

ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE
DEPARTMENT OF PSYCHIATRY

AGING PARENTS AS CAREGIVERS: CHALLENGES OF SUPPORTING ADULT CHILDREN WITH SEVERE MENTAL ILLNESS IN ADDIS ABABA, 2025

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Acronyms

SMI - Serious mental illness

GAF- Global assessment of functioning

LMIC - Low and middle income countries

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Summary

Background:

Caring for an adult child is a major, long-term commitment. This responsibility becomes even more intense when the child has a serious mental illness (SMI), due to the unpredictable and chronic nature of the condition. While any parent faces challenges as a caregiver, these difficulties are significantly greater for elderly parents.

As parents age, they often experience a decline in their physical health, diminished social circles, and an increased sense of burden. This creates a dual burden: they must manage their own aging process while also providing intensive care for their child. Although existing research shows the physical, emotional, and financial strain on caregivers, there is a clear need to understand how these challenges specifically impact elderly parents who are facing their own mortality and worrying about their child's future.

Objective:

To explore the multifaceted challenges faced by aging parents in caring for their adult children living with severe mental illness

Methods:

A qualitative study design was employed. An interpretative phenomenology study design was used to explore the challenges of parents as caregivers to their adult children with SMI , using semi structured interviews. Data management and coding was assisted using Open code v 4.03 software to ensure organization of the material.

Results:

Four major themes emerged from the data. These were Multidimensional burden of care, Uncertainty of the future, Explanatory model of the illness and Spirituality

Conclusions:

The findings emphasize the need for support systems for caregivers. Recommended interventions include routine mental health screening for parents, the formation of a peer support group and integrating culturally sensitive psychoeducation that acknowledges local explanatory models of the illness.

Budget: The total cost of the study was 22,000 birr which covered participant incentives, transportation logistics and digital equipment required for recording of the interviews.

Key words

Aging Parents

Serious Mental Illness

Interpretive phenomenological analysis

Family caregiver

Caregiver burden

Introduction

Background of the study

The term serious mental illness is defined as a severe disability that affects the functional capabilities of an individual for a prolonged time, including every day functioning, interpersonal relations and occupational as well as education. They are characterized by their impact on thought, mood, perception, and behavior. Common examples are Schizophrenia, Bipolar disorder and Psychotic depression. The onset is typically during critical developmental periods disrupting their educational attainment, career and their social formation. People living with severe mental illness face many challenges including high unemployment rate, limited social networks and financial disparities. The nature of the illness, chronic and relapsing, necessitates ongoing care and support which is mainly given by their family members.(1)

In many societies, the primary caregivers are the parents and these responsibilities span over decades. This can be a cause of much stress because most individuals with mental illness live with their family. The burden is a common challenge in developed and developing countries. As research reports, this can be stressful due to the course of the illness, the burden(physical, emotional and financial) it places on the caregivers(2). As parents age, their capacity to provide care may diminish as they face their own difficulties related to aging.

Statement of the problem

Caring for an adult child with serious mental illness is a varied and persistent burden on family caregivers, particularly parents. And this burden can have both objective and subjective dimensions. The former being significant financial difficulties, difficulty balancing their employment and social life with the caregiving process and extensive time commitments. The latter, subjective burden includes physical distress, headache, insomnia and fatigue, reduced quality of life and psychological distress such as depression and anxiety. This, in particular, predicts caregiver distress. (3)

And as parents age, they face other increasing challenges. They face dual stressors of managing their adult child’s illness as well as demands from their own age related declines. A pervasive concern among the parents is the uncertainty of who will assume care for their child long after they won't be able to(4). This is exacerbated by the longer life expectancy and shift towards community based care from institutionalization.

Despite the critical role that parents have in the lives of their adult children with SMI and the unique challenges faced by them, there is a notable gap in understanding the challenges, coping mechanisms, and potential for personal growth. This research seeks to address this gap by exploring the challenges, experiences of aging parents caring for their adult child with SMI, aiming to inform any support interventions.

Rational of the study

The rationale for this study has been formed from several observations and unmet needs within this field. First, the impact of severe mental illness is well documented, as well as the prevalence. As both parents and adult children with SMI age, the dynamics of caregiving evolve, presenting with it unique challenges that are not adequately addressed in current literature. Second, existing literature focuses on the general experience of caregiving or the negative impacts of it. These parents are simultaneously dealing with their own age related issues and increased concerns about the future of their adult child. Understanding these multifaceted concerns is essential for developing effective interventions.(5)Third, there's a noticeable gap in local research concerning parents who care for their adult children with SMI. Due to our country's unique culture, this study has the potential to provide unique and additional insights into their specific challenges. Fourth, by exploring the experiences of aging parents, including their coping mechanisms and personal growth, we can move beyond a deficit based perspective. Recognizing the resilience and their adaptations can help in developing a more holistic approach. These will provide insights for mental health care providers to implement programs that can meet

the complex needs of aging parents. Ultimately, seeking to improve the quality of life of both caregivers and their adult children.

Literature Review

Definition of Severe mental illness

In 1978, the proposed National Plan for the chronically mentally ill sought to replace the definition of severe mental illness, which was a diagnosis of non-organic psychosis lasting two or more years with a Global assessment of functioning score of 70 or less. Thus, came the term called serious mental illness, defined as a severe disability that affects the individual's functional capabilities for a long period of time.(everyday activities, interpersonal relationships, or engage in work or studies).

Clinically, severe mental illness is a diagnosis of any non-organic psychosis and a duration of treatment of two or more years and dysfunction in GAF score(70 or less). Under this definition, it includes schizophrenia, Bipolar disorder and Major depressive disorder with psychotic features. 1 in 5 adults experience a mental health condition and about 75% develop symptoms by age 24. Approximately 450 million people live with SMI. It is the cause of much stress, not only to the mentally ill but also for the family members. The experience is complicated by the Mental Health Act 2001 that urges families to care for their ill family members at home. The burden of family members is a common challenge in developed and developing countries.(6)

Modern definitions as well emphasize on the functional impairment. The National institute of mental health defines SMI as “one or more mental, behavioral or emotional disorders resulting in serious functional impairment and interferes in one or more areas of their major life activities.”(7)

Globally, these affect a significant portion of the population with schizophrenia impacting around 0.7% and bipolar disorder around 1-2% of the population. In Australia, approximately 3% of the population experiences severe mental illness in their life time.(8)

In Ethiopia, in 2017, prevalence of Schizophrenia, bipolar disorder and major depression is reported as 0.5%, 0.63% and 6.8% respectively. (9)

Understanding severe mental illness: Bipolar disorder and Schizophrenia

The history of bipolar disorder research began in the mid-19th century with Baillarger's "insanity of double form" and Falret's "circular insanity," which first identified the alternating cycles of mania, depression, and lucidity. Emil Kraepelin later unified these under the broad concepts of "manic-depressive insanity".While historical observations suggested manic episodes lasted weeks and depressions lasted longer, modern longitudinal data confirms this variability, with depressive episodes now typically averaging between 8 and 16 weeks(10).

Schizophrenia and related disorders

Schizophrenia is a severe mental disorder affecting approximately 0.7% of the population. The typical age of onset is in late adolescence to early adulthood with distinct peak ages for men and women. The neurodevelopmental "two-hit" model proposes the condition results from early brain insults during fetal development that interact with further disruptions during the critical maturation of gray and white matter in adolescence. While chronic and significantly impairing, the complex overlap of psychotic and disorganized symptoms often causes substantial delays in diagnosis and treatment(12).

Schizophrenia is associated with high rates of unemployment (80-90%), housing problems, and lower educational attainment(13). Barriers to employment can be due to negative symptoms, stigma, and deficits in social cognition. Individuals with schizophrenia also tend to have smaller and lower-quality social networks, and this social isolation can worsen the course of the illness.(14)

The chronic nature of schizophrenia places a significant burden on parents, as mental health services often focus on acute care, families are mostly responsible to manage daily activities, medication, and appointments. Less than 20% of individuals with schizophrenia

live alone, and parents are often the primary caregivers, providing support from acute illness to sustaining social and psychological care during stable times. This demanding role takes a toll on caregivers' own well-being, as they often neglect their personal needs and health.(15)

Demographics and associated factors of caregivers

A literature review on caregivers for individuals with serious mental illness reveals that most of them are mothers, making up as much as 91% of the caregiving population. The majority of these caregivers are over 60 years old, with one-sixth reporting a disability.

The degree of burden experienced by a caregiver has been associated with several factors related to both the person with SMI and the caregivers themselves. Factors associated with care recipient characteristics include their age, sex, duration of illness, functional status, symptomatology, number of previous admissions. For example, a longer duration of illness and a history of multiple hospitalizations are associated with increased caregiver burden.

Caregiver characteristics can be their sex, age, socioeconomic status,health status, kin relationship and loving situation. For instance, the emotional weight of caregiving is highest for parents, who are emotionally closest to the care recipient.

Mediating factors include social support, coping skills, and self-efficiency. (10) Among these factors, the caregiver’s ability to cope with stress is a critical determinant of their wellbeing. Adaptive coping strategies like seeking information and problem solving skills can help them feel more in control.

Caregiver burden and associated factors

Studies consistently show that female caregivers are more likely to experience higher levels of psychological distress, sense of burden and depression compared to their male counterparts. Both the age of the caregiver and duration of the caregiving correlate with greater burden, often leading to a decreased quality of life. The caregiver’s own declining

health can compromise the ability to perform physical tasks and not have the stamina to access formal support, as well as, their potential sources can decrease with age.(2)

Challenges of Parents with Children with Severe Mental Illness

The challenges faced by parents of children with severe mental illness are multifaceted and can include emotional, social, and occupational challenges. These stressors are a result of the chronic and relapsing nature of the illnesses, the high demands of care and lack of resources in services in mental health(16).

