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The Psychosocial Challenges and Coping Mechanisms of Parents of Children with Epilepsy: The Case of Adama City

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Examining Committee Approval

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Declaration

I, the undersigned, hereby declare that the thesis entitled “The Psychosocial Challenges and Coping Mechanisms of Parents of Children with Epilepsy: The Case of Adama City” is my original work, and all sources of materials used for this thesis have been duly acknowledged.

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Content

Abstract

Epilepsy is a serious health condition that affects not only children but also their families, especially their parents, who serve as primary caregivers. While much attention has been given to treating epilepsy in children, the challenges faced by their parents are often overlooked. This study aims to explore the psychosocial challenges and coping mechanisms of parents of children with epilepsy in Adama City. It focuses on parents of children with epilepsy who are members of the Adama City Association of People with Disabilities. A qualitative research design was used to better understand the experiences of these parents. Data were collected through semi-structured interviews and Focus Group Discussions from 14 parents (11 mothers and 3 fathers. These parents were selected from 24 (Male 29 and Female 13) members of the parents of children with epilepsy in the association. The findings were thematically analyzed into three main themes: (i) psychological challenges, (ii) social challenges, and (iii) coping mechanisms. The findings show that parents face significant psychological challenges such as stress, anxiety, depression, loneliness, and self-blame. Social challenges include stigma, discrimination, lack of support, financial hardship, and limited access to healthcare and counseling services. Cultural beliefs that associate epilepsy with spiritual causes or punishment for sin worsen these challenges. Despite these difficulties, parents use various coping mechanisms. These include relying on faith and spirituality, seeking help from local organizations, educating themselves about epilepsy, and drawing strength from personal resilience and commitment to their children. However, the study also revealed a lack of professional support, particularly in areas such as medical care, nutrition, and behavioral management. The study recommends that healthcare services and psychosocial support programs for families of children with epilepsy should be improved. Raising awareness in the community is also essential to reduce stigma and promote understanding.

Keywords: Epilepsy, Psychosocial Challenges, Coping Mechanisms, Stigma, Parents

Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CWE	Children with Epilepsy
EEG	electroencephalogram
FGDs	Focus Group Discussions
HIE	Hypoxic Ischemic Encephalopathy
LMICs	Low and Middle Income Countries
PTSD	Post-Traumatic Stress Disorder
PWDs	People with Disabilities
PWE	People with Epilepsy

Chapter One

Introduction

1.1 Background

The (World Health Organization [WHO], 2023) defined epilepsy as a chronic neurological disorder that affects millions of people worldwide, with considerable psychological, social, and physical challenges. Falco-Walter (2020) defined epilepsy in three different ways: i) it is a disease with two or more unprovoked or reflex episodes more than 24 hours apart; and ii) epilepsy is a single unprovoked or reflex epilepsy in people with a greater than or equal to 60% risk of another epilepsy in the next 10 years). According to Zhou et al. (2022), epilepsy is a prevalent neurological condition resulting from the irregular firing or synchronization of brain neurons. It is defined by irregular brain activity, resulting in recurrent epileptic seizures or abnormal behavior, sensation, and occasionally a loss of consciousness (WHO, 2019).

Epilepsy is one of the most misunderstood health conditions that negatively affects the lives of individuals with epilepsy. Worldwide, about 50 million people are expected to live with epilepsy, and nearly 80% of them live in poor countries due to a combination of factors, including preventable infections, limited access to quality healthcare, and lack of awareness. In low-income settings, conditions such as neurocysticercosis, malaria, meningitis, and birth-related injuries significantly contribute to the development of epilepsy (Newton & Garcia, 2012). These countries often lack the medical infrastructure, trained professionals, and diagnostic tools necessary for early detection and treatment (WHO, 2023). Additionally, misconceptions about epilepsy, such as beliefs in supernatural causes, discourage families from seeking medical help and increase reliance on traditional healers (Baskind & Birbeck, 2020). Poor maternal and child healthcare, malnutrition, and a high incidence of untreated head injuries further elevate the risk, especially among children (Munyoki et al., 2010). These overlapping medical, social, and economic challenges explain why the burden of epilepsy remains disproportionately high in poor countries.

This gap is even more concerning in rural and semi-urban areas where health services are either unavailable or under-resourced. According to Falco-Walter (2020), epilepsy is defined not only by recurrent seizures but also by the risk of having future seizures or being diagnosed with an epilepsy syndrome. However, for families, especially those with children affected by epilepsy, the experience goes far beyond clinical symptoms. Parents often face emotional exhaustion,

social isolation, financial hardship, and stigma (Reilly et al., 2020).

The psychosocial impact of epilepsy is significant and multifaceted. Research shows that children with epilepsy and their families often face widespread discrimination, social exclusion, and emotional stress (Jacoby et al., 2021). Stigma surrounding epilepsy is often rooted in misinformation and traditional beliefs, especially in Africa, where the condition is frequently associated with supernatural causes, such as possession by evil spirits or punishment for wrongdoing (Baskind & Birbeck, 2020). This belief system leads to fear and misunderstanding, which in turn isolates the affected individuals and their caregivers.

Parents of children with epilepsy often carry the burden silently. A study by Reilly et al. (2020) found that caregivers reported high levels of emotional strain, anxiety, and depressive symptoms. These challenges are compounded by a lack of practical support from healthcare systems, extended families, and community members. In many African societies, including Ethiopia, the stigma against epilepsy can force families to hide the condition of their child, avoiding schools, social gatherings, and public spaces (Girma et al., 2022).

The situation is particularly difficult in Ethiopia, where epilepsy is among the most common neurological disorders, yet it remains highly misunderstood. Cultural and religious beliefs often influence how the condition is viewed and treated. Many people believe epilepsy is caused by curses or spiritual punishment, leading them to seek help from traditional healers instead of medical professionals (Fanta et al., 2022). As a result, children may not receive proper diagnosis or treatment, and parents are left to manage the emotional and financial burden alone (Gelaye et al., 2023).

In Ethiopia, few support systems exist to address the mental and emotional well-being of parents caring for children with epilepsy. According to Tilahun et al. (2023), healthcare facilities often lack the necessary resources and trained staff to offer psychological support to caregivers. Moreover, parents frequently report financial struggles related to the ongoing costs of anti-epileptic medication, hospital visits, and travel for specialized care, especially for those living outside the capital city, Addis Ababa (Alemayehu et al., 2023).

A specific challenge in the Ethiopian context is the conflict between traditional beliefs and modern medicine. In many communities, traditional healing is more culturally accepted than clinical treatment. As noted by Danesi and Adetunji (2021), families may delay seeking medical help due to pressure from relatives or cultural expectations. This delay not only puts the child at

risk but also increases parental stress and frustration. In some cases, the condition worsens due to improper care or lack of timely treatment.

Adama City, located in the Oromia Regional State of Ethiopia, reflects many of these national challenges. Parents of children with epilepsy in this city face numerous barriers in accessing healthcare, including financial constraints, long travel distances to reach specialized centers, and a shortage of qualified professionals (Kassaw et al., 2020). Moreover, cultural misconceptions about epilepsy remain deeply rooted in the community. Mekonnen et al. (2022) reported that parents in Adama believe traditional healers are more effective in managing epilepsy than formal healthcare services. These beliefs limit access to effective treatment and contribute to persistent stigma. Despite these realities, there is limited research that specifically focuses on how these parents cope with such complex challenges.

Studies in other countries have shown that some parents adopt coping mechanisms such as relying on faith, seeking support from disability associations, educating themselves about epilepsy, and building resilience through experience (Keikelame et al., 2017). However, in Ethiopia, such strategies have not been fully documented or analyzed in depth. Therefore, more research is needed to understand how Ethiopian parents, particularly those in Adama City, navigate these psychosocial challenges.

This study aims to fill this gap by exploring the psychosocial challenges and coping mechanisms of parents of children with epilepsy in Adama City. In particular, there is a lack of qualitative research focusing on the coping mechanisms of parents in Adama City. This study addresses this gap by exploring how parents manage the emotional, social, and cultural burdens of raising a child with epilepsy in this context. Understanding these issues is crucial for developing targeted interventions that consider both the medical and cultural aspects of epilepsy care in Adama City.

As a researcher, I believe that epilepsy is not only a medical condition but also a deep social issue that is shaped by cultural beliefs, stigma, and lack of awareness. This research is guided by both professional responsibility and personal empathy, based on direct observation of families in Adama City. While respecting local traditions, the study argues for the need to integrate scientific knowledge and evidence-based approaches to improve support for parents. The findings will contribute to more inclusive health policies, community awareness programs, and holistic caregiver support services in Ethiopia

1.2 Statement of the Problem

Epilepsy is a neurological disorder among children, affecting their overall development, academic performance, and social interaction (Fine & Wirrell, 2020). Globally, the estimated incidence of childhood epilepsy ranges from 41 to 187 per 100,000 people (Camfield, 2020), with a disproportionately higher prevalence in low-income countries. The condition is often accompanied by unpredictable seizures, a long treatment course, and potential side effects from medication, which can result in emotional, physical, and psychological burdens for both the children and their caregivers (WHO, 2023). While the needs of children with epilepsy have begun to receive attention in global health discussions, the psychosocial and emotional experiences of their parents, particularly in low-income settings, remain inadequately explored.

In many developing countries, epilepsy continues to carry a significant social stigma. Despite increasing global awareness, misconceptions and prejudice surrounding the condition persist. Many parents are socially isolated due to fear of judgment or discrimination from family, neighbors, or the community (Rani & Thomas, 2019). They experience feelings of guilt, shame, fear, and anxiety, often hiding their child's condition to avoid being labeled or excluded. Research highlights that parents of children with epilepsy may withdraw from social activities, avoid seeking support, and internalize blame, all of which increase parenting pressure and emotional distress (O'Toole et al., 2015). In addition, the stigma can lead to a delay in accessing appropriate medical care, thereby exacerbating the child's health condition and placing further strain on the caregivers.

In Ethiopia, these issues are particularly severe due to deeply embedded cultural beliefs and the limited availability of medical services. Many people in the community associate epilepsy with evil spirits, curses, or other supernatural causes (Fanta et al., 2022). Such beliefs lead to discrimination and rejection of both the affected children and their families. Children are often kept out of school, and parents may be shunned by neighbors or relatives who view epilepsy as contagious or shameful (Girma et al., 2022). As a result, families live in secrecy and fear, avoiding public spaces and social interaction. This isolation prevents them from obtaining accurate information, emotional support, and medical care, leading to worsening conditions for both the children and their caregivers.

The emotional toll on parents is immense. Many suffer from anxiety, depression, and chronic stress due to the unpredictable nature of seizures, concern for their child's future, and the

continuous demand for care (Alemayehu et al., 2023). The fear of sudden seizures, especially in public, keeps parents constantly alert and worried. Feelings of helplessness and guilt are common, especially when they believe they could have prevented the illness or done more to alleviate their child's suffering. Without access to mental health support, these emotional burdens often go unnoticed and unaddressed, leaving parents vulnerable to long-term psychological consequences.

Financial challenges further intensify the burden on families. In low-income communities, the cost of managing epilepsy, ranging from medication and hospital visits to transportation for specialized care, is significant. Many families struggle to afford anti-epileptic drugs and must often choose between purchasing medicine and meeting basic needs like food or shelter (Gelaye et al., 2023). This financial pressure not only affects their ability to care for the child effectively but also increases stress within the family unit. In some cases, financial hardship drives families to seek care from traditional healers, which can delay effective treatment and worsen the condition (Mekonnen et al., 2022).

Furthermore, public awareness about epilepsy remains low, even among some healthcare providers, leading to misinformation, delayed referrals, and a lack of empathy in service delivery (Kassaw et al., 2020). These systemic challenges leave many parents without the necessary medical and psychosocial support to manage their child's condition effectively.

Despite these challenges, parents employ various coping mechanisms to survive. Many turn to their religious beliefs, praying for healing and emotional strength (Assefa et al., 2023). Others rely on family members or neighbors for emotional and financial support. However, not all parents have access to these support systems. Some are left completely alone, with no one to help them manage the emotional and logistical burdens of caregiving. The absence of organized support structures, such as counseling services, parent support groups, or educational programs, means that most parents in Adama City must navigate their struggles in isolation (Tilahun et al., 2023).

Although epilepsy is a well-recognized neurological disorder, research in Ethiopia has mainly focused on its clinical and medical management, with limited attention to its psychosocial impact on parents (Tekle-Haimanot et al., 2018). Most existing studies overlook the lived experiences of parents, especially in urban settings like Adama City, where social stigma and inadequate support systems remain critical issues. There is a significant population gap, as the

voices of parents, who serve as primary caregivers, are underrepresented in the literature (Ameha et al., 2020). Furthermore, a methodological gap exists, since most studies use quantitative approaches and fail to explore emotional and cultural dimensions qualitatively. In addition, there is an evidence gap, with little local data on how parents manage psychosocial stress, financial pressure, and community discrimination. The geographical gap is especially clear, as no known studies have deeply examined these issues in Adama City. The topical gap regarding coping mechanisms also remains, despite growing demand for culturally relevant support strategies.

This study aims to fill this critical gap by exploring the psychosocial challenges and coping mechanisms of parents of children with epilepsy in Adama City. It will provide valuable insights into the psychological and social struggles these parents face and examine the strategies they use to cope. The findings will serve as an essential resource for healthcare providers, policymakers, educators, and social workers seeking to support families affected by epilepsy. Understanding this context is vital for designing effective interventions that are culturally sensitive and practically applicable. Without this understanding, efforts to improve the lives of children with epilepsy and their families will remain incomplete and less effective.

1.3 Research Questions

The study aims to answer the following research questions.

- What are the psychological challenges that parents of children with Epilepsy face?
- What are the social challenges parents face with family members and other people?
- What coping mechanisms do parents of children with Epilepsy apply to deal with their psychosocial problems?

1.4 Research Objective

1.4.1 General Objective

The general objective of this study is to explore the psychosocial challenges and Coping Mechanisms of parents of children with Epilepsy in Adama City.

1.5 Significance of the Study

The study is primarily believed to explore the psychosocial challenges that parents of children with Epilepsy experience. Exploring the challenges of parents with Epilepsy is fundaments to effectively solving their problems through a structured approach. Particularly, programs designed to address the broader needs of children with epilepsy need to consider the importance of their parents' social and psychosocial well-being. This enhances the positive

contribution of parents in the overall development of the child. The identification of the problem also enables program implementers, policymakers, and service providers to recognize the challenges and fulfill their mandate in accessing services to parents of children with Epilepsy. The study will also provide insights into what coping mechanisms parents used to mitigate the impact of having a child with Epilepsy.

The findings will provide basic facts on how psycho-social problems are common among parents of children with Epilepsy. The targeted parents and other parents of children with Epilepsy will have insight that stress, anxiety, and social isolation are the major challenges for these parents. Having such information will help parents to reduce feelings of self-blame or helplessness.

