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COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES

DEPARTMENT OF SPECIAL NEEDSAND INCLUSIVE EDUCATION

Lived Experience of Post Stroke Aphasia among Stroke Survivors Followed At Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia: Phenomenological Study, 2024 G.C

By

Samrawit Berihun

June, 2024

Addis Ababa, Ethiopia

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By: Samrawit Berihun

A thesis submitted to Addis Ababa University Department of Special Needs and Inclusive Education, College of Education and Behavioral Studies in partial fulfillment of the requirement for the Degree of Master of Science in Speech and Language Therapy

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I, the undersigned, affirm that the thesis titled "Lived Experience of Post Stroke Aphasia among Stroke Survivors Followed at Tikur Anbessa Specialized Hospital (TASH)" is my original work. All sources of information used in its preparation have been duly acknowledged.

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This affirmation is for the thesis titled "Lived Experience of Post Stroke Aphasia among Stroke Survivors Followed at Tikur Anbessa Specialized Hospital (TASH)". It is Samrawit Berihun's original work, completed under my personal supervision.

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LIST OF ABBREVIATIONS

AAU	Addis Ababa University
TASH	Tikur Anbessa Specialized Hospital
WHO	World Health Organization
SNIE	Special Needs and Inclusive Education
LMIC	Low and Middle Income Countries
PSA	Post-Stroke Aphasia
SLT	Speech Language Therapy
G.C	Gregorian calendar
AAC	Augmentative and Alternative Communication
IRB	Institutional Review Board

ABSTRACT

Stroke survivors are greatly affected by post-stroke aphasia (PSA), complicating rehabilitation due to linguistic and motor hurdles like hemiparesis, coordination problems, gait abnormalities, and swallowing issues. Healthcare limitations in Addis Ababa, Ethiopia, including the absence of speech therapy services, insufficient research funding, and a lack of experts, exacerbate these issues. These factors further impact social, emotional, and physical obstacles, such as social isolation and communication difficulties. This study explores the lived experience of individuals with PSA, focusing on psychological and communication challenges, economic consequences, and daily activities among stroke survivors at Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia. A qualitative research approach using a phenomenological study design was conducted between February and June 2024 among seven individuals with PSA within the stroke survivor population at TASH. Purposefully selected participants underwent face-to-face, in-depth interviews using a semi-structured interview guide. Thematic analysis incorporated both a priori codes from the interview guide and emerging inductive codes. Five themes and ten sub-themes related to stroke survivors' lived experiences of PSA were identified: (i) daily interaction and communication challenges; (ii) impacts of PSA on daily living and work; (iii) economic consequences of PSA; (iv) psychological and emotional impact; and (v) reflections on improving the quality of life for individuals with PSA coping mechanisms. These findings highlight the multi-dimensional impacts of PSA among stroke survivors and underscore the importance of tailored interventions to enhance social interaction and communication abilities. Comprehensive rehabilitation programs targeting social, motor, and communication skills are vital. The economic impact of aphasia necessitates robust support systems, occupational adjustments, and regulatory changes. Improving the quality of life for individuals with aphasia requires increased social backing, better access to therapy, heightened public awareness, and addressing these emotional challenges through psychological assistance, community education, the promotion of positive coping mechanisms and alongside active family involvement, can greatly improve the quality of life for individuals with aphasia.

Keywords: post-stroke aphasia, stroke survivors, lived experience

1. Introduction

Stroke is a leading cause of disability globally, with significant for long term consequences for individuals and their families. Stroke is a neurogenic disease resulting from either a blockage in a blood vessel supplying the brain or rupture of a blood vessel in the brain, termed an ischemic or a hemorrhagic stroke respectively. Post-stroke aphasia (PSA) is a common and debilitating impairment that affects communication and language abilities in stroke survivors (Berthier, 2005). It has a profound impact on individuals' quality of life such as psychological well-being and social functioning (Code, 2000).

1.1 Background of the study

PSA presents a complex set of challenges for stroke survivors, encompassing not only linguistic impairments but also a range of motor deficits that significantly impact daily functioning and quality of life. Among the most prevalent motor problems experienced by individuals with PSA are hemiparesis, impaired coordination, gait disturbances and dysphagia (Worrall et al., 2011; Pedersen et el., 2016). Moreover, the presence of these motor issues has been shown to exacerbate the already arduous rehabilitation process following a stroke, complicating the recovery trajectory for affected individuals.

Addis Ababa, the capital and largest city of Ethiopia, encounters distinct obstacles in delivering healthcare services to stroke survivors and individuals suffering from PSA. The healthcare system in Ethiopia, including Addis Ababa, is characterized by limited resources, such as a scarcity of speech therapy services tailored for stroke survivors with aphasia, inadequate funding and research support in the field of PSA, restricted accessibility to specialized healthcare facilities for stroke patients, disparities in accessing rehabilitation services, and a shortage of specialized healthcare professionals like speech therapists and neurologists (Wondimu et al., 2018). These contextual factors significantly impact the care and support available to individuals living with the consequences of stroke, particularly aphasia, highlighting the need for a comprehensive understanding of the challenges and specific requirements within this particular setting.

Previous research has highlighted the physical, emotional, and social challenges faced by stroke survivors with aphasia. These challenges include difficulties in expression, comprehension of spoken language, reading and writing (Berthier, 2005; Dickey et al., 2010; Engelter et al., 2006). Stroke survivors may also experience isolation, reduced participation in social activities and diminished independence in daily life tasks (Cruice et.al, 2006).

1.2 Statement of the problem

Stroke is a significant healthcare issue, and the prevalence of stroke survivors with post-stroke is expected to be high in Ethiopia (World Health Organization, 2021). However, there is limited research exploring the lived experience of PSA in this specific context, particularly at TASH. The unique challenges, coping mechanisms, and perceptions of rehabilitation and therapy service among stroke survivors with post-stroke aphasia at this hospital remain largely unexplored. Therefore, this study aims to address this research gap by investigating the lived experience of stroke survivors with PSA through identifying the specific challenges faced including difficulties with communication, social interaction, and engagement in activities of daily living, addressing obtaining information about the stroke and immediate events and impact on individual and family income.

1.3 Objectives

1.3.1 General Objectives of the study

- To explore the lived experience of post-stroke aphasia among stroke survivors followed at Tikur Anbessa Specialized Hospital (TASH), Addis Ababa Ethiopia.

1.3.2 Specific Objectives of the study

- To investigate the communication challenges of individuals with post-stroke aphasia.
- To examine the impact of post-stroke aphasia on the ability of individuals to engage in activities of daily living.
- To investigate the economic consequences of post-stroke aphasia.

- The participant's reflections on what to be done to improve the quality of life of individuals with PSA.

1.4 Significance of the study

The significance of this study lies in its potential to contribute to the understanding, support, and treatment of individuals with PSA. This qualitative inquiry in to the first-hand experiences of stroke survivors with aphasia in a specific healthcare setting offers several areas of significance.

- The research offers a platform for individuals who have survived a stroke and are dealing with aphasia to express their personal experiences, allowing them to communicate their difficulties, goals, and requirements. This could help in boosting their confidence, advocating for themselves, and gaining a deeper insight into their own situation.

- Shedding light on the experiences of stroke survivors with aphasia through the study has the potential to increase public awareness, improve community understanding, and decrease the stigma surrounding aphasia. This could lead to better social inclusion and support for those affected.

- The firsthand experiences shared in the research can educate healthcare professionals about the emotional, cognitive, and social consequences of aphasia following a stroke. This information can assist in developing more patient-centered and efficient treatment plans and therapeutic interventions. Additionally, it can provide valuable insights into effective coping mechanisms for individuals newly diagnosed with post-stroke aphasia.