1. Emotional and Psychological Burden

One of the initial challenges is the difficulty in identifying the illness. The subtle onset of symptoms often leads to a delayed diagnosis and treatment, which can result in more severe symptoms later on. This delay may cause parents to feel immense guilt. The unpredictable and relapsing course of the illness, along with the high medical and social costs, creates a significant burden for parents. Because care and support are usually by families, they may face social disengagement. This is often worsened by disagreements with other family members and the increasing burden of care as both the parent and child age. (3)

Some features of bipolar disorder such as the high risk of suicide and aggression, are especially difficult for family members to manage. Attempts to provide support may be perceived as controlling by the individual with SMI. (9)

A study involving 31 participants who were all family caregivers of individuals with bipolar disorder found that they reported a strong sense of instability and lack of control and experienced a variety of psychological distress(feeling of helplessness and hopelessness) during both their manic episode(due to increased anxiety) and during depressive episodes(due to suicidal risk). The research emphasized on the importance of collaborative relapse prevention. Yet, many caregivers reported feeling as if they were ‘walking on eggshells’ fearing that they might ‘get it wrong’. This desire to prevent relapse

may cause conflict with the person with SMI(serious mental illness) for their autonomy(9). While some caregivers found that adjusting their communication style helped, others reported feeling excluded by the healthcare services, leaving them without adequate support(17).

Furthermore, a common and major concern for aging parents is who will take care of their child after their death, and who will take over their responsibilities after they are gone. As caregivers themselves age, their physical and age related health conditions can make their caregiving responsibilities even more difficult. (3)

2. Lack of Self-Care

Due to the nature of caregiving, parents often neglect their own personal needs and health. They may not seek care for themselves, leading to a decline in their physical and mental well-being. (4)

3.Social and Cultural Challenges

While social support from family can reduce relapse, it can be a source of significant emotional demands. With a recurrence rate of 68% in 4 years, it is associated with high levels of distress, not only to the individual, but also for the caregiver. High burden and expressed emotion are associated with poorer patient outcomes, though a person’s coping style can influence this dynamic. (3)

The burden of care often leads to decreased social engagement and withdrawal from social related activities. Research shows that the caregiver burden differs across societies and cultures, influencing how caregivers understand their roles and awareness about the diagnosis. In some cultures, such as collectivist societies, families may feel pressure to conceal the illness, leading to social isolation and potentially compromising patient's care. (3)

A study comparing China and the U.S. found that even mental health professionals may show negative attitudes towards their patients, which reinforces the society's bias.

4. Occupational and Functional Challenges

Parents face significant challenges in balancing their work responsibilities with the demands of caring for an adult child with a serious mental illness. This can lead to conflicts between work and family life. Literature shows that stress at work has a major impact on family life and predicts overall health and wellbeing with poorer health outcomes like higher BMI, adverse lipid profiles and increased alcohol consumptions and on the other hand affects job performance. (4)

Mental health services often focus on acute treatment and lack the resources to address the patient's basic life needs, such as housing and independent living skills. (4) As a result, a parent must navigate the service related challenges as well as the illness itself, all while enduring financial costs, family conflict and mental health outcomes.
The symptoms of the illness often affect the adult child's ability to function independently in critical life stages, such as education and work. This forces a high level of parental involvement and support for decades. (4)

5. Other factors

A growing body of research on developing interventions to address the unique needs of aging parental caregivers. In the U.S. 3-5 million SMI adults live with SMI and about 35%-75% live with family members. And from these, most are parents aged in their 50s or 60s, even if they live independently, they still seek assistance and social support from them. The increased life expectancy and deinstitutionalization has placed greater demands on parents for continued care.(18) Even with decreased days of hospital stay may mean they are discharged in a more severe form than previously.

A commonly experienced concern is the future care needs of their children with SMI long after they are gone. Long term caregiving has been associated with grief, worry, resentment and guilt. Identified major problems experienced by caregivers are coping

with behaviour problems, dealing with feelings of isolation, meeting the personal needs of other family members, interference with routines, dealing with medication adherence and appointments, not having adequate information on the illness, disruptions in family life, lack of respite from caregiving responsibilities and insufficient help from the health care system. Families who lack adequate knowledge about the illness may attribute the symptoms of their illness to behaviors like laziness. Also, this can weigh heavily on feelings of subjective burden which is a strong predictor of caregiver distress.(10)

Stigma and its impact on caregiver well-being

The other multifaceted impact of serious mental illness on parental caregivers is through stigma by association and caregiver burden. Stigma towards mental disorders has a devastating effect, being a barrier to help seeking, social performance, isolation and low self-seem. These stigmatizing effects are known as stigma by association. (4)

The societal prejudices surrounding mental illness are damaging not only to the person with the mental illness, but also for the family. This is often accentuated in the case of SMI. Caregivers may develop self-stigma, a maladaptive process where they internalize these negative beliefs about mental illness. This transforms their personal identity, as they integrate these beliefs into their self-concept and take roles consistent with the stigmatized images. For example, they may internalize the societal belief that they are responsible for their child's illness, leading to intense guilt and shame. This process is particularly marked in diagnoses like schizophrenia or bipolar disorder, which often have the reputation of the image of "madness". In contrast, diagnoses like depression and anxiety have a more socially accepted notion of " it could happen to any of us"(20).

The psychological impact of self-stigma is significant. It is strongly correlated with increased psychological distress like depression, anxiety, stress and psychological burden. (19) This, in turn, negatively affects the caregiver's self-care, such as physical activity and healthy diet.

From the moment of diagnosis, certain family roles and personal resignations occur without putting into thought the chronicity of the disease and the financial impact it has. Also, the type of diagnosis may vary the results of the emotional distress.

Objective and subjective caregiver burden

The burden of caregiving has both objective and subjective dimensions. Subjective burdens are the caregiver's emotional and physical reactions to their situation while the objectives are tangible sacrifices caregivers make including giving up working, financial difficulties and sacrifices to their social relations and time(30).

Caregivers often expressed feelings of horror and embarrassment over their loved one’s public behavior such as verbally abusing others, wearing clothes in disarray and disheveled appearance. This can lead to social isolation, loss of relationships, and a breakdown of family relationships. When the individual with SMI doesn't meet social expectations such as marriage, having children, education can make them dependent on their caregivers. Wandering away from home might be perceived as inadequate care.

Caregivers also live in fear due to unpredictable manifestation of symptoms, the possibility of violence and of the future and uncertainty of who will take over the caregiving process when they pass on. This uncertainty can feel overwhelming, while many feel a sense of helplessness and turning their worries over to fate or God’s will.

Caregiving often leads to social isolation due to a breakdown in family relations. They may stop receiving visitors or invitations to family functions, they might miss social events due to caregiving duties like basic needs, for wanting to keep the peace in the neighborhood or prevent mental health relapses. The threat of violence is a significant stressor. A high rate of violence (60% lifetime) might be influenced by deinstitutionalization and lack of sufficient services in the community. These parents who experience violence are more distressed, even Japan having the highest psychiatric bed ratio face insufficient services required for daily support. (6)

The concept of caring for another person is a complex concept that goes beyond simply doing tasks for someone who can't do the tasks themselves. It involves human values, morality, planning as well with the ultimate goal of promoting their well being and quality of life. This process is a complex interplay of meaning making, expectations, feelings and attitudes. The making of meaning is often shaped by culture. (8)

Past research focused more on the negative impact of parenting and adult children. However, a more balanced perspective is the potential for personal growth associated with the caregiving role. Caregivers often find the opportunities for positive development including personal growth, becoming more tolerant, less judgmental and more empathic towards others over time.

For many parents, the meaning they assign to informal caregiving is tied to their identity. This revolves around an inward sense of altruism and love, as well as an outward act of constructing an identity as a good, responsible parent. Parents take on their caregiving role with a sense of accountability, actively seeking knowledge about their child's illness.

Conceptual Frameworks for analyzing caregivers challenges

Ecological systems theory

Ecological systems theory provides a useful framework for understanding the challenges faced by the parent caregivers. It helps to see how different environmental levels or systems influence the caregiver. In this context, there are two systems, and within this that the caregiver interacts. The microsystem includes immediate surroundings like family and work, while the mesosystem focuses on the interaction between these two environments.

A study using this framework compared two groups: parents working full-time with a child with a serious mental illness (SMI), and a control group of full-time working parents without a child with SMI.(21)

The findings revealed that caregivers who lacked workplace flexibility, reported higher levels of negative work-to-family spillover and a greater prevalence of cardiovascular and musculoskeletal health problems compared to the control group. The results suggest that while family physicians often provide psychoeducation on SMI and coping strategies, there is little emphasis on how work related stress can increase stress at home, negatively impacting not only the family but also the person with SMI. This demonstrates how stressors from one system (work) can spill over into another (family), increasing overall burden and leading to poorer health outcomes, a key tenet of the stress process model.(21)

The stress process model: Primary and Secondary stressors

The stress process model is another framework that explains how chronic demands of caregiving can impact a person's well-being. It identifies two types of stressors. Primary stressors are the direct demands of caregiving, which can lead to secondary stressors. These include managing their child's symptoms, dealing with issues of dependency, and experiencing objective burnout(22). These initial stressors can then give rise to secondary stressors, which are the indirect consequences of the caregiving role. These include family conflicts, financial difficulties, social isolation, and persistent worry about the patient's future. These effects of both primary and secondary stressors ultimately affect the caregiver's emotional well-being and overall life satisfaction.(16)

Coping strategies of caregivers

Coping strategies are developed as a way to manage the ongoing stress. The coping process is defined as an ongoing cognitive and behavioral effort to manage psychological stress. Coping refers to the various ways of thinking and behavior used in situations of stress. Each stressful event has particular coping patterns.