Identifying the coping mechanisms of parents will also help parents of children with epilepsy to adopt better strategies to maintain better emotional well-being and social relationships.

The study will also highlight the considerable gap in providing psychosocial support for parents of children with Epilepsy. The findings will also highlight the need for mental health care services for parents that consider the religious and cultural beliefs of the community to design more sensitive and effective counseling approaches.

The research findings will also highlight to policymakers and social service providers that there is a need for a comprehensive health care system that recognizes the health needs of parents of children with Epilepsy.

The study will also contribute to future academic research, as the psychosocial impact of epilepsy on parents has not been well studied. Particularly, the study will highlight the situation of the parents of children with Epilepsy in Adama City. Besides, the study can serve as the groundwork for further research in the area of medical and rehabilitation interventions.

1.6 Delimitation of the Study

The study is limited to Adama City and has not included peripheral rural kebeles/sub-districts or other nearby rural cities. The participants were only parents of children with Epilepsy (mothers and Fathers). Other family members, like teachers, health professionals, and religious leaders, were not included in the study. Thus, further research in the area may be needed to identify the impact of epilepsy on other target groups.

The study also focused on parents of children whose age is between 8-18 years and

excluded children below eight years old and adult people with epilepsy. In terms of time, the research only focused on current psychosocial challenges; it has not tracked longitudinal changes over time.

1.7 Scope of the Study

This study focuses on exploring the psychological and social challenges faced by parents of children with epilepsy in Adama City, Ethiopia. It also examines the different coping mechanisms these parents use to manage stress and caregiving responsibilities. The study is limited to parents of children with epilepsy who live in Adama City and who are the primary caregivers of children diagnosed with epilepsy. It does not include extended family members, health professionals, or caregivers outside of Adama City. The research is qualitative and aims to provide deep insights into the lived experiences of these parents rather than generalizing findings to all populations.

1.8. Limitation of the Study

From a methodological point of view, the study has some limitations. Since it used a qualitative research design, the findings are based on the personal experiences and opinions of a small number of participants. This limits the ability to generalize the results to a larger population. Also, the data collection relied mainly on semi-structured interviews and focus group discussions, which may be influenced by social desirability or recall bias, where participants might say what they think is expected. In addition, because the study did not use standardized tools to measure psychological conditions like stress or depression, the analysis is based only on participants' descriptions and not on clinical assessments. Finally, the researcher's presence during interviews may have unintentionally influenced how participants responded.

To minimize these limitations, participants were selected purposefully to ensure they had relevant and diverse experiences. Interviews and focus groups were conducted in private, safe environments to encourage honest sharing. Probing questions were used to clarify responses and reduce misunderstandings. The researcher built rapport and remained neutral to reduce response bias. Field notes and memo writing were used to reflect on personal assumptions and minimize bias. Additionally, multiple data sources (individual and group interviews) helped to improve the credibility of the findings.

1.9 Definition of Key Terms

Epilepsy

A neurological disorder characterized by recurrent, unprovoked seizures due to abnormal electrical activity in the brain.

Children with Epilepsy

Those who have experienced recurrent, unprovoked seizures, typically at least two episodes occurring more than 24 hours apart, due to a chronic neurological condition marked by an enduring predisposition of the brain to generate seizures.

Psychological Challenges

Difficulties people encounter that cause them unpleasant emotional states, such as stress from managing a child, disappointment and sacrifice, interpersonal conflict, concern about the child's future, and a Sense of loneliness, which can impact their day-to-day activities.

Social Challenges

Difficulties that people encounter while interacting with people in society or engaging in normal social behaviors.

Coping Mechanisms

The use of mechanisms to adjust to environmental stresses and challenges without altering personal goals, whether consciously or unconsciously.

Chapter Two

Review of Related Literature

2.1 Introduction

This chapter presents a comprehensive review of global, African, and Ethiopian literature related to the psychosocial experiences of parents of children with epilepsy. The review is organized into several key sections to provide a structured analysis: the global prevalence of epilepsy; the theoretical frameworks that underpin the study, namely Family Stress Theory and Social Stigma Theory; and empirical studies that highlight psychosocial challenges and coping strategies in various geographic contexts. Special attention is given to studies conducted in Africa and Ethiopia to contextualize the issue within low- and middle-income settings where cultural beliefs, stigma, and limited healthcare access often shape parental experiences.

Additionally, this chapter identifies existing research gaps and articulates the contextual relevance and justification for focusing on Adama City. While international and national research provides valuable insights, there is a lack of in-depth, localized understanding of how urban Ethiopian parents navigate the unique psychological and social demands of caregiving for children with epilepsy. The chapter concludes by summarizing the key findings and underscoring the need for the present study.

2.1.1 Global Prevalence of Epilepsy

From the general population, the number of people with active epilepsy (i.e., continuing seizures or with the need for treatment) is expected to be 32.7 million globally. Besides, the cumulative lifetime incidence of epilepsy is 3%, and more than half of the disorders start in childhood. The annual prevalence is 0.5–1%, meaning it is an unrecognized and underreported public health problem around the world (Beghi, 2020). A meta-analysis of a door-to-door population-based survey involving 1,137,491 people in Sub-Saharan Africa revealed that 16 per 1,000 people had active epilepsy, with only modest variations between regions (Owolabi et al., 2019). Despite the scarcity of epilepsy research in Ethiopia, a door-to-door survey in Zay villages in 2006, Oromia region, found a high prevalence rate of active epilepsy of 29.5 per 1,000 people (Tekle-Haimanot et al., 2018).

2.2 Theoretical Framework

As Goffman (1963) introduced, the Family Stress Theory and Social Stigma Theory are used as the corresponding theoretical viewpoints for this study. These two perspectives provide a

lens to methodically study the psychosocial challenges that parents of children with epilepsy face due to their children.

2.2.1 Family Stress Theory

Family Stress Theory, rooted in the work of Hill (1949) and later expanded by McCubbin and Patterson (1983), posits that families experience stress when they encounter demands that exceed their available resources and coping mechanisms. The theory introduces the ABC-X model, where:

- A (Stressor) represents the triggering event (e.g., a child's epilepsy diagnosis),
- B (Resources) includes familial, social, or economic supports,
- C (Perception) reflects how the family interprets the stressor, and
- X (Crisis) denotes the potential for family dysfunction if adaptation fails.

Globally, studies have shown that caregiving for a child with epilepsy can result in significant emotional, social, and financial stress for families, often leading to role strain and mental health issues if coping resources are inadequate (Shore et al., 2021). In Sub-Saharan Africa, Kiwanuka and Anyango Olyet (2018) found that cultural beliefs and limited healthcare access exacerbate this stress, forcing families to rely on traditional healing and community coping mechanisms. In Ethiopia, similar patterns emerge, parents of children with epilepsy report high levels of stress due to financial burden, social stigma, and lack of institutional support (African Journal of Disability, 2022). Family Stress Theory helps explain why some Ethiopian families adapt better than others those with stronger social support, financial resources, and positive coping beliefs are more resilient, while others may face crisis-level strain.

2.2.2 Social Stigma Theory (Goffman, 1963)

The theory explains how individuals possessing a deeply discredited attribute, such as a chronic illness, are devalued and marginalized by society. This theory is highly relevant in understanding the stigma faced by children and individuals with epilepsy. Globally, studies have shown that people with epilepsy are frequently stereotyped as dangerous, unpredictable, or mentally unstable, leading to social exclusion and discrimination (Jacoby et al., 2021). In Africa, cultural interpretations of epilepsy, such as beliefs that seizures are caused by evil spirits or witchcraft, contribute to negative societal reactions, often isolating children and families from

educational, social, and health opportunities (Baskind & Birbeck, 2020). In Ethiopia, similar stigma is evident; people with epilepsy are frequently hidden by their families or denied access to school and public spaces due to widespread misconceptions and fear (Girma et al., 2022). Goffman's framework helps explain why the stigma persists: epilepsy disrupts what is considered "normal" in social identity, leading others to assign a spoiled or devalued status. Understanding this theory helps identify the root of societal attitudes and informs the development of culturally appropriate awareness programs and supportive interventions.

2.2.3 Integration of Theories

Together, these theories illuminate the dual burden faced by parents: internal family stress from caregiving demands (Family Stress Theory) and external societal stigma (Goffman's Theory). For instance, Ethiopian parents may perceive epilepsy as a "family shame" (Cognition in Family Stress Theory), while societal stigma (Goffman) depletes their social capital (B in the ABC-X model). This interplay justifies the study's focus on both psychological and social dimensions of parental challenges.

2.3 Empirical Review

2.3.1 Psychosocial Challenges of Parents of Children with Epilepsy Globally

Caring for a child with epilepsy often causes emotional and psychological strain for parents around the world. A recent meta-synthesis identified caregiver stress from fear of seizures, lack of social support, and financial burden as widespread issues (Yu et al., 2022). These themes reinforce earlier findings that parental stress and anxiety arise from the constant worry over seizure unpredictability and potential injury (Carter et al., 2022). Moreover, sleep disruption and poor resilience have been linked to higher caregiver burden, suggesting an interactive relationship between stress, poor sleep, and lower resilience in parents (Dogan et al., 2022).

A qualitative study in Europe found that parents also experience strained family relationships, reduced work time, and increased mental health needs when caring for children with severe epilepsy, such as developmental and epileptic encephalopathies (DEEs) (Guermazi et al., 2024). These intimate family impacts are echoed globally, demonstrating that caring for a child with epilepsy often narrows parents' attention to caregiving, neglecting self-care and other family responsibilities (Guermazi et al., 2024).

Stigma and social isolation are recurring challenges across cultures. A study in Jordan

reported high caregiver stigma, depressive symptoms, and social rejection within their communities (Abdulameera & Al-Dujaili, 2022). In South Asia and Africa, epilepsy is often viewed through spiritual or traditional lenses, causing families to seek non-medical healing routes that can delay treatment and increase distress (Carter et al., 2022; Zhou et al., 2022).

When comparing support systems, research reveals disparities. In higher-income countries, access to education and structured support can ease caregiver burdens (Carter et al., 2022); but in low- and middle-income countries (LMICs), parents often lack psychological support, must prioritize traditional healing, and bear greater out-of-pocket expenses (Zhou et al., 2022). A recent scoping review affirmed the need for more proactive engagement from healthcare systems to acknowledge and address parents' hidden fears during routine care (Carter et al., 2022).

One gap in the literature is the limited use of qualitative methods to deeply understand parents' lived experiences. While many studies use surveys and statistics to measure stress or burden, fewer studies explore the personal stories, beliefs, and coping mechanisms of parents through interviews or focus groups. This limits our understanding of how families adapt or fail to adapt over time.

In conclusion, global research clearly shows that parents of children with epilepsy face major psychosocial challenges related to emotional distress, stigma, financial strain, and lack of support. The level and type of these challenges differ by culture, economic status, and the strength of the health system. However, more qualitative and caregiver-focused studies are needed to fully understand these issues and design effective support programs.

2.3.2 Psychosocial Challenges of Parents of Children with Epilepsy in Africa

In many African countries, parents of children with epilepsy face a wide range of psychosocial challenges. One major issue is the stigma surrounding epilepsy, often linked to spiritual beliefs, witchcraft, or curses. A study by Nuhu et al. (2021) in Nigeria revealed that epilepsy is commonly misunderstood and feared, leading to social exclusion of both children and their caregivers. This stigma contributes significantly to caregivers' emotional distress, shame, and reluctance to seek timely medical support.

In Uganda, Kakooza-Mwesige et al. (2022) conducted a qualitative study and found that parents often feel isolated and emotionally burdened due to the unpredictable nature of seizures and limited social support. This emotional strain is compounded by financial hardships, as many

families struggle to afford anti-epileptic medications, transportation to clinics, and ongoing care. According to Abubakar et al. (2023), in Kenya and Tanzania, the cost of treatment remains one of the most significant barriers to effective epilepsy management.

In South Africa, a study by Mphahlele and Tjale (2023) reported that caregivers who lacked formal education and access to healthcare facilities experienced higher levels of psychological stress. Parents in rural areas often depend on traditional healers, as modern medical care is either unavailable or unaffordable. These coping mechanisms, while culturally relevant, often delay effective treatment and increase the caregiving burden (Adewumi et al., 2022).

Across African studies, common themes include stigma, emotional distress, financial burden, social isolation, and lack of support services. However, differences arise in coping strategies. While some parents rely heavily on faith and community support, others remain isolated due to fear of discrimination. Research by Tanyi et al. (2021) highlights how some families build resilience by joining support groups or participating in community health programs.

Despite these findings, there are notable gaps in the literature. Most studies are cross-sectional and qualitative, with few using longitudinal methods to track caregiver stress over time. Moreover, little is known about how caregivers adapt psychologically in the long term, especially in resource-poor settings (Owolabi et al., 2019). Future research should focus on intervention-based studies to assess how counseling, education, and economic support programs can alleviate these psychosocial challenges.

2.3.3 Psychosocial Challenges of Parents of Children with Epilepsy in Ethiopia

In Ethiopia, the psychosocial burden of caring for a child with epilepsy is significant and deeply rooted in cultural beliefs and limited healthcare access. Epilepsy is commonly perceived as a spiritual or supernatural condition, which leads to stigmatization of both the affected child and their caregivers. A study by Fanta et al. (2022) found that many parents experience intense social exclusion and fear of public judgment, which discourages them from disclosing their child’s condition or seeking help.

Emotional distress is another recurring challenge. Parents often suffer from anxiety, depression, and chronic stress, particularly due to the unpredictable nature of seizures and a lack of clear information from healthcare providers (Girma et al., 2022). The situation is worse in

rural and semi-urban areas, where specialized care is unavailable. According to Kassaw et al. (2020), most families rely on traditional healers and religious rituals instead of medical interventions, partly due to accessibility issues and partly due to community pressure.

Financial constraints are a major concern. A study by Gelaye et al. (2023) highlighted that families with children suffering from epilepsy incur significant costs for medication, transport, and clinic visits, which often worsens poverty. Parents are forced to make trade-offs between healthcare and other basic needs. This situation leads to emotional exhaustion and "role overload," as noted by Alemayehu and Kassa (2023), especially for single mothers or those with multiple caregiving responsibilities.

Despite these realities, coping mechanisms among Ethiopian parents remain under-researched. A few studies, such as Mekonnen et al. (2022) suggest that some parents use prayer, support from religious communities, or informal peer networks to manage stress. However, formal psychosocial support systems are almost nonexistent. Tilahun et al. (2023) emphasize the need for culturally adapted mental health services, as current interventions do not address the caregivers' emotional and social needs.

A critical gap in the literature is the lack of qualitative studies exploring how parents emotionally and socially navigate these challenges over time. Most research focuses on prevalence and attitudes toward epilepsy, with few in-depth analyses of family dynamics or long-term adaptation strategies (Demeke et al., 2023). As a result, more context-specific research is needed to develop effective support systems and inform national health policy.