1.5 The scope of the study

The study aims to delve into personal narratives, challenges, and triumphs of stroke survivors living with aphasia. It seeks to understand the impact of aphasia on various aspects of their lives, including communication, social relationship, emotional well-being, and day-to-day activities. The scope encompasses examining the experience of individuals with aphasia from a multidisciplinary lens, acknowledging the potential involvement of speech-language therapists, neurologists, psychologists, social workers, and other professionals in addressing the needs of stroke survivors with aphasia. The study seeks to understand how the experiences of post-stroke aphasia can inform and contribute to the development of more effective and tailored intervention, support services, and communication strategies within the healthcare setting at TASH,

2. LITERATUR REVIEW

Post-stroke aphasia is a common consequence of stroke that can have a significant impact on a survivor's ability to communicate, interact with others, and engage in daily activities (Hoffman, Yorkston, Tickle-degnen, & Barkmeier-Kraemer, 2012). Individuals with post-stroke aphasia often express feelings of frustration, embarrassment, and isolation, which can have a detrimental effect on their mental health and overall well-being (Hilari, Byng, Lamping, Smith, & Stroke Association, 2003). Despite the widespread recognition of aphasia's impact on the quality of life of stroke survivors, there exists a gap in knowledge regarding the lived experience of post-stroke aphasia among stroke survivors at TASH in Addis Ababa.

Aphasia in stroke patients is associated with increased mortality decreased rates of functional recovery and reduced probability to return to work compared with non-aphasic stroke patients (Paolucci S, Antonucci G, Pratesi L, Traballesi M,). High-intensity speech therapy has been shown recently to improve outcome, but requires the availability of a sufficient number of qualified therapists. Thus, for planning stroke rehabilitation processes and resource allocation, epidemiological data about frequency and severity of aphasia in stroke patients are crucial.

At TASH, a significant area of study resolves around how PSA affects stroke survivors' social engagement and quality of life. Research suggests that communication deficits may have an effect on people's overall well-being since communication deficits can increase the difficulty for individuals to engage in social activities and form meaningful connections. Analyzing Ethiopian stroke survivors' experiences will provide valuable insights on the social and cultural factors affecting social participation and post-stroke aphasia (Mengistu et al., 2021).

Following a stroke, aphasia is a common disability that affects a considerable number of stroke survivors, with estimates suggesting up to 40% may experience this condition (Pedersen, Vinter, & Olsen, 2004). Worku et al. (2015) reported that in Ethiopia, the age-standardized prevalence rate of stroke is approximately 182 per 100,000 individuals, with a rising incidence trend. Despite limited statistical data on the prevalence of post-stroke aphasia in the country, the high incidence rate of stroke in Ethiopia suggests that the prevalence of aphasia among stroke survivors is likely to be significant.

Individuals suffering with PSA have intricate experiences that can differ greatly from one another. Research has demonstrated that PSA can significantly impact an individual's quality of life, including their capacity to partake in social events, resume employment, and form significant relationships (Whitworth et al., 2018). Isolation, annoyance, and low self-esteem can result from communication problems (Hinckley & Carragher, 2019). Furthermore, getting the right medical care and support may be difficult for stroke survivors who also have post-stroke aphasia (Pedersen et al., 2017). It is because of communication barriers, complex healthcare interactions, healthcare decision-making and access to supportive services.

The assessment and management of PSA are critical to the recovery and quality of life of stroke survivors. Speech and language therapy is the primary treatment for PSA, with evidence showing that early intervention can improve communication outcomes (Law et al., 2013). However, there are challenges to accessing speech and language therapy services, particularly in low- and middle-income countries like Ethiopia (Pedersen et al., 2017)

Research has revealed a number of difficulties faced by Ethiopian stroke survivors who also have aphasia, including stigma, poor access to speech therapy services, and false beliefs about the condition. Studies have also brought attention to a variety of coping mechanisms used by stroke survivors, including the use of substitute forms of communication, asking for peer support, and participating in community-based activities to preserve social ties and fight feelings of loneliness (Tadesse et al., 2019).

Research on the lived experiences of stroke survivors with post-stroke aphasia is essential to inform the development of appropriate interventions and support services. Previous studies have explored the experiences of individuals with PSA and highlighted the importance of addressing communication challenges, accessing appropriate healthcare services and support, and the need for -family and community involvement in their recovery (Whitworth et al., 2018). However, there is limited research on this topic in Ethiopia.

Aphasia is a language disorder that commonly occurs after a stroke and affects the ability to speak, understand language, read, and write. There are many different types of aphasia, each with different characteristics and different challenges faced by people with aphasia. They are Broca’s, Wernicke’s, and Global aphasia.

Broca’s aphasia is characterized by a lack of fluency, difficulty forming complete sentences, and limited language ability. People with Broca’s aphasia often have difficulty expressing their thoughts and may experience frustration due to their limited ability to communicate effectively (Goodglass & Kaplan, 198).

Wernicke’s aphasia produces meaningless speech that is fluent but difficult to understand. People with Wernicke’s may speak in long, wordy sentences without meaningful content and may have difficulty understanding spoken and written language (Kertesz, 1982).

Global aphasia is the most severe form of aphasia and involves significant impairments in both expressive and receptive language. People with global aphasia have impairments in language production and comprehension, often leading to significant communication problems and increased dependence on others for daily activities (Helm-Estabrooks, 2002)

2.1 Communication Challenges and Coping Strategies

Communication plays a vital role in human interaction, and when disrupted by aphasia, it can result in significant frustration and isolation (Code, 2013). While some individuals who have had a stroke may only experience mild language difficulties, others may find it challenging to communicate even their basic needs (Engelter et al., 2006). Moreover, comprehension issues can further complicate communication, making it difficult to express and understand thoughts and emotions (Pedersen et al., 2004).

To address these obstacles, stroke survivors often develop various coping mechanisms (Hinckley & Carr, 2013). These strategies may involve supported communication, including gestures, drawing, and the use of augmentative and alternative communication (AAC) devices (Rose et al., 2012). Nevertheless, it is important to acknowledge that these methods may not completely make up for the loss of verbal language, resulting in ongoing feelings of inadequacy and reliance (Brunner et al., 2014).

2.2 Impact on Social Relationships and Identity

Aphasia reverberates beyond individual communication abilities, profoundly influencing social relationships and identity (Parr et al., 2010). Family members and friends may struggle to adapt to the changes in communication patterns, leading to strained interactions and emotional distance (Hinckley & Carr, 2013). Stroke survivors, in turn, may feel marginalized and misunderstood, grappling with a profound sense of loss regarding their pre-stroke identity (Hilari, 2011).

Moreover, societal attitudes toward aphasia often exacerbate feelings of isolation and stigma (Worrall et al., 2019). Public misconceptions about intelligence and competence perpetuate the marginalization of individuals with aphasia, hindering their integration into social settings and employment opportunities (Howe et al., 2012). These challenges underscore the importance of raising awareness and fostering inclusive communities that embrace neurodiversity (Simmons-Mackie et al., 2010).

2.3 Psychological and Emotional Impact

The psychological toll of PSA cannot be overstated (Northcott et al., 2017). Research consistently demonstrates elevated rates of depression, anxiety, and diminished self-esteem among stroke survivors with aphasia (Hackett et al., 2014). The inability to communicate effectively may evoke feelings of powerlessness and despair, amplifying pre-existing vulnerabilities and triggering existential crises (Wallace et al., 2017).

Moreover, aphasia often intersects with other cognitive and emotional consequences of stroke, further complicating the diagnostic and therapeutic landscape (Hilari et al., 2015). Fatigue, executive dysfunction, and emotional instability are common comorbidities that necessitate a holistic approach to intervention (Kauhanen et al., 2000). Addressing the psychological and emotional needs of stroke survivors with aphasia requires a nuanced understanding of their lived experiences and a commitment to fostering resilience and hope (Brown et al., 2018).