According to the transactional theory of stress and coping mechanisms, an individual's response to a stressful event involves two appraisals, the primary and secondary appraisals. Primary appraisal is the evaluation and significance a person gives to the

event, whereas secondary appraisal is their ability to manage the stressful event using adaptive coping strategies in response to the event. These coping strategies can be problem focused and emotion focused coping. Coping strategies can evolve over time. (23)

Caregivers' responsibilities have grown in the last three decades due to deinstitutionalization. In many circumstances, family members like parents, siblings, spouses are responsible, the recovery and quality of life of those with serious mental illness are significantly impacted by informal caregivers. But, caring for people with SMI, requires investment in personal resources like time, empathy, and effort. These can cause significant burden in those who care. (24)These have been associated with poor health outcomes, physical, psychological and poor sleep habits. And, these are exacerbated by the perceived stigma of mental illness. These ultimately impact the caregiver as well as the care they provide the patients. Due to this burden, they develop coping strategies or mechanisms to deal with the ongoing challenges. Coping mechanisms can be either adaptive or maladaptive. A study in Ghana found that caregivers used several coping strategies and the five identified coping strategies were religious, emotional coping, rationalization, acceptance, leisure activities, and seeking help of traditional healers. Other strategies included emotion focused coping such as religious coping, humor, avoidance, social support and engagement in leisure activities. Self-motivation deeply resonates with cultural resilience, emphasis and perseverance. Religious coping was widely used, as the caregivers' experience was often perceived as a spiritual test. Further, using leisure activities such as listening to music, watching TV to divert one's attention were reported. Social support as often responsibilities are shared amongst members of the family. (7)

Negative effects of caregiving

The act of caregiving is often accompanied by significant negative consequences, largely due to stigma, courtesy stigma or affiliate stigma. This is often rooted in lack of awareness or religious and traditional beliefs that attribute mental illness to supernatural causes such

as demon possession and back magic. Consequences include ostracizing the family, unable to marry and loss of relationships. (4)

Positive effects of caregiving

Despite the challenges, caregiving can lead to personal growth, post traumatic growth and positive personal experiences and good aspects of the relationship

Post traumatic growth

This concept describes how care gives can emerge from challenging life circumstances with a new sense of self. To understand this process, we must consider the cultural context. In many LMICs with collectivist societies, an individual's sense of self will be defined in relational terms linked to family and others in society is considered the primary entity.(25)

The explanatory model of mental illness

In many cultures, mental illness is interpreted with an explanatory model that ascribes it to supernatural forces such as as a moral punishment from a higher being or possession by evil spirits. So, up to 80% resort to religious and spiritual coping to manage their and their loved one's illness.

When faced with reality, caregivers can be affected with negative and positive changes in their life. There are differences in the nature of these challenges faced between LMIC and High income countries. In high income countries, there is a lack of involvement of caregivers in the treatment process. In contrast, caregivers in LMICs are more concerned and focus with mobilizing the involvement of other community members in care, seeking out various treatment(religious, private or govt) (26)

The Adaption, stress and coping model

This is a theoretical framework that offers explanations to understand the positive change that caregivers experience in the face of adversity.

This model suggests that finding positive meaning in a difficult situation is associated with a positive psychological state.

Similarly, the broaden and build theory suggest that positive emotions can expand a person's cognitive resources such as attention, thinking and behavior. This broadening helps in fostering a range of adaptive and durable resources that contribute to the development of resilience. Still other theories that are based on benefit finding argue that effective, adaptive coping emerges over time as a way of responding to ongoing stressful situations. (27)

Ethnicities such as African American family caregivers were less affected by depression, caregiver burden and strain than white family caregivers, with more positive coping styles and greater resilience and can be explained as a reflection of long-standing tradition through racial socialization and spiritual and cultural beliefs.

Factors that can contribute to carers' well being

Caring for a person with SMI can lead to significant personal strength, confidence and patience. A factor in this positive outcome is the strength of the relationship between caregiver and relative; many continue to provide care because of the affection and love they have for them. This experience often cultivates a desire to help others and be compassionate for those in similar situations. This role can also lead to a reinvention of self as some caregivers were able to enroll jobs in mental health, nursing assistants or community outreach.

Interventions for family caregivers of adults with SMI

To support caregivers, various interventions have been developed, falling into four main categories: psychoeducation, family education, family support groups and individual family support. Psychoeducation helps caregivers understand the diagnosis, teaches them skills on how to effectively cope. These interventions help reduce anxiety, depression, burden of stress, family functioning and their coping abilities.

Family support groups create a safe place where families receive information, where they share experiences and feelings without fear of stigma. The basic goal is creating a mutual support space. The limited research conducted reported increased perceived social support, reduction in subjective burden and psychological distress.(2)

Research objectives

General Objective

-To explore the challenges of aging parents in caring for their adult children living with severe mental illness

Specific Objectives

1.To Identify the daily challenges faced by aging parents caring for their adult children living with SMI

2.To explore the psychological burdens and physical health experienced by aging parents caring for their adult children living with SMI

3.To explore the coping strategies and current social support systems used by aging parents to manage the demands of the caregiving

4. To investigate how aging parents find positive meaning and experience personal growth despite their challenges

5.To explore the aging parent's concerns regarding the long term care and future planning of their adult children with SMI

Research questions

- What are the challenges faced by aging parents in caring for their adult children living with severe mental illness?

- What coping strategies do aging parents have to manage the demands and stresses, and to what extent are aging parents engaged in future planning associated with caring for their adult children?

- In what way does long term caregiving lead to personal growth for aging parents?

Methods

Study design

In this study, a qualitative study design was employed. And the study adopted an interpretative phenomenology study design, particularly to focus on understanding how individuals make sense of their caregiving journey, including subjective interpretation of their experiences. It moves beyond describing and delves into the meaning of the aging parents.

Study setting

The study was conducted at two sites in Addis Ababa, Ethiopia: Amanuel Specialized Mental Hospital, Tikur Anbessa Specialized Hospital.

Amanuel Specialized Mental Hospital is located in Addis Ababa, Ethiopia. Was established in 1990E.C., initially as a general hospital but later transitioning to a mental health facility. It is the only dedicated mental health specialized hospital in Ethiopia serving as a primary referral center for care nationwide. While a significant proportion of its patient population, about ⅔, come from Addis Ababa and its immediate surroundings, the other percentage originate from remote and other regions of Ethiopia. A descriptive analysis of admissions reveals a distinct patient profile. The admitted population are predominantly male, 72.4%, young,67.2% and single,70.2% and unemployed,54%. The most common discharge diagnoses are severe, long term conditions: Schizophrenia, bipolar disorder, which is a direct consequence of the hospital's referral role that concentrates on severe, acute and chronic cases from across the country. It offers outpatient and inpatient services. It has around 300 inpatient beds and over 60000 annual

visits. It has specialized wards for substance use and emergency care. It also provides family planning, HIV/AIDS related support.

Tikur Anbessa Specialized hospital is the largest tertiary care and referral hospital in Ethiopia. It serves medical treatment, education and research. It operates a 24 hour emergency department that handles substantial patient volume, seeing around 80,000 patients annually. It is the main teaching hospital for both clinical and preclinical trainees of most disciplines. It offers diagnostic treatment for approximately 500,000 patients a year in various department faculties. The hospital's multidisciplinary nature is a direct consequence of its role as a premier general referral center. It encompasses a wide range of medical and surgical specialties, including Emergency medicine, Internal medicine, Orthopedics, surgery…. A critical aspect of its evolving profile is the presence of a mental health component. It plays a growing role in the provision of mental health services, a trend that signifies the shift toward integrating psychiatric care into the broader medical framework.

The study period

The study period was from November 10/2025 to February 13/2026.

Sampling method

Using a purposive sampling approach, a total of 11 participants were included in this study. Potential participants were identified by the treating physicians at the respective study sites and referred to the principal investigator. A brief screening was then conducted for eligibility. To be included in the study, participants had to be the primary parent caregiver responsible for the daily care and support of their adult children. Of the total participants, eight caregiver parents were recruited from the inpatient departments at Amanuel Specialized Mental hospital and three were recruited from the follow up department at Tikur Anbessa Specialized hospital.The sample was people from different backgrounds in gender, duration of illness and age of parents.

Following the screening, individuals who were willing to participate were interviewed after giving verbal and written consent.

Interview process

A semi structured interview guide was developed based on the research questions. To ensure confidentiality, interviews were conducted privately at the morning room at AMSH and the OPD rooms at TASH by the principal investigator, agreed upon by the participant. Prior to data collection, written informed consent was obtained from all participants before conducting the interviews or thumb prints for those unable to write**.** Each interview lasted an average of 40min. With the participants permission, audio was recorded to ensure accuracy and completeness of data. This was also supplemented by field notes during the interview to document nonverbal cues.

Data analysis

The data employed interpretive Phenomenological Analysis (IPA) to explore the lived experiences of the aging parents caregiving for their adult children with SMI. The primary objective was to gain a detailed and deep understanding of a small number of participants' personal worlds.

The analysis followed this process:

-Audio recordings from the interview were transcribed verbatim in the original language(Amharic) to preserve the authentic expressions of the participants.

-To ensure confidentiality, all transcripts were anonymized using unique identification codes. The audio files were encrypted by the number of participants(eg. P1-research), the files were stored in multiple digitals. Only specific verbatim quotes were selected to include in the final manuscript were translated into English.