2.3.4 Coping Mechanisms of Parents of Children with Epilepsy: A Global, African, and Ethiopian Perspective

Caring for a child with epilepsy presents complex emotional, financial, and social challenges for parents worldwide. Globally, parents often rely on adaptive coping strategies such as seeking medical information, emotional support from family and peers, counseling, and faith-based practices. A recent study by Pellicano et al. (2022) noted that parents in high-income countries utilize structured support groups and psychological counseling to manage stress and improve emotional well-being. Additionally, parental resilience is often strengthened by education and awareness about the child's condition, enabling better disease management (Smith et al., 2021).

In the African context, the coping mechanisms of caregivers are often influenced by

cultural beliefs and limited access to formal mental health support. Studies show that many parents resort to spiritual practices, such as prayer and visits to religious or traditional healers, as primary sources of hope and emotional strength (Owolabi et al., 2019). Furthermore, informal community networks and extended families provide emotional and logistical support, although stigma and misconceptions about epilepsy often isolate families (Tantoh et al., 2022). Unlike global patterns, professional psychological support remains largely inaccessible in many African regions, further complicating coping efforts.

In Ethiopia, coping strategies are primarily informal and shaped by socio-cultural and economic factors. Religious coping, such as fasting, prayer, and the use of holy water, is a dominant strategy, often seen as a spiritual solution to epilepsy (Alemayehu et al., 2023). Due to the lack of trained counselors and widespread stigma, parents frequently avoid discussing their child's condition, leading to increased emotional burden. Community awareness remains low, and formal caregiver support programs are virtually non-existent. Nonetheless, some parents demonstrate high levels of resilience through self-education and participation in religious communities that offer comfort and collective empathy (Mengesha & Tsegaye, 2022).

Overall, while global coping strategies often involve medical and psychosocial services, African and Ethiopian caregivers rely more on faith, family, and informal networks. This underscores the need for culturally sensitive and context-specific interventions to support parents dealing with childhood epilepsy.

2.4 Contextual Relevance and Research Gap Identification

2.4.1 Contextual Relevance

While several international and regional studies have explored the psychosocial challenges and coping mechanisms of parents caring for children with epilepsy, there is a noticeable scarcity of localized research in Ethiopia, especially in urban settings like Adama City. Most Ethiopian studies focus broadly on knowledge, attitudes, or prevalence rates of epilepsy (Fanta et al., 2022; Gelaye et al., 2023), rather than offering an in-depth analysis of parents' emotional and social experiences. Research conducted in rural areas emphasizes stigma, traditional beliefs, and lack of access to medical services (Kassaw et al., 2020; Girma et al., 2022), which may differ from urban realities where access to healthcare facilities may be slightly better but still insufficient in addressing the psychological needs of caregivers.

Furthermore, cultural values, religious practices, and social structures vary between

regions in Ethiopia. Adama City, being a diverse and fast-growing urban center in the Oromia region, has unique characteristics in terms of healthcare access, religious diversity, and cultural attitudes. In Adama city, no study has been done focusing on the experiences of parents of children with epilepsy, leaving a geographic gap in the literature. Understanding the psychosocial realities and coping strategies of caregivers in this specific setting is essential to developing locally relevant interventions.

2.4.2 Research Gap Identification

Despite growing global and African interest in the psychological and social dimensions of caregiving for children with epilepsy, several gaps remain:

Limited Context-Specific Evidence: Existing studies in Ethiopia are either national-level surveys or focused on rural populations (Alemayehu & Kassa, 2023; Tilahun et al., 2023). There is insufficient evidence capturing the lived experiences of parents in urban environments like Adama City, where cultural stigma still exists but coexists with varying levels of education, urban stressors, and fragmented social support systems.

Neglect of Coping Mechanisms in Research: While some studies mention coping behaviors like prayer or support from religious institutions, few examine how these strategies impact parental well-being over time (Mengesha & Tsegaye, 2022). There's a lack of comprehensive, qualitative studies exploring both psychosocial challenges and adaptive or maladaptive coping mechanisms within the same study, particularly in the Ethiopian urban context.

This study aims to fill these gaps by exploring both the psychosocial stressors and the coping responses of parents in Adama City. The findings will contribute to more targeted mental health support, awareness campaigns, and culturally sensitive interventions tailored to the Ethiopian urban setting.

2.4.3 Justification of the Study in Relation to Existing Literature

While global and regional studies have established that parents of children with epilepsy commonly experience emotional distress, social stigma, and financial hardship (Yu et al., 2022; Nuhu et al., 2021; Fanta et al., 2022), few have explored these issues in depth within specific urban Ethiopian contexts like Adama City. Prior research in Ethiopia has focused mainly on generalized stigma, treatment gaps, or caregiver knowledge, often neglecting the personal psychological and social experiences of parents (Girma et al., 2022; Kassaw et al., 2020).

Furthermore, while studies in other African countries and high-income nations have discussed coping strategies, such as prayer or support groups (Owolabi et al., 2021; Mengesha & Tsegaye, 2022), little is known about how these mechanisms function in urban Ethiopian communities with diverse social dynamics and limited psychosocial services. This study builds upon the existing literature by exploring the specific psychological and social challenges faced by parents in Adama City, and by examining how they cope with these challenges in their unique cultural and urban environment. By doing so, it addresses important gaps related to localized experiences, coping practices, and support needs, thus directly aligning with and justifying the research questions and objectives of the current study.

In conclusion, the reviewed literature consistently highlights the significant psychosocial challenges faced by parents of children with epilepsy, including emotional distress, societal stigma, financial strain, and limited support systems across global, African, and Ethiopian contexts. While studies from high-income countries emphasize formal support and medical systems, those from Africa, including Ethiopia, show a reliance on informal coping strategies such as spiritual practices and community networks. However, most existing research lacks an in-depth, contextual understanding of parents' lived experiences, particularly in semi-urban Ethiopian settings. Specifically, there is limited qualitative evidence on how parents in Adama City navigate these challenges and adopt coping mechanisms. This gap underlines the need for the present study, which seeks to explore the psychosocial struggles and coping strategies of parents of children with epilepsy within the unique socio-cultural and healthcare context of Adama City.

Chapter Three

Research Methods and Procedure

3.1 Introduction

This chapter provides a comprehensive discussion about the research methods employed in this study. The research design and research approach used will be discussed in detail for a better understanding of how the research is conducted. Furthermore, major topics such as the description of the study area, target population, sample size, and sampling techniques, methods of data collection, data collection procedures, methods of data analysis and interpretation, as well as an explanation about ethical issues were included.

3.2 Research Design

The researcher applied a qualitative method to explore and understand the meaning individuals or groups ascribe to social or human experiences and emotions (Creswell, 2014). The phenomenological method was specifically chosen to deeply understand the lived experiences of participants by focusing on their subjective interpretations of reality. This method has enabled the researcher to collect detailed accounts about parents' psychological challenges, social challenges, and coping strategies they have applied to reduce the impact of the problem. Thus, the design facilitated a detailed exploration of selected parents of how their life is affected by their caregiving experiences.

3.3 Description of Study Area

The study is conducted in Adama city located in the East Shewa Zone, 99 km southeast of Addis Ababa. According to the Central Statistics Agency of Ethiopia (CSA), the total population of the city is 220,212, an increase of 72.25% over the population recorded in the 1994 census, of whom 108,872 are men and 111,340 women.

3.4 Rationale of Site Selection

Firstly, in Adama City, there is the Association of People with Disabilities, in which parents of children with epilepsy are members. Therefore, the availability of the participants is the first rationale for selecting the site. Secondly, the researcher has communicated with the Adama City Labor and Social Affairs (LSA) Office to discuss the situation of children with epilepsy and their parents. Particularly, the researcher raised the issue of services given to children with epilepsy and whether there are interventions designed to support their parents. According to their response, some non-governmental organizations are working on disability

prevention and rehabilitation. However, there are no interventions planned to support parents of children with epilepsy in Adama City. Moreover, the researcher has been asked by the officials from the labor and social affairs officials and the leaders of the association of people with disabilities if there are any studies on the psychosocial problems of parents of children with epilepsy. Based on their response, no research has been done in this area; thus, the unavailability of studies focused on this specific city has driven the researcher to study in this area.

3.5 Study Population

The total members of the Association of People with Disabilities is 113 (Male 72 and Female 41). Of which 42 (Male 29 and Female 13) are members whose children have epilepsy. The study population is 14 parents (11 mothers and 3 fathers) of children with epilepsy, considering the theoretical saturation. Their children are aged eight - eighteen years old and were clinically diagnosed with epilepsy. Participants were selected from one local organization called Adama City People with Disabilities Association, where parents of children with epilepsy are the members. As noted in similar studies by Fekadu et al. (2021), the study has included parents from different socioeconomic backgrounds, as it was critical to capture the full range of caregiving experiences. This study targeted parents who are primary caregivers and directly involved in taking care of the child with epilepsy. The selection was intentional as they are key to providing meaningful insights into the psychosocial challenges under investigation.

3.6 Sample and Sampling Technique

In qualitative studies the sample size of the population is often determined based on theoretical saturation (the point in data collection where new data no longer bring additional insights to the research questions) (Englander, 2012), As a result, the purposive sampling method was used as small and focused sample sizes are typical in qualitative studies. They allow for deep, context-rich exploration of the participants' lived experiences (Vasileiou et al., 2018). As a sampling technique following inclusion criteria were stated by the researcher. (a) Parents who identified themselves as primary caregivers of the child, (b) parents of children with Epilepsy whose children's age is between eight-eighteen. This age group of eight to eighteen years was settled to narrow the focus of the study and to decrease the variance that is likely to occur with a wide age range (c) parents closely involved in providing in day-to-day care of the child with epilepsy, (d) Parents who consented to be interviewed with an audio tape

and could speak and understand the Amharic language. This sampling approach aligns with recommendations by Guest et al. (2006) for qualitative studies aiming to achieve data saturation while maintaining methodological rigor.

3.7 Data Collection Methods

Semi-structured interviews and Focus Group Discussions (FGD) were used to collect the data from the participants. Using both methods with the same target group enriched the quality, depth, and trustworthiness of the data. It allowed the researcher to explore both individual realities and social constructions, a key strength in qualitative research, especially in psychosocial studies. This study employed a semi-structured interview format with open-ended questions as a flexible and appropriate tool within the phenomenological approach. Semi-structured interviews are commonly used in phenomenological studies because they allow the researcher to guide the conversation around key research themes, while still giving participants the freedom to express their experiences in their own words and depth (Bevan, 2014).

3.7.1 Semi-Structured Interview

A total of 14 parents were interviewed, with 60-80 minutes for each participant. The interview was conducted in Amharic as it was chosen by the participants before starting the interview. As highlighted by Kvale (2007), semi-structured interviews provide the ideal balance between consistency across participants and flexibility to explore exceptional experiences. The interview guide focused on three key thematic areas: (1) psychological challenges, (2) social challenges, and (3) coping strategies that parents used to mitigate the challenges they are facing. As described by Seidman (2019), the exploratory questions were used to stimulate detailed narratives, to obtain rich, contextualized data. The interviews were conducted in the private settings chosen by the participants to ensure confidentiality. All interviews were audio-recorded with participant consent. Anonymity was guaranteed to allow the participants to freely express their views.

3.7.2 Focus Group Discussion FGD

The second data collection method was Focus Group Discussion (FGDs). The researcher conducted two focus group discussions with seven participants each (the same 14 participants who participated in the in-depth interview). A focus group discussion was conducted to collect basic information from parents to gain deeper insights into participants' thoughts, feelings, attitudes, and experiences. The researcher also validated the information that

was collected from semi-structured interviews. The discussions were also guided by the researcher to explore social norms, shared experiences, and group dynamics.

3.8 Data Collection Procedure

The above methods of data collection tools were systematically administered by the researcher. Primarily, participants were informed about the study through their organization. They were informed about the importance of the study, particularly in identifying and exposing psychosocial problems they are facing. The initial contact was made with participants to obtain their consent to participate in the study. Then, each participants were contacted by the researcher through a telephone call with the aid of the OPD to schedule a meeting at their own time and convenience. During the interviews, parents were requested to give detailed descriptions of their psychosocial problems and coping strategies related to the issues in question. The interviews and FGDs were conducted in the Amharic language and digitally recorded to analyze the data. For FGDs, the parents were directed to discuss their interviews, and FGDs were transcribed verbatim and translated into the English language. The researcher also reviewed the transcribed data to ensure that all the details of the interview were captured accurately.

3.9 Data Analysis and Interpretation

The researcher has followed the four steps to analyze the data: (a) familiarization with the data, (b) generating initial codes and searching for themes, (c) reviewing themes, and (d) defining and naming themes. First, each transcript was read and reread to classify main quotes and phrases within each transcript. The researcher then proceeded to make notes from the transcripts and documented similar quotes and phrases. These notes represent a description of the study participants' experiences and the researchers' interpretation of the transcripts. Second, coding was performed by labeling and organizing the transcribed data in a manner that allowed for the identification of major themes emerging from the participants' responses and the relationships between them. Third, the coded data falling into similar or related topics were grouped to form the following major themes: psychological challenges, social challenges, and coping mechanisms. Finally, these themes were named and refined, and a thematic network was developed to summarize the key findings. Under each of these main themes, subthemes were also identified to reflect the different dimensions of the parents' experiences and coping strategies.

3.10 Ethical Considerations

The researcher obtained a formal letter of permission from the School of Psychology, Addis Ababa University. This letter was submitted to the Adama City People with Disabilities Association. Participants were requested to sign a consent form before the interview sessions. The consent form described the nature of the study. The form also indicated the voluntary nature of the study to participants and their right to withdraw from the study at any time without any consequence. To ensure confidentiality and anonymity, the researcher created pseudonyms for participants, and this was applied throughout the study. Moreover, permission was taken for the interviews to be audiotaped. Participants were informed that no payment would be given for participating in the study.

Chapter Four

Findings and Discussions

4.1 Findings

4.1.1 Introduction

This chapter presents the findings of the study on the psychosocial challenges and coping mechanisms of parents of children with epilepsy in Adama City. It presents three key themes: psychological problems, social challenges, and coping mechanisms among caregivers. The findings are supported by direct participant quotes, providing an in-depth understanding of their lived experiences.

