COLLEGE OF EDUCATION AND LANGUAGE STUDIES

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CAREGIVERS' EXPERIENCE OF POST-STROKE PATIENTS WITH SWALLOWING DIFFICULTIS IN ST. PETER HOSPITAL, ADDIS ABABA, ETHIOPIA

BY:

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CAREGIVERS' EXPERIENCE OF POST-STROKE PATIENTS WITH SWALLOWING DIFFICULTIES

A THESIS SUBMITTED TO COLLEGE OF EDUCATION AND LANGUAGE STUDIES, DEPARTMENT OF SPECIAL NEEDS AND INCLUSIVE EDUCATION IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR MASTER OF SCIENCE IN SPEECH-LANGUAGE THERAPY

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DECLARATIONS

I hereby declare that the thesis entitled “Caregivers' Experience of Post Stroke Patients with Swallowing Difficulty” is my original work and submitted for the degree of Master of Science in Speech and Language Therapy from Addis Ababa University College of Education and Language Studies at Addis Ababa.

I also confirm that it has not been presented for the award of any other degree of any other university or institution and that all sources of materials used for the study have been duly acknowledged.

Declared by:

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CERTIFICATIONS

Addis Ababa University

College of Education and Language Studies

Special Needs Education

This is to certify that the Thesis made by Mekamu Derese entitled “Caregivers' Experience of Post Stroke Patients with Swallowing Difficulty” submitted in partial fulfillment of the requirements of the award of Master of Science Degree in Speech-Language therapy with the regulation of the University and meets the accepted standards with respect to its originality and quality.

Signed by the Examining Committee:

Advisor: _____ Signature _____ Date _____

Internal Examiner: _____ Signature _____ Date _____

External Examiner: _____ Signature _____ Date _____

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Melkamu Derese

ABBREVIATIONS

A.D.L.s: Activities of Daily Living

WHO: World Health Organization

NGO: Non-Governmental Organization

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ABSTRACT

This study aimed to comprehensively profile the specific swallowing difficulties encountered by stroke patients, as directly observed and reported by their primary caregivers, and to thoroughly document the profound lived experiences of the caregivers themselves. Conducted at St. Peter Specialized Hospital in Addis Ababa, Ethiopia, between March and June 2025, the research rigorously employed a phenomenological approach to capture the subjective realities of caregiving. Data was meticulously collected through in-depth, one-on-one semi-structured interviews with caregivers, and subsequently analyzed using systematic thematic analysis to identify recurring patterns and core meanings within their narratives. Major findings revealed that caregivers endure substantial and pervasive emotional distress, manifesting intense fear of choking, anxiety, and feelings of social isolation, often leading to burnout. They also experience significant physical strain from constantly assisting with patient mobility and demanding feeding tasks. Practical challenges are extensive, including the complex modification of diets and managing prolonged mealtimes. A critical finding was the consistent report from caregivers regarding a severe lack of adequate training and robust support from existing healthcare systems, which compelled them to rely heavily on their own informal coping strategies and deep spiritual practices for resilience. In conclusion, caregivers of stroke patients experiencing swallowing difficulties face considerable, often unrecognized, burdens that profoundly impact their well-being. It is strongly recommended that healthcare providers, particularly at St. Peter Specialized Hospital, develop and implement targeted training programs and accessible support groups specifically designed for the caregivers. Furthermore, policymakers are urged to integrate comprehensive caregiver support into national health policies to alleviate their immense burden and concurrently improve overall patient outcomes.

***Keywords**: Stroke, Swallowing difficulties, Caregivers, Caregiver experience, Caregiver burden*

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Globally, stroke is considered as a critical health issue. It is the second leading cause of death and a leading cause of long-term disability worldwide (Jambi et al., 2024). Around one in four adults over 25 will experience a stroke in their lifetime. From this, Ischemic strokes make up about 80% of cases, while hemorrhagic strokes are less common but are more likely to be fatal. An ischemic stroke, which causes brain cells to die from lack of oxygen, occurs when a blood clot blocks an artery supplying blood to the brain (Grant et al., 2004). On the other hand, a hemorrhagic stroke happens when a blood vessel in the brain breaks and bleeds into surrounding tissue, which causes cell damage and increased pressure in the skull (Jambi et al., 2024). Each year, over 15 million people suffer strokes globally, resulting in 5 million deaths and another 5 million people will be disabled permanently (Grant et al., 2004).

Stroke survivors often face a wide range of physical, cognitive, emotional, and social challenges that greatly reduce their quality of life (Arnold et al., 2016). Some of the common physical symptoms include motor impairments such as hemiparesis, spasticity, and balance problems. These issues can make mobility difficult and increase the risk of falling. Similarly, swallowing problems like dysphagia, can affect between 19% and 81% of stroke survivors (Arnold et al., 2016; Song et al., 2024). This condition arises from damage to brain areas such as the brainstem or cerebral cortex, which are essential for controlling swallowing muscles (Arnold et al., 2016; Wang et al., 2025). Dysphagia greatly raises the risk of aspiration pneumonia, malnutrition, and dehydration, which can affect patients' overall health and

quality of life seriously (Arnold et al., 2016). The swallowing process has three stages starting from the oral phase, where food is moved into the throat; to the pharyngeal phase, which starts the swallow and pushes food downwards; and then to the esophageal phase, which directs food into the stomach (Song et al., 2024).

Common signs of dysphagia include coughing while eating, a wet or gurgling voice, a feeling of food being stuck, and after eating breathing problems (Song et al., 2024). Although it is a less common issue, damage to the brainstem often leads to more severe and lasting swallowing problems compared to cortical strokes, with about 40% of survivors experiencing chronic dysphagia, which have an effect to increase the chances of pneumonia, malnutrition, and dehydration (Rofes et al., 2018). Therefore, preventing complications and improving patient outcomes are crucial for early detection and effective management of dysphagia (Rofes et al., 2018).

In addition to physical problems, cognitive challenges like memory loss, shorter attention spans, and problems with reasoning or problem-solving are also common. These deficits can worsen over time, with some survivors may eventually develop dementia (Bugge et al., 1999; Morone & Pichiorri, 2023). It is a widespread issue that communication difficulties, including aphasia, which affects language comprehension and use, and dysarthria, leads to slurred speech (Poomalai et al., 2023). These health issues often reduce participation in daily activities and can increase social isolation (Wray & Clarke, 2017). Emotionally, about one-third of stroke survivors may face depression, often in connection with anxiety and mood changes, which stems from the heavy psychological burden of recovery and the loss of independence (Hackett & Pickles, 2014). From the social perspective, feelings of

dissatisfaction with societal roles and a reduced ability to engage in meaningful activities may worsen survivors' isolation (Ayerbe et al., 2013). These common challenges indicate the deep and complex impact of stroke on survivors' lives, which extends far beyond physical disability (Donnan, 2012).

Caregivers of stroke patients, especially those dealing with swallowing problems (dysphagia), can face a demanding task filled with many challenges regarding feeding management. One of the primary concern for these caregivers is ensuring safe and effective feeding to prevent life-threatening issues such as aspiration pneumonia (Martino et al., 2005). On the other hand, aspiration pneumonia is a serious lung infection that occurs when food, liquid, or saliva goes into the lungs instead of down the esophagus and finally into the stomach. This often happens due to a weakened swallowing reflex, which is common in stroke patients with dysphagia. The material that enters the lungs can carry bacteria, which can cause inflammation and infection (Martino et al., 2005).

Caregivers usually express a strong fear of aspiration and constant pressure to ensure proper nutrition that significantly adds to their burden (Arnold et al., 2016). They frequently need to learn complex feeding techniques, such as preparing thickened foods in special ways and monitoring the patient's swallowing safety closely. This task can be emotionally draining (Song et al., 2024). In addition, caregivers often report that there is a lack of sufficient support from healthcare services, which makes them feel isolated and stressed (Bakas et al., 2009). The emotional burden on caregivers is often considerable, as they must also deal with the patient's emotional reactions to eating issues, for instance frustration and anxiety. Managing anxiety in relation to feeding and ensuring patient comfort during mealtimes often presents

further challenges. They may also face significant challenges transitioning between various feeding methods, such as from oral feeding to tube feeding, requiring specific knowledge and tools (Crary & Groher, 2003). Although involving caregivers in the feeding process through repetitive training and support can minimize some difficulties, the general lack of extensive training and resources often makes caregivers feel overwhelmed and uncertain about the best approaches to manage feeding-related issues (Kielb et al., 2022).

While caregivers of stroke patients usually confront significant difficulties in addressing the physical, emotional, and practical needs of their loved ones, they also develop and use various techniques to navigate these challenges (Lai et al., 2018). One of the major difficulties in this regard is helping them with feeding, especially for patients living with dysphagia. Caregivers respond to such issues by carefully learning the right strategies for modifying diets, like preparing soft or thickened foods, and ensuring the patient sits upright during meals to reduce the risk of aspiration (Ye et al., 2025). They also carefully watch for signs of swallowing difficulties, such as coughing or choking, and try to adjust feeding practices accordingly (Lai et al., 2018). Proper training in feeding techniques, such as tube feeding when necessary, is important for caregivers to be confident enough in this essential responsibility (Ye et al., 2025). Beyond feeding, caregivers often confront issues to help their patients with mobility and positioning. They can learn safe transfer methods and are able to ensure proper positioning to avoid various complications related to bedsores or falls (Muhrodji et al., 2022). Emotional challenges also weigh heavily on caregivers, who often can experience a lot of stress, feelings of isolation, and anxiety. Many of them mitigate this by actively seeking emotional support from their family or by joining caregiver support groups to share experiences and advice one another (Rigby et al., 2009). Managing time is another major

issue that most caregivers encounter, as they are required to balance their duties with personal commitments and work responsibilities. To mitigate this, caregivers sometimes use well-organized schedules or seek help from healthcare professionals or community resources relevant to their time management.

