8%
	Widowed	3	23.1%
	Divorced / separated	1	7.7%
Place of origin	Addis Ababa	4	30.8%
	Amhara Region	4	30.8%

People they are looking after	Oromia region	4	30.8%
	Silte Zone	1	7.6%
	Son / daughter	8	61.5%
	Sibling	3	23.1%
	Parent	1	7.7%
Duration of caregiving	Friend	1	7.7%
	< 6 months	3	23.1%
	1-3	6	46.1%
	>5 years	4	30.8%
Support in the caregiving process	Solo caregiver	8	61.5%
	Have a social support	5	38.5%

Table 1 Caregiver participants' sociodemographic characteristics, Addis Ababa, 2026

After coding the collected data, 605 initial codes were formed. After narrowing down the initial codes into focused codes, nine subthemes were formed which was later on condensed to three main themes.

Themes formed:

1. Caregivers' Conceptualization of Mental Illness
2. Caregivers' Perceptions of People with Mental Illness and Their Life Prospects
3. Caregivers help- seeking experiences and treatment decision

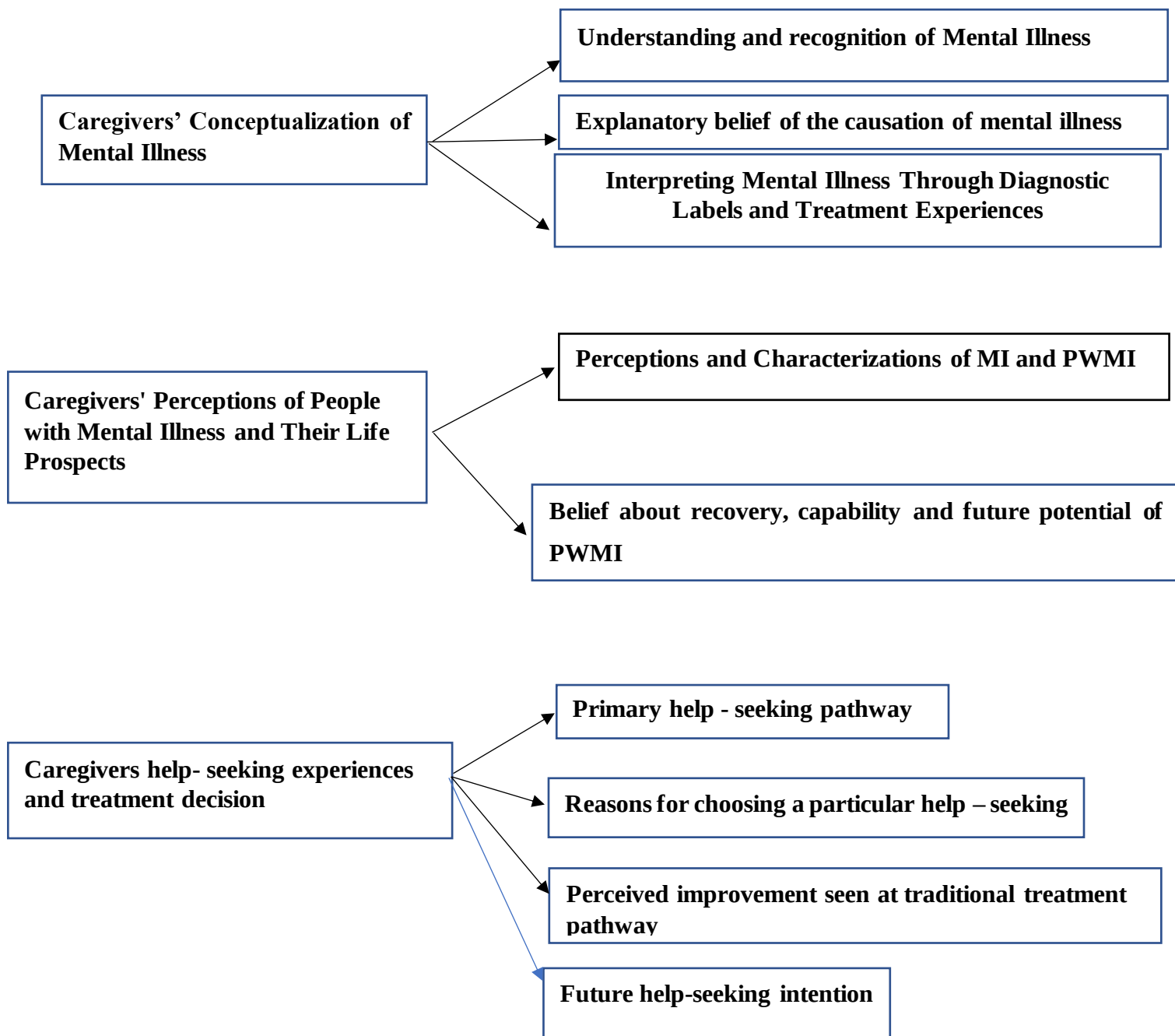


Figure 1 Thematic Analysis of Participants' Interview, Addis Ababa, 2026

4.2. Caregivers' Conceptualization of Mental Illness

4.2.1. Understanding and recognition of Mental Illness

Mental illness was commonly perceived as a severe and challenging condition that affects multiple aspects of an individual's life and functioning. Participant caregivers often described mental illness in relation to the disruptive behavioral manifestations exhibited by patients, the level of dependence it created, and the importance of maintaining mental well-being for everyday functioning.

“Even if I didn't attend school, I know that if a person has mental illness, all of his health will be in trouble. We go out and work because we are mentally well. The professionals have told me it will be cured so without mental health a person can't go out, work and eat. I think it is difficult.” (P.2, Female, age. 43)

*“It's very **difficult**. I wouldn't wish it on a stranger, or even my enemy. It's very hard. You wash his body and ask him what he wants. It's very difficult; it makes you feel disgusted. (ይዘገግኝል)” (P.9, Female, age. 55)*

“It's very difficult. It's very hard for the person who lives with them, for the person who is around them. After he got sick, I realized that any other illness is better. Because, it's only now that he is calm; when he is having an episode, it's very difficult. It's even hard to communicate. If it's another illness, you can talk and find a solution. But with this, you can't communicate at all. So, I feel another illness is better; it's just very hard. It affects their thinking. They think about something that isn't there; they think something that didn't happen has happened.” (P.10, Female, age. 28)

While caregivers generally demonstrated an understanding of mental illness, participants also described uncertainties in recognizing and interpreting the condition. The fluctuating presentation of symptoms, limited awareness of less visible manifestations, and difficulties distinguishing illness-related behaviors from intentional actions often complicated their understanding of mental illness.

“I really couldn’t understand it. I couldn't figure out how to know what it is. One moment she is fine, the next moment she is something else. It's like she knows but pretends not to know... it seems to me she acts like she doesn't know things she actually knows. It's just... sometimes it seems like she's trying to involve me in something else.” (P.13, Male, age. 25)

Participants' narratives further revealed that disruptive and overt behaviors were more readily recognized as indicators of mental illness than less visible changes such as social withdrawal, excessive sleeping, reduced communication, and loss of interest in daily activities. These subtle behavioral and emotional changes were often not interpreted as signs of mental illness until more severe symptoms emerged.

“For PWMI I know when people talk alone, disturb and such but I don’t know what it is when someone stops and wants to sleep and stops talking. It is hard to say it is this or it is not. From what I know, they want to go around, they talk a lot. What do you call this behavior of hers? sleeping a lot and not talking?” (P.5, Female, age. 40)

In accordance to this finding, one caregiver's narration reveals that in order to call a given mental illness “real”, behavioral manifestations like not knowing what to do, having destructive behavior such as walking into traffic, throwing stones, or walking into fire must be seen or else there is a possibility of calling PWMI Knowingly mad.

“... there are two types. There is one who is "mad" and there is another... what is it called? The one who is truly mad will just walk into the path of a car. They will just throw a stone. The one who is said to have "knowingly gone mad" is the one who sometimes goes and comes back, that kind of thing.... if the mind is not working correctly, then he should just walk into a fire, he should just walk off a cliff. He shouldn’t know how to save himself. If it's the mind, then the mind, if it's not working, it's not working. But this one knows everything more than you and me. If you ask, "Who is this?", if you ask, "What is he saying?", he answers everything he's asked correctly, but he just couldn't become a normal person.” (P.11, Male, age. 32)

In alignment to what has been mentioned, even though, caregivers noticed early behavioral and emotional changes, these, non – overt, signs were often not recognized as indicators of mental illness until more severe symptoms appeared.

*“.... when he started using substances heavily, he began to destroy the things he used to create. He started scraping off and ruining the drawings he had made on the walls, he would open the TV and leave it without fixing it, He stopped bathing, changing clothes, started isolating himself, he wouldn't leave the house, didn't meet with friends, slept for long hours, lost his appetite. When we see this, we took it to rehabilitation center by saying the **addiction is harming him**. Once he got there, he was forced to stop the substance use, thus, he tried to kill himself when he couldn't get the substance, he started hitting his head, and saying 'people know my feelings and my thoughts. **That's when it began**, when he was deprived of the substance.” (P.10, Female, age. 28).*

4.2.2. Explanatory belief of the causation of mental illness

Biological Explanations

Caregivers attributed mental illness to various biological factors, including complications during pregnancy, medical interventions during the prenatal period, and birth-related conditions. Participants linked the onset of mental illness to early developmental experiences and physical health complications occurring before or around the time of birth.

“When I was pregnant with him, I got sick. My body was not functioning well from my waist down and I was admitted to the hospital. I was in ICU and I was 6 months pregnant by then. I told them about it and they said not to worry. He was injected some medication. I gave birth on 9 months but once he was born, he used to cry day and night. He was 3.5 kg, he started speaking late at 3 but he was well. He was doing well at school but when he was 10, he started acting different “(P.2, Female, age. 43)

While biological explanations were evident in participants' accounts, awareness of hereditary risk factors was not always apparent. The presence of mental illness among family members was not consistently recognized as a potential contributor to the patient's current condition.