2.4 Quality of Life and Rehabilitation Outcomes

The quality of life for individuals with PSA is impacted by a number of factors, including access to comprehensive rehabilitation services, social support networks, and community resources (Brady et al., 2016). Studies have underscored the reciprocal relationship between communication competence, social engagement, and subjective well-being, highlighting the pivotal role of holistic interventions (Hinckley & Carr, 2013).

However, disparities in access to care and variability in service provision pose significant challenges to optimizing rehabilitation outcomes (Simmons-Mackie et al., 2010). Rural communities, marginalized populations, and individuals with limited financial resources may face barriers to accessing specialized aphasia therapies, augmentative communication devices, and support groups (Howe et al., 2012). Addressing these systemic inequities is paramount to ensuring equitable outcomes for all stroke survivors with aphasia (Northcott et al., 2016).

The lived experience of PSA among stroke survivors is characterized by multifaceted challenges spanning communication, social relationships, psychological well-being, and quality of life (Parr et al., 2010). By adopting a person-centered approach that prioritizes empathy, empowerment, and inclusion, healthcare providers can foster resilience and facilitate meaningful recovery journeys for individuals with aphasia (Simmons-Mackie et al., 2010). Future research endeavors should focus on dismantling systemic barriers, advancing innovative interventions, and amplifying the voices of those whose lived experiences have long been marginalized (Brady et al., 2016).

3. METHODOLOGY AND MATERIAL

3.1 Study setting and period

This study was conducted at Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia from April 15 to June 10, 2024. Addis Ababa is the capital city of Ethiopia.

3.2 Study design

This study was employed a qualitative research design using descriptive and interpretive features of phenomenological approach to explore the lived experience of stroke survivors with post-stroke aphasia.

3.3 Study participant

The study participants are stroke survivors with PSA with Broca’s and Wernicke’s aphasia type. The selection criteria included stroke survivors who have been diagnosed with PSA and who have been treated and followed at TASH.

3.4 Sample size and Sampling techniques

A purposeful sampling technique was used to select participants for this study. The selection criteria was as follow: adult patients who have been diagnosed with post-stroke aphasia, with a minimum of 1 year post-stroke and who have been treated and followed at TASH in Addis Ababa.

Participants were selected with the assistance of neurology residents and based on inclusion criteria through purposeful sampling. The study included 7 stroke survivors with PSA, comprising 6 participants with Broca's aphasia and 1 participant with Wernicke's aphasia.

The process of gathering data was carried out until saturation was achieved. Informational redundancy was used to measure data saturation, and it was deemed to have been reached when no new categories or information emerged from the data and when more interviews ceased yielding new categories.

3.5Inclusion and Exclusion criteria

3.5.1. Inclusion criteria

- Mild to moderate aphasia by using Western Aphasia Severity Measurement Tools
- Adult patients who are able to verbally communicate
- Stroke survivors who have been diagnosed with PSA with a minimum of 1 year post-stroke and who have been treated and followed at TASH

3.5.2 Exclusion criteria

- Patients with cognitive impairment
- Participants who do not consent to participate
- Those with less than a year of PSA

3.6 Data collection tools and procedure

Data was collected at the Neurology Referral Clinic of TASH by using in-depth semi structured interviews conducted with participants, allowing them to share their experiences, challenges, coping strategies, social participation, and work, impacts of communications and through review of their medical charts or records.

In this study, the Western Aphasia Severity Measurement Tool was used to identify the severity of the disorder and those who were included mild to moderate in the study.

Before the initiation of data collection, two stroke survivors with PSA, who were not part of the main sample, were interviewed as a pre-test for the interview guide. Based on feedback from these preliminary interviews, the investigator adjusted the interview guide to improve clarity and comprehensibility. To encourage participants to elaborate on their responses, prompts such as "Can you tell me more?" and "What else have you felt?" were used. Additionally, nonverbal cues, like facial expressions, were recorded in field notes to aid in interpreting their responses.

All interviews were conducted by the investigator in a quite speech therapy room at the physiotherapy clinic following the participants' neurology visits. Each interview lasted between 40 minutes to 1:5 hours. All interviews were audio-recorded and then transcribed verbatim in the original language (Amharic). The transcriptions were subsequently translated into English.

3.7 Data Analysis

The interview was transcribed verbatim and manually analyzed using a thematic analysis approach. This involves identifying themes and sub-themes in the data and interpreting the meaning and significance of these themes and sub-themes.

3.8 Ethical Considerations

The study was conducted after obtaining approval from the Ethical Review Committee of the Department of Special Needs and Inclusive Education (SNIE) and the Institutional Review Board (IRB) of College of Health Sciences of Addis Ababa University. A written informed consent was obtained from each respondent to participate in the study. Support letter was sent to Department of Neurology, College of Health Sciences, and AAU from Department of Special Needs and Inclusive Education (SNIE), to notify about the research project in advance. Detail explanation about objectives, purposes and benefit of the study was given to the respondents. The investigator was the only one who knew each participant's code; participant names were not used in the data analysis process. Private data that was only accessible to the investigator. Confidentiality was assured before conducting data collection and data collectors was trained and oriented.

3.9 Dissemination of Study Findings

The findings of this study were submitted and presented to the Department of Special Needs and Inclusive Education, as well as the School of Medicine at Addis Ababa University's College of Health Sciences. Additionally, the results will be submitted to the Neurology Department at TASH. Efforts will be made to publish portions of the research findings in reputable local and international journals. Moreover, the findings will be shared through workshops and seminars.

3.10 Conceptualization of Key Terms

Post-stroke Aphasia (PSA): A language disorder that occurs as a result of brain damage caused by stroke. Post-stroke aphasia can affect a person's ability to speak, understand, read, and write (Kertesz, 2009).

Lived Experience: Individuals subjective perception and interpretation of their unique experiences, including their thoughts, emotions and behaviors (Dahlberg, 2006).

Stroke Survivor: An individual who has experienced a stroke, which is defined as a sudden interruption of blood flow to the brain, resulting in brain damage and/or impairment (Moskowitz, 2016).

Tikur Anbessa Specialized Hospital (TASH): A teaching hospital located in the capital city of Ethiopia, Addis Ababa, that provides tertiary care services for a range of medical conditions, including stroke and post-stroke rehabilitation.

Qualitative Research Design: A research approach that seeks to understand and interpret social phenomena by exploring the experiences, thoughts, and feelings of individuals. Qualitative research typically involves data collection through interviews, observations, and/or focus groups discussions, and data analysis involves identifying themes and patterns that emerge from the data (Creswell, 2013).

In-depth Interviews: A method of data collection in which a researcher engages with an individual to gain a detailed understanding of their experiences, perspectives, and attitudes. In-depth interviews typically involve open-ended questions and encourage participants to share their thoughts and feelings in-depth (Rubin & Rubin, 2012).

Thematic Analysis: A data analysis method that involves identifying patterns and themes that arise from the data to gain insights into a research question or phenomenon. Thematic analysis involves a systematic and iterative process of coding and categorizing data into themes (Braun & Clarke, 2006).

Participant: The individuals who consent to take part in the study.

4. RESULTS

This study explores the lived experiences of PSA among stroke survivors followed at Tikur Anbessa Specialized Hospital(TASH) in Addis Ababa, Ethiopia. The results are presented in two sections: an overview of the participants' characteristics and the emerged themes.

4.1 Characteristics of the Participants

The study included 7 stroke survivors with PSA, aged between 38 and 63 years. Among them, 5 were female and 2 were male. Five participants were from urban areas, while the remaining two were from rural areas of Ethiopia. In terms of education level, 1 participant did not receive formal education, 1 had level 4, 3 had bachelor's degrees, and 2 had completed schooling up to the 10th grade. Marital status varied, with 3 participants being married, 3 unmarried, and 1 widowed. Six participants lived with their families, while 1 lived alone. Six participants' first language was Amharic, and 1 participant's first language was Afan Oromo. Six participants experienced a stroke for the first time, while 1 participant had experienced two strokes.