1.2. Statement of the Problem

Stroke survivors typically experience a range of impairments such as physical, cognitive, emotional, and social. Some of these impairments include motor dysfunctions like hemiparesis and dysphagia, cognitive issues such as memory loss and reduced problem-solving skills, and serious emotional challenges including depression and anxiety. These complications can affect survivors' quality of life greatly and often create a heavy dependency on caregivers for every daily activity.

Caregivers often have a lack of adequate training and strong support from healthcare systems, forcing them unprepared to handle these complex responsibilities in an effective way (Jafar et al., 2025; Lee et al., 2001; Teasell et al., 2013; Wang et al., 2024). This lack of support is a critical issue, as the training and well-being of caregivers are essential for the recovery and health of the stroke survivors they care for. The emotional stress on caregivers is also a significant matter; many experiences anxiety, depression, burnout, and social isolation as they encounter the constant demands of caregiving (Abubakar & Jamoh, 2017; Jafar et al., 2025; Kalra et al., 2004; Krawczyk et al., 2024).

Despite the crucial role of caregivers in stroke rehabilitation and recovery, there is a notable lack of research focusing on their specific needs and challenges (Garnett et al., 2022; Pattni & Cottrell, 2024). In addition, current healthcare policies often do not sufficiently involve

caregivers as active partners in the recovery process or offer enough accessible resources to support them adequately (Garnett et al., 2022; Jafar et al., 2025; Pattni & Cottrell, 2024; Teasell et al., 2020). This significant gap in both knowledge and practical support shows that there exists a pressing need for targeted interventions that are designed to reduce caregiver burdens and can improve outcomes for both caregivers and the stroke survivors they support.

1.3. Purpose of the Study

The main purpose of this study is to explore and document the experiences of caregivers who manage the swallowing difficulties of post-stroke patients at St. Peter Specialized Hospital in Addis Ababa, Ethiopia, during 2025. This research also focused on the challenges caregivers face and the strategies they use, as well as how these experiences affect their overall well-being.

1.4. Research Questions

This study aims to address the following specific research questions:

i) What are the characteristics of reported swallowing difficulties in post-stroke patients?

ii) What are the specific challenges faced by caregivers in providing care to post-stroke patients with swallowing difficulties?

iii) What strategies do caregivers employ to manage and provide care for post-stroke patients with swallowing difficulties?

1.5. Objectives of the Study

This research has the following research objectives:

i) To profile the reported swallowing difficulty in post-stroke patients.

ii) To document the challenges faced by caregivers in providing care to post-stroke patients with swallowing difficulties.

iii) To report the strategies used by caregivers to provide care to post-stroke patients with swallowing difficulties.

1.6. Significance of the Study

This study holds multi-faceted significance by addressing a critical knowledge gap at the intersection of stroke rehabilitation and caregiver welfare in Ethiopia. By focusing on the lived experiences of caregivers managing post-stroke dysphagia at St. Peter Specialized Hospital in Addis Ababa, the research provides value in the following ways:

Firstly, the study explains the specific physical, emotional, and social burdens that are unique to dysphagia management, an area of caregiving that remains largely invisible in the Ethiopian clinical landscape. While caregivers are the primary drivers of long-term recovery, their needs are often secondary to the patient's medical treatment. By providing an in-depth, interpretive analysis of their daily struggles and coping mechanisms, this research offers a platform to amplify the voices of this overlooked group. These insights are essential for healthcare providers to understand how caregiver well-being directly influences patient safety and nutritional outcomes.

Secondly, the findings serve as a practical resource for clinical improvement at St. Peter Specialized Hospital and similar regional institutions. Because the study is grounded in the specific cultural and economic context of Addis Ababa, it generates evidence-based data that

can be used to design targeted caregiver training programs and specialized support interventions. Unlike global studies, this research highlights how local factors—such as traditional dietary habits and resource constraints—shape the caregiving process.

Finally, this research contributes to the broader field of public health and policy formulation in Ethiopia. By documenting the challenges and strategies of these caregivers, the study provides a foundation for developing formal home-based care guidelines and informing local healthcare policies. Ultimately, it bridges the gap between clinical stroke management and the practical realities of long-term home care, promoting a more holistic approach to stroke recovery within low-resource settings.

1.7. Scope of the Study

This study is delimited to exploring the lived experiences of informal caregivers—specifically family members or close friends—who provide primary, non-professional care to adult post-stroke patients diagnosed with dysphagia. Geographically and institutionally, the research is restricted to the outpatient and inpatient departments of St. Peter Specialized Hospital in Addis Ababa, Ethiopia. The thematic focus is confined to identifying the specific physical and psychosocial challenges, adaptive coping mechanisms, and self-identified support needs of these caregivers within the period of March to June 2025. By focusing exclusively on this urban clinical population, the study excludes professional healthcare providers and patients with non-stroke-related swallowing disorders to ensure a concentrated analysis of the stroke-specific caregiving context.

1.8. Definitions of Terms

To ensure conceptual clarity and consistency within the specific context of this research, the following terms are operationally defined based on their application in this study:

- Stroke, in this study, refers to the clinical diagnosis of a cerebrovascular accident (either ischemic or hemorrhagic) recorded in the medical files of patients at St. Peter Specialized Hospital, which serves as the primary cause for the onset of the swallowing impairments under investigation.
- Dysphagia (Swallowing Difficulty), in this study, refers to the self-reported or clinically observed impairment in the physiological process of moving food, liquids, or saliva from the mouth to the stomach specifically occurring as a secondary complication of the patient's stroke.
- Caregiver, in this study, refers to the informal, unpaid family member or close friend who has been identified as the primary individual responsible for the daily nutritional management, safety supervision, and physical assistance of the stroke survivor.
- Post-Stroke Patients, in this study, refers to adult individuals who have survived an acute stroke event and are currently receiving follow-up care or inpatient services at St. Peter Specialized Hospital within the designated 2-month to 3-year recovery window.
- Lived Experience, in this study, refers to the subjective and firsthand narratives shared by the participants regarding the daily emotional, social, and physical realities of managing a loved one with dysphagia in an urban Ethiopian setting.

- Qualitative Research Design, in this study, refers to the descriptive-phenomenological framework utilized to explore the depth of caregiver experiences through in-depth interviews, focusing on meaning-making rather than statistical generalization.
- Aspiration Pneumonia, in this study, refers to the specific medical complication reported by caregivers or noted in patient histories where the inhalation of foreign material into the lungs resulted in hospitalization or significant changes in the caregiver's feeding safety protocols.
- Data Saturation, in this study, refers to the point during the seven in-depth interviews where no new themes or unique challenges regarding dysphagia caregiving emerged, indicating that the collected data was sufficient to answer the research questions.

1.9 Organization of the Paper

This research paper is divided into six chapters. Chapter one sets the stage by offering background information, outlining the research problem, formulating research questions, and defining the study's general and specific objectives. It also establishes the significance and scope of the study. Chapter two reviews existing scholarly work relevant to the research problem, which creates a theoretical foundation for analysis. Chapter three consists of details of the research design and outlines the methods used for collecting and processing primary data. Chapter four presents the study's findings, documented caregiver challenges, and coping strategies. Chapter five discusses and interprets these findings in relation to existing literature and the local context. Finally, chapter six concludes the paper with a summary of major findings, relevant conclusions, and recommendations based on the findings.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

This chapter consists of a detailed review of existing scholarly literature related to the experiences of caregivers of post-stroke patients with swallowing difficulties. It combines existing knowledge on stroke and dysphagia, examines the essential role and significant burden of caregivers, explores their different coping mechanisms and resilience factors, identifies specific challenges they face in managing dysphagia, and looks at the available support systems and interventions.

2.1. Definition and Impact of Stroke and Dysphagia

Stroke is a significant global health crisis, consistently ranking as the second most leading cause of death and a primary cause of long-term disability in the world in general (Jambi et al., 2024).

2.1.1. Understanding Stroke and its Global Burden

Medically, stroke is defined as an acute neurological deficit caused by a vascular event affecting the brain. This can either be ischemic, resulting from a blood clot that blocks blood flow to the brain, or hemorrhagic, caused by bleeding into brain tissue (Jambi et al., 2024). Ischemic strokes make up about 80% of all cases, while hemorrhagic strokes, though less common, usually have a higher fatality rate (Jambi et al., 2024). The global burden of stroke

is staggering, with over 15 million people affected each year, resulting in 5 million deaths and another 5 million permanently disabled (Grant et al., 2004). This widespread condition puts immense pressure on healthcare systems and carries significant socio-economic costs globally.

After a stroke, survivors may face a range of impairments that have a profound impact on their quality of life. These include major motor impairments, typically considered as weaknesses on one side of the body, spasticity, and issues with balance. Such challenges can severely limit mobility, can increase the risk of falls, and may hinder daily activities (Bushnell et al., 2024).

Similarly, many stroke survivors deal with cognitive impairments such as memory loss, reduced attention span, impaired executive functions such as reasoning and problem-solving, and difficulty in processing languages. These challenges often relate to damage in specific brain areas and may worsen over time, with some individuals developing post-stroke dementia (Bugge et al., 1999; Morone & Pichiorri, 2023).