Psychosocial Explanations

Psychosocial explanations were prominently noted in caregivers' narratives. Participants frequently associated mental illness with challenging life circumstances and psychosocial stressors, including educational difficulties, migration, poverty, family conflict, unemployment, loss of loved ones, limited social support, deprivation of parental affection, and unmet life aspirations.

"I think mental illness is related to how we live, he did not get his father's love, his families love. he doesn't have any life, friends, especially, after he stopped going to school, he has become lonely, I think that is the reason." (P.3, Female, age. 37)

"... after I gave birth to his younger brother, he (the patient) and his older brother quit their education to help the family out, so we wouldn't be poor. but things didn't go as planned for him. The market didn't give us a good price; it went so low. You see, he had built a house for us that we wouldn't live in a rent house, this boy did, he bought us cattle, he was planning to buy a car. But the illness took him. I think in the middle of all that, his mind got affected. When what he envisioned didn't work out, the anger, the frustration leads him to illness. that's what it seems as a cause for to me." (P.12, Female, age. 45)

These accounts reflected caregivers' beliefs that prolonged exposure to emotional distress, social adversity, and accumulated life challenges could contribute to the development of mental illness.

Substance use related factors

Substance use was additional factor that was commonly mentioned as a contributing factor to mental illness. Caregivers described prolonged and excessive use of substances, particularly khat, cigarettes, alcohol, and other psychoactive substances, as precipitating or worsening mental health problems.

“The cause is Khat, because he became addicted and came back from Sudan. But his father became like that after chewing too much Khat. He would chew Khat excessively and give me a lot of trouble.” (P.9, Female, age. 55)

“When we look at the condition of mental illness, it's from addiction, from Khat, from cigarettes, his friends also got him used to alcohol, there is also something call Ganja, they say it's bad, that too. That's his life. Nothing else. After chewing chat for a long, long time, his eyes get blurry, and he just spends the day and night like that. For two days, he will be sleeping through the night and the day. It was like that.” (P.7, Female, age. 70)

In addition to substance use itself, one participant perceived sudden or improper discontinuation of substance use as a contributing factor to the development of mental illness.

“In his case, yes, it's addiction. This happened after he quit his addiction. It was after he went to a rehabilitation center and couldn't get the substance, he was using that his mind became disturbed like this. Before that, he was very healthy, just four months ago.” (P.10, Female, age. 28)

Spiritual Explanations

Spiritual and supernatural explanations were also evident in caregivers' description. Mental illness was attributed to evil spirit possession, Satanic influence, curses, ልክፍት, and other culturally embedded spiritual beliefs and practices. These explanations reflected the influence of religious and traditional belief systems in shaping caregivers' understanding of mental illness.

“You see, this illness, firstly, it's not a normal illness, but something related to Satan. It is. It's not like an illness anyone can get. This illness is different. So, this illness is related to Satan. Sometimes they become normal people. Other times, they become sick. And I don't think there is any other illness that does this. Unless it comes from Satan.” (P.11, Male age. 32)

“... but the reason for his illness is evil spirit. In his household there is lots of family issue going on. there is a family issue that put spell on him.” (P.8, Male, age. 28)

“ Wallahi , I don't know. On my side, we are normal. But on his father's side, there might be some kind of spell or teeth grinding, or something. But on my side, it is clean. Now, the only thing I suspect is that the problem is hereditary from that lineage. No one can tell you for sure.” (P.9, Female, age. 55)

Uncertainty regarding the cause of Mental illness

Despite offering various explanations for mental illness, uncertainty regarding its cause was also evident in some caregivers' narratives. Participants described difficulties identifying a specific reason for the illness and often deferred such explanations to healthcare professionals.

“I don't know. she got sick, I brought her in. Let the doctors know that, or else I know nothing.” (P.5, Female, age. 40)

4.2.3. Interpreting Mental Illness Through Diagnostic Labels and Treatment Experiences

Awareness of the name of the illness

Limited awareness of formal diagnostic labels was evident in caregivers' accounts. Mental illness was often described using broad terms such as "mental illness" or "a problem of the mind" rather than specific clinical diagnoses. In several instances, caregivers explained the illness in relation to what they believed had caused it, rather than referring to a medically assigned diagnosis.

“The name of the illness? It doesn't have a name, it's a mental illness, we say his mind is affected. That's what we say.” (P.7, Female, age. 70)

“Well, the name of his problem, the disease, is due to graduating and not finding a job. There is no other big thing. It is the job. A person studies for five years, graduates as an engineer, and even as an award winner, joblessness itself is a disease.” (P.1, Male, age. 72)

Awareness of specific diagnostic labels was primarily linked to information communicated by healthcare professionals. When a diagnosis had been discussed during clinical encounters, a couple caregivers were able to identify and describe the condition using the terminology provided by professionals.

“... They told us that it is depression and stress. Or else he is normal. (ውስጡ ሰላም ነው።) They have made assessments, and the doctor told us it is depression and stress. He's mind is clean. (አይኖርም ግልፅ ነው)። But he has stress.” (P.8, Male, age. 28)

Awareness of the side-effect of the medication

Limited awareness of medication side effects was evident in caregivers' narratives. While caregivers readily discussed the therapeutic benefits of medication and its role in managing symptoms, descriptions of adverse effects were less prominent. Among those who reported such experiences, side effects including excessive drooling, tongue protrusion, and changes in eye appearance were identified as treatment-related concerns.

“Yes, he had the Side effects. He was Drooling uncontrollably. and things like that. They gave him another medicine, calling it an antidote for the side effects of the first medicine.” (P.10, Female, age. 28)

“What I saw is his eyes would turn white, his tongue will be out and he will drool. During that time, he was admitted in Ward 8. They give him medication and he became fine”(P.3, Female, age. 37)

4.3. Caregivers' Perceptions of People with Mental Illness and Their Life Prospects

4.3.1. Perceptions and Characterizations of MI and PWMI

Caregivers commonly described people with mental illness (PWMI) in relation to the overt behavioral manifestations associated with the condition, including shouting, talking to oneself, and difficulties distinguishing right from wrong. These behaviors were often viewed as creating a need for close supervision and support. Importantly, caregivers frequently framed such behaviors as consequences of the illness rather than defining characteristics of the individual, expressing compassion and emphasizing the importance of patience, care, and continued support.

“They all have different behavior. For example, mine shouts and disturbs while some stay quiet for long time. I think the illness by itself is different from person to person. They need care like babies. They act how their mind tells them. If they feel like disappearing, they will. It is difficult so they need care. We need to talk softly we don’t have to shout or blame them. His brothers say he is doing some things intentionally but I always tell them ‘You have gone to school and you have to know he is not doing thing intentionally, he is struggling. They could get into car or fire or disappear so a close attention and care is needed.” (P.2, Female, age. 43)

“Some think like kids and act that way, and they need to be taken care of. Here for example some of them hit them, treat them badly and it shouldn’t be that way. They need love and care until they feel fine.” (P.3, Female, age. 37)

Alongside these compassionate views, caregivers also described challenges associated with caring for PWMI showing how difficult PWMI can be. Participants referred to behaviors such as verbal insults, disruptive actions, and socially inappropriate conduct, which contributed to the demanding nature of caregiving.

“The people who are here, everything about them is very difficult. First, they don't agree with each other. Second, they can't distinguish between what is useful and what is not. One person eats his own lunch and then insists on eating another person's. That's what I have seen here. There are various other problems. And after

eating his own lunch, he goes to another person's room and says, "Give it to me." He leaves his dorm and goes to another person and says, "Give it to me." Also, they don't let a newcomer, like you, pass. They demand, "Give me." "Give me money, give me ten birr, give me one birr," they say, and they don't let them pass." (P.1, Male, age. 72)

"For instance, with ours, when it gets severe, when he starts being very mischievous, we tie him up. But here, in a place like this, he doesn't do anything. They differentiate between a place with no people and a place with people. Now, in a place with people, ours... well, he doesn't cause any harm, he doesn't think of any mischief. But some others, whether there are people around or not, they continue with their own business, with mischief and bad deeds." (P.11, Male, age. 32)

Caregivers also highlighted positive qualities among PWMI, portraying them as peaceful, caring, and capable of maintaining supportive relationships with others.

"They have been through a lot. I have learned a lot since coming here. It made me think about my own life. If their condition got better, they can live a better life more than anyone, most of the patients have knowledge, they can speak good English with a good knowledge and accent, they help each other out, even when one roommate has food delivered to him there is no such thing as "this food is Christian food, this one is Muslim's food." Everyone will come together; they will call their friends and they eat together. They are so nice." (P.8, Male, age. 28)

Caregivers' perceptions of dangerousness and aggressiveness were closely linked to the severity of the illness and its symptom manifestation. Aggressive behaviors, when reported, were often interpreted as expressions of the illness rather than intentional acts.

"Yes sometimes, he hits me. I don't want to say my son hit me because it is beyond his control. He also hits his sisters and they don't understand him like I do. They get angry at him. He even hit me recently, the doctors were talking to me and he came

and he slapped me. I didn't feel pain; even if I do, I won't hold a grudge against him. I know it is the illness not him. Now that I think of him, our brain is a major organ without it everything collapses.” (P.2, Female, age. 43)

“For instance, with ours, when it gets severe, when he starts being very mischievous, we tie him up. But here, in a place like this, he doesn't do anything. They differentiate between a place with no people and a place with people. Now, in a place with people, ours... well, he doesn't cause any harm, he doesn't think of any mischief. But some others, whether there are people around or not, they continue with their own business, with mischief and bad deeds. It has types.” (P.11, Male, age. 32)

“There are patients here who have killed their mother and father. Yes. There is one who killed his father with a coffee pestle, with a piece of wood, and then killed him with the same thing. Now, my brother who drove me here was sitting on one side of the car, and I was on the other. I'm telling you; the illness is very serious; it makes you disgusted.” (P.9, Female, age. 55)

On the other hand, Caregivers reported that they had not encountered dangerous or aggressive behavior among people with mental illness, despite initially fearing such behaviors due to commonly held beliefs within the community. Participants explained that their concerns were largely shaped by what they had heard from others rather than their own lived experiences. Many caregivers attributed the perception that people with mental illness are dangerous to community myths and negative stereotypes surrounding St. Amanuel Specialized Mental Hospital.