Table 1: Characteristics of post-stroke aphasia among stroke survivors followed at Tikur Anbessa Specialized Hospital (n= 7 participants).

Variable	Frequency
Age	
38-48 years	4
>48 years	3
Resident	
Urban	5
Rural	2
Educational status	
No formal education	1
Secondary education	2
Level 4	1
Bachelor degree	3
Occupation before stroke	
Unemployed	1
Government office	5
Private	1
Occupation after stroke	
Unemployed	5
Government office	1
Private	1
Living situation	
With family	6
Alone	1
Language status	
First language Amharic	6
First language A/Oromo	1

4.2 Case History

The medical information of the 7 participants in this study is summarized in the following table. This information was extracted from the participants' medical charts, which were deemed important for the study. It has been confirmed that these 7 participants have been monitored by TASH and continue to receive care there. The medical history includes details such as the duration of hospital stay, stroke onset, year and location of stroke occurrence, satisfaction with medical services, type of aphasia, stroke recurrence, and whether they are receiving speech and language therapy (SLT) services or not.

Table 2: Case history of PSA among stroke survivors followed at Tikur Anbessa Specialized Hospital (TASH)

Variable	Frequency
Stroke occurrence	
First time Second time	6 1
Years of onset of strokes	
2008E.C – 2012 E.C 2012 E.C – 2015 E.C	3 4
Stroke occurrence location	
Home Street Work place	4 2 1
Duration of hospital stay	
7-15 days 16-25 days	3 4
Event of stroke occurrence	
Sudden	7
Type of aphasia	
Broca’s aphasia Wernicke’s aphasia	6 1
Medical services satisfaction	
Satisfied Not satisfied	6 1
Received Speech language Therapy services	
Yes No	2 5

4.3 Emerged Themes

Five themes emerged from the analysis of the survivors' in-depth interviews. These themes were identified as rich and detailed accounts of the lived experiences of post-stroke aphasia among stroke survivors at TASH. The themes, along with their respective sub-themes, codes, and code descriptions are summarized in the following table.

Table 3: Themes, Sub-themes, Codes, and Code Descriptions Identified Through Interviews of PSA Among Stroke Survivors

Theme	Sub-theme	Code	Code description
Daily interaction and communication challenges in PSA	Participation in social and community activities	Community event Social gathering	Frequency and nature of participation
		Quality life	Impact on quality life
		At the family level	Impact of Social participation
	Communication challenge	Difficulty in finding word Forming sentence Understanding others	Types of communication barriers
		Using non-verbal cues Communication aid	Adaptation and coping strategies
		Inclusivity and exclusivity	Social perception and reaction
Impact of PSA on activities of daily living and work	Self-care and daily routine	Bathing Grooming Dressing Eating	Effect on personal care task Dependency on assistance
	Work related challenges	Ability to perform job duties Maintain productive level	Job performance and production
		Modified work schedules use of communication aid Support from colleges	Work place adaptation and support
Economic consequence of PSA	Impact on employments	Job loss Reduced hour	Change in job statues
		Movement Speech	Barriers to Re-employment
	Effect on financial independence	Stop working	Decrease in person income
Psychological and emotional impact	Emotional reaction	Stress Frustration	Coping strategies
	Coping mechanism	Self-encouragement Maintain positive mindset	Strategies for boosting confidence and self esteem
Reflection on improving quality of life for individual with PSA	Therapeutic and medical intervention	Speech therapy	Effectiveness of speech language therapy
	Social support and integration	Social activities	Community program

Theme 1: Daily Interaction and Communication Challenges in Post-Stroke Aphasia

Participants were asked to describe the challenges in daily interactions and communications due to PSA. Based on their responses, the challenges were divided into two sub-themes: participation in social and community activities, and communication challenges.

Subtheme 1: Participation in Social and Community Activities

According to the participants, PSA had a significant impact on their social and community activities. Most participants reported that PSA prevented them from engaging in their daily activities. They mentioned difficulties such as not meeting neighbors as they used to, not spending time together during happy or sad occasions, and not participating in association meetings. Additionally, some participants expressed that their inability to move hindered their desired activities.

"At the time, I could not move on my own. I couldn't say what I wanted. I was not able to connect with the community and play, do social things like before. As a result, I could not communicate or spend time with people around me. I spent most of my time away from people." [Participant 1, male, 41 years]

A few participants reported that they had difficulty reintegrating into society after experiencing PSA.

"People in the area where I live have no understanding of stroke and post-stroke aphasia. When they saw me, I could not move or speak. At that time, people around me isolated me. The reason was that they did not come to ask me because they thought it would be transmitted. As a result, I had a hard time integrating into society."[pt 1, male, 41yrs]

In addition, as other participants specifically stated, they did not experience a negative impact on social relations.

''It didn't affect my social life much. Most of the people around me helped me. I think they were aware of the problem. I think this is the reason that helped me to recover faster.'' [Pt 3, male, 41yrs, Pt 4, male, 63yrs]

According to the participants, this issue significantly impacted their family's social relationships. They mentioned that their families spent most of their time caring for them, which led to social isolation.

One participant shared;

"I was unable to move or speak at that time, so I stayed at home and didn't meet anyone. My wife dedicated most of her time to taking care of me, which completely cut us off from our social life. With no one else at home to assist, and our children being in school most of the time, my wife and I found it challenging to connect with the community. This situation greatly affected our social life."[Pt 4, male 63yrs]

Additionally, one of the participants explained that due to her post-stroke aphasia, her sister, who is a family member, had to sacrifice a lot to spend time with her. She shared,

"After the stroke, I quit my job and became completely estranged from my friends. I wanted to be alone. But my sister gave up her social life and spent all her time with me. She was worried I might harm myself if left alone, so she stayed with me most of the time. She stopped participating in any social interactions because she didn't want to leave me."[Pt 6, female 38yrs]

Subtheme 2: Communication Challenges

Most participants stated that difficulties with speech significantly impacted their communication. They described challenges such as struggling to say words, difficulty speaking for extended periods, stopping conversations prematurely, not understanding others' speech, and having trouble expressing their thoughts quickly. Additionally, they mentioned that writing, reading, and using the language they previously communicated in became problematic after the onset of PSA.

"When we were talking to my colleagues at work, it would take me a long time to think and talk, so they used to finish the conversation I started by saying, 'You want to say this.'" [Pt 5, male, 56yrs]

"It was very difficult for me to speak out words, so I used to communicate with people in sign language most of the time." [Pt 7, female, 50yrs]

A few participants also mentioned facing disagreements and difficulties in transportation and shopping areas.

"Most of the time, I don't move alone in the market or transport. Because I can't put words to what I want to buy, I have to have someone with me wherever I go. When I say where I'm going or getting off on the transport, I'm not clear about it, so I don't go anywhere alone in case I end up at a different place." [Pt 2, male, 60yrs, Pt 7, female, 50yrs]

“There were many times when I visited doctors at the hospital without explaining the problems. I was experiencing because they didn't understand what I was saying.’’[Pt 2, male, 60yrs]

Most of the participants stated that they isolated themselves from society.

"I stopped seeing friends because I couldn't communicate. I don't leave the house. I prefer to spend time at home away from everything." [Pt 6, female, 38yrs, Pt 1, male, 41yrs]

When asked how they communicated and what alternative strategies they used, participants provided their insights.

"When I was speaking, I knew that people would not understand me quickly, so most of the time I wrote down what I wanted to say or the message I wanted to convey." [Pt 5, male, 56yrs]

"When I speak, people don't understand me, so I try to explain using sign language as much as possible. I used to try to explain using different hand and body movements." [Pt 3, male, 41yrs]

Theme 2: Impact of PSA on activities of Daily Living and Work

Among the data collected by the second theme, participants were asked to share the impact of PSA on their daily lives and work activities. The responses were categorized into two subthemes: self-care and daily routines, and work-related challenges. Within these subthemes, participants expressed a variety of experiences and perspectives.