Communication difficulties are also quite common, such as aphasia, which affects understanding and use of language, and dysarthria, which involves slurred or difficult speech. These communication barriers often can lead to reduced social participation and feelings of isolation (Poomalai et al., 2023; Wray & Clarke, 2017). On the other hand, emotional and psychological challenges are also common. Often alongside anxiety, nearly one-third of stroke survivors experience depression, mood swings, and emotional instability. These emotional burdens usually stem from the recovery process, loss of independence, and changes in brain chemistry (Hackett & Pickles, 2014).

On the other hand, social challenges are also widespread. Because survivors frequently express dissatisfaction with their social roles and reduced ability to engage in meaningful community activities, which leads them to isolation and decreased social well-being (Ayerbe et al., 2013). These varied challenges show the broad impact of stroke on survivors' lives, extending beyond initial physical impairments (Donnan, 2012).

2.1.2. The Nature and Consequences of Post-Stroke Dysphagia

Dysphagia, also known as swallowing difficulty, is one of the most critical and commonly encountered complications next to a stroke. A significant number of patients consistently report this issue, with instances varying from 19% to as high as 81% (Arnold et al., 2016; Song et al., 2024). This difficult condition arises from neurological damage on areas essential for coordinating the complex muscle movements essential for swallowing, such as the brainstem or cerebral cortex (Arnold et al., 2016; Wang et al., 2025).

The swallowing process involves three distinct phases. The oral phase, which includes chewing and forming a bolus; the pharyngeal phase, which activates the swallowing reflex to move the bolus through the throat while protecting the airway; and the esophageal phase, which involves peristaltic movements that transport the bolus into the stomach (Song et al., 2024). This implies that disruption at any of these stages due to neurological damage can cause dysphagia.

Dysphagia poses serious health risks on a patient's quality of life with a profound effect on it. One of the key complications is aspiration pneumonia, which is a life-threatening condition that occurs when food, liquid, or saliva enters the lungs and leads to infection. Dysphagia has

a significant effect on aspiration, and it makes pneumonia a common and dangerous complication (Martino et al., 2005; Rofes et al., 2018).

Moreover, difficulty swallowing often results in insufficient intake of nutrients and fluids, which leads to significant weight loss, muscle wasting, and issues in relation to electrolytes. All of these issues can hinder recovery and worsen overall health outcomes, and may result in malnutrition and dehydration (Arnold et al., 2016; Rofes et al., 2018). Beyond physical health, dysphagia has an impact on social enjoyment. It may create a fear of eating in public, embarrassment, and social isolation, may substantially reduce overall quality of life (Arnold et al., 2016; Rofes et al., 2018).

Signs of dysphagia may include coughing or choking during meals, which produces a wet or gurgly sound after swallowing, feeling food is stuck inside the throat, and having trouble in breathing after eating (Song et al., 2024). Brainstem lesions, though a less common issue, often result in more severe and long-lasting swallowing difficulties, with around 40% of stroke survivors facing chronic dysphagia (Rofes et al., 2018). Given all these serious outcomes, early and careful detection of dysphagia, its assessment, and management are essential for preventing complications, which improves nutritional status, and enhances stroke patients' overall quality of life (Rofes et al., 2018).

2.2. The Role and Burden of Caregivers

Caregivers, usually family members or close friends, can play a crucial and often challenging role in the long-term recovery and daily care of stroke patients, especially in the case of patients having dysphagia. Their responsibilities can go beyond just physical help; rather they have many duties that can deeply affect the well-being of patients.

2.2.1. The Evolving Role of Informal Caregivers

In many areas, caregivers of stroke survivors become the main source of support, including basic daily activities such as bathing and dressing, managing medication, providing emotional support, and in coordinating healthcare appointments and services (Muhrodji et al., 2022; Wang et al., 2023). Such sudden changes in responsibility usually alter family dynamics and personal routines. For patients with dysphagia, caregivers usually have a more specific roles, from nutrition managers, to feeding assistants, and to vigilant monitors for aspiration risks. Usually, they serve as advocates for their loved ones within the healthcare system and can facilitate communication by ensuring that their needs are adequately addressed. However, the significant challenge is that many caregivers take on these roles without even getting formal training or having proper preparation.

2.2.2. Dimensions of Caregiver Burden

The demands of caregiving often result in complex burdens that can affect many aspects of the caregiver's life.

2.2.2.1. Physical Burden

Caregivers frequently face physical strain from the ongoing need to help their patients with mobility, transfers, and personal care. This strain often brings chronic fatigue, lack of rest, and a higher chance of musculoskeletal injuries (Han & Haley, 1999). Many caregivers report difficulties in maintaining their own physical health which can lead to serious health complications due to persistent tiredness and insufficient sleep (Han & Haley, 1999).

2.2.2.2. Emotional and Psychological Burden

The emotional and psychological challenges for caregivers are also significant concerns. Many of them may experience increased levels of stress, anxiety, and depression (Abubakar & Jamoh, 2017; Kalra et al., 2004). They often grieve for the loss of their loved one's abilities before the stroke and may experience feelings of helplessness. Burnout, depersonalization, and a diminished sense of accomplishment, are also serious risks which stem from the relentless nature of caregiving (Abubakar & Jamoh, 2017). Similarly, caregivers of patients with dysphagia may face additional emotional burdens due to the constant fear of aspiration and the distress of witnessing feeding difficulties (Arnold et al., 2016; Reimer et al., 1998).

2.2.2.3. Social and Financial Burden

One of the consequences of caregiving is social isolation, which is due to the fact that caregivers may find their social activities limited by the need to be present or by lack of time and energy. This can result in changes or even loss of relationships with friends and family, increasing feelings of loneliness (Bakas et al., 2022).

From the financial point of view, caregiving can create immense pressure. Many caregivers, typically one- to two-thirds, work outside the home (Bakas et al., 2022; Rigby et al., 2009). However, what is alarming is that at least a quarter of caregivers under 65 must either leave their jobs or decrease their hours to fulfill their caregiving duties. This situation may lead to lost income and increased financial strain, which may even be worsened by medical costs (Camak, 2015).

2.2.3. Specific Challenges in Dysphagia Management for Caregivers

Caregivers of individuals with dysphagia may face unique challenges that require specialized attention. A major concern here is ensuring safe and effective feeding to avoid life-threatening complications including aspiration pneumonia (Martino et al., 2005). Due to this, caregivers often express fear of aspiration and the pressure to ensure proper nutrition, which then adds to their burden (Arnold et al., 2016). They often need to carefully choose complex feeding strategies, including preparing texture-modified foods like pureed meals and thickened liquids. This process and closely monitoring the patient's swallowing safety during meals can be very stressful (Song et al., 2024).

Moreover, caregivers are required to manage the patient's emotional responses to eating difficulties, including frustration, anxiety, or even refusal to eat, which makes mealtimes more complex (Reimer et al., 1998). Similarly, ensuring the patient's comfort during meals and managing feeding-related anxiety are also significant hurdles. Transitional feeding methods, like moving from oral intake to tube feeding, can create additional challenges that require specific knowledge, equipment, and emotional adjustments for both the patient and the caregiver (Crary & Groher, 2003). On the other hand, the lack of comprehensive training and accessible resources often makes caregivers feel overwhelmed and unsure about how to manage these complex feeding issues (Kielb et al., 2022). This in turn usually results in feelings of isolation and increased stress (Bakas et al., 2009).

2.3. Coping Strategies and Resilience in Caregivers

Despite the considerable difficulties in caring for post-stroke patients with dysphagia, caregivers often find various strategies to manage challenges and build resilience. Knowing these coping strategies is essential for creating effective support programs for caregivers.

2.3.1. Adaptive Coping Mechanisms

Mostly caregivers use a mix of practical and emotional strategies to manage their demanding roles. For feeding challenges, caregivers can learn proper techniques for preparing modified diets, such as soft or thickened foods, and ensure that patients are positioned correctly during meals. They keep an eye out for signs of swallowing problems, such as coughing or choking, and adjust feeding practices as needed (Lai et al., 2018). Training in feeding techniques, including tube feeding if medically allowed and necessary, is critical for caregivers to feel confident and capable in this responsibility (Ye et al., 2025).

In addition to feeding, caregivers may learn safe transfer techniques and may be able to ensure proper positioning to avoid complications like bedsores or falls (Muhrodji et al., 2022). They often are successful in managing their time better by creating structured daily schedules or seeking outside help from healthcare professionals or community services. From emotional perspective, many caregivers cope with the challenges by reaching out for support from family or joining caregiver support groups, which provide spaces to share their experiences, advice, and lessen unwanted feelings such as feelings of isolation (Rigby et al., 2009). On the other hand, seeking professional counseling can also be a valuable strategy for managing stress, anxiety, and depression. Caregivers often seek knowledge about stroke and dysphagia to understand the condition, and to decide how to manage it in a better way, and any possible complications. This knowledge can empower them to make informed choices and manage their loved one’s care better (Rigby et al., 2009).

2.3.2. Factors Influencing Caregiver Resilience

Caregiver resilience, which is the ability to cope positively with stress and challenges, depends on several factors. Strong support networks, including family, friends, community groups, and healthcare professionals, are vital for caregivers to ease the weight of their burden (Rigby et al., 2009). Provision of timely quality education about dysphagia management, caregiving skills, and available resources can greatly boost caregivers' confidence and can reduce feelings of being overwhelmed (Kielb et al., 2022; Ye et al., 2025).