4.1.2 Demographic data of participants

Table 1

Demographic Data of Participants

Code	Parents name	Current age of the child	Sex	Parents' educational level	Parents' occupation
1	Mother (Zinash)	11	F	Grade 5	House wife
2	Mother (Alemitu)	16	F	Grade 11	KG teacher
3	Mother (Shewaye)	18	M	Grade 10	Merchant
4	Mother (Genet)	8	F	Grade 6	Housewife
5	Mother (Sifen)	12	M	Diploma	Housewife
6	Father (Dejene)	13	M	Grade 9	Shopkeeper
7	Father (Teshome)	12	F	Grade 6	Guard
8	Mother (Fozia)	10	F	Diploma	Teacher
9	Mother (Tsehay)	13	F	Grade 11	Pity trade
10	Mother (Derartu)	9	M	Grade 4	House wife
11	Father (Sheleme)	8	M	Degree	Accountant
12	Mother (Nejat)	16	F	Grade 10	Janitor
13	Mother (Muna)	17	M	Certificate	House wife
14	Mother (Tsehay)	9	F	Grade 4	Merchant

Table 2

Major Themes and Subthemes

	Major Themes	Sub-themes
1	Psychological Problem	• Stress • Self-blame • Loneliness • Marital-related problems • Depression • Anxiety
2.	Social Problems	• Isolation from Friends/Relatives • Parents' Emotional Withdrawal • Stress on marriage • The burden of childcare • Challenges to the family • Lack of knowledge about epilepsy
3	Coping Mechanisms	• Institutional and professional support • Social support • Religion support • Self-support through training oneself • Commitment • Resilience and Acceptance

4.1.3 Psychological Challenges Faced by Parents of Children with Epilepsy

4.1.3.1 Stress. Parents of children with epilepsy experience constant stress as their children's seizures can occur unexpectedly. They also need to be watchful as the seizures can happen at any time and any place. Financial constraints also exacerbate their worries, as they involve regular hospital visits, the cost of anti-epileptic medicine, and emergency care whenever an injury occurs. Parents fear that their child might get hurt while the seizure occurs; they worry if their children fall in dangerous places like drowning in the water, fall near fire, or in rocky areas. Handling both work and caring for the child is extremely challenging; these parents have

never-ending demands, and they are emotionally and physically exhausted. Their daily activity is stressful as they constantly watch their children to identify the warning signs of seizure. Their sleep suffers too, as parents worry that the seizure can occur in the middle of the night. The stress affects their overall health. They report stress-related health problems such as nausea, headaches, constant tiredness, and weight loss.

As one of the participants described in an interview:

> I always live in fear and worry. I ask myself what my child falls when I'm not with her. I always worry she might fall into the water or fire and get seriously injured while the seizure occurs. Our toilet is traditional and has a wide hole. I always go with her to the toilet in fear of the hole. The school situation is very similar, it is rocky and hazardous for students like mine. I always tell her not to play in school. I also told her to pee every morning at home before going to school so that she would not have to go to the school's toilet. In addition, the anti-epileptic drugs are very costly. I should compromise, including the cost of our necessities. The drug must be purchased every month; however, there are times we can't buy, knowing that the seizure immediately occurs. (Participant 1, personal communication, February 25, 2025)

Another participant reflected in an interview:

> I have a small shop. For every sale, I should be attentive. But my mind has never been with me since my child's diagnosis. When I sell, I always make mistakes. Sadly, even people who know about my situation don't hesitate to cheat me. Sometimes I wish he had another illness that would not affect the whole family. His mother is stressed that she cannot meet the needs of other children. If his mom and I heard a noise from outside, we would immediately run, even if the child is at home. We have associated every problem with the child. Calling from school especially frightened me. I do not listen to what they are saying, as I am sure he has fallen. I immediately close my shop and rush to him. My income is decreasing, yet the monthly anti-epileptic cost is increasing. Besides, there are times when the drug is unavailable, which increases our stress. This time, his mother or I should go to Addis Ababa, where the transport and accommodation costs will be much higher than the drug cost.
>
> (Participant 6, personal communication, February 25, 2025)

According to the respondents, epilepsy creates consistent stress on parents. As shown by

Participant 1 and Participant 6, they experienced constant worries about their child's well-being, especially when the children were out of their sight.

In the words of a participant from FGD 1, “Our stress increases as unpredictable seizures can occur at school. This fear disrupts our day-to-day life in the workplace. We always imagine the child might fall on places that can harm them” (Participant 8, personal communication, March 4, 2025)

Due to a lack of proper support in the area, parents face significant challenges in addressing the child's broader needs. Parents usually stretched to fill the gap created due to their child. They worry about next month's medication, as the cost of the medication is very high compared to their income. Other parents in the study reported similar challenges. They feel constant worries about their child's health and financial constraints for anti-epileptic drugs and treatment. Parents usually experience never-ending emotional and physical exhaustion due to the additional burden resulting from their children's conditions.

4.1.3.2 Self-blame. Parents consider themselves responsible for their child's epilepsy. They believe it is because of their sin that their child has epilepsy. This feeling will not go away even after they have received counseling from a health professional. They always ask themselves, "Why me? What did I do? What was my sin?" Some feel guilty for having a child, thinking they shouldn't establish a family. Others blamed themselves as they couldn’t prevent it from happening. Thus, they always associate the condition with their failure and weakness. Living with constant blame on oneself, family, and health professionals increases their emotional pain and suffering.

During the interview, one participant expressed deep emotional pain regarding her child’s condition:

> I have heard people saying that epilepsy comes from curses of wrongdoing (She is crying and covering her face with a scarf). I have been searching for my fault since her diagnosis. However, I can't find one from my side. Maybe her father may have done something wrong that made God upset. Since we knew the condition, I've been constantly fasting and praying. We have also visited various religious places for holy water. But we have not seen any change that completely stops the seizure. When I see my child having seizures, I feel as if God is punishing me through her suffering. These thoughts have hurt me a lot, even if the doctors told me that I can’t be blamed for the

condition.

(Participant 4, personal communication, February 14, 2025)

Another participant in the interview has also mentioned:

> I always remember the day. When he asked me to play outside. Soon, people brought him unconscious. I still curse that day. I also blame myself for letting him play outside. I am the reason. I could tell him to stay home. He couldn't be like this. Every seizure reminds me of the day and the mistake I made.
>
> (Participant 7, personal communication, February 15, 2025)

As shown by (Participant 4 and 7), self-blame is very common among parents of children with epilepsy. This feeling led to constant pain that lasted for a long time. Others blame themselves for the decision they have made. As one of the participants stated on the FGD 2, “I always blame myself, I say I shouldn’t have a child. I also blame health professionals for not having a healthy child”. (Participant 12, personal communication, March 5, 2025)

Another respondent from the FGD 2 also mentioned that “blaming ourselves has not brought any change except wasting energy and time. As a parent, we need to fight discriminatory attitudes and advocate for the rights of our children”. (Participant 9, personal communication, March 5, 2025)

The feeling of blaming oneself will not go away even after medical assurance that they are not accountable for their children's health condition. Even though it is not always the case, most parents do not understand that this feeling prevents them from focusing on a possible solution that can help both the child and the parents. As a researcher, I have observed this feeling in six respondents.

4.1.3.3 Loneliness. Since there is a deep understanding that epilepsy is contagious, most people are not willing to establish a relationship with the parents of children with epilepsy. Children also suffer at school and in the village due to stigma and discrimination. Often, parents face considerable challenges in establishing a relationship. They struggle with deep loneliness as their relatives and friends distance themselves, fearing the condition can be transmitted to them and their children. Besides, caring for the children takes more energy and time, which negatively affects the needs of parents to establish relationships with others. Misconceptions about epilepsy are the major causes for parents to be misunderstood and unaccepted. They experience day-to-

day challenges due to social exclusion as they do not get emotional support from the people around them.

As one of the participants in an interview described:

> Nobody wants to come to our home. It is our tradition to invite neighbors during the holidays. However, no one comes, including my relatives and religious leaders. When my child and I pass through the village, I see people whispering. Maybe they are saying a bad thing about me and my child. I can't take my child to anyone's home. They started hiding their children in the backyard. Now, I have decided to be alone. I don't go anywhere, and nobody comes to my home.
>
> (Participant 5, personal communication, February 14, 2025)

One participant also described the experiences as follows:

> Whenever I meet people, I try to teach them that epilepsy is not contagious. But people do not listen. The health extension workers once came to the village and taught the community about epilepsy. However, I have not seen that much change. They still exclude me from various community engagements, including Idir, Equip, and other religious events. The discrimination that I have seen against my child is more painful. When the seizure occurs, the students and the teachers will leave her alone until she becomes conscious. When I arrived at school, I usually met her in an empty class separated from other students (Started crying).
>
> (Participant 12, personal communication, February 21, 2025)

Loneliness is the most common experience among the ten interviewed parents. As a participant stated on the FGD 2, "Loneliness is the most painful experience to me. I was recently diagnosed with depression. I think loneliness is the major reason for my sickness." (Participant 10, personal communication, March 5, 2025)

In most cases, the parents experienced a sense of helplessness as they are the ones carrying the burden on their shoulders, and nobody is willing to help. They lack emotional support due to the negative perception from the community.

As one mother also mentioned in the FGDs 2:

> We live in a community where our emotional connection is very strong. However, we are excluded just because we have a child with epilepsy. This is painful to me and my husband. We always have the feeling of being unwanted by the situation, and we are not

accountable.

(Participant 11, personal communication, March 5, 2025)

From the two FGDs, six respondents (Respondents 3, 6, 8, 9, and 12) have reflected that they have experienced loneliness due to the stigma from the community.

4.1.3.4 Marital-Related Problems. Having a child with epilepsy can affect the marriage. These parents experience high stress levels due to certain responsibilities, including medical follow-up, caring during seizures, and managing social stigma and discrimination. When these commitments are not kept, they affect the relationship and lead to marital problems. Lack of a supportive social system is another problem that most parents do not get the professional and religious support that can ease the burden. In some cases, some parents blame each other for having a child with epilepsy. The responsibility of taking care of the child will fall on one partner and cause physical and emotional strain. The financial burden for medicine, treatment, and other epilepsy related costs also causes strong tension between spouses.

As one of the participants reflected:

> My husband left me when my child was 7 years old. He used to complain that I was the cause of the problem. He was complaining that it was a mistake to marry me. One day, we went to my relatives to take part in one of my relatives' wedding ceremonies. There, he heard that one of our close relatives has epilepsy. When we came back to Adama, he told me that he doesn't want to live with me. I told his family and religious leaders. However, they told me that he has made a good decision. Now, I live alone with my daughter, thanks God, I sell vegetables on the street. When she is fine, she helps me sell things after school. The doctors have confirmed to me that her epilepsy is not severe."
>
> (Participant 9, personal communication, February 20, 2025)

As one interviewee shared:

> I have never been at peace with my wife. She always complains as if the whole burden is on her shoulders. A year ago, I left her and started living alone. It is because of her brother that we settled our quarrel and started living together. From my side, I never tired. In my profession, I'm an accountant. In my part-time work, I work for three organizations to ease the financial burden. From her side, she has never done anything except cry. She doesn't value the contribution I make to the family. I am tired of living with her. I don't think our marriage will survive anymore.

(Participant 11, personal communication, February 21, 2025)

As demonstrated by Participants 9 and Participant 11, raising a child with epilepsy can lead to marital problems. Parents experience consistent stress due to the financial constraints, caring responsibilities, and social isolation from relatives, friends, and neighbors. This situation usually leads to misunderstandings among couples that put the marriage in danger.

Participant 9 can be a good example of how cultural misconceptions can affect a marital relationship. It shows how community and religious leaders negatively affect her marriage. As the other mother stated in an interview:

> It is his family that caused my marriage to be divorced. He was a good person. However, his family repeatedly told him that he would have a chance to have another child with the same problem. He finally left me alone. Now it has been two years since I saw him.
>
> (Participant 2, personal communication, February 13, 2025)

Another mother from FGDs also mentioned:

> In most cases, our husbands support us, but in some cases, they prefer to leave and establish another family. In this case, the legal system will not support us adequately. The whole burden falls on us, which intensifies our emotional problem.
>
> (Participant 12, personal communication, February 21, 2025)

In a family where parents do not share the caring burden equally, there is a conflict due to the stress on one side. These spouses are more likely to be separated as their relationship gradually erodes. These incidents are common among other respondents; they report similar challenges in their marriages. Lack of social support is another factor that leaves parents to cope with the challenges alone. Most of the findings indicate that mothers bear the burden of childcare after a marriage breakdown. These caused single mother to live under consistent pressure that affects their well-being.

4.1.3.5 Depression. Most parents of children with epilepsy experience deep depression due to constant stress and helplessness. These parents expected to provide endless care and protection for their children with epilepsy. Most of them are also emotionally exhausted and hopeless. They also have a feeling of inadequacy as a parent because they can't stop the seizure and make their child free. Some even think of making suicide as their effort is worthless in many ways.

The financial burden is unbearable to most parents. They are expected to buy the anti- epileptic drug every month. There are also times when parents can't find the drug in Adama City. Thus, they may need to pay double the price. Stigma and discrimination are also another factor that leads parents to depression. Relatives and friends might not be willing to share the burden. Parents with depression have a hard time effectively managing their emotions and providing adequate support to their children and other family members. Most of these parents will make maximum effort to hide their pain, and crying is the only solution to ease their pain. In most cases, due to the lack of professional help, their pain continues silently.

During the interview, as one of the participants described:

> I don’t want to wake up in the morning. There is no difference between morning and night to me. In my life, there are no new things. Because I am still unable to change my child's situation. I am still the mother of the child with epilepsy. The community despises me as if I am worthless, that is way nobody comes to my home. I have told God to forgive me if the problem is caused by my sin. However, nothing has changed. I cannot understand the meaning of life. I’m getting tired of pretending to be strong. Deep inside, I’m broken and helpless.
>
> (Participant 13, personal communication, February 22, 2025)

As another mother also shared:

> The doctors told me that I’m depressed. I lost what I had due to my child. I have gone to different places in search of a cure for my child. Not only to the health professionals. I have also gone to witchcrafts and religious places. I have sold every property, including the house I inherited from my parents. Now, I am in the position where I can't buy medicine for my child. What I am seeing now is dark. I want to disappear. But I worry who is going to take care of my child. The antidepressant drug I am taking is very bad. I can't sleep since I started taking it.

(Participant 10, personal communication, February 20, 2025)

As stated above, parents face significant challenges that cause them to develop depression. Like Participant 13 and Participant 10, the other two parents (Participant 5 and Participant 12) have indicated that they have similar experiences with depression. They feel pressured as they need to fulfill the needs of their child and maintain their health amidst all these adversities.

As one of the mothers described in the FDG 1, "Most parents here, including myself, have felt deep sadness and even depression. It's not just the illness, it's the loneliness and exhaustion that come with it." (Participant 10, personal communication, March 04, 2025)

Parents feel desperate as they cannot help their child to be cured. These parents do not want to expose their mental status to protect their children. Thus, they prefer suffering in silence.

4.1.3.6 Anxiety. Parents of children with epilepsy lead a life full of fear and worry due to the unexpected nature of seizures. It makes them wait for the next emergency that prevents them from relaxed life. They also struggle to ensure the next month's medication is available. Particularly for low-income families, the availability of anti-epileptic medication is uncertain. There are times when parents cannot provide the medication and see their children with constant seizures. This is the most painful experience for parents. Parents also fear social stigma when their child's seizure occurs in public areas. This never-ending fear and worry cause them to live in constant fear and anxiety. They lose confidence to do things and show anxiety symptoms like shaking body, sweating, and stuttering when they communicate with others. Especially in areas where mental health care services are limited, parents suffer anxiety alone and might need more support than the child with epilepsy.