Subtheme 1: Self-Care and Daily Routines

Most participants stated that, in addition to speech difficulties, they also had trouble with mobility. Many experienced significant challenges in taking care of themselves. They reported difficulties such as not being able to go to the toilet on their own, not being able to eat the food they wanted, not being able to wear the clothes they wanted, and not being able to wash themselves. These issues made it difficult for them to perform daily activities and greatly increased their dependence on others.

"I had a hard time taking care of myself. The biggest problem was not only being unable to move but also being unable to speak. I remember one time when I needed to go to the toilet; I couldn't move and couldn't call for help, so I was forced to defecate where I was sitting."[Pt 1, male, 41yrs]

A few participants said that they were unable to perform their daily activities because they could not move.

"I had trouble leaving home for a long time, especially participating in activities with my neighbors. We used to spend time together every day, but because of my condition, I stayed isolated at home. I didn't go out, and they didn't come to visit. They stopped coming because I couldn't participate in activities as well as they could, and I also couldn't move easily."[Pt 7, female, 50yrs]

Subtheme 2: Work related Challenges

Participants were asked to describe their difficulties with speaking, reading, understanding, and writing in the workplace. They shared various challenges they faced in different ways. Most of the participants who were working before the stroke stated that they were unable to return to work. A few mentioned that they were able to return to work and perform almost all of their tasks.

"My job was in advocacy. Reading, writing, understanding, and speaking are essential for a lawyer. After my stroke, I was unable to read, write, or speak. I still can't read or write, so I am unable to continue my work. [Pt 2, male, 60yrs]

"I used to work as a waitress. After experiencing the stroke, I was unable to continue working. I couldn't communicate or move as I needed to. As a result, I was dismissed from my job because I could not perform my duties properly."[Pt 6, female, 38yrs]

A few participants explained that they were forced to retire early because they were unable to perform their work properly after experiencing post-stroke aphasia.

"I had served for a long time in the office where I was working, so when my bosses realized that I could not do my job properly, they made me retire. I couldn't keep up because my work was so focused on writing, reading, and speaking." [Pt 4, male, 63yrs]

Other participants said that due to post-stroke aphasia, they stopped working for a while but were able to return to their workplace after some recovery.

"I quit my job for about six months. When I returned, I received a warm welcome at my workplace. However, I had difficulty speaking while working, so I often chose not to speak. My colleagues would guess what I wanted to say and offer me options. Because of this, I tried not to talk or interact with others. I would just do my job and leave."[pt 5, male, 56yrs]

Most participants stated that they used different methods to communicate because they could not speak, write, read, or understand effectively. Some participants mentioned that they tried to communicate using text when they were unable to speak. When they could not write or speak, they resorted to various communication methods such as sign language, body movements, and pointing to what they wanted.

"When I spoke at my workplace, it took a long time for people to understand me, so I tried to communicate by writing down the message I wanted to convey." [Pt 5, male, 56yrs]

Theme 3: Economic Consequences of PSA

Participants were asked to describe the impact of PSA on themselves and their families in terms of income. They described the various problems they experienced related to income. Based on their responses, the answers were divided into two sub-themes: impact on employment and effect on financial independence and family income.

Subtheme 1: Impact on Employment

According to the participants, PSA prevented them from fully returning to their previous lives and continuing their routines. Most participants explained that they were displaced from their jobs and forced into early retirement. As a result, many are now unemployed and without income. Additionally, most participants stated that they were heads of households and supported their families through their wages.

“I can't move or communicate, so I quit my job and spend my time at home. I am currently unemployed. After I recovered, I tried to find a job, but when employers met and saw me, they refused to hire me.”[Pt , male, 41yrs,Pt 6,female, 38yrs]

A few participants explained that their income has decreased due to early retirement caused by PSA.

"I am supported by the money I get from my pension. I am able to work now, but no one is willing to hire me. I have children, and I was living a good life before, but now I am facing many difficulties because my income has decreased. My speech has changed, and I have some movement problems."[Pt 4, male, 63]

As one participant explained;

"I am still at work, but I used to do a lot of extra work. I was involved in fieldwork, worked overtime, and earned a lot. However, my current situation has made it impossible for me to do all this extra work and earn the same income."[Pt 5, male, 56]

Most participants said that even though they stopped working due to impairments in their movement and speech, they tried to return to work but were not successful.

Sub-theme 2: Effect on Financial Independence and Family Income

According to the participants, their income has decreased for various reasons. Some mentioned that their income has been completely cut off, forcing them to live dependent on family and others.

"I used to be paid very well. I earned money by doing many jobs myself and was able to help many people beyond just myself. But now, with no income, I depend on my family."[Pt 2, male, 60yrs]

Another participant explained;

"I had no income before. I was supported by the money my husband and children earned. Our current situation is very difficult. My son left his job to take care of me because there is no one else to do so. My husband's salary is not enough; a lot of it goes toward my medication and various tests. We are now dependent on our relatives because life is difficult."[Pt 7, female, 50yrs]

Some participants said they did not experience much impact on their income. This was mentioned by participants who worked independently;

"I was self-employed, and my children were helping me. They continued to work non-stop when I had this problem, so my income was not cut off. It was somewhat reduced, but the decrease did not significantly affect my family."[Pt 3, male, 41yrs]

"I could not manage my life as before because of post-stroke aphasia. I can't buy my own clothing or basic tools because my income was terminated. I used to be able to buy everything I needed, but now I can't do that. The loss of this income prevents me from taking care of myself as I used do."[Pt 7, female, 38yrs]

Theme 4: Psychological and Emotional Impact

Participants were asked about the psychological and emotional impact of PSA. Their responses were divided into two sub-themes: emotional reaction and coping mechanisms.

Subtheme 1: Emotional Reaction

Most participants described experiencing a range of emotions when they first had a stroke. Some mentioned that those around them were shocked by the event. One participant shared;

"The first time I had a stroke, I collapsed. I had no idea what was happening at the time. I woke up in the hospital a week later, only then did my family explain what had occurred."[Pt 4, male, 41yrs]

Other participants reported significant emotional trauma due to PSA. They described feelings of isolation from society, depression stemming from an inability to perform daily tasks, spending prolonged periods alone at home, and worrying about recovery. One participant expressed;

"I am deeply traumatized. I had no family around, and the community where I live ostracized me due to their lack of understanding about my condition. Sometimes, I wish I had died and been spared from this."[Pt 1, male, 41yrs]

Subtheme 2: Coping Mechanisms

Many participants shared various methods they used to cope with communication difficulties and facilitate recovery. These included self-encouragement, maintaining a positive mindset, and persevering through challenges with the hope of improvement and change.

“My children and wife were incredibly supportive, putting in a lot of effort to help me improve. Watching their dedication motivated me to believe in my recovery and strive to return to my previous job and living conditions. Thankfully, I am in a good condition now.”[Pt 5, male 56yrs]

“At first, I was very disappointed. I couldn't move or speak, which forced me to withdraw from many aspects of my life. I left my social life and workplace and stayed at home. However, over time, I began to make a greater effort to improve my situation. I started to believe that everything would eventually be alright.”[Pt 1, male 41yrs]

Theme 5: Reflection on Improving the Quality of Life for Individuals with PSA

All participants in this study shared their views on the problems they faced after experiencing PSA and their thoughts on how things could be improved. They addressed the questions on improving the quality of life for individuals with PSA, focusing on two main themes: Therapeutic and Medical Interventions, and Social Support and Integration.