“Regarding dangerousness that's what we hear about people with mental illness from outside. At first, I was afraid to come here. At that time, I would have been happy if he wasn't not admitted here. But after being admitted here and seeing his changes it is really good. I haven't seen anything that makes me fear them until now. It might be different in other wards but at ours there are peaceful, you have

seen it how he was hugging me. I don't agree with that statement.” (P.8, Male, age. 28)

“Yes, most people say like that. I also used to think like that it. But after I come here, I didn't saw any of that. There is a saying that they hit people, quarrel with others and even it can be transmitted, don't get close to this people, but after coming here I haven't seen that kind of thing. It is peaceful, I haven't encountered anything that will make me fearful of them.” (P.4, Male, age. 20)

“Here, they are calm. I mean, they might not know what should or shouldn't be done on their own, but they don't harm other people or anything. I haven't. In fact, it's the mentally ill patients out on the streets who are like that. Those without treatment. But the ones here aren't like that.” (P.10, Female, age. 28)

Caregivers frequently rejected the notion that mental illness results from personal weakness. Rather, mental illness was often understood as a legitimate health condition that could affect anyone, regardless of personal strength, intelligence, or character.

“Yes, people assume that it is caused by individual weakness. They say if he was strong enough this wouldn't have happened and stigmatize them thinking they would never get it back to their self. I don't think it is caused by personal weakness. I think it is from God but it can be recovered. Like any other illness it can happen” (P.3, Female, age. 37)

“that's not it. How can you say it is there fault, once it is given? It is praying not to be sick or else if it is given to someone, it is given. How can we say someone is clever, strong and can't have a certain illness? I don't know but how can we say that. Even doctors can be sick right? It is hard to say that “ (P.12, Female, age. 45)

At the same time, alternative views were also present. Mental illness was sometimes attributed to personal factors such as emotional suppression or substance use. Spiritual explanations were also stated implying mental illness as not a proper illness and emphasize that it is from evil spirit.

“There are some who are like that (the disorder is caused by the client’s personal weakness), for instance the person I am attending to, it is because he doesn’t share what he is feeling, if he had shared his stress, he wouldn’t be here. but what can be done about this as well, this is his personality. If he shares what has been bothering, if he had share what’s inside him, if he had been transparent, he wouldn’t have been like this. ” (P.8, Male, age. 28)

“If it's like my brother, then yes, it's like that. Because if he hadn't used substances, if he hadn't overdone it, he wouldn't have ended up here. He was healthy. But there are others who get sick on their own. Meaning, just as other parts like the heart and kidneys get sick, a person's mind can also get sick. When that happens, he didn't bring it on himself. But when it's due to addiction, like my brother, it's on him.” (P.10, Female, age. 28)

“I believe so, I don’t think it comes from proper sickness. many mental health concerns are because of evil spirit, the devil is playing with them” (P.8, Male, age. 25)

Caregivers differed in their views regarding the visibility of mental illness. For some, mental illness was considered identifiable through observable behavioral and physical characteristics, including unusual walking patterns, talking to oneself, withdrawal, and disruptive behavior as visible signs of illness.

“Yes, you can know. They walk differently, they talk alone, fast. So, you can know.” (P.2, Female, age. 43)

“Yes, it can be seen. Yes. It can be visible when they are childlike. It can be seen when they become withdrawn. Or when they've grown up, they might act foolishly,

and it can be seen then. Or when they become disruptive, when they turn everything upside down. In this situation, many people will say 'he is sick.' Since they bring them saying he is sick... it's visible, and he is said to be sick.” (P.7, Female, age.70)

Others argued that mental illness could not be readily identified through appearance alone, emphasizing the need for closer interaction, assessment, and conversation to understand a person's mental state.

“I think that would be difficult. It needs close examination and questioning.” (P.3, Female, age. 37)

“How would you know? It's not identifiable. For example, now, just by looking at this boy, how can you tell he is sick? Except the fact that he is wearing hospital clothes. It's not identifiable.” (P.12, Female, age. 45)

Living and working with PWMI was frequently described as challenging. Caregivers referred to experiences of aggression, verbal insults, property destruction, and attempts to leave home, all of which contributed to the demands of caregiving. Despite these difficulties, participants often expressed patience, acceptance, and a strong commitment to providing care.

“It is difficult. He does mistakes; he tries to hit you so it is not easy. You have to tolerate them.” (P.2, Female, age. 43)

“To work together, they mightn't accept what you would say and might not communicate well. I think it is better if they work alone, a dispute might happen. You will live by tolerating their behavior. But your interest might not align.” (P.3, Female, age. 37)

“It requires patience. Since you can't talk back to them, you just have to be negligent and let it pass. I don't care if any property is lost or whatever. I only worry about him not hitting me. I'm very afraid of that. Why would I be hit? He is

sick, and people won't pity you if he is like that. So, it's very hard.” (P.9, Female, age. 55)

Caregivers also described living with PWMI as less frightening and more manageable than commonly perceived. They attributed this to factors such as ongoing treatment and proper medication adherence, which help stabilize behavior and make cohabitation manageable.

“Alhamdulillah, it's not as scary as one might fear. After they enter mental health treatment, it's not scary. They become like sociable people.... he used to fight with me. This fighting stopped after he came here. When they give them injections, when they give them pills, that aggressive energy goes away. The remaining illness, even if it's there, it will be in a reduced state; it won't be like before. The disruptive behavior, the fighting, stops. There are many like that. He has also stopped. He doesn't fight. He is peaceful.” (P.7, Female, age. 70)

“For me it is good, not difference. Before coming and seeing this place I had lots of fear towards this hospital. Even when someone makes mistakes, people say you need to go to Amanuel as a joke. This hospital is seen as danger, since it is a perceived as a hospital for the crazy, insane people. Thus, on the first day I come here I refused to come inside and told my family that they should go in and I will wait in the outside. But once I got inside, there is nothing to be fearful of.” (P.4, Male, age. 20)

One participant reported that living with PWMI can be highly stressful, to the extent that it negatively affects the caregiver's own mental well-being. The participant described experiencing anxiety, emotional strain, and a sense of instability and “starting to become like the patient”, while managing the responsibilities of caregiving.

*“You see, they don't know it, but for me, who is healthy, **I start to become like them.** Because knowing what they know, since it makes them do other things, it's their reliability itself that worries me. For living itself, for reliability's sake, I feel a sense of uncertainty. My mind also gets into a state of anxiety.” (P.13, Male, age. 25)*

4.3.2. Belief about recovery, capability and future potential of PWMI

Caregivers generally expressed optimism regarding the ability of PWMI to lead meaningful and independent lives. Recovery, medication adherence, and ongoing family support were viewed as important conditions for achieving future goals and maintaining daily functioning.

“If they take their medications and recover well, yes they can do that. They will recover is they are supported well by family and medication” (P.2, Female, age. 43)

“Yes, I can testify that. They are capable of creating the life they want. It makes you jealous in a good way, to see them supporting each other, living together. I believe they can educate the society after they are discharged from here. They can be a role model for the society.” (P.8, Male, age. 28)

For some caregivers, future functioning was also viewed through a spiritual lens, with recovery and independence ultimately understood as dependent on divine intervention and God's mercy.

“That is up to God. They will become capable when God shows them mercy and they are fully recovered. It's certain they will then think about "my life.”(P.7, Female, age. 70)

Nevertheless, uncertainty regarding future independence was also evident. Concerns centered on the persistence of life stressors, ongoing symptoms, and continued exposure to substances, all of which were perceived as potential barriers to long-term recovery.

“No, it might not be very possible. Not like before. You see, even now as she takes her medication, she only sleeps for about three or four hours. On top of that, some days she stays awake for three days and then sleeps a lot. Sometimes, because of things like that, she might not have the ability to support herself, manage their house.” (P.13, Male, age. 25)

“... But in the state, we see them in now, they don't talk about "life." Now, even since they've come here, let alone getting better, there are people who smuggle things in for them from outside—for those accustomed to cigarettes, those accustomed to substances... Before, even khat used to be smuggled in, right? It would get into how many rooms? Two, three. And when they conspire, if one gets it, they call each other and get in. The life they have is what we know of, that is.”

(P.7, Female, age. 70)

Belief in the possibility of recovery was a prominent recorded across caregivers' narration. Recovery was commonly associated with consistent medication use, access to treatment, and spiritual hope.

“I know someone from my home town who came here during similar time with us. He is now well and has opened a shop and leading his life. He has gained some weight but he was doing fine. But he stopped his medication and he relapse. I think if the medication is taken properly, they will recover.” **(P.3, Female, age. 37)**

“ They have hope. May Allah heal them. It is up to Allah. The doctors are just a means. By coming here, we found the means. Alhamdulillah.” **(P.6, Female, age. 50)**

“They recover. Haven't I saw it with my own son? Everyone recovers. No one who comes in here leaves without recovering. It just takes time, but everyone recovers.”

(P.12, Female, age. 45)

Despite these hopeful perspectives, uncertainty regarding recovery was also present. Caregivers expressed concerns about recurring stressors, symptom relapse, and the unpredictable nature of the illness, which were perceived as challenges to sustained recovery.

“No, because many things, just some frustration, stress, always trigger it, so I think it will always come back. With certain things, if something happens to her, for that

reason, I think it will come back... I don't think she can cope with it.” (P.13, Male, age. 25)

“I don't know about that; I think they should have recovered till now. Some seems normal I don't know why they are still here, staying here longer. Some come due to stress. I believe my sister is also here for a long time, she should have been recovered by now“ (P.4, Male, age. 20)

4.4. Caregivers help-seeking experiences and treatment decision

4.4.1. primary help seeking pathway

At the onset of illness, caregivers commonly described seeking help through traditional and faith-based treatment pathways, including holy water sites, Quranic healing, traditional healing practices, and rehabilitation centers incorporating spiritual treatment approaches. These pathways were often the first point of contact when caregivers attempted to understand and manage the illness.