As one mother emotionally conveyed:

> I have never had peace since she was diagnosed. Whenever I heard people shout, it was my child falling. I see my phone now and then. I repeatedly call to school to ask about my daughter. The teacher complained so many times. They said they would call if there was any problem. But in my mind, I always see her fall and get hurt. That is something that I cannot avoid.
>
> (Participant 8, personal communication, February 19, 2025)

One participant shared an emotional experience, stating:

> I have planned to close the shop because I am not paying the shop rent properly. What worries me most is the cost of medicine. My wife left her job a year ago to look after the child and his siblings. The financial burden is so severe that it cannot be handled by my income. I don't know what must be done. I went to one of the NGOs in our kebele. They told me that they do not support children with epilepsy. I know what it means to miss one medication. I don't want to see my child suffer. When his mother tells me that the medicine is running out, my hands begin shaking due to the constant fears and worry. I ask myself where I can get the money.
>
> (Participants 6, personal communication. February 15, 2025)

Participants 2, 4, 5. 6, 9, 10 and 12 of children with epilepsy share similar life experiences. Their life is highly controlled by constant anxiety.

As one participant in the FGD 2 shared her experience:

> There is a rope that I tied from my child's leg to mine. I always fear that he might get out at night. Nobody knows this. My life is messed up, as I am in constant fear that something bad will happen to my child.
>
> (Participant 14, personal communication, March 05, 2025)

As one participant reflected on their worry in an interview:

> The doctors told me what kinds of food I should provide to my child. But they don't know that there are times I don't have money to buy medicine. I am ready to give the child to Mekedonia if they are willing.
>
> (Participant 4, personal communication, February 14, 2025)

Another mother in the FGD 1 mentioned*, "*Due to the emotional and financial burden, I have started forgetting things. I don't do things properly. Maybe I need to go to a mental health hospital*."* (Participant 9, personal communication, February 15, 2025)

The majority of parents interviewed are financially insecure due to low income and epilepsy related expenses. They struggle to cover the monthly medicine cost. The medicine is becoming very costly. Especially the cost from the private pharmacy is unbearable. Besides, social isolation is another challenge; parents' afraid to socialize and take part in public events. They thought people were talking about them, which intensified their anxiety. The FGDs have exhibited that this anxiety is very common among most parents.

4.1.4 Social Challenges Faced by Parents of Children with Epilepsy

4.1.4.1 Isolation from Friends and Relatives. Parents reported being abandoned because of their child's epilepsy. Relatives and friends will no longer be willing to have a relationship with them due to their negative perception that epilepsy is contagious. They also believe that epilepsy is the result of a curse for wrong wrongdoings of parents. The majority of parents reported that they are not invited to take part in many social events such as weddings, graduations, community activities, or even religious gatherings. This creates the feeling of being unwanted and rejected.

One participant conveyed their sense of isolation, stating:

> It has been a long time since I've seen people visiting us. Other children ask me why people are not coming to our home. I have no answer for this question because I don't want to insert bad things into my children's minds. However, I know that it's because of my child.
>
> (Participant 5, personal communication, February 14, 2025)

During the interview, a participant expresses the dual burden of loneliness and rejection:

> Nobody comes to my home. I have accepted this, and now I do not expect others to come to my home. What makes me wonder is that most people do not want me to go to their home. Especially if I go to them with my child. They start hiding their children as if the epilepsy is contagious. The community is far behind in terms of understanding what causes epilepsy. They even think that epileptic children are possessed by an evil spirit.
>
> (Participant 12, personal communication, February 21, 2025)

As it is described by one of the respondents in a FGD 2, "It's common among us to avoid public places. The fear of a seizure happening in front of others and being judged or stared at, it's something every parent here has experienced."(Participant 14, personal communication, March 05, 2025)

One participant in the FGD 1 has also mentioned about the stigma he experienced, "In all of our neighborhoods, people still believe epilepsy is contagious or caused by evil spirits. This ignorance isolates not just our children, but our families too."(Participant 5, personal communication, March 04, 2025)

The accounts of the two Participants, 5 and 12, reveal how epilepsy is associated with

stigma and discrimination in the study area. Both Participants explained that the community is shunned due to wrong beliefs that epilepsy is the indicator that the child is possessed by an evil spirit that can pass from child to child. In a collectivist society, where social bonds are vital to survive, parents of children with epilepsy experience severe loneliness due to societal rejection, with the unbearable burden of taking care of their child with epilepsy. As mentioned in the FGDs, parents mentioned that the isolation carries severe consequences. It drained the support systems during immense caregiving burdens. As one participant stated in the FGD 1, “Due to the social stigma, the relationship we have with our relatives and friends is interrupted.” (Participant 7, personal communication, March 4, 2025)

4.1.4.2 Parents' Emotional Withdrawal. Stigma and discrimination have a long-term effect as they cause parents to pull themselves out of social interaction. This resulted in deep pain, especially in Ethiopian culture, where community connection is very strong. Parents feel discomfort when people stare at them and whisper behind their backs. This makes most parents stop taking part in social activities such as the coffee ceremony and other religious events. Even though consistent isolation helps parents not to face hurtful words and actions, it leads them to painful loneliness, which can lead to mental distress.

One participant expressed emotional isolation, stating:

> When I go to different social gatherings, people try to show me their empathy because I have a child with epilepsy. If they were thinking about me, they would come to my home and try to ease my burden. Now I have decided to stay home even if I feel lonely. (Participant 13, personal communication, February 22, 2025)

Describing the emotional pain of social stigma, one parent shared:

> Before my child was diagnosed with epilepsy, I was sociable and I had too many friends. Now, none of them visit me. They do not call, and they don’t even greet me well when I meet them in church and other events. I tried to maintain my relationship with my family and friends. However, the rejection I have experienced is very painful. Now, I have accepted the rejection and decided to live alone, whatever the cost is. (Participant 10, personal communication, February 20, 2025)

The story of Participant 13 and Participant 10 shows how stigma resulted in parents being emotionally withdrawn. Both parents have avoided social interaction due to the community judgment and negative perceptions about their children. When parents withdraw,

they are not only losing the friendship, but they are also losing the emotional support they can get from their relatives and friends. Weak community support causes parents' stress to increase, which leads to severe mental illness.

4.1.4.3 Stress on Marriage. Life is very stressful for parents of children with epilepsy. Unpredictable seizures are one of the major sources of stress for parents. Especially when the seizure is frequent, the tension will be higher, which makes parents weaker in controlling their emotions. They also face financial burdens as they are expected to cover treatment, medicine, and other related expenses every month. These create constant worry between husbands and wives. In the study area's context, most fathers expected to fulfill the responsibility of covering the cost for treatment and medicine, while mothers are expected to give care for the child. Due to addressing their role, they may not provide emotional support to each other, which leads to conflict and misunderstanding.

In addition, epilepsy is highly associated with traditional and religious thoughts. Fathers usually blame their wives for having a child with epilepsy. Therefore, they may leave their wives. Having another person with epilepsy in the family intensifies the situation as they are thought to be cursed for their sin.

One participant described how their child's condition severely affected their marriage:

> My husband told me that he doesn't want to live with me. He always associates the problem with me. Last time, he gathered some religious leaders from the Mosque. In front of them, he requested me if there was any sin I had committed before our marriage. The people gathered also told me that they will pray to Allah to forgive me. However, I can't remember any sin that can make my child have epilepsy.
>
> (Participant 12, personal communication, February 21, 2025)

Reflecting on the strain within their marriage, a parent shared:

> I always try to address the financial burden of the family. Therefore, I have engaged in other side jobs that keep me late at night. My wife thought that I was doing this to flee the stress. Due to this, we are fighting consistently. I don't think I would live with her like this.
>
> (Participant 11, personal communication, February 21, 2025)
>
> Epilepsy can cause parental destruction if parents are not in a position to handle their emotions. As one of the participants described on the FGD 2," When my husband left

> the home, I had to start selling charcoal on the street, leaving the child alone at home. There were days I did not eat to save money for my child's medicine." (Participant 9, personal communication, March 05, 2025)

4.1.4.4 The Burden of Childcare. In Ethiopia, the responsibility of taking care of a child often falls on mothers. Fathers are breadwinners who struggle to address the broader needs of the family. However, providing adequate care to the child with epilepsy is very challenging for these mothers. Mothers ensure that no injury occurs during a seizure. The need to make sure the house is clear of things that can hurt the child. They are also responsible for making the child emotionally stable to reduce the occurrence of seizures. Besides, they follow that the child is taking the drug properly. For most mothers, not giving adequate attention to the child is very dangerous. Such events may lead to additional costs and caregiving burden. Husbands may not clearly understand the burden; thus, they do not emotionally support their wives. The endless responsibility leads to a physical and emotional drain that affects the quality of care and support given to the child.

Highlighting the overwhelming nature of their burdens, one parent stated:

> I should always be standing by. Especially when she is upset and emotionally disturbed, I usually stand next to her to protect her from falling. I never have a good sleep. I had to listen to her if the seizure occurred at night. I had to lay her in the proper position to prevent her from choking. I have a job with a good salary. I stopped working because she needs intensive follow-up and care. I have to work hard day and night. Making a small mistake can cost you a lot when you have a child with epilepsy. Since her diagnosis, I have never associated with people outside. I don’t know how long these things have been happening.
>
> (Participant 1, personal communication, February 13, 2025)

A parent states about the mental and physical toll of childcare, noting:

> I am a teacher. I was one of the best teachers at the school. Now, I have started forgetting. I even forgot minor things due to the pressure I went through. I went to a mental hospital twice last year. They told me it is depression. Every day I have to go to my child’s school, some 30 minutes’ walk from where I teach. When I have a call from school, I never even ask what happened; instead, I run. It has become my routine responsibility. I am afraid of thinking about what will happen if I die.

(Participant 8, personal communication, February 19, 2025)

The experiences of Participants 1 and 8 reveal how parents bear the responsibility of caring for their children. They live in consistent uncertainty, fear, and unrest due to the heavy burden of taking care of the child. Participants from FGD 2 have also revealed that "Most of us feel overwhelmed and helpless when the seizures happen. It's like watching your child suffer and being unable to stop it, it breaks all of us inside." (Participant 8, personal communication, March 5, 2025). Issues concerning nutrition, medication, hospital visits, and injury prevention are a day-to-day work that needs continuous curiosity.

4.1.4.5 Challenges to the Family. When a child has epilepsy, it may put the family's well-being at risk. Parents may compromise the other children's needs for the sake of addressing the burden of the child with epilepsy. This may affect the family unity and lead to division that disrupting the emotional support that can be given to each other. Relatives distance themselves due to misconceptions such as that epilepsy is contagious, it happens due to a curse on parents or ancestors, and children with epilepsy is possessed by an evil spirit. Most households fracture under this pressure, leaving parents to cope alone in a society where family support is essential for survival.

A parent conveyed the challenge of meeting every child's needs, stating:

> His brothers and sisters do not understand why more attention is given to him. I always do what he asks me because the doctors told me that he should not be frustrated. When I buy something others also need. I cannot address all. Sometimes we may even skip our meals when we don't have enough money to buy medicine. I don't have time to be with my husband. It has been years since I went out with him to visit families and friends.
>
> (Participant 2, personal communication, February 13, 2025)

A participant spoke about the strain on family matters related to children, saying:

> Before my son's diagnosis, my wife and I had a strong family tie with my relatives. We had a gathering program every two months. Now, nobody wants to come to my home. My children always ask me why our relatives are not coming home. I say they are busy. It is embarrassing to be discriminated against for something that you are not accountable for.
>
> (Participant 7, personal communication, February 15, 2025)
>
> In an interview, another participant also described, "I have made my daughter drop out

of school so that she can help her brother as the seizure is still present." (Participant 4, personal communication, February 14, 2025). Parents usually give more attention to the child with epilepsy, which drains the emotional well-being of other children in the family. Lack of extended family support due to the misconception is also another challenge.

4.1.4.6 Lack of Knowledge about Epilepsy. Epilepsy is the most misunderstood health condition that is highly associated with religious and traditional thoughts. In many parts of Ethiopia, the cause of epilepsy is an evil spirit. The child is thought to be possessed by an evil spirit that can be contagious to others. People who are educated also believe in these myths. The religious and community leaders provide information that traditional healers are the only solution to epilepsy. Holy water is also recommended by the religious leaders, as epilepsy is thought to result from an evil spirit. This is the reason that makes it harder to get proper support. Often, the misconception causes the treatment to be delayed and worsen the condition due to a late medication start. Parents are not accessible to the right information due to the limited awareness campaign by the government and other responsible institutions.

A participant described how limited awareness could have worsened the condition, stating:

> To be honest, I didn't take my child to the hospital on time. People from my religion told me that the child is possessed by an evil spirit. Thus, whenever the seizure occurred, I used to pray. I always think that it is because of my prayer that the child returns to normal condition. One day, the health extension worker told me that the condition can be managed with medication. She repeatedly came home to ensure the child was taken to the hospital. However, I didn't take her advice because I didn't believe that medicine could be a solution. I have caused a lot of damage to my child due to my arrogance. Now, my attitude has completely changed.
>
> (Participant 12, personal communication, February 21, 2025)

Reflecting on the consequences of limited awareness, one parent shared:

> I used to strike a match when a seizure occurred. I have done these for about two years. I used to have a match in my pocket every time. However, one day the doctor told me that striking a match is very bad as it affects the child's respiratory system. I cried when I learned this. Now I strongly oppose when people strike a match during a seizure. I am one of the parents who believe medicine is the only solution to control the seizures.
>
> (Participant 11, personal communication, February 21, 2025)

The other participant in an interview also mentioned that:

> I once visited a witch. It was a few months after his diagnosis. The woman gave me some herbs to give to my child. However, the seizures worsened, and the child was hospitalized due to an intestinal issue. I informed the doctors about everything, and they told me that it was the herbs that damaged his intestines.
>
> (Participant 5, personal communication, February 14, 2025)

Another participant in an interview also stated:

> I was told that my child was "switched by demons" at birth. I took him to witchcraft in search of a cure. The witchcraft gave me something to put on fire and smoke. I used to put it on fire and hold the child by covering him with a blanket. However, this local treatment worsens the seizure. Now I feel pain when I remember those days.
>
> (Participant 10, personal communication, February 20, 2025)

During FGD 1 and 2, Participants 3, 6, 7, 9, 11, and 14 mentioned that they have a considerable knowledge gap, as there are no structured institutions that train them to effectively manage their children's health conditions. They have witnessed that a lot of problems occurred due to their lack of knowledge, particularly in the area of medication and managing the behavioral problems of their children.

4.1.5 Coping Mechanisms of Parents of Children with Epilepsy

Parents of children with epilepsy in Ethiopia develop a variety of coping mechanisms to mitigate the negative impact of the condition on their lives. By using these strategies, they try to manage their social, emotional, and financial challenges. Some mechanisms support them while others provide short-lived relief. Even though it is on a different level, they rely on Institutional/professional support, Social support, and religious support, Self-support through training oneself, Commitment, Resilience, and Acceptance.