- Each interview transcript was read multiple times alongside repeated listening to the audio recordings to allow for a comprehensive understanding of the participant's narrative. Initial notes were made on the transcripts (focusing on key words, emotional content).

- Developing emergent themes:From the initial notes, emergent themes were identified. These represent key concepts or patterns of meaning within each participant's account. This process was interpretive, as it moved from beyond the participant's specific words to a conceptual understanding of their experience.

- Connecting themes- Once the emergent themes were established for each participant, the analysis progressed to a cross-case examination to identify shared patterns across the data set. These shared themes were then refined to super-ordinate themes.

- Interpretation- Grounded in double hermeneutics, the researcher looked for patterns and interpreted the participants' reflections.

- Finally, a detailed narrative account of the findings was written

Data management

The interview guide was continuously reviewed and refined through the data collection process, when participants demonstrated difficulty in understanding specific questions, were adapted and rephrased for subsequent interviews to improve clarity and depth of response.
While formal member checking was not conducted, dependability was maintained through peer debriefing.

Data management was facilitated by the software open code version 4.03. Transcripts were imported in the software, and codes were given to emotional and repeated contents. Then, similar codes were then categorized in themes and were encoded under the synthesis. By using this, subthemes were also emerged and written accordingly.

Source population

Aging parents who are 60 or more years who are the primary caregivers for their adult children diagnosed with SMI

Study population

Aging parents who are primary caregivers for adult children with SMI for at least 2 years who have follow up at the two sites' OutPatient departments and Inpatient departments.

Eligibility criteria

Inclusion criteria

1.Parents aged 60 years or more

2.Parents who are primary caregivers who have an adult child with SMI

3. Parents who are willing and able to provide informed consent and participate in in depth interviews

Exclusion criteria

1.Parents with cognitive impairment and diagnosed with severe mental illness

2. Parents who are not the primary caregivers

Operational definition

Severe mental illness- a non organic diagnosis of schizophrenia, bipolar disorder and major depression, duration of treatment of 2 or more years and GAF scores of 70 or less.

Aging parents- primary informal caregivers aged 60 or more years who are the major responsible person for their adult child with SMI.

Primary informal caregiver- those who provide informal support predominantly family members. The person with SMI as a relative and the carer as a parent of the person with SMI.

Results

Demographic data

There were 11 parent participants(10 Parents and 1 grandparent participant), of which 7 were fathers and 4 identified as mothers. Their ages ranged from 60 years to 77 years old. In terms of educational status, four participants had a degree, 5 were retired and 3 continue to do their job. Three of the participants were widowed. Four participants had additional caregiving responsibilities(other children with serious mental illness).

In terms of diagnosis, five were diagnosed with Schizophrenia, 4 were diagnosed with bipolar disorder and one with major depressive disorder with psychotic features and one was diagnosed with Schizoaffective disorder. Their ages ranged from between 29 years and 46 years old. All of them reside with their parents. In terms of religion, 4 were of Orthodox religion followers and 4 were Muslim, and 2 were Protestant in religion and one was Jehovah witness follower.

Variable	Category	Frequency (n)
Caregiver Characteristics		
Age Group	60–69 years	7
	≥70 years	4
Caregiver role	Father	7
	Mother	4
Marital Status	Married	8
	Widowed	3
Occupation	Retired	5
	Self-employed	2
	Public welfare	2
	Farmer	1
	Vegetable seller	1
Education Level	Primary education	6
	Secondary education	1
	College level	4

Variable	Category	Frequency (n)
Religion	Orthodox	5
	Muslim	3
	Protestant	2
	Jehovah's Witness	1
Patient (Child) Characteristics		
Age Group	25–30 years	6
	31–40 years	3
	≥41 years	2
Diagnosis	Schizophrenia	5
	Bipolar disorder	4
	Schizoaffective disorder	1
	Psychotic depression	1
Duration of Care	1–10 years	7
	11–20 years	1
	≥21 years	3

Table 1: Caregiver and Patient Characteristics (n = 11)

There were 4 major themes that were identified:
The multidimensional burden of care, uncertainty of the future and pursuit for lasting cure, explanatory model of the illness and Spirituality as coping and meaning making

Theme 1: The multidimensional burden of care

The burden of care refers to the negative effects experienced by caregivers of their children with serious mental illness. This includes the physical well being, emotional well being, financial stability and social connections/support. It describes the toll caregiving has on the person's overall health, social life and psychological health.
Under this theme, there are several subthemes:

1.1. Social burden

The shrinking world of the caregiver

This theme addresses the social depletion and isolation they face as the years of caregiving go on. As the patient's symptoms worsen, their social networks start to shrink.

One participant said, "In the past, I had many people around me. But recently, things have changed. Now, she also seems to be struggling. Even so, no matter what happens, she tries very hard not to be a burden to her father." 75 years old, retired father.

Another mother said" It has a huge impact. Usually, you go to the funeral, stay at the house and talk with people. But for me, I just go to the burial and leave quickly. It has pushed me away from people. People ask," Where did you go?" Or " what happened to you?", but I stay silent. That is my situation……" I have a women's community group(Idir) that I helped start. But now I have canceled and left all of that. The members gave me a letter because they are unhappy that I am not participating anymore. " a 70 year old, retired mother.

Most participants felt that they couldn't leave their children alone due to the risk of destruction of property. They feared their child might accidentally damage or destroy their house.

1.2 Emotional burden

This theme describes the emotional toll of caring for their child with serious mental illness and the silent struggle they face as an attempt to protect them from stress. 'The silent struggle' shows how caregivers stay silent even when they are experiencing negative emotions.

One participant said ” Yes, even when things are difficult, I don't want my child to know. I swallow my problems and push through them. I don't want him to be upset or feel like we have nothing. For example, I make sure I always have 50 kilos of Teff in the house, no matter what I have to do to get it. I do this quietly so he doesn't see the struggle." 68 years old, grandmother

While a few participants were on their last straw and weren’t able to cope due to the compounding stresses they were facing.

A mother of 4 said "Everything has become too much for me to handle; I am overwhelmed by everything. If I tell people, they don’t truly understand. My heart is burning with pain. I have even lost hope in my own life. I ask myself, 'Until when? How much longer?' Sometimes I get so frustrated that I think, 'Let her go out and live on the streets like a mad person, and let the children find food or go anywhere.' Some days, I am just so angry and tired of it all." 60 years old mother, widowed

This pressure is greater for those caregivers when facing multiple stressors without support. Being the sole care provider while having financial instability and having multiple dependent children under their care.

1.3. Physical burden

This refers to the impact of caregiving on their body health and the toll it faces. The daily demands of caregiving like medication control, providing basic needs like washing their body and providing supervision leads to worsening of medical comorbidities and physical exhaustion.
Even more, their own health becomes secondary to their caregiving role.

One participant "I have diabetes, and my blood sugar spikes whenever I get upset or stressed. It increases a lot. After you raise children, you expect them to find their place in life and settle down. When a child succeeds, it makes you happy. But there are others who still struggle or cause trouble… I didn't grow up in comfort. I thought that

after working so hard my whole life, I would finally find rest—but then this problem happened. I am so frustrated. Even my diabetes was caused by this constant stress."63 years old father, married

Others express how the duty of care over weighs the toll it has on their body.

” Yes, even when my legs are hurting, I feel I cannot leave him. I have to come because he has no one else. When I am not there, he gets very frustrated. If I visit on Monday, I should be able to stay home Tuesday and Wednesday and return on Thursday. But he insists, ‘Come all three days, come quickly,’ so I have to be here every day." A 68 years old grandmother, widowed and sole caregiver

1.4 Financial burden

In this study, financial strain emerged as a barrier to seeking help and providing basic needs to their children.

From the daily provisions of living to costs of hospital admissions is yet another struggle. Being in the hospital during admissions means a cut in the income.
One participant says” If I lack something, I borrow it. Just recently, I couldn't find money for a taxi , and I said to my nephew, 'I plead, my daughter is dying, can you help me?' When I told him I lacked the taxi money, he gave it to me. Then I brought her here and took her back.” 75 years old mother, widowed

Others sacrifice their own needs and prioritize the needs of their children.
One participant says ‘ "I only spend on what I truly need. People want new clothes, don't they? I have 50,000 to 60,000birr. Do you think this just happens by chance? Look at this shirt; it has been turned inside out. When this side wears out, I will take it to be tailored again. I know I could buy a new one, but I choose not to.”.....Sometimes, when she gets high(manic) at 11:00 PM or 2:00 AM, I search for her but can't find her, then there are times she arrives by ride, and I have to pay 400 Birr for it. There is nothing I can do.”75 years old male father

The endless provider

"It is all for her. There is so much trouble at home; if she lacks even a little bit, it triggers her. If she gets anxious or hungry, she starts saying, 'Where am I supposed to get it from?' she says, 'I'll go to the shop and get it on credit.' When I ask, 'Who will pay for it when it's delivered?' she tells me, 'I'll work and pay it back.' But when she starts a job, she won't even last two days; it's like a demon just won't let her work. No one understands what I'm going through. I am confused; everything has gone dark for me." 60 years old mother, widowed

In contrast to the above challenges, participants frequently emphasized on the encounter and kindness of strangers who provide temporary support. Many are grateful for the help they receive from professionals(Nurses and Doctors) during admission of their child.

One participant "They(the nurses) are the ones helping me. I go there now to feed her, and I try to go back in the evening if I can. I have kidney stones, a urinary infection, and my stomach is hurting. Today, I will be late leaving here, and it will be past mealtime. Because of this, the nurses help me. May Allah help them." 75 years old mother, 3 children with serious mental illness.