“Yes, he was at holy water for 4 years. He comes back home and goes back when he becomes sick.” (P.8, Male, age. 28)

“At first we took him to rehabilitation center. It's a private, traditional treatment and addiction rehabilitation center. They also have Quranic healing. There's traditional medicine and addiction rehabilitation center.” (P.10, Female, age. 28)

Modern mental health services also emerged as an initial source of care in caregivers' narratives. Participants described seeking treatment from health centers and specialized mental health facilities shortly after recognizing the illness.

“It was to health center. They refer me here and he has been getting treatment here ever since. I didn't take him anywhere.” (P.2, Female, age. 43)

4.4.2. Reasons for choosing a particular help - seeking pathways

Caregivers' treatment decisions were shaped by their beliefs about the causes of mental illness, recommendations from family and community members, and culturally established pathways for addressing illness. Traditional and faith-based treatments were often pursued when mental illness was attributed to spiritual or supernatural causes, or when trusted community members recommended such approaches. Those who selected modern treatment as their first option did so primarily based on recommendations as Amanuel is a place for mental illness.

"... Holy water, well, I thought it might be an evil spirit that possessed him. That's why I took him to the holy water place. The child was tied with a chain, like this, when it happened. " (P.1, Male, age. 72)

"...Sometimes we hear the recovery of people by Quran, Holly water and that's why we tried those, it is from people's suggestion." (P.4, Male, age. 72)

"I just... Allah guided me. peoples say Amanuel Amanuel right? We came thinking there is hope." (P.6, Female, age. 50)

4.4.3. Perceived improvement seen at traditional treatment pathway

Experiences with traditional treatment varied across caregivers' accounts. Some participants described observing improvements in patients' behavior, communication, and social functioning following engagement with traditional or faith-based treatment. These participants also believed that if that type of care continued the patient would have healed.

"There was a change, we were suggested to go from Quran to cultural treatment. and at the cultural treatment she was getting better, her behavior was improving. But she refused to take the medicine. I am sure if she took the medication properly, she would have recovered. that's why we brought her to this hospital." (P.4, Male, age. 20)

“At the prayer house, he had changes, He would recognize people, he would talk, he was starting to behave like a normal person. But he escaped. And so, it's the devil. Sometimes, when he is on the direct path to being healed, so that he doesn't get healed, it creates some kind of obstacle and... it hinders them. It paves a way for him not to be healed.” (P.11, Male, age. 32)

At the same time, other caregivers reported little or no observable improvement despite prolonged engagement with traditional treatment approaches.

“No change at all. Now, others would babble, 'I am this, I am bewitched, I am a demon.' He says nothing.” (P.12, Female, age. 45)

4.4.4. Future help seeking intention

Caregivers frequently expressed a preference for modern mental health services when discussing future help-seeking intentions. Their recommendations were largely informed by observed improvements following treatment and exposure to recovery stories from other patients.

“I will say, take them to hospital. Not to the witchcraft (Wukabi bet) or other places. They will recover and I have seen people recover.” (P.2, Female, age. 43)

“Here, medical help is being provided. There is improvement. There are also those who have been cured. In our hometown, when they call them, they say, 'So-and-so was cured after going there. So-and-so was sick like this. This person was sick like this. They get cured,' they say. Even in the countryside. So, I believe that anyone can be cured.” (P.12, Female, age. 45)

Alongside this preference for modern treatment, caregivers also described an integrative approach that combined religious, traditional, and biomedical forms of care. In these accounts, spiritual treatment was often viewed as an important initial step, while medical treatment was considered complementary or necessary when symptoms persisted.

“I recommend to take them to, holy water. everyone is healed there. The modern treatment is also good. I have seen change on him after 2 days of treatment. Regarding his movements and the like the medication is helping him. Both the holy water and the medication is good. There is nothing that prohibit from using both.
“(P.8, Male, age. 28)

“When someone first gets sick, from my part, I would be happy if they took them to a prayer house first. After that, they should also go to a holy water site and try that. If that doesn't work, they should proceed to medical treatment.” **(P.11, Male, age. 32)**

Chapter 5: Discussion

Caregivers' Conceptualization of Mental Illness

To assess caregivers' knowledge of mental illness, the study first examined their understanding of the condition. The findings showed that participants view mental illness as a challenging condition. They often describe it based on the observable behavioral changes and the impact it imposes on the patients. This corresponds with studies from Tanzania and Ethiopia (N. S. Habtamu et al., 2025; Hovland et al., 2025) which indicate that caregivers typically define mental illness as the most difficult illness and explained it through its behavioral manifestation.

Beyond describing mental illness through observable behaviors, caregivers described difficulty understanding patients whose symptoms were not overtly disruptive, such as excessive sleeping, social isolation, quietness, or those who appeared to understand and be aware of their actions. This finding implies limited awareness regarding symptom recognition, the overgeneralization of mental illness manifestations into specific disorders, and pre-existing perceptions of people with mental illness as dangerous, disruptive, lacking awareness of their actions, and prone to risky behaviors. This pattern mirrors studies done in the general public of Ethiopia, which indicates that participants largely understood mental illness through observable behavioral signs, including meaningless speech, aggression, unpredictable actions, wandering, rough sleeping, and poor hygiene, leading to a conclusion that one has to display behavior that attracts public attention to be recognized as mentally ill (Alem et al., 1999; Tekola et al., 2021).

This finding also aligns with Jorm's study (Jorm, 2000), where symptoms of depression were sometimes misunderstood as physical issues such as a virus, nutritional deficiency, or cancer. Moreover, a study conducted on family caregivers of patients with schizophrenia (Harrison et al., 1998) found that caregivers often fail to recognize non-visible symptoms due to limited mental health knowledge and bias. Subtle changes like withdrawal, low motivation, or reduced speech may be misinterpreted as personality traits instead of symptoms of illness. Since these subtle

symptoms can indicate various mental illnesses—such as Major Depressive Disorder (MDD), anxiety disorders or critical early signs of several psychotic disorders—difficulty in recognizing them can hinder or delay individuals from seeking help. This is supported by (Altweck et al., 2015; van der Ham et al., 2011) who showed that poor symptom recognition directly leads to delays in professional care and a preference for informal explanations.

In addition to this, caregivers participants expressed confusion due to fluctuating behaviors, leading them to believe that the patient might be pretending. This finding matches (M. S. et al., 2012; Nabi & Rizvi, 2022) where caregivers reported similar suspicions about the individual faking their condition. This clearly shows that gaps in mental health knowledge influence caregivers' views of people with mental illness (PWMI), affecting their attitudes and actions.

When discussing the causes of illness, participants mentioned several factors. Psychosocial causes, like unemployment, poverty, and lack of parental love—were the most common. This corresponds with the study conducted in China (Li & Reavley, 2020), which reported that caregivers in various settings often link mental illness to social and environmental stressors, along with biomedical factors. Following psychosocial factors, participants often quoted spiritual factors as a cause. They attributed mental illness to evil spirits, spell casting, and bewitchment. This finding is similar to that of Tanzania's study (Hovland et al., 2025) where caregivers also viewed mental illness through a supernatural lens.

Regarding awareness of the specific mental disorder affecting the patient, caregivers were unaware of the specific name of the diagnosis. Only two participants were able to identify the diagnosis by name. The rest of the caregivers referred to the condition broadly as "mental illness" without distinguishing between specific psychiatric disorders. This limited ability to identify particular diagnoses may be partly explained by the continued influence of traditional conceptualizations of mental illness in Ethiopia. The Mental Health Report in Ethiopia (Alem et al., 2017) describes how mental and behavioral disturbances have historically been understood through culturally specific labels that emphasize observable symptoms, illness severity, and social functioning rather than biomedical diagnostic categories. A similar finding was reported among caregivers in Tanzania, where participants commonly used the Swahili term "kichaa" (insanity) as a general label for

mental illness without differentiating between specific disorders (Hovland et al., 2025). As a result, caregivers may be more familiar with traditional descriptions of mental illness than with formal psychiatric terminology, contributing to the diagnosis-specific knowledge gaps observed in the present study. In contrast, studies conducted in Asia and other regions have reported higher levels of recognition and understanding of specific mental disorders among caregivers (Li & Reavley, 2020; Roelandt et al., 2020).

Knowledge of a patient's specific psychiatric diagnosis may support more effective caregiving by helping caregivers recognize disorder-specific symptoms, identify signs of relapse, and better understand treatment recommendations. Mental health literacy literature considers the recognition of specific mental disorders an important component of understanding and managing mental illness (Jorm, 2000). Furthermore, diagnosis-related knowledge has been associated with earlier recognition of mental health problems, more appropriate help-seeking, and better engagement with mental health services (Chen et al., 2017; Wei et al., 2015).

When it comes to medication side effects, only two caregivers mentioned extrapyramidal side effects of antipsychotic medications, whereas the other participants, didn't identify any side effects. Although not all patients use antipsychotics medications, but most psychiatric medications also produce certain side effects ranging from mild to moderate, such as sleep disturbance, weight gain, dryness of mouth and sedative effect. Thus, the participants' inability to mention medication side effects aligns with several studies findings (Ahmed & Baruah, 2017; Li & Reavley, 2020; O. Jack-Ide & E. Amegheme, 2016) all of which demonstrating limited caregiver knowledge about medication side effects and their management.

Caregivers' Perceptions of People with Mental Illness and Their Life Prospects

The present study found that caregivers largely perceived people with mental illness (PWMI) through the behavioral manifestations associated with the illness, including shouting, talking to themselves, impaired judgment, and behaviors requiring close supervision. However, despite recognizing disruptive or difficult behaviors, caregivers demonstrated compassionate and supportive attitudes, framing such actions as consequences of illness rather than intentional wrongdoing or inherent character traits. This finding may suggest that prolonged caregiving exposure and lived experience can foster empathy and greater understanding toward mental illness. Similar findings have been reported in previous studies indicating that caregivers, due to frequent contact and caregiving responsibilities, often develop more accepting attitudes and are more likely to attribute problematic behaviors to illness rather than personal fault (Corrigan & Watson, 2002). Furthermore, participants frequently emphasized patience, care, and emotional support, reflecting a relatively non-stigmatizing attitude despite acknowledging caregiving difficulties.