Generally, caregivers with a positive outlook, good emotional management, and strong problem-solving skills can handle caregiving demands in a better way (Wang et al., 2023). In contrast, negative viewpoints can predict depression in new caregivers and may be harmful for care recipients (Wang et al., 2023). Hence, supporting emotional well-being of caregivers and promoting positive thinking are key to reduce depression and enhance their confidence (Wang et al., 2023).

2.4. Perceived Challenges in Managing Dysphagia from the Caregiver's Perspective

Managing dysphagia in post-stroke patients can present a specific set of daily challenges that may go beyond clinical issues. These challenges are often expressed by emotional strain, practical difficulties, and a lack of support. More importantly, a major concern for caregivers is the constant fear of aspiration, which may require them to remain vigilant during meals, watching for signs of choking, coughing, or breathing problems. This anxiety can have an effect to increase their overall burden and can turn mealtimes into stressful situations instead of moments of comfort (Arnold et al., 2016; Martino et al., 2005).

Caregivers may also face the time-consuming task of preparing modified diets, which includes thickening liquids and pureeing foods to ensure safety for their patients. For caregivers, the emotional situation of watching a loved one struggle with something as basic as eating can be heartbreaking. They must also manage the patient's emotional reactions, such as frustration or refusal to eat, which leads them to conflicts and more distress at mealtimes (Song et al., 2024). In addition to the above, transitioning between feeding methods, like moving from oral intake to tube feeding (e.g., nasogastric tube or gastrostomy tube), can bring notable challenges. These changes require specific knowledge, proper equipment management, and emotional adjustments for both patients and caregivers, often without adequate guidance (Crary & Groher, 2003).

In general, a common theme in the literature is the lack of proper training and accessible resources for caregivers, which affects many caregivers in a way to feel unprepared and overwhelmed due to the complex feeding strategies and potential complications (Kielb et al., 2022). This lack of support can deepen caregivers' feelings of isolation and increase stress on their duties (Bakas et al., 2009).

2.5. Support Systems and Interventions for Caregivers

Even though evidence specifically addressing caregivers of dysphagic stroke patients is somewhat lacking, the available literature points to various support systems and interventions designed to ease caregiver burden. Hence, effective support is essential for improving caregiver's well-being, which in turn enhances patient outcomes.

2.5.1. Formal Support Systems

Learning about dysphagia, including its signs, symptoms, and management strategies, is crucial. Professional psychological support, such as individual counseling or family therapy, can help caregivers manage grief, stress, anxiety, and depression, and develop healthier coping methods. Formal support systems usually come from healthcare professionals and institutions. These include educational programs that provide caregivers with practical skills for patient care, like safe feeding techniques, proper positioning, medication management, and mobility help (Ye et al., 2025).

Moreover, access to rehabilitation services from speech and language therapists, dietitians, occupational therapists, and physical therapists can offer specialized help for dysphagia management, nutritional planning, and adaptive strategies for day-to-day experiences. Respite care, although often limited and hard to find, may allow caregivers a break from their duties, which provides needed rest and time for personal activities to prevent burnout. The use of assistive technologies, like adaptive tools, can also reduce physical demands on caregivers and boost patient independence, which may help lower caregiver burden (Kielb et al., 2022).

2.5.2. Informal Support Networks

Informal support networks can play an important role in adding formal care. Help from family and friends can be a great way to provide practical support such as assisting with chores or caring for the patient for a few hours, as well as emotional support, which can lessen feelings of isolation. Peer support groups offer valuable space for caregivers to connect with other people facing similar challenges, which allow for shared experiences, advice, and emotional support. Local community groups or charities may also provide various supports, including educational workshops, social activities, or assistance programs (Rigby et al., 2009).

2.5.3. Effectiveness and Gaps in Current Interventions

Though various interventions exist, systematic reviews show that evidence of their effectiveness in significantly reducing caregiver burden and improving outcomes is often limited. Many interventions lack strong research methods, and there's a clear gap in evidence-based programs designed specifically to the unique needs of caregivers of dysphagic stroke patients (Mack & Hildebrand, 2023).

On the other hand, a significant gap exists in policy and practice. Current healthcare policies often do not involve caregivers as active partners in the process of recovery or provide enough accessible resources to thoroughly support them (Garnett et al., 2022; Teasell et al., 2020). This shows that there is a critical need for integrated care models that formally recognize the caregiver's role, provide continuous education and training, offer psychological support, and ensure access to respite and financial assistance. The lack of coordination between healthcare providers and a lack of standardized support programs can contribute to the unmet needs of this vulnerable population.

2.6. Theoretical Frameworks for Understanding Caregiver Experiences

Established theoretical frameworks can benefit in understanding the complex experiences of caregivers for post-stroke patients with dysphagia benefits from. These frameworks can help interpret and analyze the various factors contributing to caregiver burden, coping, and well-being.

2.6.1. Stress and Coping Theory (Lazarus & Folkman)

The transactional model of stress and coping, developed by Lazarus and Folkman in 1984, is very relevant for understanding caregiver experiences and practices. This theory states that stress is not just an external event but a dynamic interaction between the individuals and environment they are in. Therefore, when faced with a stressor, such as caring for a stroke patient with dysphagia, the individual goes through a two-stage appraisal process as follows:

• Primary appraisal: in this appraisal process, the caregiver assesses the situation to see if it is threatening, harmful, or challenging. For caregivers of dysphagia patients, the daily threat of aspiration, the demanding nature of feeding, and the fear of complications are viewed as highly threatening.

• Secondary appraisal: in this appraisal, caregivers evaluate their resources and coping options for managing the perceived threat. This evaluation may include assessing personal coping skills, available social support, and access to external resources.

According to the theory, coping is a dynamic process involving both problem-focused (e.g., learning feeding techniques, seeking information) and emotion-focused strategies (e.g., seeking emotional support, positive reappraisal). Similarly, the effectiveness of these coping strategies can have an influence on the caregiver's well-being and levels of burden. This framework shows the subjective nature of caregiver burden and can signify how important individual appraisal and coping efforts are for the caregivers in general (Folkman & Moskowitz, 2004).

2.6.2. Caregiver Burden Theory

This theory, which builds on earlier models, states that the demands of caregiving, when they exceed the caregiver's perceived resources, can lead to various forms of burden (Zarit et al., 1980). Encompassing the caregiver's perception of distress and difficulty, caregivers' burden is not solely objective (e.g., hours spent caregiving) but also highly subjective. The theory identifies several dimensions of burden, which includes physical, emotional, social, and financial. In the context of caregiving for dysphagia patients, the constant care required for safe feeding, the emotional distress related to choking, and the financial implications of specialized diets or lost income all these can have their own contribution to this perceived burden (Zarit, 2017). The theory also states that interventions reducing burden should focus on both reducing objective demands and enhancing the caregiver's perceived coping capacity and support.

2.6.3. Social Support Theory

Social support theory states that social networks and relationships have a critical role in buffering the negative impacts of stress and promoting well-being (Cohen & Wills, 1985). For caregivers, both formal and informal social support can provide emotional comfort, practical assistance, and informational resources. In the context of dysphagia, feelings of isolation and inadequacy can be significantly alleviated by receiving practical advice on feeding techniques from other caregivers or emotional validation from a support group. On the other hand, a lack of adequate social support can exacerbate burden of caregivers and can have a negative impact on health outcomes (House et al., 1988). Recent research consistently underscores the importance of tailored social support interventions for caregivers of individuals with complex medical needs (Kim et al., 2023).

2.6.4. Self-Efficacy Theory (Bandura)

Bandura's Self-Efficacy Theory proposes that an individual's belief in their ability to successfully perform a task (self-efficacy) can have a profound influence on their motivation, behavior, and emotional well-being (Bandura, 1997). Especially for caregivers of dysphagia patients, high self-efficacy in managing feeding, identifying aspiration signs, and implementing therapeutic strategies can bring reduced stress, improved confidence, and better patient outcomes. However, low self-efficacy can result in feelings of helplessness, anxiety, and avoidance behaviors. Therefore, interventions designed to enhance caregiver self-efficacy through education, skill training, and positive reinforcement are important for empowering caregivers and improving their caregiving experience (Schwarzer & Jerusalem, 1995).

2.6.5. Family Systems Theory

According to this theory, the family is viewed as an interconnected system where the actions and experiences of one member affect all others (Bowen, 1978). Thais means that when a family member experiences a stroke and develops dysphagia, it creates a ripple effect throughout the entire family unit. The role of caregivers may be changed, family routines may be disrupted, and existing family dynamics may be significantly challenged. The theory emphasizes how family communication patterns, roles, and coping styles can influence the family adapts to the illness (Walsh, 2012).