Subtheme 1: Therapeutic and Medical Interventions

Only a few participants had access to speech and language therapy. Most reported being unable to receive treatment. They mentioned that their doctors recommended speech and language therapy, but they were unable to find therapists. Some participants who did not receive therapy described their experiences as follows;

"When this problem occurred, speech and language therapy services had not yet started here in Ethiopia. However, since my children were grown up and educated, they taught me many things to improve my speech in different ways. Due to the ample time I had and my focus on following their instructions without distraction, my speech has been gradually improving."[Pt 5, male, 56yrs]

"I was advised by doctors to get speech therapy, but due to a lack of professionals, I couldn't get an appointment. Instead, I practice daily by watching YouTube videos, which has helped me improve my speaking. Thank God, I have made progress. However, due to the shortage of experts, many people cannot access the necessary treatment, making it very difficult to find the right care."[Pt 3, male, 41yrs]

Among the participants, those who received speech therapy also reported significant improvements.

"I attended speech therapy for about three months, with sessions once a week for 30 minutes. The treatment has really benefited me, although the duration and frequency of the sessions were insufficient. The reason I am able to speak now is because of this therapy."[Pt 6, female, 38yrs]

Additionally, participants emphasized the importance of speech therapy and stated that, if accessible, it could bring about rapid improvements. They also noted that increasing the number of experts would help address the problem.

"If I had received speech therapy treatment under better conditions and at the right time, I believe I could have returned to my favorite job. I am still convinced that with the opportunity to attend consistent speech therapy, I could have made a significant difference. The two days of speech therapy I did receive brought about substantial improvement for me. If every government

hospital had a speech language therapist, these services would be accessible to everyone, allowing more people to benefit and make progress much sooner."[pt 2, male 60yrs]

According to the majority of the participants, physiotherapy was the only treatment they could quickly access for their speech and movement problems after a stroke. They also mentioned that they undergo medical follow-ups at Tikur Anbessa Specialized Hospitalevery three to six months. Furthermore, they noted that having more speech therapists would make speech therapy more accessible to the community, which would greatly benefit those in need of treatment.

When asked about their thoughts on treatment in general, the participants shared the following insights;

"Everything is good in the hospital. Having access to physiotherapy is very beneficial and many participants expressed that they would be pleased to find a speech-language therapy specialist as quickly as they did for physiotherapy."

They stated that the lack of access to speech-language therapy had significantly impacted their social lives and work. One participant said;

"What I need now is a speech therapist for better recovery. I love my job and want to return to work. The speech therapists I consulted told me that with speech therapy, my speech will improve, and my reading and writing problems will be resolved."[Pt 2, male, 60yrs]

Subtheme 2: Social Support and Integration

Most participants emphasized the importance of family and community support in coping with PSA. Six participants mentioned that they experienced faster recovery due to the excellent care provided by their families. One participant shared their perspective;

"I don't have family members living with me, so when the problem occurred, it was my friends who were there for me. It's extremely challenging to face such a problem alone, and it had a profound impact on me."[Pt 1, male, 41yrs]

All participants in the study emphasized the importance of raising awareness in society, stating that it could lead to better understanding among people.

Furthermore, they expressed how not being able to speak and communicate had a profound impact on their lives and livelihoods. One participant shared;

"I was unable to speak and move, so my wife became the one who participated in social life. I spent a lot of time at home."[Pt 4, male, 41yrs]

According to all participants, it is essential to expand the availability of speech therapy services in the future. Currently, speech therapy is available privately, but the costs are prohibitively high. Making these services accessible in all government hospitals would be greatly beneficial.

One participant explained;

"In our country, there is a significant lack of understanding about the nature of stroke and post-stroke aphasia. People around me were unaware of my condition and avoided me, mistakenly thinking it was contagious. However, if we implement community awareness programs and distribute informational leaflets, we can greatly improve public understanding and awareness of these conditions."[Pt 1, male, 41yrs]

5. DISCUSSION

The purpose of this study is to explore the lived experience of stroke survivors with PSA in the Neurology Department of Tikur Anbessa Specialized Hospital. The finding of this study is that stroke survivors undergoing treatment with PSA have self-care, daily living, communication, socio-emotional, and financial challenges.

The study identified lived experiences of participants PSA through 5 organized themes. These are daily interaction and communication challenges in PSA, impact of PSA and activities of daily living and stroke, economic consequence of post-stroke aphasia, impact of psychological and emotional, and reflection on improving quality of life for individuals with PSA. The daily interaction and communication challenges in post-stroke aphasia are identified from two categories. One is related to the participation in social and community activities and the second one is communication challenges.

PSA significantly impacts daily interactions and communication, as evidenced by the experiences shared by stroke survivors at Tikur Anbessa Specialized Hospital. These challenges can be broadly categorized into two sections: participation in social and community activities, and communication difficulties.

The study participants emphasized the impact of PSA on their involvement in social and community activities. This interference, as supported by earlier studies, arises from a blend of physical limitations and difficulties in communication. For example, research by Hilari and Northcott (2006) revealed that people with aphasia frequently experience social exclusion because they struggle to communicate and engage in social events. The narratives shared by the participants in this research parallel these results, with numerous individuals noting decreased interaction with neighbors, restricted involvement in social events, and an overall decline in community engagement.

The experience of isolation faced by one participant as a result of misunderstandings surrounding stroke and aphasia highlights a notable societal concern. This negative perception and lack of understanding can exacerbate feelings of seclusion and impede the process of reintegrating into society. According to Brown et al. (2013), societal beliefs and misconceptions regarding aphasia have the potential to heighten isolation and diminish the overall quality of life for those who have survived a stroke. Therefore, raising awareness about aphasia among the general public could be instrumental in enhancing social reintegration and providing adequate support for individuals affected by this condition.

Nevertheless, it is essential to emphasize that not all subjects experienced a detrimental impact on their social relationships. Some individuals reported positive environments that enhanced their survival and social connections. This variability suggests that the level of social involvement after a stroke may be influenced by the level of understanding and support from the community, as highlighted by Vickers (2010), who stressed the importance of a supportive social network in the rehabilitation process of individuals with aphasia.

The impact of PSA on family dynamics and social relationships is significant. Participants highlighted that care giving often led to social isolation for both the stroke survivor and their family members.

Aphasia has a substantial negative impact on the quality of life for both stroke patients and those who care for them, according to research by Hilari et al. (2010). The social isolation that the study's participants experienced is consistent with Hilari's findings, which imply that communication problems cause social involvement to decline and isolation to rise. This isolation can exacerbate the psychological burden on both the survivor and their family members.

As one of the participant noted that his wife's care giving duties disrupted their social life, reflecting Vickers' (2010) findings that care giving often demands sacrifices in social activities. This need for constant support limits caregivers' social and professional engagements.

Studies emphasize the importance of social support and community integration for the well-being of both stroke survivors and their caregivers. Pierce et al. (2004) highlight the positive impact of support groups and social networks in reducing isolation and improving caregivers' emotional well-being. This suggests that establishing support systems and providing resources for social engagement can help mitigate some of the negative social impacts observed in this study.

Communication challenges were a widespread issue among the participants, affecting their ability to involve in conversations, express their needs, and maintain social relationships. Continuously identifies communication difficulties as a central concern for individuals with aphasia (Parr, 2007). Participants in this study described a range of communication issues, including difficulty in speaking, understanding others, reading, writing and using alternative communication methods.

The impact of communication challenges extends beyond personal interactions to practical aspects of daily life, such as navigating transportation and shopping. Participants addressed needing support for these activities, which underscores the broader implications of aphasia on independence and quality of life. These findings are consistent with those of Cruice et al. (2003), who reported that communication impairments could significantly affect everyday activities and lead to raise dependency on others.

The impact of PSA extends beyond communication challenges, substantially affecting stroke survivors' abilities to manage daily activities and sustain employment.

The participants faced significant challenges in carrying out self-care tasks and adhering to their daily routines as a result of the combined impact of speech and mobility impairments. These findings align with the research conducted by Flowers et al. (2013), which revealed that individuals with post-stroke aphasia frequently encounter a decrease in their functional autonomy, resulting in heightened dependence on caregivers. The participants' difficulties with fundamental activities like using the toilet, eating, getting dressed, and bathing highlight the profound influence of aphasia on their everyday existence.