Regarding dangerousness and aggressiveness, caregivers in the present study held diverse perspectives. A group of participants associated aggressive behavior with the severity or manifestation of the illness, particularly during acute episodes, while still emphasizing that such actions were beyond the patient's control. This finding aligns with studies conducted in Nepal (Neupane et al., 2016; Pandey, 2019) representing greater percent of caregivers perceiving people with mental illness as dangerous and violent. From a stigma perspective, this finding reflects the peril dimension of mental illness stigma, which refers to the perception that people with mental illness are dangerous, unpredictable, or likely to cause harm to others (Ahmedani, 2011; Corrigan & Watson, 2002). Such beliefs can contribute to fear and social distancing from people with mental illness. However, unlike traditional stigmatizing views that portray individuals as inherently dangerous, some caregivers in the present study attributed aggressive behavior to acute symptoms of the illness rather than to the individual's character, suggesting a more nuanced understanding of mental illness.

Literature suggesting that although certain severe mental illnesses may involve behavioral disturbances during periods of relapse or untreated symptoms, public perceptions often overestimate the association between mental illness and violence (STUART, 2003).

Interestingly, participant caregivers reported initially fearing PWMI based on community narratives and stereotypes surrounding mental illness and St. Amanuel Specialized Mental Hospital; however, these perceptions shifted after direct caregiving experience and hospital exposure. This finding supports the contact hypothesis, which proposes that closer interpersonal contact with stigmatized groups can reduce fear, stereotypes, and discriminatory attitudes (Corrigan & Watson, 2002). Participants' accounts suggest that direct interaction with treated patients challenged commonly held community myths portraying PWMI as uniformly dangerous, highlighting the role of experience in reshaping mental illness perceptions.

In addition to this caregivers viewed people with mental illness as capable of building a future life, provided that if they adhered to medication and received family support. In line with this finding, several studies (Iseselo & Ambikile, 2020; Singh et al., 2023) reported that caregivers commonly see recovery as a gradual process involving structured support, self-care, and participation in everyday roles and moderately optimistic expectations about improvement in symptoms, social functioning, and independence, especially when treatment is sustained and services are accessible. All caregivers reported feeling burdened by the caregiving process however the majority believed and had witnessed that recovery was attainable especially when medication was taken consistently and support from family is provided. This finding is in accordance with studies (Cham et al., 2022; Iseselo & Ambikile, 2020; Sharma et al., 2021) that demonstrate caregivers hope in recovery and burden of caregivers do not necessarily predict pessimism about recovery.

Regarding caregivers' perception of Mental illness as a legitimate illness, participant caregivers show mixed stand. Half of the participant caregivers rejected the idea that mental illness is a sign of personal weakness. They equate mental illness to the rest of physical illness and argued that no one should be blamed for becoming ill. On the contrary, the rest participant caregivers still interpreted mental illness as personal weakness, poor emotional expression, or self-inflicted illness due to substance use. This finding is crucial because it shows that blame and moral judgment were not absent, even among caregivers who otherwise expressed sympathy. This result is in agreement with a study conducted in Zambia (Sichimba et al., 2022) and Tanzania (Hovland et al., 2025) where caregivers were mentioning patients' prior behavior such as adultery, substance use,

disagreement with elderly figures as the explanation of the illness rather than considering as proper illness. Such viewpoint has implications on many aspects of the care giving process. It demonstrates that there is absence of strong foundation knowledge regarding the causation of the illness and results in criticizing and blaming the patient, which makes them develop negative attitude towards patients and further affects the type of care and support provided and the help seeking behavior.

Perceiving mental illness as a sign of personal weakness rather than a legitimate health condition may have important implications for caregiving. Such beliefs can lead caregivers to attribute responsibility for the illness to the affected individual, potentially resulting in blame, criticism, and reduced empathy. This finding can be understood through Attribution Theory, which suggests that conditions perceived as controllable are more likely to evoke negative judgments than those viewed as beyond personal control. Similarly, the origin dimension of stigma proposes that illnesses believed to be self-inflicted attract greater blame and social disapproval (Ahmedani, 2011; Hilbert et al., 1985). In the present study, caregivers who linked mental illness to personal weakness, poor emotional control, or substance use appeared to view the condition as being under the individual's control rather than as a medical disorder. Such perceptions may contribute to stigmatizing attitudes and negatively influence the support provided to people with mental illness, as well as caregivers' engagement with professional treatment (Corrigan et al., 2003).

Regarding the detectability of mental illness through physical appearance, about half of the Participants reported that mental illness is clearly visible in the patient's outward appearance. Commonly mentioned signs included an unusual way of walking, talking to oneself, social withdrawal, and some disruptive behaviors. In contrast, the other half of the caregivers insisted that mental illness cannot be reliably judged from appearance alone and argued that closer interaction, conversation, and questioning are necessary to understand the person's condition. While certain mental disorders can present with clear behavioral manifestations that make them more noticeable to others, this should not lead to the assumption that all mental illnesses are externally visible. Many conditions, including mood disorders and early or prodromal phases of psychosis, may present with minimal or non-overt symptoms. Overreliance on visible cues may therefore delay recognition and care-seeking for individuals whose symptoms are less apparent,

underscoring the importance of combining behavioral observation with communication and professional assessment rather than relying solely on physical appearance(Sichimba et al., 2022). From a stigma theoretical framework, the belief that mental illness can be identified through physical appearance can be interpreted through the concealability dimension of stigma. This dimension refers to the extent to which a condition is perceived as visible or hidden(Ahmedani, 2011; Hilbert et al., 1985). When caregivers assume that mental illness is readily detectable through outward appearance or observable behaviors, this may reinforce the perception that individuals with mental illness possess identifiable characteristics that distinguish them from the general population. Such beliefs can contribute to labeling and stereotyping by encouraging judgments based on visible cues rather than a comprehensive understanding of an individual's subjective experiences and symptoms. Conversely, caregivers who recognized that mental illness is not always outwardly visible demonstrated a more nuanced understanding of the condition and acknowledged that many mental health problems may remain concealed despite significant distress. Overall, while visible behavioral changes may facilitate recognition of severe cases, overgeneralizing this assumption to all forms of mental illness may reinforce stigmatizing beliefs and obscure the experiences of individuals whose symptoms are less apparent.

Most caregivers in this study reported that living and working with People with Mental Illness (PWMI) is possible, but it requires considerable patience, flexibility, and efforts to avoid triggering anger or aggression. Some caregivers added that the situation becomes manageable once treatment is established, particularly through regular medication, and that in practice caring for the person is often “better than it seemed at first,” especially after the initial fear and uncertainty have decreased over time. This pattern of initial anxiety followed by cautious adaptation and improved co-living is consistent with findings showing that caregivers gradually develop coping strategies and more realistic expectations once they gain experience and support and having better understanding of MI after having a contact with PWMI(Cham et al., 2022; Corrigan & Watson, 2002; Hovland et al., 2025; Mathew & Mathias, 2021).

At the same time, one caregiver described living with a person with mental illness as highly stressful for the caregiver, highlighting the emotional toll and constant vigilance that can accompany such arrangements. This finding echoes broader evidence that family caregivers of PWMI commonly experience elevated levels of stress, anxiety, and burden, particularly when they

live with the patient and are responsible for monitoring behavior, medication, and potential crises(Ae-Ngibise et al., 2015; Cruz et al., 2024).

In addition to the stress, participant expressed his fear and anxiety about developing mental illness themselves due to the stress while living with patients with mental illness (PWMI). This finding has a similar connotation with the Nepal caregivers (Neupane et al., 2016) believing mental illness could be contagious through association with PWMI or stress.

Caregivers help-seeking experiences and treatment decision

The study finding indicate that caregivers went to traditional help seeking behavior mainly to religious center and cultural healing places and very few care givers went to health centers at the onset. This finding goes hand in hand with a study conducted in Egypt(Gabra et al., 2020) where, the majority of caregivers (80.2%) sought advice for the care of their mentally ill relatives primarily from traditional healers, while only 17.4% pursued psychiatric care initially.

While assessing for the reason why most caregivers seek traditional help seeking behavior, participants commonly reported that causative factor and community members suggestion. Several studies (Mokwena, 2025; Sichimba et al., 2022)including Mental health report conducted in Ethiopia (Alem et al., 2017) support this finding by signifying the relationship of causal factor to type of help seeking behavior. Due to this factor the traditional healing methods are used more by most people, from the point of view of the majority of the population having the deeply ingrained religious and inherited beliefs that all mental illnesses are of spiritual origin, their preventions and cure are achieved via traditional healers whose methods of treatment have a spiritual theme.

Regarding modern help seeking behaviors, although initial use of modern services was low, the study found that almost all participants perceived improvement in the patient's condition and recommended modern treatment as the preferred solution for mental illness. This finding is consistent with that of (O. Jack-Ide & E. Amegheme, 2016) which reported that, despite gaps in knowledge, the majority of participants believed their relatives' conditions would improve with treatment and expressed satisfaction with the care provided by mental health professionals.

Chapter 6: Conclusion, Limitation and Recommendation

6.1. Conclusion

The study revealed that caregivers' have knowledge in certain areas such as defining mental illness, causative factors of mental illness however, they demonstrated significant gaps in recognizing non-overt symptoms, identifying specific diagnosis and side effect of medication. They exhibited positive attitudes toward compassionate attitude towards PWMI, capabilities of PWMI and living with PWMI, and possibility of recovery. However, Negative attitude was displayed among few participants regarding their perception towards People with Mental illness, perceiving Mental illness as illegitimate illness and perceiving detectability of mental illness purely through physical attribute. Regarding Help-seeking behavior almost all participant seeks traditional help seeking behavior at the onset of the illness and they have showed promising orientation toward modern treatment pathways for the future.