2.6.6. Ecological Systems Theory (Bronfenbrenner)

Bronfenbrenner's Ecological Systems Theory (1979) provides valuable framework which helps to understand how multiple layers of environmental influences interact to shape the

experiences of caregivers. This theory states that an individual's development is influenced by five interconnected systems:

- **Microsystem:** This refers to the immediate environments with which the caregiver directly interacts, such as the home, family members, healthcare professionals, and the stroke patient themselves. Within this layer, the direct interactions during feeding, the quality of communication with medical staff, and the dynamics within the household can have a direct impact on the caregiver's daily experience of dysphagia management.
- **Mesosystem:** This layer involves the interconnections between different microsystems. For example, the communication and coordination between the rehabilitation team (a microsystem) and the family (another microsystem) can have a significant effect on how well caregivers are prepared and supported in managing dysphagia at home.
- **Exosystem:** This layer comprises external settings that have an indirect effect on the caregiver. For instance, the caregiver's workplace policies (e.g., flexible hours, leave options), the availability and accessibility of community support services (e.g., respite care centers, support groups), or hospital discharge planning protocols, all these can be included here. While the caregiver is not expected to directly participate in these settings, their policies and resources significantly impact their capacity to provide care and maintain their own well-being.
- **Macrosystem:** This refers to broader cultural values, laws, customs, and economic conditions having an influence on the other systems. This system may include societal attitudes towards disability and caregiving, healthcare policies regarding caregiver

support and funding, and cultural norms around family responsibility. For instance, a culture that places high value on family care may increase family expectations on caregivers, while inadequate national healthcare policies for long-term care can have an impact on caregivers to feel unsupported.

- **Chronosystem:** This refers to the patterns of environmental events and transitions over the course of life, as well as sociohistorical circumstances. For instance, the timing of the stroke, the progression of the patient's dysphagia, changes in the caregiver's own life stage (e.g., retirement, children leaving home), and broader societal shifts in caregiving trends or healthcare innovations, are included under the chronosystem. The system acknowledges that the caregiver's experience is not static, but it is evolving over time (Bronfenbrenner & Ceci, 1994).

2.6.7. Conservation of Resources Theory (Hobfoll)

Hobfoll's Conservation of Resources (COR) theory (1989) proposes that individuals strive to obtain, retain, and protect resources. Resources are broadly defined as anything that an individual values, such as objects (e.g., money, home), personal characteristics (e.g., self-esteem, coping skills), conditions (e.g., employment, marriage), and energies (e.g., time, knowledge). Stress occurs when individuals face one or more of the following:

- **Threat of resource loss:** The fear of losing existing resources (e.g., losing a job due to caregiving demands, losing personal health).
- **Actual resource loss:** The actual depletion of resources (e.g., financial strain, loss of social life, emotional exhaustion).

- **Lack of resource gain after investment:** Investing resources (e.g., time, energy in caregiving) without receiving a commensurate return or benefit.

The COR theory is highly pertinent especially for caregivers of post-stroke patients with dysphagia. Caregiving requires a lot of resources: time spent on feeding, physical energy for transfers, financial resources for special diets, and emotional energy to manage patient distress. These resources often come with the threat or actual loss of other valuable resources, such as personal leisure time, social connections, career opportunities, and even their own health. The constant fear of aspiration (threat of resource loss: patient's health, caregiver's peace of mind) and the demanding nature of meal preparation (loss of time, energy) can have a direct impact on COR principles. This means that when caregivers perceive a net loss of resources, they may experience increased stress and burnout. Conversely, interventions that help caregivers conserve or gain resources (e.g., respite care providing time, education improving skills/knowledge, financial aid) can have an effect in reducing stress and enhance well-being (Hobfoll & Shirom, 2000).

2.6.8. Neuroplasticity Theory

Neuroplasticity refers to the central nervous system's capacity to undergo structural and functional changes in response to internal or external stimuli. In the context of communication recovery, such as following a stroke or traumatic brain injury, neuroplasticity is the mechanism through which the brain reorganizes itself by forming new neural pathways to compensate for damaged areas (Grefkes & Fink, 2020). Caregiver support is a critical environmental catalyst for this process. Research indicates that frequent, high-quality communicative interactions provided by trained caregivers can stimulate neural rewiring

through "experience-dependent plasticity" (Kleim & Jones, 2008). Recent studies emphasize that when caregivers provide consistent, socially engaging environments, they help maintain the "dosage" of therapy required to trigger these biological changes, leading to superior functional recovery compared to isolated patients (Cramer et al., 2011; Grefkes & Fink, 2020).

2.6.9. Person-Centered Care (PCC) Theory

Person-Centered Care moves away from the traditional medical model, prioritizing the patient’s individual values, preferences, and biographical history over the disease itself. This theory posits that rehabilitation is most effective when the patient is an active collaborator rather than a passive recipient of care (Kogan et al., 2016). When caregivers adopt a person-centered approach, they tailor communication strategies to align with the patient’s specific life goals, which significantly boosts patient motivation and self-efficacy. By respecting the patient's autonomy, caregivers reduce the psychological distress often associated with communication disorders. According to McCormack and McCance (2017), PCC fosters a "therapeutic narrative" where the patient feels heard, which has been shown to improve adherence to rehabilitation protocols and overall quality of life outcomes (Kogan et al., 2016).

2.6.10. The Biopsychosocial Model

The Biopsychosocial Model provides a holistic framework, suggesting that health and recovery are not merely biological events but are shaped by the intricate interplay of biological, psychological, and social factors. In communication rehabilitation, the "biological" involves the physical injury, the "psychological" involves the patient's mental health and

coping mechanisms, and the "social" involves the support system. Caregivers are the primary agents of the "social" pillar (Engel, 1977/2023 reprint). A strong social support network can mitigate the biological impact of stress hormones that hinder recovery, while simultaneously providing the emotional stability necessary for the patient to engage in demanding speech therapies. Recent literature suggests that integrating the caregiver into the care plan addresses the "social" determinants of health, resulting in more sustainable long-term recovery than treating the physiological symptoms in isolation (Wade & Halligan, 2017).

2.7. Empirical Review of Literature

The empirical literature consistently shows that stroke and dysphagia have profound and multifaceted impact on both patients and their informal caregivers, predominantly family members. Research emphasizes the high occurrence of dysphagia after stroke. For instance, studies like that by Martino et al. (2005), a systematic review and meta-analysis, revealed that up to 65% of acute stroke patients experience swallowing difficulties, which significantly increase their risk of life-threatening aspiration pneumonia. This clinical reality has a direct implication in substantial challenges for caregivers.

The role of caregivers is often comprehensive and unplanned, from physical assistance, medication management, emotional support, to critical coordination within the healthcare system (Muhrodji et al., 2022; Wang et al., 2023). For those caregivers dealing with individuals with dysphagia, this role intensifies, requiring specialized skills in nutrition management, feeding assistance, and vigilant monitoring for aspiration. Qualitative studies, such as the work by Arnold et al. (2016) who interviewed 15 caregivers, showed the profound fear of aspiration, the emotional distress of witnessing feeding difficulties, and the practical challenges of preparing texture-modified diets. Similarly, Rofes et al. (2018), in their mixed-

methods study involving 70 patient-caregiver dyads, confirmed that dysphagia can severely impair the quality of life for both stroke survivors and their caregivers. This in turn extends beyond physical symptoms as it encompasses significant emotional and social challenges.

The burden on caregivers can be manifested from different perspectives such as physical, emotional, social, and financial. Muhrodji et al. (2022), in a quantitative study with 100 family caregivers, found that there is a moderate to high levels of physical strain due to assisting with mobility and daily care, frequently reporting fatigue and musculoskeletal pain. Emotionally, caregivers may face elevated levels of stress, anxiety, and depression, with a risk of burnout (Abubakar & Jamoh, 2017; Kalra et al., 2004). This emotional distress is amplified for dysphagia caregivers because they constantly worry about aspiration (Arnold et al., 2016; Reimer et al., 1998). From the social perspective, caregivers often experience isolation due to restricted social activities and strained relationships (Bakas et al., 2022). On the other hand, research also showed that financial issues are also among the challenges faced by caregivers. Studies showed that a significant proportion, often one- to two-thirds, are employed, yet many (at least a quarter of those under 65) are forced to reduce work hours or leave their jobs, which leads to lost income and increased hardship (Bakas et al., 2022; Camak, 2015; Rigby et al., 2009). The challenges on caregivers may also be further compounded by communication difficulties, as highlighted by Poomalai et al. (2023) in their quantitative study of 150 stroke survivors and caregivers, which found that aphasia and dysarthria can significantly correlate with lower patient quality of life and higher caregiver burden.

Despite the abovementioned challenges, caregivers employ various coping strategies and exhibit resilience. Lai et al. (2018) noted caregivers' adaptive learning of feeding techniques

and patient positioning. Proactive information seeking about stroke and dysphagia is also a common adaptive strategy (Kielb et al., 2022). Among the factors that influence resilience, strong formal and informal support networks (Rigby et al., 2009), adequate education on dysphagia management (Kielb et al., 2022; Ye et al., 2025), a positive outlook, effective emotional regulation, and high self-efficacy in problem-solving (Wang et al., 2023) can be mentioned. Wang et al. (2023), in their study of 120 new caregivers, found that a negative problem orientation attracted higher depression, while self-efficacy was linked to lower depression, which underscores the importance of psychological support.

However, a consistent theme in existing literature was the perceived lack of comprehensive training and accessible resources for caregivers. (Kielb et al., 2022). The transition between different feeding methods (e.g., oral to tube feeding) was particularly challenged due to insufficient professional guidance (Crary & Groher, 2003). Song et al. (2024), using questionnaires and focus groups with 60 caregivers, identified in his study that there exists a significant community-level challenges in preparing texture-modified foods and managing patient refusal to eat. This indicates that there is a strong desire for practical guidance.

Research showed that existing support systems, both formal and informal, can alleviate caregiver burden. Formal supports including educational programs (Ye et al., 2025), psychological counseling, and access to rehabilitation services. Respite care and assistive technologies can also provide relief. Informal support networks, such as family, friends, and peer support groups, are also essential for practical assistance and emotional comfort (Rigby et al., 2009). However, systematic reviews, such as Mack and Hildebrand (2023), indicate that the evidence for the overall effectiveness of existing interventions in significantly reducing

caregiver burden is often limited, with a particular scarcity of specifically tailored for caregivers of dysphagic stroke patients.