Another participant mentions "During COVID-19, she was a founder of the 'L' association. While I was sick in bed with COVID, she became very hyperactive. I was very ill and had to keep calling and searching for her. When I told Doctor 'A' about my situation, he covered 39,400 Birr for me. Doctor 'A' is a very good person; no one else would do that for you." A 75 years old male, retired father, has 3 children with serious mental illness.

Theme 2: The uncertainty of the future and the pursuit for lasting cure

2.1. The failing of the retirement dream

Many participants were hopeful of the day they would give over the responsibility to their children. When this doesn't happen, the caregivers will be obliged to continue the role of provider. With their advancing age and the ongoing demands of care leads to a significant burden.

One participant says ‘ I worked so hard for my children, struggling for so many years, only to find no rest at the end. His mother is also suffering now; she has so many illnesses. She has high blood pressure, cholesterol, and nerve issues. She can’t even go into the hospital to see [the patient]. I am the one who has to keep going back and forth. It’s all because of the stress, you see? And that is a very bad thing." 65 years old, self employed

2.2. Uncertainty of the future

Most participants expressed a sense of concern for the future of their child. The constant dread of ‘who will take care of them after I pass’ is a constant worry for these aging parents. To direct this worry, they relinquished the uncontrollable to the divine. On the other hand, they put their hope in assets.

One participant said, “ For example, I have land, and I want him to build a house in his own name and live there, without being a parasite on anyone. I also want him to educate and support his younger siblings. I want him to gather and manage the family's different assets so his mother doesn't struggle. She is much younger than me—I am about 20 years older—so I don't want her to suffer after I'm gone. I don't want the little ones to drop out of school or be in trouble. I want my son to take over this responsibility." 67 years old father, self employed

2.3. The pursuit for the cure/pathways to cure

Families go to great lengths to find ways to cure their children. And these methods can be Spiritual, Traditional and Western treatment.

While most participants mentioned they didn’t find solace in spiritual treatment, they preferred the Western treatment for continuity and the benefits of adhering to Medicine, often citing adherence issues as a primary factor for relapse.

One participant “We tried both traditional Ethiopian medicine (Habesha) and Western medicine (Ferenj), and she was finally cured through Western medicine. But now, after she recovered from the initial problem, she has started chewing Khat." 75 years old mother, widowed

Yet few others mentioned the benefit of spiritual treatment as an adjunct
One participant mentions” Even though she told me, 'I am not Orthodox,' while she was studying, I still took her to the Holy Water (Tsebel) whenever she relapsed or lost her way. I continued giving her the [modern] medicine as well. The Holy Water brought her back to her senses; she became well for me. She was even able to continue her education and pass into her third year." 70 years old mother, retired

2.4. The conflict between the obligations of a father and the respite in old age

One participant is conflicted about his role as provider and narrates it as follows “So, this child is a trial. There is a story that goes, 'The cow gave birth to fire, if she licks it, it burns her; if she leaves it, it is her own offspring. I am at that stage of confusion. That is the trouble with the one you gave birth to; you can't throw them away, and you can't abandon them. You can't just cut them off and cast them out. That is the only reason I stay otherwise, things haven't been all that bad.” 63 years old, self employed

Theme 3: Explanatory model: what caused my child’s illness? Sin or biology?

3.1External attribution of illness

The way caregivers understand the origins of the illness directs how they treat their child and their coping strategies

Most participants say they attribute the illness to something external to their individual’s control such are spiritual harm, psychosocial distress as well as the contribution of having family history of similar illness

One participant’s say” Later, when I am sitting quietly, I try to make sense of what happened. I can’t speak my mind in the heat of the moment because it would ruin our relationship; things would just get more tense. So, I weigh the situation and tell myself, 'They did this because of the illness.' I put it on a scale and balance it that way." A 75 years old, retired father

Another participant says "This illness isn't something that disappears overnight or stays away for just a year. It is a long process where hormones slowly balance out, and the individual gradually learns to control and lead themselves. It's an ongoing journey. I believe this is a reaction occurring within the natural hormones—something that happens whether a person likes it or not. Personally, I believe that 'endurance' (መቻል) is the most important thing.” 67 years old father, self employed

One participant used internal attribution by blaming the patient’s character “ a flow in his character or choices’ that brought this illness.

"The boy brought this illness upon himself, by his own hand. There was a time when he lived on the streets. Eight or ten years ago, there were times he even slept outside in [concrete] pipes.”…..”It is because he didn't take care of himself. By not looking after his own body and also because of his 'innocence' (የዋህነት). He lets anyone lead him astray.

He wants to snatch things from anyone just to eat. If he weren't so naive, if he were a clever boy, he wouldn't do these things.” 65 years old, working father

3.2 The informed advocate: from feeling overwhelmed to taking agency

Some participants initially felt overwhelmed and a loss of control. However, as the time for caregiving progressed, the gradual accumulation of knowledge regarding the illness worked as a shift from passive sufferer to one of active agency. This empowerment often extended beyond their family and played a role in advocacy. By sharing their knowledge, they worked to challenge the stigma and inform others.

One participant says” I have gained a wealth of knowledge through both my workplace and my experiences with my child. Even without formal opportunities like this one, I am constantly teaching others wherever I go; believe me, whenever I encounter someone in a similar situation, I offer them guidance."

3.3 From coercion to compassion

In the earlier stages of the illness, many caregivers used coercion to correct what they perceived as behavioral problems. But, after recognizing its harm, which often worsens their child’s aggression, they transitioned to relational empathy and patience.

“She is a bit quick-tempered, while I am calmer and yielding. We live by being tolerant of one another and making adjustments." 77 years old retired father

"One thing we do is protect his mood. When he gets angry, so he doesn't become aggressive, we cool down on our end. We just stay quiet. We give him his space; we go to our rooms and don't disturb him. We don't want him to feel like he’s lacking anything. If he wants something from the kitchen, let him take whatever makes him happy, let him eat or drink. We have consulted with each other and decided not to stand in the way of his desires; we just let him be." 68 years old self-employed father.

One father recounts how his ex-son-in -law met him by devaluing his daughter who was diagnosed with bipolar disorder. He was able to maintain his posture and focused on his daughter's immediate needs.

“My son in law and daughter weren't doing well. I was thinking ahead. When I arrived, my son in law started by saying, 'This rude, ill-mannered child you raised her without any discipline!' I just calmed things down. I told them, "There is food downstairs, let him come and eat." 75 years old father

Theme 4: Spirituality: “The Lord does as the Lord wills” and meaning making

This theme is characterized by the belief that the Lord does as He wills’ serves for most as a way to cope and a way to outsource their distress and burden of caregiving

4.1Divine attribution

By framing the illness as an act of the divine, the crisis shifts to a meaningful, spiritual reason

One participant “Even though friends and family may feel sorry for you, only Allah is of any help. People just talk; they say, 'She did this, this happened to her, why did this happen to her?' They try to question Allah's work. As for me, I say, 'He gave this to me.' I say, 'He is the one who brought this upon me, so what can be done?' To be patient.” A 75 years old female, with 3 children with serious mental illness

4.2The role of God’s Providence

It is the belief that the strength to preserve and endure is a provision granted by the Creator. This allows caregivers to withstand their burden for transcendental reasons. It helps them find meaning in their suffering.

One participant says "It is God who watches over her; one must leave it to Him. I will help her as long as a person is able as long as I am alive, I will support her. Beyond that, what can be done?” 63 years old self-employed father.

Most of the caregivers hope for a ‘better’ future to see their children independent and supported by their family.

The dream of retirement has largely slipped away, replaced by the hope for a future for their children, where they are integrated in the social norms and they can get married, have their own family and also maintain the family business. For some, it's not only their independence, but also seeing them caring for their loved ones.

One participant said ” I told you, I wish for this to happen before I die. I have been saving for a condominium for her. If that were to come through, if she could have her own house if I could see it in her own name, saying 'this is mine,’ I would be so happy. This would be a real change for her. It would make her happy, and it would make me happy too.” 70 years, married, retired.5

4.3 Meaning making as a coping skill

Even though many participants narrate the burdens of care, they also make meaning of the adversity they are facing. From systematic planning to Spiritual reframing, many caregivers sought sanctuary in their adaptive coping skills.

A participant mentions “ It is always prayer,for us and for him. When we pray and kneel, we rise, having cast all of those [burdens] aside, so we have hope. I am speaking to you as a human being; I am speaking from a physical perspective. In our spiritual life, we are people of hope; there is no anxiety.” 68 years old father, self employed

For one participant, the caregiving journey was vital to her existence, saying she is alive for her son. By being the sole caregiver,it transcended an obligation and became her primary existential purpose. Her survival is perceived as a necessity for her son’s well being.

In her own words” I rose after lying in a sickbed for many years. When I contemplate, I realize I am standing here just to care for him. I didn't think I would be spared, but now I thank God through him. Had I died, my child would have been left like this, consumed by his suffering. I say, "Praise be to Him." 68 years old mother, widowed

A participant narrates how having been in the military where discipline was a major mode of survival, to being a civilian brought with itself a unique challenge of caregiver

burden. He successfully adapted to this change by cognitive reframing. Seeing the rigid way didn’t work, he put a new order on himself by distancing himself

“Discipline is a very critical thing for everything. When that is lacking, if you are telling someone and they just don't understand, a sense of frustration arises when you run out of options (Participant laughs at this point). Personally, this is one of my challenges. Even so, I don't take it as a major problem; I immediately distance myself. I remove myself from that situation right away and stay away; I go into my room and stay there for a while. Then, my honorable wife comes and calms me down, saying, 'Oh, come on, you too...' and settles me.”