4.1.5.1 Institutional and Professional Support. Parents who have access to proper medical care are more likely to handle their children’s health conditions. However, in many parts of Ethiopia, medical professionals are more focused on providing medication for the patient. Other crucial supports, such as counseling usually forgotten. This health system ignores the parents' emotional and technical support needs that could help manage their children's epilepsy. Particularly lack of epilepsy management training for parents leaves them dependent on external support. Furthermore, such a condition hinders their potential by only focusing on

the medical aspects of intervention.

One participant describes frustration with what is perceived to be ignorance of parents' need for emotional and technical support, stating:

> I have gone to many hospitals. The doctors do not even give me a chance to talk about my problem. They are always ready to prescribe the drug. Whatever I ask questions, they would say it is common for epileptic children. I want to know why the seizure can't stop. But they don't have ears. I need further support from the doctors as their medicine has not brought the change I desired.
>
> (Participant 8, personal communication, February 19, 2025)

Emphasizing that Doctors show little or no concern for helping parents understand how to manage their child's condition, a parent shared:

> Whenever I go to the clinic, the doctors increase my son's medication. Now I am observing behavioral change. But when I raised the question, the doctor told me that it's not his job to talk about his behavior. I was shocked. What's difficult for me now is his bad behavior. He does not want to eat, frequently quarrels with his brothers, and wakes up in the middle of the night. The health professional does not care about all these things.
>
> (Participant 11, personal communication, February 21, 2025)

The experiences of participants 8 and 11 clearly show how the health professional lacks in providing comprehensive services. They only focused on medication while ignoring the parents' contribution that could have a positive impact on the children's overall development. As it is explained by another participant in FGD 1,

> Health professionals never listen to the questions we raise related to nutrition, medication, and behavioral problems in children. They do not want to listen to the side effects of the drug, and the drugs that their children are taking have not stopped the seizures. They always complain as if the medicine has not been properly given to the children.
>
> (Participant 9, personal communication, March 4, 2025)

4.1.5.2 Social Support for Parents of Children with Epilepsy. In collectivist societies like Ethiopia, social support plays a significant role in mitigating psychological, social, and economic challenges. However, parents of children with epilepsy do not access this support due

to the wrong perception associated with epilepsy. The stigma attached to epilepsy hinders the parents' access to social support.

Relatives, friends, and neighbors distance themselves due to a negative perception, fearing that epilepsy is contagious or a result of a curse. The level of social support is highly limited by the awareness level of the relatives, friends, and neighbors. People with limited information about epilepsy discriminate against the children and parents of children with epilepsy. People with adequate awareness are more likely to be non-judgmental and provide social support that helps parents manage their caregiving-related challenges. In the community where parents do not access relevant social support, the burden will fall on parents, which leads to emotional breakdown and physical exhaustion.

One parent warmly shared their experience of feeling accepted, stating:

> Back of our village, there is a nurse. She is very kind and comforts me whenever we meet. She is also not afraid of my child. She even called her name and hugged her. She is always the same. There are people like her who helped me understand that all people are not the same.
>
> (Participant 12, personal communication, February 21, 2025)

One parent described their experience of feeling truly connected with others in the same condition, stating:

> I have established a friendship with someone whose child has epilepsy. We met at the clinic. We understood each other. He helps me emotionally and financially. When there is no medicine in Adama, one of us goes to Addis Ababa to reduce the financial burden. I wish all people understood me like him.
>
> (Participant 6, personal communication, February 15, 2025)

Another respondent in an interview also described: "Only my younger sister still comes to our home. When I'm overwhelmed, she cooks for us and looks after my child so I can rest. (Participant 3, personal communication, February 13, 2025)

4.1.5.3 Religious Support for Parents of Children with Epilepsy. As a religious society, Ethiopian parents of the child with epilepsy take religion as a major coping mechanism to reduce epilepsy related challenges. They go to mosques or churches to receive spiritual support to maintain their emotional well-being. Most parents apply the religious and medical practices jointly. However, some families believe religion is the only way to avoid the problem.

Religious leaders preach to their followers that epilepsy is the result of demon possession. They teach that holy water and prayer are the only solution. There are very few priests and imams who believe medical interventions help in treating children with epilepsy. However, some religious leaders advise parents not to take their children to the hospital.

As one of the parents described during the interview:

> For about one year, I never took my child to the hospital, I used to take her to religious places for the holy water. I believe the water would cure my child. However, the seizure got worse. One day, the priest who baptized my child told me to take him to the hospital. Since she started the medicine, the seizures have reduced. I have never seen a priest like that. Because no priest advised me to take my child to health institutions. One thing that I am still doing is praying. I pray every day, and it has helped me a lot, especially when I am emotionally disturbed.
>
> (Participant 4, personal communication, February 14, 2025)

A participant explained their perspective on seeking spiritual, rather than medical, intervention for children, noting:

> My Imam always tells me that I should pray to handle the stress. Every Friday after prayer, people come to me and tell me that they are also praying for my child. I think one day the seizure will leave my child. Without Allah's support, the medicine will not work. (Participant 8, personal communication, February 19, 2025)

The accounts of participants 4 and 8 reveal the complex relationship between religious beliefs and medicine in the study area. The majority of religious leaders advise parents of children with epilepsy to take their children to a spiritual place for the holy water and other practices. However, as described in the FGDs, the participants 2, 4, 6, 9, 11, and 12 have shared their experiences that religious and traditional healers are not effective in reducing seizures or curing the child. However, they described that prayer and sharing burdens with God have supported the parents to reduce the stress and frustration, especially during loneliness and financial constraints.

Another participant in an interview also described how she was influenced to stop giving the anti-epileptic drug to the child and depend only on the holy water for years. "I made this mistake because of the priests. I didn't take her to the hospital for about a year, and she had frequent seizures. The religious leaders should learn about epilepsy." (Participant 9, personal

communication, February 20, 2025)

During the interview, another participant also mentioned the challenges faced from the relatives, “I have taken my child to different religious and traditional healers; however, it is the medicine that helps me reduce the seizures. Of course, the religious practices I am doing in church have helped me to accept the condition.” (Participant 10, personal communication, February 20, 2025)

4.1.5.4 Self-Support through Training for Parents of Children with Epilepsy. Most parents of children with disabilities lack resources due to epilepsy related expenses such as treatment, medicine, and epilepsy induced injuries. As a result, parents do not have enough money to learn about epilepsy management and other skills to properly manage epilepsy. Most often, parents of children do not get training or advice on how they can handle the pressure related to caregiving for their children. Thus, they are highly reliant on teaching themselves through personal experience and challenges.

Parents do not get training or information in a structured manner in the hospitals or health centers. The information they get from health professionals is highly dependent on the interest of the practitioner. Some health workers teach parents how they can provide first aid during a seizure, while others are only concerned about the child and provide medicine. When caregivers teach themselves, they better identify triggers, improve safety measures, and better understand their child's condition. However, the lack of structured training programs means knowledge gaps remain, forcing parents to rely on trial and error. The motivation to self-educate demonstrates remarkable resilience, yet highlights the need for more accessible epilepsy education resources. Emphasizing the role of technical and self-support in managing their condition, a participant states:

A participant described needing practical, behavioral management training over solely medical aid, noting:

> I have gone to the hospital so many times due to unexpected seizure and injury. However, nobody told me what I should do during the seizure. The doctors do not provide adequate information about epilepsy management. They are only concerned about medicine. Besides, I have never been trained on how can manage my children’s behavior. For us, it would be much more valuable if we get training on nutrition, epilepsy medicine, first aid, and behavior management**.**

(Participant 9, personal communication, February 20, 2025)

Emphasizing the role of technical and self-support in managing their condition, a participant states:

> One day, he fell on the stairs during a seizure. Then, I took him to the nearby health center. There, the health practitioner taught me what I should do during a seizure. He told me that the child should lie on one side to prevent choking and to get out the saliva from his mouth. He also told me the signs that the child can show before a seizure. What surprised me is that the doctor who has prescribed the drug didn't tell me anything.
>
> (Participant 3, personal communication, February 13, 2025)

The experiences of participants 9 and 3 reveal the challenges that the majority of parents experience due to the lack of professional help. As participants 4, 6, 9, 10, and 12 revealed, they do not have access to structured training on how to manage epilepsy related problems. As one of the participants in the FGD 1 described, "We got most of our knowledge from many ups and downs. We have made so many mistakes before we teach ourselves. (Participant 1, personal communication, March 4, 2025)

In a resource-limited setting, parents teach themselves through experiences and challenges. There are also health professionals who are willing to teach parents how to protect their children from injury and provide post-seizure care.

4.1.5.5 Commitments of Parents of Children with Epilepsy. Social stigma and financial hardship are a day-to-day experience for most parents of children with epilepsy. In most cases, parents are required to show exceptional commitment to address the needs of their children and maintain their family dynamics. Even though they live under extreme poverty, caregiving-related exhaustion, and discrimination, they prioritize the needs of their child with many sacrifices and commitments. Parents may compromise the family's basic needs, such as clothes, food, and school fees. They also experience being abandoned by their relatives and friends because of their children. They do multiple jobs to mitigate the financial constraints. One parent passionately articulated their dedication to their children's well-being, stating:

> I sold everything I have, and I have even sold my gold to pay for the medicine. Sometimes, the whole family goes to bed without a meal to save money for the child's medicine. I was told to give the child to institutions, but I will never do that. I am

> always ready to make sacrifices for my child. None of us is accountable for the problem that happened.
>
> (Participant 10, personal communication, February 20, 2025)

A parent expressed their unwavering efforts to ensure their child's health, stating:

> I work as a shopkeeper. I am also working as a broker. I try to do everything to cover the medicine expense and other related costs. I try so many things to get money. People do not like me due to my behavior. What they don't know is that I have run away from the financial constraints. I don't want my child to have a seizure. I don't care what people think about me.
>
> (Participant 6, personal communication, February 15, 2025)

As stated by one of the participants in the FGD 2, "From this group, most of us sold our properties for the sake of our children. There are parents who sold their houses and jewelries to help their children get proper treatment." (Participant 14, personal communication, March 5, 2025)

Such sacrifices are common among some parents, including developing depression and other mental health problems. Losing a job to give care is also common among some participants.

4.1.5.6 Resilience and Acceptance among Parents of Children with Epilepsy. For most parents of children with epilepsy, resilience and acceptance are painful due to social discrimination, financial constraints, and emotional distress. Due to consistent pressure and adversities, some parents become stronger and can manage their circumstances. They accept epilepsy as a medical condition that requires long-term treatment and care. They appreciate small progress rather than dwelling in thinking about the problem. This attitudinal shift does not eliminate the challenges but helps them to endure stigma and develop a positive attitude.

A participant shared how they cultivated endurance against stigma and developed an optimistic attitude, stating:

> I had hidden my child in the backyard for many years. Now I am no longer ashamed of my child. When people are confused during a seizure, I will calmly manage the situation and teach people about epilepsy. I tell them it is not contagious. I have also informed the teacher what they must do during a seizure.
>
> (Participant 5, personal communication, February 14, 2025)

Describing their resilience and sanguinity, one participant stated:

> I never wanted to talk about my child's epilepsy for many years. When I quarrel with people, I used to fear that they might insult me by mentioning my child's epilepsy. Now, I am no more afraid. I never feel ashamed of going with my child. I also go to school to check my child's academic status. I will try to help my child as much as I can. (Participant 11, personal communication, February 21, 2025)

Another participant in an interview also mentioned how she became resilient, “Now what others say does not bother me. I feel sorry about the time and energy I lost thinking about my relatives. Now, I have understood how to manage others' feelings without harming myself. (Participant 12, personal communication, February 21, 2025)

4.2. Discussion

4.2.1 Introduction

This chapter presents a comprehensive discussion of the major findings from the study exploring the psychosocial challenges and coping mechanisms of parents of children with epilepsy in Adama City, Ethiopia. The discussion is structured around three central themes that emerged from the analysis: psychological challenges, social challenges, and coping mechanisms. Each theme is interpreted through relevant theoretical frameworks, primarily Family Stress Theory and Social Stigma Theory, and contextualized within existing global, African, and Ethiopian literature. The chapter critically examines how cultural beliefs, healthcare limitations, and social norms interact to shape the lived experiences of caregiving parents in this urban Ethiopian setting.

The findings reveal that parents experience multifaceted psychological burdens, including stress, self-blame, loneliness, depression, and marital strain. Socially, they confront stigma, isolation, and strained family dynamics, compounded by community misconceptions about epilepsy. Despite these challenges, parents draw upon various coping mechanisms, such as religious faith, personal commitment, informal social support, and self-education, to manage the pressures of caregiving. These coping strategies, however, are often shaped by limited resources and sociocultural constraints. The following sections will discuss each theme in detail, comparing the findings with prior research, interpreting them through theoretical lenses, and highlighting implications for practice, policy, and future research.

4.2.2 Discussion of the Psychological Challenges of Parents of Children with Epilepsy

Participants consistently reported high levels of psychological distress due to the unpredictable nature of seizures, financial insecurity, social stigma, and limited support. Stress manifested through constant fear of injury during seizures, disrupted sleep, and emotional exhaustion. Feelings of guilt and self-blame were widespread, often influenced by cultural beliefs linking illness to personal or spiritual failure. Parents also expressed loneliness, particularly due to stigma and community rejection, which in some cases contributed to marital breakdowns and deep depressive episodes. Anxiety over medical expenses, social rejection, and the safety of the child was a persistent theme throughout both individual interviews and focus group discussions.

These findings can be clearly interpreted and explained through the lens of the Family Stress Theory. According to Hill's ABC-X model, the child's diagnosis with epilepsy serves as the primary stressor (A), and when parents lack sufficient emotional, financial, or social resources (B), their subjective perception of the crisis (C) often leads to psychological breakdown or family dysfunction (X). In this study, most participants lacked adequate resources and support systems, which intensified their vulnerability to psychological distress. The emotional toll of caregiving, especially when undertaken by one parent alone (usually the mother), also reveals how resource deficits exacerbate stress.

Furthermore, the Social Stigma Theory (Goffman, 1963) helps explain why participants frequently reported loneliness, shame, and rejection. The stigma of epilepsy in Ethiopian communities, particularly the belief that it is contagious or caused by sin, results in social exclusion, which heightens psychological strain and erodes coping capacities. One mother, for instance, spoke about how neighbors refused to visit her home and teachers left her child alone during seizures. These experiences align with Goffman's notion of a "spoiled identity" and demonstrate how societal labeling can intensify emotional hardship for caregivers.

In terms of study comparison and contrasts, the psychological challenges faced by parents of children with epilepsy in this study, particularly chronic stress, self-blame, loneliness, depression, and anxiety, are well-documented in global literature, though the context of Adama City introduces unique cultural and systemic nuances that deepen these experiences.