The lack of autonomy in carrying out these tasks not only leads to a greater reliance on others but also leads to a sense of social seclusion. The experiences shared by the participants, who expressed their inability to venture outside their homes or take part in community events, align with the observations made by Parr et al. (1997), who highlighted that aphasia often results in social isolation. The limited mobility and communication abilities impede their capacity to actively participate in social exchanges, intensifying their feelings of isolation and solitude.

The impact of PSA on work activities is profound, with most participants reporting an inability to return to their previous employment. This aligns with the findings of Wozniak et al. (2009), who noted that aphasia significantly impairs vocational outcomes. Participants described various challenges, including difficulties with speaking, reading, writing, and understanding skills essential for most professional roles.

The experience of a lawyer who could no longer perform his job due to aphasia highlights the critical importance of communication skills in certain professions. Similarly, other participants, such as the waitress and office worker, faced job loss or early retirement due to their inability to meet the demands of their roles. These experiences are consistent with the individuals with aphasia often face significant barriers to employment and may be forced to retire or change careers (Brady et al., 2016).

However, some participants reported positive experiences upon returning to work after a period of recovery. This variability suggests that with appropriate support and accommodations, some individuals with aphasia can reintegrate into the workforce. As highlighted by Thomas et al. (2013), workplace accommodations and supportive colleagues can play a crucial role in facilitating the return to work for individuals with aphasia. The participants' use of reading and writing underscores the importance of adaptive strategies in managing work-related challenges.

This study sheds light on the significant challenges faced by individuals with PSA and underscores the critical areas that need attention to improve their quality of life. The themes of Therapeutic and Medical Interventions, and Social Support and Integration, provide a comprehensive overview of the participants’ experiences and align with prior research on the subject.

The inclusion of speech and language therapy has proven to be a crucial element in the rehabilitation journey of individuals with PSA.

However, the limited availability of speech therapists has posed a significant obstacle, preventing many participants from accessing the necessary therapy. This issue is not unique to the specific study but is consistent with global research that highlights the scarcity of speech language therapy services, particularly in low-resource regions like Ethiopia (Worrall et al., 2011). The fact that participants had to resort to alternative methods, such as seeking guidance from educated family members or utilizing online platforms like YouTube, further emphasizes the substantial gap in professional care that exists.

One participant's account of self-improvement through daily practice, despite the absence of formal therapy, mirrors findings from studies that emphasize the importance of regular, structured practice in speech recovery (Brady et al., 2016). However, this approach is not universally accessible or effective for all patients, emphasizing the need for more speech language therapy professionals.

Participants who did receive speech language therapy reported substantial benefits, although they often found the therapy sessions to be too infrequent and short. This reflects the broader consensus in the literature that intensive and prolonged SLT is more effective in improving communication abilities (Bhogal et al., 2003). The call for increased availability of speech language therapy services and professionals resonates with recommendations from numerous studies advocating for expanded access to rehabilitation services (Brady et al., 2016).

The participants' positive feedback on physiotherapy access highlights a model that could be replicated for speech language therapy. Integrating speech language therapy into existing rehabilitation frameworks and ensuring regular medical follow-ups could enhance the continuity and effectiveness of care for individuals with post-stroke aphasia (Ellis et al., 2012).

Social support emerged as another crucial factor influencing the recovery and quality of life for individuals with PSA. Participants highlighted the indispensable role of family and friends in their recovery journey. This aligns with the literature, which consistently shows that strong social support networks significantly contribute to better rehabilitation outcomes and emotional well-being (Visser-Meily et al., 2009).

The significance of wider community engagement is highlighted by an individual's dependence on friends for emotional support when family is not available. This discovery reinforces the necessity for community-oriented initiatives and support networks that can offer aid and companionship to individuals who lack immediate familial assistance (Northcott et al., 2016).

The participants also stressed the profound impact of aphasia on their social lives and livelihoods. The inability to communicate effectively often leads to social isolation and reduced participation in community activities, which is well-documented in aphasia research (Hilari & Northcott,2017). Raising societal awareness about aphasia can foster a more inclusive environment, reducing stigma and promoting better integration of individuals with aphasia into social and professional spheres (Worrall et al., 2011).

The psychological and emotional impacts of PSA are ambiguous and multifaceted, as evidenced by the participants in this study. This theme encompasses the emotional reactions experienced by the individuals and the coping mechanisms they employed to navigate their new realities. These findings align with and add depth to the existing literature on the psychological burden of post-stroke aphasia.

PSA caused significant psychological and emotional distress among participants. Many experienced feelings of isolation, depression, and anxiety due to their communication impairments and the subsequent social exclusion. Coping mechanisms varied, with some finding solace in self-encouragement and others struggling with profound emotional trauma.

Participants in this study described a range of intense emotional responses following their onset of stroke and aphasia. Initial reactions included shock and confusion, not only for the individuals but also for their families. This aligns with the literature, which indicates that the sudden onset of stroke and resulting aphasia can be a traumatic event, leading to significant psychological distress (Hilari et al., 2010).

The feeling of being ostracized by the community, as described by one participant, underscores the additional burden of social stigma and misunderstanding surrounding aphasia. This societal reaction exacerbates the emotional distress experienced by stroke survivors, reinforcing feelings of loneliness and helplessness (Northcott et al., 2016). Despite the significant emotional challenges, many participants demonstrated resilience through various coping mechanisms. These strategies included self-encouragement, maintaining a positive mindset, and a determination to improve. The use of positive coping mechanisms is critical in managing the psychological impact of aphasia and is supported by a prior that emphasizes the importance of psychological resilience in stroke recovery (Jellema et al., 2016).

For example, the power of self-motivation and a positive mindset can have a profound impact on the process of recovery, enabling individuals to overcome the hurdles of rehabilitation. The willingness to make progress, despite encountering immense obstacles, demonstrates an effective coping mechanism that plays a vital role in achieving sustained recovery in the long run (Kendall et al., 2007).

6. STRENGTH AND LIMITATIONS

6.1 Strength

This research delves deeply into the real-life experiences of individuals who have survived a stroke and are living with aphasia, shedding light on a diverse array of personal and emotional encounters. By incorporating participants from different age groups and backgrounds, the study aims to present a comprehensive view of how post-stroke aphasia affects various segments of the population.

The investigation delves into various aspects of the participants' daily lives, such as their social interactions, professional hurdles, financial implications, emotional repercussions, and proposals for enhancing their quality of life. The results underscore the necessity for enhanced therapeutic approaches and social support networks, providing practical suggestions for healthcare professionals and policymakers.

6.2 Limitations

The findings of the study conducted at Tikur Anbessa Specialized Hospital in Ethiopia may not be applicable to other regions or populations due to its specific nature and setting. The accuracy of participants' responses could be influenced by recall bias or social desirability bias, which may impact the reliability of the reported experiences.

Furthermore, the study only provides a snapshot of participants' experiences at a particular moment in time, lacking longitudinal data that could provide insights into the progression of their conditions and coping mechanisms over time. To enhance the study, it could be beneficial to incorporate objective measures of speech and language function alongside the subjective reports, thus adding a more comprehensive perspective.

7. CONCLUSION AND RECOMMENDATION

7.1 Conclusion

The experiences of stroke survivors with aphasia at Tikur Anbessa Specialized Hospital highlight the significant obstacles they face in daily interactions and communication. These findings align with existing research and stress the importance of targeted interventions to enhance social participation and communication skills for individuals with aphasia. The profound effects of aphasia on daily activities and employment among stroke survivors at Tikur Anbessa Specialized Hospital underscore the need for comprehensive rehabilitation programs. These programs should not only tackle communication and mobility issues but also address the broader social and vocational impacts of aphasia. The economic ramifications of PSA are substantial and varied, impacting both individuals and their families.