4.4 Spiritual crisis

However, in contrast one participant expressed a state of existential despair. She felt abandoned, suggesting that when the burden of care surpasses a threshold, spiritual hope can collapse to the extent of passive suicidal ideation

This participant said “I took her to many churches, but nothing changed here or there. Lately, I have started saying to God, 'Enough, You are exhausted [You have no strength left].' I’ve become consumed by the thought of just... leaving my children here, ending my life.” 60 years old mother, widowed

Discussion

This study explores the challenges of aging parents and the findings center on dual burden, the intersection of aging parents due to their age-related difficulties and the demands of caring for their adult children with serious mental illness. There were 4 major themes identified in this study.

These were the multidimensional burden of care, attribution of their illness and how it affects their care, the uncertain future and Spirituality

The multidimensional burden of care had 4 subthemes: physical burden, emotional burden, social burden and financial burden. Caregivers reported their physical comorbidities were exacerbated by the burden of caregiving. The age-related physical decline created incapacity to work, thus exacerbating their financial strain. Caregivers often stressed on how to provide for their family as well as their health-related expenses.

Socially, the participants reported ‘a shrinking social world’, where the extended social networks become ‘fed up’ and withdraw their support and second, caregivers withdraw from the community due to constant supervision their children need. These compounded burdens created emotional load. All these created emotional burdens characterized by persistent anger, worry and angst. These findings were similar to previous literature from Iran that showed inefficient support and disruption of interpersonal relationships dominates the caregiver experience(3). Similarly, a previous research conducted in Ethiopia, shows that informal support tends to decline over the long course of the illness(28).

However, in contrast to previous literature, family disagreements were less reported. Instead, spousal or sibling support emerged as a support system. Although, being the sole caregiver and lack of support from others has been confirmed in other studies which were primary drivers of caregiver distress.

Furthermore, having existing financial strain worsened the burden of care as the dual demands of clinic health care costs and the daily provision necessary for survival. The

hope of cure pursuing pluralistic treatment modalities led families to invest their remaining assets. This, for many, was a sacrifice to restore their child's autonomy. However, this often exacerbated the strain, as many didn't find solace in these modalities. This aligns with existing Ethiopian literature emphasizing the financial costs by families who constantly prioritize the needs of their ill family above their own(28). This multidimensional burden resonates with findings from other collectivist societies like India and Iran(3).

The next theme was the explanatory models: attribution of illness and parents' caregiving style. Most participants attributed the illness to external factors such as 'a gift from God' and 'hormonal difficulties'. This understanding led to a transition from early coercive methods to a more compassionate and patient centered approach. These findings contrast with other studies of similar cultures, which document negative attitudes towards their children, labeling them derogatory terms such as 'crazy' (4). However, it aligns with a study done in Tanzania, which showed that when families attribute challenging behaviors to the illness itself, they adopt a caregiving rooted in affection and patience rather than discipline(29).

Only one participant attributed his son's illness to the patient's character, showed higher expressed emotion and frustration which was in alignment with other research. A study done in Iran showed a lack of understanding of the illness led to blaming the family for the patient's condition (3). This often leads to concealment of the illness from society to avoid external judgement. Although, participants reported a different motivation for secrecy. Rather than fearing blame, they withdrew due to lack of tangible social support and the communal gossip regarding the parent's strength or the perceived origins of the illness. In contrast to the study done in Iran, many participants reported receiving sympathy from their community, suggesting a more supportive social inter-connectedness.

Among the most challenging symptoms, participants reported high risk of suicidality and aggressive behaviors. These behaviors significantly increased the psychological distress of caregiving and hypervigilance. These findings are similar to existing literature which

showed such symptoms are the primary risks for caregivers' feelings of hopelessness and helplessness and helplessness (1).

The third theme was the ‘uncertainty of the future’ where participants expressed a sense of loss regarding the expected role reversal, where children take care of their parents, and were met with the endless provision even in their old age. Parents go to great lengths in a desperate search for a cure that would allow their children to achieve independence. Most of the participants reported engaging in dual or pluralistic treatment strategies simultaneously or combined treatment. They invested both their time and finances for the hope of cure, thus eventual independence. This is supported by other similar studies, where the ‘Holy water’ is the first point of entry for treatment and urban residents were more likely to combine it with modern treatment (9). Existing literature done in the Holy water sites in Addis Ababa, confirmed that religious healing sites serve as the first point of entry into the healthcare system. Furthermore, the worry regarding the fate of the patient mirrors existing literature in Ethiopia(28). The fourth theme was Spirituality, both serving as a coping mechanism and a source of resilience. By reframing how they see the illness, they are able to externalize their distress and find strength to endure. This outsources their burnout to a higher power. This spiritual path also sustains a future hope where parents envision their children marry and fulfill the social milestones. This provides a cushion against the current grief. While this finding is similar to other studies, there is a significant cultural/ religious divergence. A study done in the U.S., where caregivers reduce their future anxiety through financial assistance and trust funds, participants in this study relied on divine providence (1)

Further, many participants reported spiritual coping and maintaining a relationship with God. Many participants mentioned personal gains as being internally strong to care for their children and being more tolerant and a capacity for patience. However, caregivers expressed difficulties with reflecting how the caregiving journey affected their sense of self and how they changed as an individual. This might suggest that when caregivers are preoccupied by current stressors and basic survival needs, a reflection on self becomes a secondary priority. This finding is similar to a study done in India, where they had similar difficulties (4).

In contrast to global literature, which identifies institutional barriers as a primary stressor, Participants reported a high degree of satisfaction with institutional support(4). A prominent theme identified in other studies was the difficulty accessing appropriate mental health services and accessing information about their child's mental health. This is caused by the legal frameworks that maintain a patient's capacity for treatment decisions despite being non adherent to the medication. (1). Participants however, described the major roles they play in the treatment decisions of their child. Also, in contrast to the Iranian study (4), which identified a perceived lack of support from the government, participants expressed a high degree of gratitude specifically, the governmental health insurance. They also viewed the institutions as places of rest

Conclusions

This study explored the complex challenges that aging parents face as caregivers to their children with serious mental illness. The findings highlight a multidimensional burden including physical, social as well as financial burden. It was notable that the severity of the burden is aggravated for those who are sole caregivers and who have other compounding stressors. Additionally, these parents have unique challenges in their anxiety about the future after they are gone and regarding the generational gap in caregiving.

However, despite these challenges, most participants tried to make sense of the situation and used adaptive spiritual coping skills, a few expressed that they reached a breaking point and expressed deep despair. This emphasizes the urgent need for interventions that address the psychological distress of the aging caregivers.

Recommendations

The clinical setting should implement routine psychosocial screening for aging caregivers early in the treatment process. Clinicians must assess the caregiver for psychological distress. Once identified, possible mental health interventions should be implemented, such as brief counseling or stress management interventions.

Psychoeducation programs tailored to the patient should be developed to understand the possible risk factors and disease course. This will help parents move from a state of overwhelm to one of informed agency. This ultimately will improve a more collaborative parent child dynamic

Establish a peer to peer (caregiver) support group to be a safe space to talk about their difficulties and share positive experiences

Although caregivers are technically allowed to stay with their children during inpatient care, the absence of structural resources creates a significant burden on these aging parents. So policy revisions to address the logistics, such as subsidized meals, transportation assistance and allowing formal caregivers will reduce caregiver burnout.

Limitations

This research is with some limitations

A primary limitation was the presence of social/ desirability bias. Many participants initially focused more on spirituality and endurance rather than talking about their distress. This might be included by the religious and cultural norms that prioritize patience and ‘strength’ rather than publicly talking about their hardships. This likely led to an underreporting of negative emotions until more rapport was established.

The presence of audio recording and microphone caused a notable effect. Despite being repeatedly reassured of the anonymity and confidentiality, participants showed hesitation and concern that their voices would be made public.

The hospital setting may have introduced authority bias. Participants may have perceived the researcher as a clinical authority figure, leading them to mention positive institutional experiences in the institution though they were reassured of the academic nature of the study.

Translating deep Amharic metaphors into English is a challenge. Many participants expressed their burden in cultural terms which may have been lost in translation.

Ethical considerations and consenting

Ethical clearance was obtained from the department of Psychiatry, Addis Ababa University.

The interviewer provided participants with information concerning the goal and purpose of this study in their original language. Participants were also asked for permission regarding the audio and the written recordings and confidentiality was assured by removing their personal information.

Any potential risks and benefits were discussed with the participants. They were informed that the acceptance or decline of the research participation won't have any effect on the quality of treatment and care they receive in the hospital.