6.2. Limitation of the study

As the study was conducted among caregivers attending a specialized mental health hospital, which may have influenced participants' responses. Being interviewed within a healthcare setting and having ongoing contact with mental health professionals may have encouraged some participants to provide responses that reflected socially acceptable views regarding mental illness, treatment, and caregiving practices. Although efforts were made to establish rapport and ensure confidentiality, the possibility of social desirability bias cannot be entirely excluded.

Although the St. Amanuel Mental Specialized Hospital serves a diverse patient population from different parts of the country, the findings may not fully represent caregivers in other healthcare settings, rural communities, or regions with different sociocultural contexts. As a qualitative study, the findings are intended to provide in-depth insights rather than statistical generalization, and their transferability to other contexts should be considered with caution.

6.3. Recommendation

Based on the finding of this study, The following recommendation points are forwarded.

1. **Caregiver-Targeted Psychoeducation:** Implementing structured awareness campaigns in hospital waiting areas and OPD rooms to improve caregivers' knowledge of symptom recognition, specific disorder of their attendee, legitimacy of mental illness and attitudinal stand.

As AMSH has launched the new “caring for care-givers program” which support families of psychiatric patient is a great initiative to address this gap and reduce caregivers’ burden in the caregiving process.

2. **Community-Wide Mental Health Literacy:** Launching public awareness campaigns aimed at the general community. Since caregivers are embedded in the community, educating the community members about Mental health literacy will further influence caregivers’ perception and decision making in a positive way. In-order to make this recommendation feasible, using public gatherings like administrative gathering in Zones, Woredas or teaching in hospital waiting area can be used.
3. **Awareness towards Religious leaders:** working in collaboration with religious leaders is a crucial step. Organizing awareness campaign at different religious centers to educate them the biopsychosocial model of Mental illness is needed. By doing so, caregivers will get the knowledge at the onset of the illness. In addition to this using religious leader’s advocacy to inform caregivers that spiritual treatment can go simultaneously with modern treatment is recommended.
4. **Enhancement on the topic:** I encourage further research examining caregivers' knowledge, attitudes, and help-seeking behaviors in relation to specific mental disorders, such as schizophrenia, bipolar disorder, depression, or substance use disorders. As perceptions and caregiving experiences may vary across different conditions, diagnosis-specific studies could provide a more nuanced understanding of caregivers' needs and inform targeted mental health education and support interventions.

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Annexes

Annex I - Information Sheet

Code No _____

My name is Julia Wondemu, a postgraduate student of Counseling Psychology at Addis Ababa University, School of Psychology. Currently, I am conducting qualitative research on Knowledge, Attitude, and Help-Seeking behavior among caregivers of patients with mental illness at St. Amanuel Mental Specialized Hospital in **Addis Ababa, Ethiopia**.

Introduction: This study aims to explore caregivers' knowledge and attitudes towards mental illness and their help-seeking behavior.

Procedure: The reason I chose you as the study participant is because you are a primary caregiver of an individual attending inpatient care at St. Amanuel Mental Specialized Hospital. I will be asking you some questions including demographical data, your knowledge, attitude and help seeking behaviors towards mental illness. If you are willing to participate in this project, you have to understand and sign the agreement form. The interview will take 30 - 45 minutes. The interview will be audio-recorded to facilitate the use and analysis of the data. The recording will be used for the study purposes only.

Risk/Discomfort: There is no risk in participating in this research project.

Benefits: If you participate in this research project, there may not be a direct benefit to you, but your participation is likely to help us to meet the research objective.

Incentives: You will not be provided any incentives or payment to take part in this project.

Confidentiality: If you agree to this interview, all the information you will give remain confidential and anonymous in addition the information collected from you will be coded using numbers.

Right to refuse or withdraw: You have full right to refuse from participating in this research.

If you don't want to answer a question or stop the interview, you can withdraw from participation at any given moment in the interview.

Person to contact: Julia Wondemu

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Email Address: juliawondemu@gmail.com

Are you willing to participate in the study?

Yes

No

Annex II - Informed Consent Form

I hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate voluntarily in the research project. I understand that I am at autonomy to withdraw from the project at any time.

Signature of participant _____

Date _____

Name and signature of Researcher _____

Date _____

Annex IV - Interview Topic Guide

1. Caregivers' knowledge about mental illness

- Can you tell me your understanding of mental illness?
 - ✚ Definition, cause, risk factor
 - ✚ What is your opinion regarding the treatment of mental illness?
 - ✚ What are the Treatment options, and what to expect from this treatment?
- Can you tell me about the patient's mental health condition and its treatment?
 - ✚ Diagnosis, manifestation, side effect and management
- What is your understanding on the cause of your relative's mental health condition?

2. Caregivers' attitude towards mental illness

- What do you feel about people with mental illness?
- What do you think about the future of people with mental illness? Can you give me a hypothetical future life-style of PWMI?
 - ✚ Capability to create future life, their own family
- What are your beliefs about the possibility of recovery for someone with a serious mental illness?
- There are some saying among the society that goes, "Mental illness is a form of personal weakness or it is not an actual medical problem.", what do you think about this?
- In your opinion, how recognizable is mental illness based on an individual's physical appearance?
- What is your opinion about living or working with people with Mental illness?
- In your opinion, how should people with mental illness be cared for?

3. Caregivers' help-seeking behavior towards mental illness

- Tell me about the very first step you took to get help for your relative's health?
- What led you to choose that particular option first? Any witnessed change?
- With the knowledge and experience you have now, what do you think is the appropriate place to seek help? Why do you prefer that?

4. Anything you want to add?

Annex V - Sample interview translations

1. Participant code – P.2 (Female , age. 43)

Q- Marital status?

A- I am a widower.

Q- Educational Status?

A- I didn't go to school

Q- Where are you from?

A- Around Sebeta town. Our sub city is sebeta, and the place is called DIMA, kebele 05

Q- What do you do?

A- I have no job

Q- Are u the main care giver?

A- Yes

Q- Relationship with the patient?

A- He is my son

Q- For how long have you taken care of him?

A- 18 years. He started being sick when he was 10. He started his treatment here since then. I go out to search when he gets lost, I tolerate when he hits me and I provide care through all this. He has been on treatment here for 18 years and he is now 28 years old.

Q- How much care does he require? Is it always or is it sometimes?

A- He is dependent on my care because he doesn't know how to dress, how to eat, how to wash his hand. He tries but he leaves it after he put soap on his hand. He needs my care all the time.

Q- What about using toilet?

A- I tell him to go and use. He can sit by his own but I have to go back and get him up. Unless, he will stay there shouting and blabbing. I need to get him out once he is done.

Q- Is there anyone who supports you to take care of him?

A- It is just me. I raised him being his mother and father. I raised him in low livelihood status. I also have a daughter who is sick. Her dad hit her and now she has a nerve disorder, she is attending treatment at black lion hospital. She was operated and I take care of 2 sick kids.

Q- Based on what you understand what does mental illness/disorder means?

A- I know even if I didn't attend school, if a person has mental problem all of his health will be in trouble. We go out and work because we are mentally well. The professionals has told me it will be cured so without mental health a person can't go out, work and eat. I think it is difficult

Q- You are right. As our mind is core to multiple things, having a mental illness might hinders most activities. What about the causes? What do you think?

A- A professional will know that better. I think it might be psychological and also that is how some people are born with. But I don't know much

Q- What do you mean by psychological?

A- When parents couldn't get along and are in dispute. Also it could be nature, some people

Q- Why do you think some people have more risk to mental illness?

A- You mean?

Q- For example, a bad smell might not do anything to some people but to people with Asthma it could suffocate them. And in mental illness, some people are prone to it while some aren't. Why do you think that happens?

A- A mentally unwell person doesn't differentiate good from bad. He goes where he wants and eats what he wants so this might put him at risk of catching diseases.

Q- Tell me a bit about the treatment options for mental illness?

A- I know the modern treatment. Doctors will check on him, will decide if they need to be admitted or not and give him medication.

Q- What is expected from this treatment?

A- To get well.

Q- Tell me about how his condition started?

A- When I was pregnant with him, I got sick. My body was not functioning well from my waist down and I was admitted to the hospital. I was in ICU and I was 6 month pregnant by then. I told them about it and they said no to worry. He was injected some medication. I gave birth on 9 month but once he was born, he used to cry day and night. He was 3.5 kg, he started speaking late at 3 but he was well. He was doing well at school but when he was 10 he started acting different. He spins a lot and when I ask him he used to say 'I will make it rain' and he makes noises like a thunder with his eyes closed. He used to run around and started hitting people. That is when I brought him here.

Q- What was the cause for his behavior?

A- I think it might be the injection I took and his father and I was not good, he used to drink and disturb and he hurt his daughter as I told you. That also could be the cause. One of the two reasons might cause his illness.

Q- Mental illness has different names like different health conditions. Do you know the name of your son's condition?

A- They just say mental illness I don't know the specific name.

Q- In the last 18 years, has he ever been well and relapsed?

A- Yes. He was lost for 5 days with 2 dogs. After the 3rd day one dog returned, we posted his picture around and he was people found him around 4 killo. He also got lost after a while for 07 month. After his first disappearance he took a match and burned himself so I tied his hands and legs.

Q- Was there a time, where he was doing fine/in recovery?

A- Yes when he takes his medication right, he stops disturbing, he stays quite. I can't say he is fine but he does better but when he stops taking the medications all his disturbing acts comes back. When he takes the medication, he becomes more dormant and wants to sleep more.

Q- Can you tell me about the medication he takes?

A- I don't know the name. One is small, one is white. And he takes 2 from each morning and night.

Q- Do you know about the side effects of the medication?

A- No

Q- Has he ever experience side effects?

A- No.

Q- Has the professionals told you what he might experience as side effects?

A- No they haven't.

Q- Where did you get the knowledge about mental illness?

A- It is from experience. Doctors who treated my daughter at tikur anbessa have told me, his name is DR. Andualem. But I didn't get any information about mental illness from here.