Research conducted by Garnett et al. (2022) showed that a significant policy and practice gap exists. Current healthcare policies often fail to adequately integrate caregivers or provide sufficient, readily accessible resources (Teasell et al., 2020). There is also a need for integrated care models that formally acknowledge the caregiver's role, provide continuous education and training, offer psychological support, and make sure that access to respite and financial assistance is available. Furthermore, Jambi et al. (2024), in his quantitative study of 200 family caregivers, found gaps in the caregivers' knowledge regarding stroke management, including dysphagia, which shows that there is a need for targeted educational interventions. On the other hand, Bushnell et al. (2024)'s review of stroke rehabilitation guidelines implicitly shows the importance of caregiver involvement in the long-term management and functional outcomes of stroke survivors.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

This chapter discusses the methods used for the study, specifically the research design, setting, participants, sampling procedures, data collection tools, and analysis methods, along with key ethical considerations.

3.1. Research Approach and Design

This study adopted a qualitative research approach, specifically employing a descriptive and interpretive phenomenological design. This approach was chosen to gain an in-depth understanding of the lived experiences and subjective realities of caregivers providing care to post-stroke patients with swallowing difficulties. A phenomenological approach is particularly suited to exploring complex human experiences that quantitative methods might overlook. Its purpose was to describe the essence of the phenomenon as experienced by the participants, focusing on their perceptions, interpretations, and the meaning they ascribe to their caregiving roles.

3.2. Research Site

The study was conducted at St. Peter Specialized Hospital in Addis Ababa, Ethiopia. Addis Ababa, as the capital city, serves as a major healthcare hub, where patients from various regions are involved. This provides a relevant and accessible setting for recruiting participants. St. Peter Specialized Hospital was selected due to its specialized neurology department and stroke outpatient clinic, which regularly manage post-stroke patients, including those with swallowing difficulties. The study period was extended from March 2025 to June 2025.

3.3. Target Population

The target population for this study comprised all caregivers of post-stroke patients with swallowing difficulties who attend evaluations or follow-up appointments at the stroke outpatient department of St. Peter Specialized Hospital during the abovementioned study period. This ensures that the study population is directly involved in the daily care of individuals.

3.4. Study Participants

The study participants were caregivers (family members), primarily responsible for providing care to post-stroke patients who are diagnosed with swallowing difficulty. The selection criteria for participants are designed to ensure that the caregivers have sufficient experience and insight into the topic under study.

3.5. Eligibility Criteria

3.5.1. Inclusion Criteria

To be included in this study, participants are required to meet the following criteria:

• Caregivers providing care to patients who have had a stroke within 2 months to 1 year before the investigation. This timeframe ensures that caregivers have enough experience with post-stroke care, including managing dysphagia, but are also recent enough in their caregiving task to recall their experiences clearly.

• Caregivers who have provided post-stroke care for at least two months after the stroke. This criterion ensures a minimum level of experience with the caregiving role.

• Participants age must be 18 years and older, which ensures that they have the legal and ethical capacity to provide informed consent.

• Caregivers must be able to communicate effectively in Amharic, the local language, to allow for rich and accurate data collection through interviews.

• Caregivers must voluntarily provide informed consent to participate in the study.

3.5.2. Exclusion Criteria

Caregivers who met any of the following criteria were excluded from the study:

• Caregivers of patients with swallowing difficulties not related to stroke, to keep the focus of the study specific.

• Caregivers who are not directly involved in feeding or managing the patient's swallowing needs. Their experiences would not directly answer the core research questions.

• Caregivers who cannot provide informed consent.

• Caregivers who have been involved in caregiving for less than two months after the stroke, as their experiences may be too recent for the intended purpose.

3.6. Sample Size and Sampling Techniques

3.6.1. Sampling Techniques

A purposeful sampling technique was employed to select participants for this study. This non-probability sampling method is best for qualitative research as it allows the researcher to intentionally choose participants who are most knowledgeable about and experienced with the topic. The selection criteria was aimed at adult caregivers who have been caring for post-stroke patients with swallowing difficulties for at least two months and who have received treatment and follow-up at St. Peter Specialized Hospital in Addis Ababa. Participants were identified and selected with help from neurologists and their staff considering the predetermined inclusion and exclusion criteria.

3.6.2. Sample Size

The sample size for this qualitative study was determined by data saturation. This means that participant recruitment and data collection continued until no new themes or information appeared from the data, and further interviews have no value in providing new insights. Redundancy of information was served as the key indicator for data saturation. Based on similar qualitative studies, a sample size of 7 post-stroke caregivers (4 female and 3 male) with swallowing difficulties was determined to achieve saturation. Considering the provided information, the study included 7 (seven) caregivers.

3.7. Data Collection Tools and Procedure

3.7.1. Data Collection Tools

The primary data collection tool for this study was in-depth, semi-structured interviews conducted with participants. An interview guide was developed, having open-ended questions designed to encourage participants to share their experiences, challenges, coping strategies, social participation, work-life balance, and any additional support.

3.7.2. Procedure of Data Collection

Data was collected at the Neurology Referral Clinic of St. Peter Specialized Hospital. Before the main data collection, a pilot test of the interview guide was conducted with three stroke caregivers who were not part of the main sample. Feedback from these preliminary interviews was then used to revise the interview guide, to ensure clarity, comprehensibility, and effectiveness in eliciting detailed responses. During the interviews, the researcher used questions such as “Can you tell me more?” and “What else have you felt?” to encourage participants to elaborate on their responses. Nonverbal cues, such as facial expressions, were also recorded in field notes to aid in the interpretation of responses. All interviews were conducted by the researcher in a quiet room, following the participants' neurology visits, to ensure privacy and comfort. Each interview lasted between 40 minutes to 110 minutes. All interviews were audio-recorded with the participants' explicit consent and then transcribed verbatim in the original language (Amharic). Finally, these transcriptions were translated into English for analysis.

3.8. Data Analysis Approach

The interview data was transcribed verbatim and manually analyzed using a thematic analysis approach. This method involves systematically identifying, analyzing, and reporting patterns (themes) within the data. The process has several stages from the beginning to the end:

1. **Familiarization:** The researcher repeatedly read the transcribed interviews to gain a comprehensive understanding of the participants' narratives.
2. **Initial Coding:** The data was coded line-by-line, so that initial codes that capture interesting features of the data relevant to the research questions are generated.
3. **Searching for Themes:** Similar codes were grouped together to form potential themes, which represent broader patterns of meaning.
4. **Reviewing Themes:** The identified themes were reviewed against the entire dataset to ensure they accurately reflect the data and to refine their scope and definition. This stage involved splitting, combining, or discarding themes.
5. **Defining and Naming Themes:** Each theme was clearly defined, and a concise, descriptive name was assigned to it. The relationship between themes and sub-themes were also articulated.
6. **Producing the Report:** The final report included the findings, illustrating each theme with rich, verbatim quotes from the participants to enhance credibility.

3.9. Reliability of the Data

To ensure the reliability of the qualitative findings, the study adhered to the following established criteria:

- **Credibility:** This was ensured through prolonged engagement with the data, which allows for deep immersion and understanding. Member checking, where findings are shared with participants for validation, was also employed. An external check on the analysis was provided using peer debriefing, involving discussions with an experienced qualitative researcher.

- **Transferability:** To enable readers to assess the applicability of the findings to other similar settings, broad descriptions of the research context, participants' characteristics, and the phenomenon under study were provided.
- **Dependability:** An audit trail of all research decisions was maintained to get external scrutiny of the research process. For instance, methodological choices, data collection procedures, and analytical steps were checked and confirmed.
- **Confirmability:** The researcher maintained a reflexive journal to acknowledge and mitigate potential biases. The analysis was grounded in the data, ensuring that interpretations are derived from the participants' accounts rather than researcher preconceptions. Illustrative quotes were also employed to demonstrate the link between the data and its interpretations.

3.10. Ethical Considerations

The study was conducted in strict accordance with ethical guidelines to protect the rights and welfare of all participants.

Firstly, ethical clearance was obtained from the Ethical Review Committee before any data collection. A support letter was sent to the Neurology Department at St. Peter Specialized Hospital to notify them about the research project in advance.

Secondly, written informed consent was acquired from each participant and voluntary participation was ensured by the participants. Before obtaining consent, a detailed explanation of the study's goals, methods, significance of the study, and any foreseeable risks were provided.

Thirdly, participants' identities and personal information were kept strictly confidential. Names of participants were not used in data analysis or the final report. Each participant was

assigned a unique code known only to the researcher to ensure anonymity and all personal data was accessible only to the researcher.

Finally, participants were clearly informed of their right to withdraw from the study at any time, without any negative consequence.

CHAPTER FOUR

RESULTS

This chapter presents the findings of the study derived from the in-depth interviews conducted with seven caregivers of post-stroke patients experiencing swallowing difficulties in Addis Ababa. The section begins by introducing the demographic characteristics of the participating caregivers, followed by a comprehensive thematic analysis of their lived experiences, challenges, coping strategies, and perceived support needs in managing dysphagia. The findings are organized according to the core interview questions.