Budget plan

Number	Items needed	cost
1	audio recording	2500
2	Internet	3000
3	pen and agenda	500
4	Printing material	1000

5	Translation and transcription	15000
6	Compensation fee for participants	5000

Work plan

Activities	Aug	Sep	Oct	Nov	Dec	Jan	Feb
Submission of the Proposal							
Proposal Defense							
Proposal Approval							
Data Collection and Analysis							
Thesis Submission							
Thesis Approval							

References

1. Raymond KY, Willis DG, Sullivan-Bolyai S. Parents Caring For Adult Children With Serious Mental Illness. J Am Psychiatr Nurses Assoc. 2017;23(2):119–32.
2. Carswell C, Brown JVE, Shiers D, Ajjan R, Balogun-Katung A, Bellass S, et al. The Lived Experience of Informal Caregivers of People Who Have Severe Mental Illness and Coexisting Long-Term Conditions: A Qualitative Study. Health Expect Int J Public Particip Health Care Health Policy. 2024 June;27(3):e14119.
3. Sharifi M, Younesi SJ, Foroughan M, Safi MH, Khanjani MS. The Challenges of Caring for an Adult Child with Schizophrenia in the Family: An Analysis of the Lived Experiences of Older Parents. Inq J Med Care Organ Provis Financ. 2023;60:469580221148867.
4. Dijkxhoorn MA, Padmakar A, Bunders JFG, Regeer BJ. Stigma, lost opportunities, and growth: Understanding experiences of caregivers of persons with mental illness in Tamil Nadu, India. Transcult Psychiatry. 2023 Apr;60(2):255–71.
5. Sharifi M, Younesi SJ, Foroughan M, Safi MH, Khanjani MS. The Challenges of Caring for an Adult Child with Schizophrenia in the Family: An Analysis of the Lived Experiences of Older Parents. Inq J Med Care Organ Provis Financ. 2023;60:469580221148867.
6. Talbott JA. The National Plan for the Chronically Mentally Ill: a programmatic analysis. Hosp Community Psychiatry. 1981 Oct;32(10):699–704.
7. Bucy T, Moeller K, Bowblis JR, Shippee N, Fashaw-Walters S, Winkelman T, et al. Serious Mental Illness in the Nursing Home Literature: A Scoping Review. Gerontol Geriatr Med. 2022;8:23337214221101260.
8. Cham CQ, Ibrahim N, Siau CS, Kalaman CR, Ho MC, Yahya AN, et al. Caregiver Burden among Caregivers of Patients with Mental Illness: A Systematic Review and Meta-Analysis. Healthc Basel Switz. 2022 Nov 30;10(12):2423.
9. Girma E, Ketema B, Mulatu T, Kohrt BA, Wahid SS, Heim E, et al. Mental health stigma and discrimination in Ethiopia: evidence synthesis to inform stigma reduction interventions. Int J Ment Health Syst. 2022 June 23;16(1):30.
10. Mason BL, Brown ES, Croarkin PE. Historical Underpinnings of Bipolar Disorder Diagnostic Criteria. Behav Sci Basel Switz. 2016 July 15;6(3):14.
11. Charney AW, Mullins N, Park YJ, Xu J. On the diagnostic and neurobiological origins of bipolar disorder. Transl Psychiatry. 2020 Apr 23;10(1):118.
12. Rybakowski J. Etiopathogenesis of schizophrenia - the state of the art for 2021. Psychiatr Pol. 2021 Apr 30;55(2):261–74.
13. Marwaha S, Johnson S. Schizophrenia and employment - a review. Soc Psychiatry Psychiatr Epidemiol. 2004 May;39(5):337–49.

14. Pejlert A. Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. Health Soc Care Community. 2001 July;9(4):194–204.
15. Awad AG, Voruganti LNP. The burden of schizophrenia on caregivers: a review. PharmacoEconomics. 2008;26(2):149–62.
16. Barker ET, Greenberg JS, Seltzer MM, Almeida DM. Daily stress and cortisol patterns in parents of adult children with a serious mental illness. Health Psychol Off J Div Health Psychol Am Psychol Assoc. 2012 Jan;31(1):130–4.
17. Girdhar A, Patil R. Caregivers' Burden in Patients With Bipolar Disorder and Schizophrenia and Its Relationship With Anxiety and Depression in Caregivers: A Narrative Review. Cureus. 2023 Oct;15(10):e47497.
18. Kaufman AV, Scogin F, Macneil G, Leeper J, Wimberly J. Helping Aging Parents of Adult Children with Serious Mental Illness. J Soc Serv Res. 2010 Oct;36(5):445–59.
19. Kaggwa MM, Najjuka SM, Mamun MA, Griffiths MD, Nyemara N, Ashaba S. Involvement and burden of informal caregivers of patients with mental illness: the mediating role of affiliated stigma. BMC Psychiatry. 2023 Jan 26;23(1):72.
20. Gonzalez JM, Perlick DA, Miklowitz DJ, Kaczynski R, Hernandez M, Rosenheck RA, et al. Factors associated with stigma among caregivers of patients with bipolar disorder in the STEP-BD study. Psychiatr Serv Wash DC. 2007 Jan;58(1):41–8.
21. Song J, Mailick MR, Greenberg JS. Work and Health of Parents of Adult Children with Serious Mental Illness. Fam Relat. 2014 Feb 1;63(1):122–34.
22. Domeisen Benedetti F, Hechinger M, Fringer A. Self-Assessment Instruments for Supporting Family Caregivers: An Integrative Review. Healthc Basel Switz. 2024 May 14;12(10):1016.
23. Kageyama M, Yokoyama K, Nakamura Y, Kobayashi S, Fujii C. The coping process of Japanese parents who experience violence from adult children with schizophrenia. Arch Psychiatr Nurs. 2018 Aug;32(4):549–54.
24. Chadda RK. Caring for the family caregivers of persons with mental illness. Indian J Psychiatry. 2014 July;56(3):221–7.
25. Chadda RK. Caring for the family caregivers of persons with mental illness. Indian J Psychiatry. 2014 July;56(3):221–7.
26. Kasperek-Zimowska B, Chadzyńska M. [Sense of coherence and coping styles among parents of adult children with schizophrenia]. Psychiatr Pol. 2011;45(5):643–52.
27. Han SH. Revisiting the caregiver stress process: Does family caregiving really lead to worse mental health outcomes? Adv Life Course Res. 2023 Dec;58:100579.
28. Bahiretibeb Y, Wondimagegn D, Andermann L, Law S. "Blood is thicker than water" - experiences and perspectives of family caregivers of people living with severe mental illness at Holy Water traditional healing sites, Addis Ababa, Ethiopia. Frontiers Psychiatry. 2025;16:1495058.

29. Swai P, Desjardins M, Minja AA, Kaaya SF, Lawala P, Lukens E, et al. Social support and managing schizophrenia in Tanzania: Perspectives from treatment-engaged individuals and relative caregivers. SSM Ment Health. 2024;5:100295.
30. Girmay A, Atnafu A, Tadesse B, Girma M, Aliyi S. Family caregiver burden and associated factors among caregivers of people with mental illness attending outpatient treatment in public hospital in Eastern Ethiopia, Ethiopia: hospital-based cross-sectional study. BMJ Open. 2025;15(10):e098359.

Annex

Annex 1 – Information Sheet

My name is Dr. Lydia Kenneth. I am a Psychiatry resident at the department of Psychiatry of Addis Ababa University. My advisors are Dr. Dawit Wondimagegn and Dr.Selam Aberra. I am conducting a study on the Aging parents as caregivers: challenges of supporting adult children with severe mental illness in Amanuel Specialized mental hospital and Tikur Anbessa Specialized hospital. The purpose of this study is to explore the challenges of the aging caregivers. You are selected to participate in this study because you are the primary caregiver for your child with severe mental illness who has follow up at this hospital and you agreed to participate. By doing this, you will be contributing to a better understanding and subsequent possible interventions for the caregivers.

The interview will take about 40-60 minutes, in a secure available space. Notes will be taken as well as audio recording during the interview. The interview will be conducted in Amharic language. Personal information will be kept confidential. Your participation in this study is entirely voluntary. If you decide to take part in this study, you will be asked about your understanding of the study and once that is checked, you will sign a consent for. Even after signing, you are still free to withdraw anytime during the interview.Your participation has no effect on the care and service you and your child receive from this hospital. After completing the interview, you will be paid 300birr reimbursement for your time and transportation. If you require further support, you will be linked to the OPD for further assessment and management.If you have questions or complaints about this study, you can contact me, my advisors and the department of Psychiatry, the contact information provided in this information sheet.

Contact information
Name-Dr. Lydia Kenneth
Phone number:+251-913967758

Email:naylorlydia25@gmail.com

ስሜ ዶክተር ሊዲያ ኬኔት እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ የሳይካትሪ ትምህርት ክፍል የሳይካትሪ ሬዚደንት ነኝ። አማካሪዎቼ ዶ/ር ዳዊት ወንድማገኝ እና ዶ/ር ሰላም አበራ ናቸው። በአማኑኤል ስፔሻላይዝድ አእምሮ ሆስፒታል እና በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል ከባድ የአእምሮ ሕመም ያለባቸውን ጎልማሳ ልጆችን የመደገፍ ተግዳሮቶች በአረጋውያን ወላጆች ላይ እንደ ተንከባካቢ ጥናት እያካሄድኩ ነው። የዚህ ጥናት አላማ እድሜያቸው የገፋን ተንከባካቢዎችን ተግዳሮቶች መመርመር ነው. በዚህ ጥናት ላይ ለመሳተፍ ተመርጠዋል ምክንያቱም በዚህ ሆስፒታል ውስጥ ክትትል ያደረጉ እና ከባድ የአእምሮ ህመም ላለባቸው ልጅዎ ዋና ተንከባካቢ ስለሆኑ እና ለመሳተፍ ተስማምተዋል. ይህን በማድረግዎ ለተሻለ ግንዛቤ እና ለተንከባካቢዎች ቀጣይ ጣልቃገብነት አስተዋፅዖ ያደርጋሉ።

ቃለ መጠይቁ ከ40-60 ደቂቃ ይወስዳል፣ ደህንነቱ በተጠበቀ ቦታ። በቃለ መጠይቁ ወቅት ማስታወሻዎች እንዲሁም የድምጽ ቅጂዎች ይወሰዳሉ. ቃለ ምልልሱ የሚካሄደው በአማርኛ ቋንቋ ነው። የግል መረጃ በሚስጥር ይጠበቃል። በዚህ ጥናት ውስጥ ያለዎት ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው። በዚህ ጥናት ላይ ለመሳተፍ ከወሰኑ ስለ ጥናቱ ያለዎትን ግንዛቤ ይጠየቃሉ እና አንዴ ከተመረመሩ በኋላ ስምምነት ይፈርማሉ። ከፈረሙ በኋላም ቢሆን፣ በቃለ መጠይቁ ወቅት በማንኛውም ጊዜ ለመውጣት ነፃ ነዎት። የእርስዎ ተሳትፎ እርስዎ እና ልጅዎ ከዚህ ሆስፒታል በሚሰጡት እንክብካቤ እና አገልግሎት ላይ ምንም ተጽእኖ አይኖረውም። ቃለ-መጠይቁን ከጨረሱ በኋላ ለጊዜዎ እና ለመጓጓዣዎ 300ብር ክፍያ ይከፈልዎታል። ተጨማሪ ድጋፍ ከፈለጉ፣ ለበለጠ ግምገማ እና አስተዳደር ከኦፒዲ ጋር ይገናኛሉ።ስለዚህ ጥናት ጥያቄዎች ወይም ቅሬታዎች ካሉዎት እኔን፣ አማካሪዎቼን እና የስነ አእምሮ ህክምና ክፍልን በዚህ የመረጃ ወረቀት ላይ የቀረበውን የእውቂያ መረጃ ማግኘት ይችላሉ።

ለመረጃ

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Annex 2 – Consent Form

I have received enough information about this study, its purpose and the confidentiality by the primary researcher. I have understood the information given and that my participation is voluntary. I understood that my participation has no direct effect on the treatment given for my child. I was reimbursed 300birr for my transportation and my time taken for this study.