Q- Now am going to ask you about attitudes. How do you explain their behavior?

A- They all have different behavior. For example mine shouts and disturbs while some stay quite for long time. I think the illness by itself is different from person to person.

Q- What do you understand the saying 'they are dangerous, they can't make decision, they need attention....'?

A- They need care like babies. They act how their mind tells them. If they feel like disappearing they will. It is difficult so they need care. We need to talk softly we don't have to shout or blame them. His brothers say he is doing some things intentionally but I always tell them 'you have gone to school and you have to know he is not doing thing intentionally, he is struggling. They could get into car or fire or disappear so a close attention and care is needed.

Q- Do they have aggressive and impulsive behaviors?

A- Yes sometimes, he hits me. I don't want to say my son hitted me because it is beyond his control. He also its his sisters and they don't understand him like I do. They get angry at him. He even hitted me recently, the doctors was talking to me and he came and he slapped me. I didn't feel pain; even if I do I won't hold a grudge against him. I know it is the illness not him. Now that I think of him, our brain is a major organ without it everything collapses. For example my daughter was hurt in her right side but her left side is not functioning well, this means the brain does all the functioning.

Q- What do you think about their future? Do you think they will have their own family, kids and job?

A-If they take their medications and recover well, yes they can do that. They will recover is they are supported well by family and medication.

Q- What is their chance of recovery?

A- They can recover if they get treatment.

Q- Have you notice any change in the past 18 years?

A- At first his neck was twisted and he was treated for that. He could have recovered well if he didn't stop his medication in between when he disappeared and when I left him with relatives when my daughter got sick.

Q- Some believe mental illness is caused due to personal weakness of the individual. What do you think about that?

A-That's right. Some say it is a curse and other things and avoids taking them to hospital. This do harm to the person so yes it is personal weakness.

Q-What about before that? Is the illness because of the individual weakness?

A- Yes if they come early to hospital and consulted with doctors he could have recovers. A person with mental illness cant tell, I am sick here or there so it is the family responsibility to bring them to hospital.

Q- So is the ill person responsible for what happened to him? Is it because he is weak or lazy?

A- No. It is illness it is not his fault. It could happen to anyone; rich or poor.

Q- Can you say someone has mental illness by just looking at them, by their appearance?

A- Yes you can know. They walk differently, they talk alone, fast. So you can know.

Q- How do you feel about working and living with people with mental illness?

A- It is difficult. He does mistakes; he tries to hit you so it is not easy. You have to tolerate them.

Q- What kind of care do you think they need?

A- You need to take care of them as a baby. You need to feed them, give them medication, do their clothing, wash them and take of them differently like a baby. In that way, their chance to recover is also high.

Q- Where did you take him first when you seek help?

A- It was to health center. They refer me here and he has been getting treatment here ever since. I didn't take him anywhere.

Q- How did you decide to take him to health center?

A- I consulted with people, and the health center referred me here.

Q- With the knowledge and experience you have now, what do you recommend for people seeking help?

A- I always say don't hit them, don't treat them badly, they are like kids. Kids actually know what they do some time, but mentally ill people don't know what they are doing. So care for them while feeding, clothing cause it is difficult.

Q- What about where to take them?

A- I will say, take them to hospital. Not to the witchcraft (Wukabi Bet) or other places. They will recover and I have seen people recover.

Q- Do you want to and anything? A - No.

Q- Thank you.

2. Participant Code – P.12 (Female, age.45)

Q: how old are you?

A: 45

Q: What is your marital status?

A: I am married.

Q: What is your education level?

A: Up to seven [grade 7].

Q: Where did you come from?

A: From this side of fiche from Goha Tsion, at Felfelqe. Do you even know it for me to be telling you all this?

Q: Is it on the Fiche road?

A: Yes, on the Fiche road.

Q: Goha Tsion. Is it in the town or the countryside?

A: In the town.

Q: Okay. What is your work situation now?

A: In agriculture.

Q: what's your relationship with the patient?

A: He is my child.

Q: Are you the primary caregiver?

A: Yes, I am.

Q: Primary caregiver... how long have you been caring for him?

A: For... it's my 17th day. Since I came here.

Q: Since you came here?

A: Yes.

Q: Before coming here, did he receive medical treatment or...?

A: It was holy water (*Tsebel*).

Q: Did you stay at the holy water site for a long time?

A: Yes.

Q: In total, how long has it been since it started?

A: It started... in Tahsas [approx. December/January].

Q: Tahsas of last year, it is around 9 month?

A: Yes.

(Sound of people talking and moving in the background)

Q: ...There is some noise, so if I find a quiet place... Let me find a quiet place, there is some noise because people are coming and going. The sound is getting in the recording...

(Sound of people walking)

Q: Since there won't be another bed, and we can't sit on a bed, there is a bench over here and it's quiet. If you need to go back and check on what he's eating...

A: Is that the patient, you look after?

Q: Yes. I thought you could go back and see him later. There is some noise.

(Sound of people talking in the background)

Q: Let's fill it out for you here. So for the past 9 month you have been the primary caregiver.

A: I am.

Q: Is he your only child, or do you have other children?

A: I have others. Besides him, I have three other sons.

Q: Do they help you?

A: When they work, they send money. When they work. He has a father. It's me and his father.

Q: So you have four children... out of the three... you are the one primarily providing care?

A: Yes.

Q: Okay. How do you manage? Your son's day-to-day... his day-to-day activities, how much... activity does he have? How much of your help does he need?

A: Now, he is getting better. He has become self-sufficient now. He can go to the toilet by himself. You know... but now he has refused to eat... he is asleep.

Q: So, he needs help from time to time... but he is getting better?

A: He is well. Thank God.

Q: You told me he sometimes needs your help. Okay. So now, as I told you, we will move to the main topic. About mental illness... I will ask you some questions. You will explain his situation to me in detail. But to start with, how would you generally describe mental illness?

A: Mental illness... it has become... It makes you less than your peers. He had ambitions, dreams, this boy. But since he got sick, all his ambition is gone. To change our lives, our family's... He quit 10th grade and went into development work. In development, he would grow tomatoes, red onions,

there in the valley... The Abay [Blue Nile] river water would flow, and in the dry season, it would dry up. That dried part... they would use it... isn't it like fertilizer? They use the silt to enrich the soil on top. He and his older brother—one quit in sixth grade, this one in tenth—after I gave birth to him... they quit their education so we wouldn't be poor. I am telling you in the name of Medhane Alem [Savior of the World]. So that we wouldn't be poor, you see... I also used to spin cotton, we would make decorative cloth. All of that would be gone, right? So that our efforts wouldn't be for nothing, they quit their education, but it didn't work out. This illness took him. He said he would buy a car, and so many things... The market didn't give us a good price; it crashed. When the price of onions and tomatoes went down... You see, he had built a house for us that we rent out, this boy did. With his brother. He bought us cattle... I think in the middle of all that, his mind got affected. When what he envisioned didn't work out...

Q: When it didn't work out...

A: The anger, the frustration... that's what it seems like to me. As a reason, as a cause, that's what you would raise?

Q: That's it.

A: On top of that, the Abay valley is hot. You may have heard them talk about it, even on TV... It's a valley, people don't live there because it's hot. Otherwise, someone like him, a life-builder without land... but most people hate the valley. And while he was there, he started saying, "Satan shone a light on me." While he was inside, in the river, in the flowing river, he asked his father, "Why did you shine the light when I was shining my own?" "Does Satan have authority?" he asked, and he prayed a lot. He is a prayerful man. We are Christians. And I would pray over him... Then at midnight [12 AM]... he left the light on. And I got scared, and he spent three days alone in that valley. There are leopards, tigers, and so on, monkeys that eat the crops. The watermelon, the onions. So they wouldn't eat it, he stayed there alone. His brother was late. Now, from there, when he was coming back at midnight, the federal police who guard the crossing, the bridge... the Abay bridge, they asked him, "Hey, what happened, why are you coming now?" "Satan shone a light on me." When they tried to hug him and say "It's okay," he was apparently completely incoherent. "It's okay, it's okay, you are the son of a respected man." "Yes." "Why didn't your family come?" "It was Satan, he got ahead of me on the road, even now as I was coming." "It's okay." That's also why I wouldn't take him to the holy water, thinking it was related to his name.

Q: When you say, "Satan shined a light on me," can you explain what that means?

A: You know, Satan from inside the water... haven't you heard when they turn on Satan's light? He brought it upon the boy.

Q: Like saying, "Satan saw me"?

A: Yes, he shined the light on me. Later, when I said, "Are you sure? Stop it," he said, "No, it's Satan." Then he said, "[Satan] got ahead of me on the road." When he got ahead of me, my mouth was completely tied. I don't even know if I made the sign of the cross. It was like a dream to me. They said it was like he was shocked in a dream. And he's a child; 18 years old is very young. So, that's how I came here. What can I say?

Q: So, you're raising the cause as his plans not working out and him saying, "Satan shined a light on me." Is that the cause of the illness?

A: That is his cause.

Q: Besides his situation, since there are many other patients you see, what other causes do you think mental health or mental illness has in general? Just based on your assumption.

A: For others? How?

Q: What do you think is the reason for the illness? Their mental health?

A: You see, for me, what brought the mental health problem was that we were going to buy a car. Watermelon is very expensive, onions... and for me, the market just went down. Forget a car, we couldn't even afford to buy small things from the market. The market was just not balanced for us. The market didn't give us a chance. Tomatoes became cheap for us, peppers became cheap, so I sold what I brought at a low price. And that money, how far could it stretch? So that's why I said this and came here.

Q: Okay, very good. And what about the treatment? Since you came here, what kind of things...

A: The treatment is very good. He used to shout. He used to hit me too. He would hit me randomly. He even loosened my tooth when he hit me like this. He also broke his father's knee. His brothers too, when they were trying to calm him down, saying "it's okay," he would hit them. He would get close to the child he was playing with... they are still children. I have a seven-year-old and a two-year-old. His younger sibling is 16, as I told you. And he would tell them, "Don't hit them." When they said, "Oh, he hit me," she would tell them to stop. And now he is fine. Thank God, when you see him.