4.1. Demographic Characteristics of Caregivers and Stroke Survivors

The demographic profile of the participants provides the essential context required to interpret the qualitative findings of this study. In qualitative research, the socio-economic and cultural background of the caregiver-patient dyad is not merely descriptive; it is a critical determinant of the resources available for dysphagia management and the specific challenges faced in a home-based setting.

The caregivers' relationships with the stroke survivors varied, including spouses, daughters, and girlfriends. This shows that different family structures were involved in long-term care.

Caregiving periods ranged from four months to three years, which indicates that experiences from early adaptation to more established routines were considered. Specifically, most of the caregivers provided care for three years. Some caregivers had been guardians for over 5 years and had been caring for stroke-related issues for more than a year.

Gender: The stroke survivors included both 3 male and 4 female patients.

Age: Caregivers' ages ranged from 25 to 47 years.

Duration of Stroke: The time since the stroke event for patients spanned four months to three years, matching the caregivers' duration of care.

Medical Conditions: All stroke survivors were diagnosed with dysphagia, with some also having other health issues like hypertension and diabetes, common risk factors for stroke.

4.1.1. Contextual Relevance of the Study Setting

The study was conducted at St. Peter Specialized Hospital in Addis Ababa, which serves a diverse urban population. The demographic data gathered—including age, gender, and duration of care—functions as a baseline to understand the "caregiver burden." For instance, the length of time a caregiver has managed dysphagia (ranging from four months to five years) directly correlates with their level of psychological exhaustion versus their mastery of adaptive feeding techniques.

4.1.2. Relevance of Ethnicity and Cultural Context

While this study does not focus on biological differences between ethnic groups, ethnicity is highly relevant in the Ethiopian context as it dictates dietary habits, linguistic communication, and spiritual coping mechanisms. In Addis Ababa, a multi-ethnic urban center, ethnicity shapes the "food culture" that caregivers must navigate. For example, the preparation of traditional staples like Injera or different types of "Wot" (stews) requires specific modifications for a dysphagic patient. Understanding the ethnic and cultural background of the stroke survivors helps explain why certain caregivers struggle more with "texture modification" than others, as some traditional diets are harder to liquefy or mash than Western-style diets. Furthermore, ethnicity often influences the "Extended Family Support" system, where certain cultural norms may place a heavier burden on a single female relative rather than a communal effort.

4.2. Caregivers' Experiences and Challenges in Managing Dysphagia

The qualitative data revealed that caregiving for post-stroke dysphagia is not merely a task-oriented role but an emotionally taxing journey characterized by a profound sense of responsibility and fear. The following sub-themes represent the core challenges identified by the participants.

4.2.1. The Psychological Trauma of Aspiration and Choking

For most caregivers, the most significant challenge was the acute anxiety associated with the risk of aspiration. This fear was not localized to mealtimes but persisted as a constant psychological burden.

Caregiver 3 (C3) provided a vivid verbatim account of the life-threatening nature of these episodes:

"Sometimes, after just one bite, he would start hiccupping... I feared it could even be life-threatening. Once, he became unresponsive after choking on water; we had to call doctors immediately. Every meal feels like a gamble where his life is the stake."

This sentiment was echoed by Caregiver 5 (C5), who described the "paralysis of fear" that affects both the caregiver and the patient:

"The constant fear that she might choke seriously was the biggest challenge. It led to a tense environment... I worried when she refused to eat, even though it brought temporary relief from my immediate fear of her aspiration."

4.2.2. Challenges in Mechanical Feeding and Mealtime Management

The Results indicate that caregivers must become lay experts in the mechanics of swallowing. They described the physical labor required to ensure a safe bolus transit, often without formal training.

Caregiver 1 (C1) detailed the physical exhaustion of assisting a patient with poor oral control:

"She needed a long time to chew and swallow a single bolus. Food would get stuck to the roof of her mouth... I would have to raise her from her back and slightly pound her chest as the doctor instructed. It is a slow, grueling process."

Caregiver 7 (C7) highlighted the transition from social eating to a clinical "procedure":

"He could hardly swallow anything—not even water. We had to thicken every liquid and keep suction equipment nearby. Mealtimes became a period of constant tension regarding his posture and the pace of eating."

4.3. Impact on Caregivers' Lives: The "Totalizing" Nature of Care

Dysphagia caregiving was found to permeate every aspect of the participants' lives, leading to what sociologists call "biographical disruption"—where one's life plans are completely halted by the illness of another.

4.3.1. Social Isolation and the "Shrinking" Social Circle

The social impact was characterized by a sense of abandonment. C1 described the emotional toll of social withdrawal:

"I stopped meeting and chatting with almost all my friends. The people that were close to me became distant. I felt completely abandoned... I initially used to hate my life and ask God why he created me."

4.3.2. Economic Displacement and Educational Loss

In the Ethiopian context, the lack of professional home-care services forces family members to sacrifice their careers or education. Caregiver 4 (C4) provided a poignant verbatim account:

"I stopped going to school and dropped out of my education to provide care... I became physically weak and tired, and the economic difficulties are constant."

4.4. Adaptive Strategies: Practical and Spiritual Resilience

Despite the lack of formal resources, caregivers developed sophisticated, culture-specific strategies to manage the condition.

4.4.1. Texture Modification and Dietary Adaptation

Caregivers utilized trial-and-error to modify traditional Ethiopian staples. C2 and C4 noted the use of "Beso" and "Shiro" as effective textures, while emphasizing the need to moisten "Injera" to prevent choking.

Caregiver 5 (C5) summarized her systematic approach:

"I prepare only soft foods—porridge, mashed vegetables, and soft bread. I am always present to remind her to take small bites and chew well. Vigilance is my only strategy."

4.4.2. Spirituality as a Foundational Coping Mechanism

The results show that spirituality is not just a personal belief but a functional "coping tool."

Caregiver 1 (C1) reflected on the sustainability of her role:

"Learning about spirituality and applying it made the caregiving experience easier and more sustainable. It gives me the strength to clean her and walk with her when I am exhausted."

4.5. Perceived Support Needs and the Clinical Gap

The final theme highlights a significant disparity between the caregivers' efforts and the support provided by the healthcare system.

4.5.1. The Need for Professional Speech-Language Pathology (SLP) Services

There was a unanimous call for professionalization. Caregiver 7 (C7) provided a powerful concluding statement:

"We’re not professionals, but we’re on the frontlines every day. Training for family caregivers would make a big difference. Right now, everything I do is based on trial and error or Google searches."

4.5.2. Access to Medical Resources

Caregivers specifically identified the need for "affordable thickening agents" and "respite care" to allow them to maintain their own health while providing long-term support.

CHAPTER FIVE

DISCUSSION

This chapter explores the findings presented in Chapter Four and examines the experiences of caregivers within the context of existing literature. It provides information on how to clarify the challenges, coping strategies, and support needs. The chapter also discussed implications for clinical practice, policy, and future research.

5.1. The Pervasive Burden of Dysphagia Caregiving

The findings of this study are aligned with existing literature on the significant burden faced by caregivers of stroke survivors, especially when dysphagia is involved. The widespread "fear of aspiration" expressed by nearly all caregivers in this study (Caregiver 1, 2, 3, 4, 5, 7) confirms previous research showing aspiration pneumonia as a major life-threatening complication and a primary source of caregiver anxiety (Martino et al., 2005; Arnold et al., 2016). This constant vigilance during mealtimes, leading to "tense" environments (Caregiver 5, 7), is a common theme in studies on dysphagia management. The emotional stress of seeing

a loved one choke or refuse food (Caregiver 2, 3, 5, 7) aligns with Arnold et al.'s (2016) findings on the significant emotional burden linked to managing dysphagia.

Beyond the fear of aspiration, the practical challenges of preparing modified diets and the prolonged feeding times described by Caregivers 1, 3, 5, and 7 emphasize the physical and time demands on caregivers. This finding aligned with literature that shows the need for careful food preparation and patient positioning in dysphagia care (Song et al., 2024). The physical strain, such as "back pain" reported by Caregiver 1, 2, 5, and 7, is a documented aspect of caregiver burden, especially when physical assistance with mobility and transfers is involved (Han & Haley, 1999).

The significant disruption to social life and work, shown by Caregiver 1, 2, 4, 5, and 7, further indicates the isolation and financial strain on caregivers. Caregiver 1 and 5 specifically mentioned quitting jobs, while Caregiver 2 and 7 left part-time work, reflecting the tough choices caregivers often face, as discussed by Camak (2015) and Bakas et al. (2022). This comprehensive impact on physical, emotional, social, and financial areas confirms that caregiving for post-stroke dysphagic patients imposes a heavy and complex burden on informal caregivers.

5.2. Coping Strategies and Resilience in an Ethiopian Context

Caregivers in this study showed various coping methods. Respondents showed some strategies found in global literature while also revealing culture-specific adaptations. The practical changes to food consistency and feeding techniques, such as moistening foods (Caregiver 1) or preparing soft, mashed meals (Caregiver 2, 5, 6, 7), align directly with clinical guidelines for dysphagia management (Lai et al., 2018; Song et al., 2024). The use of

structured routines, like feeding schedules and reminders (Caregiver 7), shows effective time management strategies consistent with efficient care (Muhrodji et al., 2022).

A notable aspect of coping in this Ethiopian context is the significant role of spirituality and informal support networks. Caregiver 1 and 4 stated that "Praying and learning spiritual lessons made caregiving easier and more sustainable," and Caregiver 3 relied on "Prayer" as a major part of her life. This illustrates the importance of faith and spiritual resilience, which may be particularly common in culturally and religiously conservative societies like Ethiopia, offering a deep sense of meaning, hope, and strength in tough times. While global literature on caregiver resilience often includes spiritual coping, its prominence here stands out.