I give my consent to Dr. Lydia for my participation on the research for Aging parents as caregivers: challenges of supporting adult children with severe mental illness.

Participant's signature

Date

Researcher's signature

Date

ስለዚህ ጥናት፣ አላማ እና ምስጢራዊነት በዋና ተመራማሪው በቂ መረጃ አግኝቻለሁ። የተሰጠውን መረጃ ተረድቻለሁ እና ተሳትፎዬ በፈቃደኝነት ነው። የእኔ ተሳትፎ ለልጄ በሚሰጠው ህክምና ላይ ቀጥተኛ ተጽእኖ እንደሌለው ተረድቻለሁ። ለትራንስፖርት ወጪዬ 300ብር ተመለስኩኝ እና ለዚህ ጥናት የወሰድኩት ጊዜ ወስጄ ነበር።

ለአረጋውያን ወላጆች እንደ ተንከባካቢ በተደረገው ጥናት ላይ ለመሳተፍ ለዶክተር ሊዲያ ፈቃዴን እሰጣለሁ፡ ከባድ የአእምሮ ሕመም ያለባቸው አዋቂ ልጆችን የመደገፍ ተግዳሮቶች።

የተሳታፊው ፊርማ

ቀን

የተመራማሪው ፊርማ

ቀን

Annex 3 – Interview Guide

1.Information

- Age, gender, Educational status, Occupational status, Marital status, diagnosis of child

2.What are the challenges faced by elderly parents who serve as caregivers for their adult children with severe mental illness?

- Can you tell me about your adult child's diagnosis and when they were first diagnosed?
- How old were you when you first started becoming their primary caregiver? How old are you now?
- Can you describe a typical day or week in your life as a caregiver?
- What kind of care and support do you provide for your child?
- Are there other family members involved in the caregiving? If so, what are their roles?

3 Physical & Emotional Challenges

- Has caregiving affected your physical health?

- If Yes, How has caregiving affected your physical health?
- Do you have any health conditions of your own that make caregiving more difficult?
- How would you describe your emotional state?
- Can you tell me about a time you felt particularly stressed or overwhelmed by your caregiving duties?
- Has caregiving impacted your social life and your relationship with your spouse, friends, or other family members?

- If Yes, then how has caregiving impacted your relationship with others?

4. Financial & Practical Challenges

- Does caregiving have any financial impact?

- If Yes, how has caregiving affected your financial situation in your life?
- Have you had to make any significant financial sacrifices to provide care for your child?
- What are the biggest challenges you face in navigating the healthcare system for your child?
- What are your biggest fears or concerns for the future, both for yourself and for your child?

- What are your worries or concerns about the future, especially as you get older?

- Have you any plans for your child's care in the future? If so, what doesn that looks like?

5 Social Support & Coping Mechanisms

- Where do you find support, if any?
- Is there a support group specifically for parents of adults with mental illness?
- What are some things you do to take care of yourself and manage your stress?
- Do you ever get a break from your caregiving responsibilities? If so, what does that look like?
- What is the one thing you wish people outside of your situation understood about being a caregiver for a child with severe mental illness?

6. Personal growth and giving meaning

- As a result of your caregiving experience, have you found a new purpose in life?
- Have you developed any new skills, hobbies or interests that you might not have otherwise?
- Has this experience changed the way you relate to other people?
- Do you remember a time when you faced a difficult situation and discovered a strength you didn't know you had?
- Has your caregiving experience changed your spiritual or religious beliefs?

1. መረጃ

● ዕድሜ፣ ጾታ፣ የትምህርት ደረጃ፣ የሙያ ደረጃ፣ የጋብቻ ሁኔታ፣ የልጅ ምርመራ

2. ከባድ የአእምሮ ሕመም ላለባቸው አዋቂ ልጆቻቸው ተንከባካቢ ሆነው የሚያገለግሉ በዕድሜ የገፉ ወላጆች የሚያጋጥሟቸው ችግሮች ምንድን ናቸው?

● ስለ አዋቂ ልጃችሁ ምርመራ እና ለመጀመሪያ ጊዜ መቼ እንደታወቀ ሊነግሩኝ ይችላሉ?

● የመጀመሪያ ተንከባካቢዎቻቸው መሆን ስትጀምር ዕድሜህ ስንት ነበር? አሁን ስንት አመትህ ነው?

● በሕይወትህ ውስጥ የተለመደውን ቀን ወይም ሳምንት እንደ ተንከባካቢ ልትገልጸው ትችላለህ?

● ለልጅዎ ምን ዓይነት እንክብካቤ እና ድጋፍ ይሰጣሉ?

● በእንክብካቤው ውስጥ ሌሎች የቤተሰብ አባላት አሉ? ከሆነስ ሚናቸው ምንድን ነው?

3 አካላዊ እና ስሜታዊ ተግዳሮቶች

● እንክብካቤ ማድረግ አካላዊ ጤንነትህን የነካው እንዴት ነው?

● እንክብካቤን የበለጠ ከባድ የሚያደርጉ የራስዎ የጤና ችግሮች አሎት?

● ስሜታዊ ሁኔታህን እንዴት ትገልጸዋለህ?

● በእንክብካቤ ሥራዎ ምክንያት በተለይ የተጨነቁበት ወይም የተጨነቁበትን ጊዜ ሊነግሩኝ ይችላሉ?

● እንክብካቤ በማህበራዊ ኑሮህ እና ከትዳር ጓደኛህ፣ ከጓደኞችህ ወይም ከሌሎች የቤተሰብ አባላት ጋር ባለህ ግንኙነት ላይ ምን ተጽዕኖ አሳድሯል?

4. የገንዘብ እና ተግባራዊ ፈተናዎች

● የእንክብካቤ አገልግሎት በሕይወታችሁ ላይ ያለውን የገንዘብ ተጽዕኖ መግለፅ ትችላላችሁ?

● ልጅዎን ለመንከባከብ ከፍተኛ የገንዘብ መስዋዕትነት ከፍለው ያውቃሉ?

● የልጅዎን የጤና አጠባበቅ ሥርዓት ለመከታተል የሚያጋጥሙዎት ትልልቅ ፈተናዎች የትኞቹ ናቸው?

● ለራስህም ሆነ ለልጅህ ትልቅ ስጋትህ ምንድን ነው?

● ስለ ወደፊቱ ጊዜ፣ በተለይም በዕድሜ እየገፋህ ስትሄድ የምታስጨንቀው ነገር ምንድን ነው?

● ወደፊት ለልጅዎ እንክብካቤ እቅድ አለዎት? ከሆነ ምን ይመስላል?

5 ማህበራዊ ድጋፍ እና የመቋቋሚያ ዘዴዎች

● ድጋፍ ከየት ታገኛለህ?

● የአእምሮ ሕመም ላለባቸው አዋቂዎች ወላጆች የተለየ የድጋፍ ቡድን አለ?

● ራስህን ለመንከባከብ እና ጭንቀትህን ለመቆጣጠር የምታደርጋቸው አንዳንድ ነገሮች ምንድን ናቸው?

● ከእንክብካቤ ኃላፊነቶቻችሁ እረፍት ታውቃላችሁ? ከሆነ ምን ይመስላል?

● ከባድ የአእምሮ ሕመም ላለበት ልጅ ተንከባካቢ ስለመሆን ከሁኔታዎ ውጪ ያሉ ሰዎች እንዲረዱት የምትፈልገው ነገር ምንድን ነው?

6. የግል እድገት እና ትርጉም መስጠት

● በእንክብካቤ ተሞክሮህ ምክንያት በሕይወትህ ውስጥ አዲስ ዓላማ አግኝተሃል?

● ሌላ ላይኖርህ የምትችለውን አዳዲስ ክህሎቶችን፣ የትርፍ ጊዜ ማሳለፊያዎችን ወይም ፍላጎቶችን አዳብረሃል?

● ይህ ተሞክሮ ከሌሎች ሰዎች ጋር ያለዎትን ግንኙነት ለውጦታል?

● አስቸጋሪ ሁኔታ ያጋጠመህ እና እንዳለህ የማታውቀው ጥንካሬ ያገኘህበትን ጊዜ ታስታውሳለህ?

● የመንከባከብ ልምድህ መንፈሳዊ ወይም ሃይማኖታዊ እምነትህን ቀይሮታል?