Q: So you've seen a change in him since he came here?

A: I myself don't believe it, thinking it might suddenly return, but they say it won't. If he takes his medicine properly, it won't return. But properly... And now he is fine. Thank God.

Q: What other treatment options do you know of? We are now talking about the medicine he is taking here in the hospital and the changes you've seen. Are there other treatment options you know of?

A: What else is there? It's the mental health pill. Nothing else... he hasn't been infected by malaria. You know, it's for the mind, he's using it here. There's no other option besides this. There's the pill. That's what he takes.

Q: That's what he's taking.

A: Yes, he's taking the pill.

Q: Very good. Okay. For physical illnesses, we have names like tuberculosis or liver disease. Mental health problems are also many and have different names. Have you been told the name of his illness? You don't know what it's called?

A: I don't know.

Q: Okay. The medicine he's taking, side effects... have you been told that the medicine he's taking has side effects? Is there anything you know?

A: I haven't been told.

Q: So far, you haven't seen any side effects?

A: None.

Q: Okay. In general, how would you describe mental health patients? How...

A: It's good, he's become well, thank God. He's fine, you can say normal. He is fine now.

Q: He's fine now.

A: My sisters and relatives, when they talk to him... I could actually go now, but you know, it's... because he is a homebody, he doesn't actively get food for himself. He asks all the relatives, "Give me some, give me some." And I worry it might return because of hunger, but I could go.

Q: he is doing well, but you are here to give better care for him?

A: Uh... I can, he's become well. I've left one child with one sister and another with another sister. My children are very scattered now, the little ones. It's always better when you raise them yourself. And also, I'm staying here because I'm afraid it might get worse for him.

Q: It's very good that you're nursing him; it helps him to have a better change. Okay. How would you describe the behavior of mental health patients? You've been here nursing for a while, so how would you describe the behavior you've seen in your son and in other patients?

A: It's good. They take very good care of them. Even when I'm not here, sometimes when I go to church and I'm late, they wake him up and give him his medicine. They also check his blood. It's good. It's just like family. They don't ask if he has anyone or not.

Q: Are you saying the treatment you received here is good?

A: Yes, very much. It's very good. Even if you don't have family, anyone takes care of you. They wake him up. Mine is at 11 o'clock now. If he doesn't take his medicine at 11, and if his blood pressure isn't checked at 11, they say. And that's good.

Q: Okay. There are things we hear. Sometimes, due to the illness, they can become dangerous. You yourself told me that he used to hit you before. It's said they can be dangerous, can be aggressive, so how do you see this?

A: What do you mean how?

Q: Being dangerous, being aggressive... it's a behavior you yourself have seen, but in general, when you think about it, can we say that mental health patients are always like that, or is it only when the illness flares up?

A: It's very good. He got better for me, thank God. He doesn't act strange with me anymore. He sees me as a mother now. When people talk to him... the other day when his father called him, he said, "Should I spit out my saliva or swallow it?" I was very sad. "Oh my, spit it out! How can you say that to me? Does it mean you're not better yet?" [He said] "I am better, but should I spit out my saliva or swallow it?" It means he wasn't better. Now he is fine. Fine.

Q: So his dangerousness and aggression were there when the illness was at its worst. Now everything is fixed.

A: Now he is fine, he's corrected. Thank God. Thanks be to God who worked through people to give us this. Savior of the world.

Q: What do you think about his future? With him following his treatment, taking his medicine... can he be independent, build a life, and live...?

A: For me, it would be better if he continues his education. If he could continue his education, he is a smart student. When he just started first grade, before the year was even over, they promoted

him to second grade. He's been very smart since childhood. So even if it costs a thousand birr, it's better for me if he gets his education. I'd rather struggle for that.

Q: Exactly. Very good. What I wanted to ask was, as you said, it could be in his education, or in other fields, in his work, but while following his treatment, will he have the capability? Will he have the ability? Do you think he can shape his future?

A: Yes. Whatever he wants... if you ask me, I'd say his education. But you know, today's kids don't listen to you. He might not agree with me. If I had commanded him, this illness wouldn't have happened. It's because I didn't command him. If I hadn't, I would have lived in my poverty, and he would have been educated.

When he's ready, do you think he has the capability, that he can do it?

Q: Okay.

What do you think about the chances of recovery for mental health patients? You've told me about the changes you've seen so far. In general, what do you see as the chance of recovery?

A: They recover. Aren't I seeing it with my own son? Everyone recovers. No one who comes in here leaves without recovering. It just takes time, but everyone recovers.

Q: Okay. Whether we know it or not, in our community, there's a belief that a mental health problem comes from the individual's personal weakness. How do you see this?

A: I don't understand. Please tell me again

Q: In our community, there's a tendency to think that mental health patients' problems come from the individual's or that person's personal weakness, meaning that person wasn't strong, or couldn't handle their stress. If he was strong he would be ill kind of narrations.

A: that's not it. How can you say it is there fault, once it is given? It is praying not to be sick or else if it is given to someone, it is given. How can we say someone is clever, strong and can't have a certain illness? I don't know but how can we say that. Even doctors can be sick right? It is hard to say that

Q: So, it's not their fault, but there are other reasons, right?

A: Yes.

Q: Very good. Okay. Based on physical appearance, how much do you think can be seen?

A: Physical appearance?

Q: When I say a person's physical appearance, I mean their external look. By looking at physical appearance, the external look, can one say this person is a mental health patient, that they are sick? How is it? By looking at their physical appearance, I mean. Their external appearance.

A: By looking at their condition? How would you know? It's not knowable. For example, Now, just by looking at this boy, how can you tell he is sick? Except the fact that he is wearing hospital clothe. It's not knowable.

Q: Okay. What about the people around you? The community around you, what kind of response did they give you? When your son got sick, what kind of response did they give you? Did they accept the situation...

A: To whom?

Q: To you, to you, to your son. When your son got sick, did they accept it and support you, or was there any kind of exclusion?

A: Oh my, am I seeing exclusion towards my son? How can I exclude my son?

Q: No, not you. The community, the people around you. Were they supporting you or...

A: Very much! Very much! They are very sympathetic. They are very sad. My son is also gentle, as I told you, not hyperactive. He doesn't even look up at people. The people are the ones who are sad now. People themselves make me cry over what I have already let go of. I have let it go. They come and cry. Just his condition, his quality, how he has served the family since he was a child... How... People just looking at him makes me cry. Even now, people call and ask, 'What happened to my boy? What happened? How? Where did it get him? And he doesn't drink like others, he is not even seen on the asphalt. Our house is by the main road. How?' When they say that, you just cry. He's your son, isn't he? So I...

Q: So there was community support?

A: Yes, yes.

Q: There was support?

A: Very, very much.

Q: Good. Okay. What kind of care do you think they need? The patients.

A: The patients? Well, that there should be no discrimination against them, whether they are rich or poor, everyone should be seen equally, and it should continue like that until the end. Isn't it? What really hurts your mind is when they discriminate against you.

Q: Discrimination.

A: Meaning, how is it... they see everyone equally now, and it should be like that until the end. One from the other... Yes. That they see everyone equally. That's it. It's like that now. It should continue like that until the end.

Q: Very good. Okay. You told me that when it first started, you took him to holy water. How long did you stay at the holy water sites?

A: Oh dear, I didn't stay long. If I were to say I stayed, it was about three weeks. I didn't stay long. Since I am a mother, and farm work was left, this and that was left behind, I came back right away. I don't stay long. Why blame God for... He brings you down, and He also lifts you up. I don't stay, I don't stay long. We stayed at Debre Libanos for a short time, three weeks. I went to Gojjam, and came back right away. I didn't stay long.

Q: Did you see any change when you went there?

A: No change at all. Now, others would babble, 'I am this, I am bewitched, I am a demon.' He says nothing. He says nothing.

Q: There was no change? How did you decide to first take him to a... a place of faith, to holy water? How did you manage to take him initially?

A: Well, with us, when you get sick, you go to holy water. But the one who brought him here is my sister's husband, who is here around Teji. He knows about such things. I mean, he is from Nazareth. So, when I told him what happened, he said, 'Wait, maybe because that thing didn't work out for him, his mind was suddenly affected,' and he's the one who brought him. They had given him pills, and he was at home. Then he stopped the pills and started shouting nonsense. He got into a rage and told me, 'Come,' and so on. Yes. Then, he [the brother-in-law] works in a factory. They have a hotel and things like that. He brought him. He said, 'It's not possible without her [me], he's in, what will he do now?' He bent over. When he came, they told me to get a bed. They said, 'Who will stay on the bed?' Meaning, you need someone with him. The person cannot stay alone. I said, 'Oh, no problem at all,' and I locked my house, and came with my two children. I have a seven-year-old and a two-year-old. I came with them. I left the older one with his father. I came. He [the brother-in-law] stayed for two days. Until I came from the countryside, until I got there. So, I came here. He told me, 'He needs care.' He stayed for two days. On the third day, I came. He went back to his home.

Q: Okay. With your current knowledge and experience, where do you think is the right treatment option? For other people who don't have this kind of experience, where would you suggest they go to get the right medical help?

A: Ver... Here, medical help is being provided here. There is improvement. There are also those who have been cured. In our hometown, when they call them, they say, 'So-and-so was cured after going there. So-and-so was sick like this. This person was sick like this. They get cured,' they say. Even in the countryside. So I believe that anyone can be cured.

Q: So you would advise or suggest they go to modern medicine, to a hospital?

A: Yes.

Q: Okay. Is there any additional point you would like to raise? Is there any additional point you would like to raise?

A: Well, what's nice is that everyone is treated like family. But sometimes when you see, the one who is able hits the one who is weak. When you see them. That also hurts you inside. My son now is weak, he doesn't have strength. I worry that they might hit him. So, that's it. I don't have anything else to add.

Q: Okay. Thank you very much for giving me your time and talking to me.

A: May God bless you too.

Q: Okay, thank you.