Furthermore, the strong informal support from "relatives, friends, and neighbors" (Caregiver 4) and family help (Caregiver 2, 3, 6) shows the crucial role of community and kinship networks in shared caregiving, a common aspect of many non-Western cultures (Rigby et al., 2009). This informal support acts as an important barrier against caregiver isolation and burden. Caregiver 7's participation in an "online support group for caregivers" indicates a modern strategy for seeking peer support and practical advice. This shows global trends in using digital platforms for caregiver communities.

The caregivers' emphasis on "patience" (Caregiver 7) and their active attempts to soothe and motivate their loved ones (Caregiver 1), even when faced with food refusal (Caregiver 3), show emotional regulation and a positive problem-solving attitude, which literature links to caregiver resilience and reduced depression (Wang et al., 2023).

5.3. Gaps in Formal Support and Implications for Practice

The study finds significant gaps in the formal support systems for caregivers in Addis Ababa. These gaps reflect challenges shown in global research about inadequate caregiver interventions (Mack & Hildebrand, 2023; Garnett et al., 2022). A common theme is the perceived "lack of comprehensive training and readily accessible resources" (Caregiver 7). Many caregivers feel "unprepared and overwhelmed" (Kielb et al., 2022). Caregiver 7's comment, "Right now, everything I do is based on trial and error or Google searches," clearly shows the informal and often random way caregivers develop their skills due to the absence of structured programs.

The request for "guidance from a speech or swallowing therapist" and the desire for a "speech therapist could visit regularly" (Caregiver 5, 7) indicate a major need for specialized professional input. While formal rehabilitation services are essential, they seem limited in accessibility and integration into a complete caregiver support system for these participants. The demand for "affordable thickening agents and suction machines" (Caregiver 7) indicates a shortage of necessary medical supplies for safe dysphagia management. This situation contrasts with places where such resources may be more available through healthcare systems or insurance.

The lack of mentions of formal respite care, psychological counseling, or structured educational programs (aside from Caregiver 6's mention of psychotherapy for the patient) shows either unawareness of such services or their limited availability in Addis Ababa. This aligns with findings by Teasell et al. (2020), who noted that healthcare policies often do not adequately engage caregivers or provide enough resources.

The study shows a clear need for healthcare systems in Addis Ababa to:

• Create and implement hands-on training programs on dysphagia management, feeding techniques, and aspiration prevention for family caregivers. These programs should be easily accessible and culturally sensitive.

• Increase the availability and access to speech and language therapy services, possibly through home visits or community outreach, to give direct guidance and ongoing support to caregivers.

• Address the affordability and availability of essential medical supplies such as thickening agents and suction equipment.

• Create care pathways that formally recognize the caregiver's role, integrate them into the care team, and ensure easy access to multidisciplinary support, such as psychological counseling and respite services when possible.

5.4. Limitations of the Study

While this study provides valuable insights into the experiences of caregivers of post-stroke patients with swallowing difficulties in Addis Ababa, several limitations should be acknowledged when interpreting its findings and guiding future research.

Firstly, as it is a qualitative study using a phenomenological approach, its findings are more specific to the context and participants under study. The sample consisted solely of caregivers linked to St. Peter Specialized Hospital in Addis Ababa during the defined period i.e. March to June 2025. This specific focus implies that the findings may not be applicable to caregivers

in other regions of Ethiopia, rural areas, or those associated with different healthcare facilities. Because variations in culture, economy, and access to healthcare across different areas could greatly influence caregiver experiences, challenges, and strategies that they are coping with.

The second limitation was that relying on self-reported data through semi-structured interviews may introduce the possibility of recall bias and social desirability bias. This means that participants might unintentionally or intentionally leave out details, misremember events, or present their experiences in a more positive way. Despite their efforts to create a comfortable and private interview setting, the sensitive nature of caregiving burdens might have an impact to lead some participants to underreport their difficulties or emotional distress.

Thirdly, the study's timeframe (March to June 2025) is relatively short to capture the changing nature of caregiving. As the patient's condition fluctuates or as caregivers become more experienced, caregiver burden and coping strategies can change significantly over time. A longitudinal study would give a better understanding of these dynamic shifts.

Finally, while the study aimed to have data saturation, the smaller sample size typical of qualitative research shows some less common but possibly important experiences or challenges that might not have been included in the research. In addition, the study did not explore specific details on how severe dysphagia in patients is, which could influence the level of caregiver burden. Future research could benefit from a larger, more diverse sample incorporating quantitative measures to assess the prevalence and severity of identified burdens and exploring both patient and professional caregivers' perspectives to get a more complete understanding.

5.5. Dissemination of Results

The findings of this study were formally submitted and presented to the Department of Special Needs and Inclusive Education at Addis Ababa University.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

This chapter presents the conclusions of the study and recommendations derived from the research findings. The chapter presents in detail the recommendations for healthcare professionals and institutions, policymakers and stakeholders, and future research

6.1. Conclusion of the Study

The study clearly shows that caregivers of post-stroke patients with dysphagia in Addis Ababa carry a heavy and complex burden. The widespread "fear of aspiration" stands out as a major

concern, significantly affecting mealtimes and the emotional well-being of caregivers. Beyond this fear, caregivers encounter significant practical challenges such as careful food preparation, prolonged feeding times, and managing unpredictable choking incidents. These challenges severely impact their personal lives, which leads to emotional distress, social isolation, physical strain, and financial difficulties due to changes in employment.

Despite these serious challenges, caregivers demonstrate remarkable resilience and resourcefulness. Their coping strategies include practical changes in feeding techniques, seeking emotional support from their informal networks, and a strong reliance on spiritual coping methods, which are particularly significant in the Ethiopian context. While informal support from family, friends, and neighbors is vital, the study shows serious gaps in formal support systems, especially regarding access to specialized professional guidance from speech and language therapists, thorough training, and affordable medical resources.

6.2. Recommendations

Based on this study's findings, the following recommendations are drawn from the conclusions of the study.

6.2.1. Recommendations for Healthcare Professionals and Institutions

Healthcare Professionals and Institutions should do the following:

1) Hospitals and rehabilitation centers should create practical training programs for caregivers of dysphagia patients. These should include safe feeding techniques, food modification strategies, aspiration precautions, recognizing choking signs, and basic emergency response.

2) Increase the availability of speech and language therapists for post-stroke follow-up, particularly for dysphagia management. This could involve hospital-based outpatient clinics, community outreach programs, or home visit services to provide direct guidance, personalized feeding plans, and ongoing support for caregivers.

3) Acknowledge and address the emotional and psychological challenges faced by caregivers by providing easy access to psychological counseling services, stress management techniques, and support groups where caregivers can share experiences and coping strategies.

4) Collaborate with pharmaceutical companies, NGOs, or government agencies to ensure affordable and accessible supplies of thickening agents, adaptive feeding equipment, and suction machines for home use where necessary.

6.2.2. Recommendations for Policymakers and Stakeholders

Policymakers and Stakeholders should do the following:

1) Officially recognize the vital role of informal caregivers in post-stroke recovery and integrate caregiver support into national health policies related to stroke and rehabilitation.

2) Allocate funding and resources to establish and maintain caregiver training initiatives and explore practical models for respite care, offering caregivers temporary relief from their responsibilities.

3) Launch public awareness campaigns to educate communities about stroke, dysphagia, and the needs of caregivers, fostering a more supportive and understanding environment. Encourage community organizations to build volunteer networks to provide practical help to caregiving families.

4) Fund research that examines the effectiveness of culturally adapted interventions and support programs for caregivers of stroke patients with dysphagia in Ethiopia.

6.2.3. Recommendations for Future Research

Future Research should be conducted to:

1) Conduct larger-scale quantitative studies to measure the prevalence and severity of caregiver burden linked to dysphagia in Addis Ababa and rigorously evaluate the effectiveness of specific interventions.

2) Undertake longitudinal studies to understand how caregiver experiences, coping strategies, and support needs change over time as patients progress in recovery or face chronic conditions.

3) Further investigate the role of spiritual practices and traditional beliefs in caregiver resilience and well-being in Ethiopia, identifying how these can be effectively integrated into support frameworks.

4) Examine the feasibility and impact of using telehealth or digital platforms to provide caregiver training, counseling, and peer support, keeping in mind local infrastructure and digital literacy.

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APPENDIX

ANNEX: INTERVIEW QUESTIONS

Interview Questions: Caregivers' Experience of Post-Stroke Patients with Swallowing Difficulty

I. Background Information

1. What is your relationship to the person you are caring for?
2. How long have you been providing care for them?

II. Core Interview Questions

1. Could you tell me about your experience caring for someone who has had a stroke with swallowing difficulties?
    - Probe: What has been most challenging?
2. What specific challenges do you face in managing feeding and mealtimes?
    - Probe: Can you describe a typical mealtime?
    - Probe: How do you manage concerns about choking?
3. What impact has providing care had on your own life, both emotionally and practically?
    - Probe: How has it affected your health, social life, or work?
4. What strategies have you found helpful in managing the challenges of caring for someone with swallowing difficulties?
    - Probe: Have you made any changes to your routine to make things easier?
5. What would make the caregiving experience easier and more sustainable for you?

- Probe: What additional support would be helpful?

III. Closing

1. Is there anything else you would like to share about your experiences that we haven't discussed?