Globally, studies have consistently shown that caregiving for a child with epilepsy contributes to increased psychological strain. For instance, Yu et al. (2022) emphasized that the

unpredictability of seizures causes persistent anxiety among parents, especially when they are not physically present to protect their children. Similarly, Dogan et al. (2022) found that caregivers often suffer from sleep disruption, chronic exhaustion, and emotional burnout due to the need for constant vigilance. These findings are strongly reflected in the experiences of parents in Adama City, who described being unable to rest, constantly fearing their children might fall into dangerous situations like open fires or water pits, especially when left unsupervised.

A systematic review of caregiver burdens reported that psychological concerns were most prominent among caregivers in both developed and developing countries, with mental health strains often exacerbated by social and economic factors (Khanna et al., 2025). Similar findings were reported by Hussain (2020), who showed that 64.2% of caregivers of children with epilepsy experience moderate to severe anxiety, compared to 47.9% of adult-epilepsy caregivers. These statistics reflect our findings: participants consistently voiced chronic anxiety over their children's safety, echoing hypervigilance described in Western contexts, but here compounded by a lack of institutional and community support.

However, unlike high-income countries where psychosocial support is often built into medical care, Ethiopian caregivers reported little to no institutional support to manage their emotional burden. While Carter et al. (2022) noted that many caregivers in European countries have access to counseling, peer support groups, and structured psychoeducation programs, the Ethiopian context presents a stark contrast. The absence of mental health services within epilepsy care systems exacerbates feelings of helplessness and isolation, as seen in this study.

Cultural beliefs further complicate the psychological experience in Ethiopia. While some degree of caregiver guilt has been observed globally Guermazi et al. (2024), the intensity of self-blame among Ethiopian parents appears more deeply rooted in spiritual and cultural understandings. In interviews, parents expressed feelings of punishment or divine disapproval, believing their child's illness was caused by personal wrongdoing or ancestral curses. This resonates with findings from Fanta et al. (2022) and Girma et al. (2022), who documented widespread beliefs in Ethiopia that epilepsy is a result of sin, spiritual possession, or family disgrace. In contrast, studies from Western contexts often frame caregiver stress in more medicalized or behavioral terms, such as parental burden due to a child's neurodevelopmental disorder, without the added layer of spiritual guilt (Pellicano et al., 2022).

The findings on marital strain also distinguish this study from others. While research from sub-Saharan Africa, e.g Nuhu et al. (2021), in Nigeria has acknowledged stress on spousal relationships, the detailed accounts from parents in Adama City provide a clearer picture of how gender norms contribute to emotional abandonment, blame, or divorce. Mothers in particular described being left to carry the burden alone, often without emotional or financial support from their husbands. These experiences were not as pronounced in studies from high-income countries, where shared caregiving responsibilities and family counseling are more common (Smith et al., 2021). Even in some African studies, such as Kakooza-Mwesige et al. (2022) in Uganda, while emotional fatigue was reported, the role of the extended family was more emphasized in buffering stress, a resource that was inconsistently available to the participants in Adama City.

Furthermore, loneliness and emotional isolation, while globally reported, take on unique characteristics in this Ethiopian setting. Some participants described not only being avoided but also being actively excluded from religious spaces, social events, and even public places like schools and markets. This aligns with observations made by Baskind and Birbeck (2020), who found that in many African societies, epilepsy is seen not just as a personal issue but as a socially contaminating condition. Such forms of exclusion intensify loneliness and reduce the informal support networks typically crucial for psychological resilience.

The experience of loneliness reported in Adama City is reinforced by research on affiliate stigma, an emotional burden experienced by parents because of their association with epilepsy. Studies from Greece Kochilas et al. (2017), and Uganda Nsamba Kamwesiga et al. (2022) indicate that caregivers isolate themselves to protect their children from judgment and themselves from guilt. The Ethiopian caregivers interviewed described isolation not as a choice, but a forced condition, rooted in community stigma reinforced by beliefs about epilepsy as contagious or cursed.

Lastly, the theme of parental anxiety due to economic vulnerability adds an important comparative layer. While financial anxiety exists globally, in Ethiopia, the stakes are often more extreme. Parents in this study reported sacrificing food, housing, and schooling expenses to afford anti-epileptic drugs. Alemayehu and Kassa (2023) similarly found that financial trade-offs are a daily reality for Ethiopian caregivers. In high-income settings, by contrast, while drug costs and healthcare access are concerns, government subsidies or insurance may alleviate some of the

economic burden, thereby reducing associated anxiety (Zhou et al., 2022). Similarly, Hussain (2020) found that anxiety was present in 64% of caregivers, significantly higher than caregivers of adults with epilepsy. These figures mirror those of parents in Adama City, as some participants described mood disturbances, sleep issues, and persistent worry without access to mental health care.

In summary, while the psychological burdens reported in this study, such as stress, guilt, and anxiety, are reflected in global and regional literature, the Ethiopian experience is shaped by distinct cultural, spiritual, and socio-economic realities. These include profound self-blame rooted in religious beliefs, limited institutional and emotional spousal support, social exclusion based on stigma, and extreme economic trade-offs. The findings from Adama City not only support existing research but also highlight underexplored dimensions of caregiver psychology that are critical for culturally grounded intervention design.

4.2.3 Discussion of the Social Challenges of Parents of Children with Epilepsy

The study revealed that parents in Adama City face widespread social exclusion and community rejection due to deep-rooted stigma and misinformation about epilepsy. Caregivers were frequently avoided by friends and excluded from social events. Some reported their children being treated as spiritually cursed or contagious, contributing to emotional withdrawal. Some participants experienced marital conflict, often driven by financial stress and gendered blame for the child's condition. Moreover, the heavy burden of childcare, often falling solely on mothers, led to fatigue and loss of personal and professional identity. Families were often fractured, with parents forced to compromise attention and care for other children, leading to strained household dynamics. A major contributing factor to these issues was limited knowledge and widespread misconceptions about epilepsy, especially regarding its causes and treatment.

These findings are interpreted and well-explained through the Social Stigma Theory Goffman (1963), which asserts that individuals with a socially devalued attribute, such as epilepsy, face marginalization and rejection. In this study, epilepsy was perceived by the community as a mysterious or spiritual affliction, contributing to fear, avoidance, and exclusion of families. Parents were seen as "tainted" or "blameworthy," causing social distancing that eroded crucial communal bonds.

Additionally, Family Stress Theory Hill (1949) provides insight into how social challenges, particularly loss of support networks and stigmatization, compound caregiving stress.

In the ABC-X model, a child's epilepsy (A) combines with low social and emotional resources (B) and negative community perceptions (C) to result in a crisis (X). For example, mothers reported being solely responsible for caregiving, while also coping with neglect from spouses and isolation from extended family, leading to mental and physical exhaustion. The theory also explains the strain in marital relationships, as emotional and financial stressors were intensified by rigid gender roles and community expectations, often resulting in blame, abandonment, or silence.

When compared to global literature, the social challenges reported in this study reflect similar findings in diverse cultural settings. For instance, Yu et al. (2022) and Carter et al. (2022) emphasize that caregivers worldwide experience social isolation due to the unpredictability of seizures and misunderstanding about epilepsy. However, unlike in higher-income countries where epilepsy is typically recognized as a medical condition and stigma is relatively reduced due to public health education, in Ethiopia and many parts of Africa, stigma is closely tied to spiritual and cultural beliefs (Baskind & Birbeck, 2020). In these contexts, families often attribute epilepsy to curses or supernatural causes, which escalates fear, rejection, and discrimination, dynamics widely reported by participants in this study.

In the African context, several studies support these findings. For instance, Nuhu et al. (2021) found in Nigeria that community rejection and spiritual explanations of epilepsy deeply affected caregiver social life. Similarly, Kakooza-Mwesige et al. (2022) in Uganda reported emotional burden and social alienation of caregivers due to prevailing community misconceptions. However, one contrast noted in these African studies is that some caregivers were able to access church- or mosque-based support systems, which occasionally helped alleviate stigma. In contrast, this study found that in Adama City, even religious leaders at times contributed to stigma by discouraging medical treatment and promoting spiritual explanations. Participants shared that some priests and imams framed epilepsy as a demonic affliction, which delayed medical intervention and compounded social alienation. Only a few religious leaders provided support, highlighting the inconsistency of institutional support within Ethiopia's spiritual communities.

Within Ethiopia, the findings resonate strongly with those of Fanta et al. (2022) and Teferi and Shewangizaw (2020), who noted that epilepsy is widely misunderstood and stigmatized, often leading families to isolate themselves or hide their children. The current study

contributes additional insight by showing how this stigma not only affects the child but also fractures the entire family system. Several participants reported marital tension, abandonment by spouses, and emotional neglect by extended family members, highlighting the ripple effect of stigma. Alemayehu and Kassa (2023) also emphasized that Ethiopian fathers tend to disengage emotionally or shift the burden to mothers, which mirrors the current findings where women overwhelmingly reported caregiving fatigue and spousal neglect.

This study also expands on the social implications by documenting how the lack of knowledge about epilepsy contributes to a broader societal gap. As noted in Tilahun et al. (2023), many Ethiopians are unaware of epilepsy's causes and management. Parents in this study observed that community members often misinterpreted seizures as contagious or violent episodes, leading to exclusion from school, playgrounds, or religious gatherings. In comparison to more developed settings where community health education and disability awareness programs are in place, Ethiopian urban contexts like Adama still struggle with widespread misinformation and limited public discourse on epilepsy.

Unlike some global and African studies that noted emerging support networks or awareness efforts Pellicano et al. (2022), Owolabi et al. (2021), this study shows a stark absence of structured community-based or institutional interventions in Adama City. Parents repeatedly indicated that they had never received training or community-based support and felt socially isolated due to a lack of coordinated services. This reinforces the urgent need for integrated education and awareness programs in schools, health centers, and religious institutions to combat misinformation and foster inclusion.

In conclusion, while the social challenges identified in this study align with findings across global, African, and Ethiopian contexts, the intensity and depth of exclusion in Adama City underscore a need for urgent, culturally grounded interventions. Unlike contexts where systemic support is gradually improving, the caregivers in this urban Ethiopian setting navigate profound social exclusion with minimal support, revealing both the universality and the local specificity of the psychosocial burden they bear.

4.2.4 Discussion of Coping Mechanisms of Parents of Children with Epilepsy

The findings of this study highlight a range of coping strategies employed by parents of children with epilepsy in Adama City, Ethiopia, shaped by sociocultural, religious, and institutional contexts. These strategies include institutional/professional support, social and

religious support, self-directed learning, personal commitment, and the development of resilience and acceptance. These approaches reflect both adaptive and constrained forms of coping shaped by resource scarcity, stigma, and cultural norms.

A key finding is the limited and narrowly medicalized nature of institutional support, which reflects parents' frustration with healthcare providers who emphasize medication while neglecting psychoeducation and emotional counseling. As seen in the responses from participants, parents often feel dismissed when attempting to ask about their children's behavior, nutrition, or long-term management. These concerns mirror earlier findings in Ethiopian literature, which report the absence of holistic epilepsy care and caregiver training in urban settings (Alemayehu & Kassa, 2023; Mengesha & Tsegaye, 2022). According to Family Stress Theory, when families perceive that resources (in this case, institutional support) are lacking, they experience higher stress and are pushed to seek alternative means of adaptation. Parents' perceptions of institutional neglect intensify their emotional distress, reduce their trust in the system, and force them to depend more on informal support systems.

The role of social support, although pivotal remains inconsistent and fragmented. Some parents benefit from empathetic friends or relatives, while others suffer deep isolation due to prevailing beliefs that epilepsy is contagious or a curse. These findings are aligned with Goffman's Social Stigma Theory, which posits that individuals associated with a stigmatized attribute (such as epilepsy) are often devalued and distanced socially (Goffman, 1963). This is especially significant in Ethiopian contexts where stigma is often reinforced by cultural misconceptions and low public awareness (Girma et al., 2022). However, the findings also offer hope: for those who find allies in the community, such as another parent of a child with epilepsy or an informed healthcare worker, these relationships offer not only emotional solace but also practical aid, such as sharing transportation costs or information about drug availability. These social bonds demonstrate that social capital can function as a resilience resource, as predicted by the "B" component in the ABC-X model of Family Stress Theory.

Religious coping emerged as one of the most dominant strategies. Almost all participants reported relying on prayer, holy water, or religious leaders either in addition to or instead of medical care. This reflects broader trends in African and Ethiopian studies, where spiritual coping is often prioritized due to the cultural framing of epilepsy as a spiritual or supernatural condition (Owolabi et al., 2021; Alemayehu et al., 2023). While spiritual support provides

parents with emotional comfort and a sense of control, its dual-edged nature is also evident: some religious leaders discouraged hospital visits, leading to delays in treatment and increased seizure frequency. Yet, a shift is also seen in some parents' narratives, as they learn to balance faith with medical advice, a reflection of adaptive resilience. The coexistence of religious belief and pragmatic medical care represents a culturally integrated coping strategy unique to Ethiopian caregivers.

Another significant theme is self-education and self-training, which parents described as a response to the absence of structured training on epilepsy management. This aligns with global literature, which identifies self-education as a common coping mechanism in low-resource settings where formal services are limited (Pellicano et al., 2022). In Ethiopia, where healthcare systems are overburdened and under-resourced, parents become "experts by necessity." This finding supports previous calls for the integration of structured parent training programs on epilepsy management, nutrition, first aid, and behavioral care (Mengesha & Tsegaye, 2022). Although such trial-and-error learning reflects high resilience, it is not sustainable or equitable, as families with lower literacy or fewer experiences may struggle more. Therefore, the lack of institutional training widens inequalities among caregivers.

Personal commitment and sacrifice were commonly cited coping responses. Parents often shared stories of selling personal belongings, quitting jobs, or facing social criticism in their efforts to care for their children. Such sacrifices demonstrate strong parental agency and emotional investment, but also highlight the absence of systemic support mechanisms. These forms of commitment align with the "C" component of the Family Stress Theory, parental perceptions of duty and responsibility, shaping their responses even in high-stress situations. While admirable, this heavy personal burden risks leading to burnout and secondary trauma, especially for mothers who are usually the primary caregivers.

Finally, resilience and acceptance were identified as powerful adaptive outcomes, especially in families who had experienced stigma, misinformation, or loss. Several participants revealed that after years of hiding their children or battling shame, they now feel proud, better informed, and emotionally stronger. This attitudinal shift demonstrates the potential for positive transformation through lived experience, social exposure, and time. Resilience, as a coping mechanism, has also been supported by international research, which links resilience with higher levels of caregiving satisfaction and better psychological adjustment (Smith et al., 2021). In the

Ethiopian context, however, this resilience often develops in the absence of systemic help, making it a more fragile and uneven resource.

In sum, coping mechanisms among parents of children with epilepsy in Adama City represent a dynamic interplay between cultural beliefs, social stigma, faith-based practices, personal agency, and institutional gaps. While informal support systems such as religious communities and peer connections provide some relief, they are not sufficient substitutes for professional, structured psychosocial services. These findings suggest an urgent need for culturally appropriate, locally tailored interventions, including public awareness campaigns, parent training programs, and collaborative efforts between healthcare providers and community leaders. The experiences of these parents reveal a powerful story of resilience, but also of unmet needs that continue to shape the coping landscape in urban Ethiopia.

4.2.5 Theoretical Implications

The findings of this study carry significant theoretical implications, particularly for the application of Family Stress Theory and Social Stigma Theory in understanding the psychosocial challenges faced by parents of children with epilepsy in Ethiopia. The Family Stress Theory, through Hill's ABC-X model, effectively explains how the child's epilepsy diagnosis (stressor A), combined with limited resources (B) and negative perceptions (C), leads to psychological and social crises (X). This study validates the theory's relevance in low-resource settings, where systemic gaps intensify stress and strain family dynamics.

Similarly, Goffman's Social Stigma Theory (1963) provides a robust framework for interpreting the social exclusion and marginalization experienced by caregivers. The theory's concept of "spoiled identity" is particularly salient in the Ethiopian context, where epilepsy is often perceived as a spiritual or contagious condition. The study extends the theory's application by highlighting how stigma not only affects the individual with epilepsy but also their caregivers, reinforcing the need for broader societal interventions.

Together, these theories underscore the interconnectedness of psychological, social, and cultural factors in shaping caregiver experiences. They also highlight the need for culturally sensitive adaptations of these frameworks to address the unique challenges faced by families in resource-limited and stigma-heavy environments.

4.2.6 Practical Implications

The findings underline several critical implications for practice and policy. First, there is

a pressing need for community-wide epilepsy education, especially involving religious and traditional leaders who are highly influential in shaping beliefs. Interventions should aim to deconstruct harmful myths and replace them with medically accurate and culturally respectful information. Second, support structures for caregivers, especially mothers, must be strengthened, including marital counseling, parenting groups, and social welfare initiatives. These would help mitigate the marital strain and social isolation commonly reported.

Moreover, local health centers should integrate psychosocial support into epilepsy care, not just for the children but also for their families. Since stigma is often driven by fear and misinformation, incorporating epilepsy education into school curricula, public health campaigns, and religious gatherings can help build an informed and compassionate community.

4.2.7 Limitations of the Study

While the study provides rich insights, some limitations should be acknowledged. The research focused only on parents in Adama City, and findings may not fully represent experiences in rural or pastoralist regions where healthcare access is different. Additionally, while the study used qualitative interviews and FGDs to explore psychological challenges, it did not include standardized clinical assessments for depression or anxiety. Future studies might integrate qualitative and quantitative tools to measure caregiver mental health outcomes more precisely.

In conclusion, the psychological and social challenges faced by parents of children with epilepsy in Adama City are profound and multifaceted, shaped by cultural beliefs, stigma, and systemic gaps. The coping mechanisms they employ reflect resilience but also highlight unmet needs for institutional and community support. The findings underscore the urgency of culturally grounded interventions that address both medical and psychosocial dimensions of caregiving. By integrating theoretical insights with practical strategies, this study contributes to a deeper understanding of caregiver experiences in Adama and calls for actionable steps to improve their well-being and social inclusion.

Chapter Five

Summary, Conclusion, and Recommendations

5.1 Introduction

This chapter gives a summary of the main findings of the study, draws conclusions based on those findings, and provides recommendations for action. The study explored the psychological and social challenges faced by parents of children with epilepsy in Adama City, along with the different ways they tried to cope with the challenges. The chapter highlights what the study has discovered, explains what the results mean, and suggests ways to improve support for these parents.

5.2 Summary of Key Findings

This study found that parents of children with epilepsy in Adama City face serious psychological and social problems. Parents reported feeling of constant stress, guilt, and fear because of their child's condition. They often blamed themselves and felt lonely or depressed, especially when community members treated them differently. Some families also struggled with marital problems, mostly because mothers were left to carry the full burden of caregiving without enough help or emotional support.

Social stigma was another major issue. People in the community believed epilepsy was a curse or something contagious. As a result, parents and children were often excluded from school, religious events, and social activities. This created isolation and made life even harder for the caregivers. The situation was made worse by the lack of correct information about epilepsy and the absence of support systems.

Despite all these challenges, parents used different ways to cope. Some relied on religious faith and prayer, while others learned on their own how to care for their children. A few received help from friends, relatives, or health workers. However, most parents said they didn't get proper guidance or emotional support from the healthcare system. Their strength and personal commitment helped them manage daily life, but many still felt alone and overwhelmed.

5.3 Conclusion

The study confirms that parents of children with epilepsy face severe psychological and social challenges due to societal discrimination, economic constraints, and lack of emotional and practical support from the community. Cultural misunderstanding intensifies their isolation, while limited access to health care services and proper counseling. The emotional distress that

most parents experience underlines the need for holistic and structured interventions.

Despite some of the parents' commitment and resilience, the consistent barriers they are facing impaired their abilities to extend improved care and support for their children. The caregiving burden on mothers also reflects societal expectations, intensifying their struggles and emotional distress. Without accessing targeted interventions to the parents, financial strain, mental health issues, and social stigma will persist for these families.

The findings of the study call for a multi-sectoral approach involving adequate healthcare services, system strengthening, and changing the negative attitude of the community. Strengthening the capacity of parents through knowledge, financial support, and psychosocial support can substantially enhance their quality of life.

5.4 Recommendations

The findings of this study, with all its limitations and delimitations, suggest the following recommendations:

5.4.1 Community Education and Awareness

Raising public awareness about epilepsy is essential to reduce stigma and misinformation. Working with religious leaders can help communities understand that epilepsy is a medical condition, not a curse. Awareness sessions in churches, mosques, and community gatherings should share accurate information. In schools, teachers and students should receive training to understand epilepsy better. This can help reduce fear and ensure children with epilepsy are supported and included.

5.4.2 Healthcare System Strengthening

The healthcare system should be improved to support both the child and the caregiver. Mental health screenings should be added during regular epilepsy checkups to identify caregivers who may be struggling with anxiety or depression. Local health centers should also offer training for parents on topics like how to handle seizures, proper nutrition, and managing stress. This will help parents feel more prepared and confident in caring for their children.

5.4.3 Support Networks for Caregivers:

Parents need spaces where they can share their experiences and learn from each other. Peer support groups can provide emotional relief and practical tips. It's also important to involve fathers and other family members in caregiving. Community discussions can encourage men to take a more active role, easing the pressure on mothers and promoting shared responsibility.

5.4.4 Research and Advocacy

More long-term studies are needed to see how caregiving challenges change as children grow. This can help identify when parents need the most help. There should also be researches that help to develop culturally tailored interventions in resource-limited settings.

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Addis Ababa University, Department of Psychology Information sheet and consent

Appendix A1: Amharic Version Interview Guide

1. ልጅዎን ሲያሳድጉ ያጋጠሞት የስነልቦና ችግር አለ?

- ጭንቀት (ስለልጁ ጤናና የወደፊት ሁኔታ መጨነቅ)
- እራስን መውቀስ
- ብቸኝነት መሰማት
- ትዳር ላይ የሚፈጠር ችግር
- ድብርት
- መረበሽ

2. ልጅዎን ሲያሳድጉ ያጋጠምዎት ማህበራዊ ችግር ምንድን ነው?

- ማህበራዊ ተፅዕኖ
- ትዳር ላይ ያለ ተፅዕኖ
- እንክብካቤ ከመስጠት ጋር የሚመጣ ተፅዕኖ
- ቤተሰብ ላይ ያለው ተፅዕኖ
- ስለችግሩ ካለማወቅ የሚመጣ ተጽህኖ

3. የገጠሞትን ችግሮች ለመወጣት የተጠቀሙባቸው መንገዶች ካሉ

- የባለሙያ ድጋፍ
- ማህበራዊ ድጋፍ
- ሃይማኖታዊ ድጋፍ
- ስለችግሩ እራስን ማስተማር
- ቁርጠኝነት

ችግሩን መቀበሌ እና ጥረት ማደርግ

Appendix A2: English Version Interview Guide

1. What were the psychological problems you faced during raising your child?

- Stress
- Self-blame
- Loneliness
- Marital-related problems
- Depression
- Anxiety

2. What were the Social challenges you faced while raising your child?

- Social challenge
- Stress on marriage
- The burden of childcare
- Challenges on family
- Lack of knowledge about the Epilepsy

3. What were the coping strategies you used to overcome some of the challenges?

- Institutional and professional support
- Social support
- Religion support
- Self-support through training oneself
- Commitment
- Resilience and Acceptance

Appendix B1: Amharic Version Consent form

በኃይሉ ሙሉጌታ እባላለሁ፡፡ በአዲስ አበባ ዩኒቨርስቲ የድህረ ምረቃ ተማሪ ነኝ፡፡እርስዎን ለትምህርት ለማጠናው ጥናት ቃለ-መጠይቅ ለማድረግ የመረጥክዎት ሲሆን የማደርግሎት ቃለ-መጠይቅ የሚጥል በሽታ ያለበትን ልጆን ሲያሳድጉ ያጋጠሞትን የስነልቦናና የማህበራዊ ችግሮችን ለማወቅ ነው፡፡በተጨማሪም ጥናቱ እነዚህን ችግሮችን ለመቋቋም የተጠቀሙባቸውን ዘዴዎች ወይንም የመፍትሔ እርምጃዎችን ያጠቃልላል፡፡የጥናቱ ውጤት ለእርሶና ለሌሎች የሚጥል በሽታ ላለባቸው ህፃናት ቤተሰቦች መረጃ የሚሰጥ ሲሆን በተለይ ቤተሰቦች ስለሚያጋጥማቸው ስነልቦናዊ ችግሮች፣ ከማህበረሰቡ የሚደርስባቸው ጫናዎች፣ ከትዳር እና ከቤተሰብ ጋር የሚኖሩ ችግሮችን እንዲሁም የችግሩን አሉታዊ ተፅዕኖ ለመቀነስ የተጠቀሚቸውን መንገዶችን ይመለከታል፡፡

ስለሆነም በዚህ ጥናት ውስጥ ለመሳተፍ ከላይ የተገለፀውን የጥናቱን ዓላማ ተረድተው ቃለ መጠይቁን ለዚህ ጥናት ግብዓት እንዲሆን በሙሉ ፈቃደኝነት ለመመለስ ፈቃደኛ በመሆንዎት ምስጋና እያቀረብኩ ቃለመጠይቁን ለመመለስ የማይገደዱ መሆኑንና ከቃለመጠይቁ በፊትም ሆነ መሀል ላይ ቃለመጠይቁን ለማቋረጥ ከፈለጉ ሙሉ በሙሉ የሚችሉ መሆኑን እንዲሁም ለምጠይቅዎት ጥያቄዎች ትክክል ወይም ትክክል ያልሆነ መልስ እንደሌለና የጥያቄዎቹ ዓላማ የእርስዎን ተሞክሮ ለማወቅ ብቻ መሆኑን ልገልፅ እወዳለሁ፡፡

ይህ ቃለ-መጠይቅ ከአንድ ሰዓት እስከ አንድ ሰዓት ከሰላሳ ደቂቃ ሊፈጅ የሚችልና በቃለመጠይቁ ወቅት አንዳንድ ግላዊ ወይም ምቾት የማይሰጡ ጥያቄዎች ሉኖሩ እንደሚችሉ በቅድሚያ እያሳወኩ ይህንን ጥናት እርሶ በሚሰጡኝ መረጃ ላይ ተመርኩዤ ስፅፍ የእርሶ ስም የማይጠቀስ መሆኑንና የሚነገረኝ መረጃ በሙሉ በሚስጥር እንደሚያዝ አረጋግጥሎታለሁ፡፡

ጥናቱን የሚያካሄደው ሰው ስም _____

ስልክ:- 0911097452

ኢሜይል:- helubehailu@gmail.com

ቀን _____

Consent form (Amharic version)

የስምምነት መግለጫ ቅፅ

ከዚህ በታች የተጠቀሰውን ጥናት ምንነቱ ፣ዓላማው ፣ ጥቅሙ እና ጉዳቱ በሚገባኝ ቋንቋ ከተነገረኝ በኋላ በገዛ ፍቃዴ ለመሳተፍ መስማማቴን እገልፃለሁ፡፡ በዚህ ጥናት የሚሰበሰበው መረጃ ጥናቱን ከሚያካሂዱት ሰዎች ውጪ ለሌላ አካል የሚገለፅ አለመሆኑን እና ከዚህ ጥናት በማንኛውም ጊዜ አቋርጬ መውጣት የምችል መሆኑን የተገለፀልኝ መሆኑን አረጋግጣለሁ፡፡

ስም _____

ፊርማ _____

ቀን _____

Appendix B2: English Version Consent Form

My name is Behailu Mulugeta. I am a Social Psychology graduate student at the Addis Ababa University. I have chosen you to interview to explore the psychosocial challenges you experienced due to your child with Epilepsy and also to identify what kind of coping mechanisms you used to overcome those challenges.

This study provides information to you and other parents about the psychosocial challenges faced by parents of children with Epilepsy. Mainly, the study focuses on exploring major issues such as the psychological challenges of parents, the social challenges they face from society, and the coping mechanisms they use to mitigate or overcome the negative effects of having children with Epilepsy.

Therefore, I thank you for your willingness to participate in this study and to fully understand the purpose of the interview. I would like to let you know that you are not obligated to answer the questions and have the right to withdraw from the interview at any time. Since the purpose of the questions is simply to know the challenges you faced, I want you to know that there is no right or wrong answer. This interview can take from an hour to an hour and a half, and there might be some personal or uncomfortable questions during the interview. The information collected from this research will be kept confidential. The information I collected from you will be collected and stored in a file, in which your name and story will remain anonymous.

Name: Behailu Mulugeta
Tel: 0911097452
Email: helubehailu@gmail.com

Date

Consent form

I would like to confirm that I have consented to take part in this study after being told about the purpose, the objectives and the possible outcomes of the study in the language that I understand and I have consented to take part in the study at my own will without any coercion. I have also been informed that the information that I am about to give will be kept confidential and that I have the right to withdraw from the study at any time if I feel uncomfortable.

Name

Sign Date

Appendix C1: English Version Focus Group Discussion Guide for Parents

1. What were the psychological problems you faced while raising your children?

2. Social Challenges you faced while raising your children?

3. What kind of coping Mechanisms did you use to overcome those challenges?

Appendix C2: Amharic Version Focus Group Discussion Guide for Parents:

1. ልጆቻችሁን ስታሳድጉ ያጋጠማችሁ ስነ ልቦናዊ ችግር ካለ
2. ልጆቻችሁን ስታሳድጉ ያጋጠማችሁ ማህበራዊ ችግር ካለ
3. ከገጠማችሁ ችግር ለመውጣት የተጠቀማችሁት መንገድ ካለ