Overcoming these challenges requires a holistic approach involving policy adjustments, workplace accommodations, and robust support networks. Enhancing the quality of life for individuals with PSA demands a multifaceted strategy. This includes improving access to therapeutic interventions, strengthening social support structures, and raising awareness and integration within society. Family engagement plays a crucial role in this process, as supportive family environments can significantly enhance recovery and adaptation by providing emotional support, facilitating communication practice, and assisting in daily activities. The emotional and psychological effects of PSA are deep and complex, necessitating a comprehensive and integrated care approach. Addressing these emotional challenges through psychological assistance, community education, the promotion of positive coping mechanisms and alongside active family involvement, can greatly improve the quality of life for individuals with aphasia.

7.2 Recommendation

Expanding training programs and employing qualified therapists can help reduce the existing scarcity of specialists and improve access to speech and language therapy for stroke survivors. This will guarantee prompt and appropriate therapy for those affected by stroke. Furthermore, educational initiatives that aim to reduce stigma and increase knowledge about stroke and post-stroke aphasia must be used to bolster community awareness and support. Family and neighborhood support groups can also give aphasia sufferers and their families a forum for experience sharing, support from one another, and a reduction in social isolation.

Another crucial area is the improvement of rehabilitation services, which may be done by creating all-inclusive rehabilitation facilities that include interdisciplinary services including occupational therapy, physiotherapy, and speech therapy. It's essential to do follow-ups on a regular basis to assess progress and modify treatment programs as needed. Programs for financial assistance can lessen the financial strain on families of stroke victims who are unable to work, and employers should be encouraged to provide reasonable workplace accommodations, like flexible work schedules and redesigned job responsibilities, to help stroke victims return to the workforce.

It is equally crucial to have access to emotional and psychological support. Stroke survivors should have access to mental health treatments to help them deal with hopelessness and emotional stress. Providing family counseling services can also help relatives better comprehend the difficulties associated with aphasia and discover practical strategies for helping their loved ones. It is critical to advocate for laws that meet the requirements of stroke victims, such as those that provide financing for rehabilitative programs and investigations on post-stroke aphasia. Along with advocating for the creation of inclusive healthcare practices, this lobbying should make sure that insurance plans pay for complete rehabilitation therapies, such as speech and language therapy.

Addressing stroke prevention is essential for a comprehensive strategy. Preventive measures can significantly reduce the incidence of stroke and, consequently, the occurrence of post-stroke aphasia. Public health campaigns to raise awareness about risk factors such as hypertension, diabetes, smoking, and physical inactivity are crucial. Community health programs should provide regular screenings and education on managing these conditions. Ensuring access to preventive healthcare and promoting healthy lifestyles through policies and educational initiatives can further mitigate stroke risks. By integrating these preventive strategies, we can reduce the burden on rehabilitation services and improve overall community health.

In addition to qualitative results, mixed-methods research and quantitative assessments will offer a more thorough knowledge of the effects of post-stroke aphasia.

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Addis Ababa University

College of Education and Behavioral Studies

Department of Special Needs and Inclusive Education and Department of Plastic Surgery and Department of Neurology

Date ________________

Consent Letter

My name is Samrawit Berihun. I am a graduate student studying Speech and Language Therapy at Addis Ababa University. This study is conducted to complete the prerequisites for a MSC degree in Speech and Language Therapy. The purpose of this interview guide is to gather information from Post-stroke aphasia among stroke survivors at Tikur Anbessa Specialized Hospital.

The objective of this study is to explore the lived experience of post-stroke aphasia among stroke survivors followed at Tikur Anbessa Specialized Hospital. As a result, your response contributes significantly to meet the central theme of the study. I am pleased to confirm you that the information collected from your interview will be used only for the purpose of the study and it will be kept confidential. Hence, I kindly request your cooperation for the provision of clear and genuine response to the questions presented below, and the researcher appreciates your collaborative engagement.

The researcher would like to let you know that you are under no obligation to continue sharing any kind of information and can suspend your involvement at any time during the interview process. I would also like to let you know that the interview may last an hour, and I may record your interview on digital recorder only based on your consent, and once the final document of the study is accepted, the recorded Information will be deleted.

Lastly, but not least, I would like to express my utmost respect and thank you for your willingness to participate in the interview.

Date ----------------

Interview Agreement

I am Ms. Samrawit Berihun, I am a graduate student in Speech and Language Therapy at the Department of Special Needs and Inclusive Education, Department of Plastic Surgery and Department of Neurology Addis Ababa University, and I am currently working on my thesis at Tikur Anbessa Specialized Hospital. Therefore, in order to collect important information for the thesis, I have chosen to interview Mr/Mrs.__________________. I agree to keep the information collected during the interview confidential and use it only for the intended purpose. I confirm my agreement with my signature.

I, Ms/Mrs. __________________, participate in the services given to myself at Tikur Anbessa Specialized Hospital. Having the above stated points in mind I also agree to participate in the interview with my consent. I also confirm my agreement with my signature.

Agreement Acceptor

Name____________________

Signature _________________

Date ____________________

Agreement Giver

Name ____________________

Signature _________________

Date_________________

Interview guide for post-stroke aphasia survivors

First of all I would like to thank you for your participation in my study on the lived experience of people with post-stroke aphasia among stroke survivors followed at Tikur Anbessa Specialized Hospital. I will record your voice during the interview and want to know if you are willing. and are you willing? I will destroy this audio recording when I finish my research. I appreciate your willingness to participate in this research and candidness in answering questions your contribution to this research is important.

General and Demographic Data

Address:

1. Age:
2. Sex:

    A. Male……… B. Female……….

3. Education Background:
    A. No Education
    B. Read and writing only
    C. Grade 1-6
    D. Grades 7-8 and 9-12
    E. Higher Education
4. Occupation:
5. Marital status:

    A. Single C. Divorced

    B. Married D. Widowed/widower

6. With whom do you currently live?
7. What is your first language?
8. What other languages do you speak?

Case History

- Medical and health related history?
- Is this your first ever stroke?
- When and where did the stroke happen?
- How long were you hospitalized?
- Tell me about the follow up?

Pre- Stroke Awareness and Family History

- Did you know anything about stroke or post-stroke aphasia before it happened to you?
- Is there anyone who had stroke or post-stroke aphasia in your family?

Initial Experience and Immediate Reactions

- At the onset of your first symptoms, were you immediately aware of what was happening? What was your family's reaction?
- What were you doing at the time the stroke occurred?
- Tell me about what was happening at the time the stroke occurred? For example did the stroke happen suddenly, by accident, or were there other events that occurred, such as when you fell, who were around you?
- When you had a stroke, who did you consult for the first time? What was their response when you asked them about the problem?
- After the problem happened, how were you treated by the family member?

Impact on Daily Life and Communication

- Has your life remained the same as it was before the post-stroke aphasia? If not, please explain how it was changed.
- How has post-stroke aphasia affected your ability to communicate in your daily interaction with family and the community?
- How has post-stroke aphasia influenced your ability to engage in activities of daily living such as self-care, household management, and personal routine?
- How has post-stroke aphasia impacted your income and financial stability, both at individual and family level?
- Please describe any challenges you have encountered due to post-stroke aphasia?
- Can you describe any emotional and psychological challenges you have faced as a result of post-stroke aphasia, particularly in relation to social interactions and daily activities?

Medical Follow-Up and Treatment

- Please tell me what your medical follow-up looked like? How long did it take?
- Did the doctors suggest treatments for speech and language problems?
- What type of treatment did you receive after experiencing a stroke?
- Please tell me about the nature of your difficulty or problem following the stroke?
- Did you visit a speech and language therapist? If yes, how did you come to know about the services?
- Were there any differences in the language used in therapy and the language spoken at home post-stroke? Did all languages get treatment with the SLT? If not, which language did they focus on? Did they notice improvements in other languages?
- How did you communicate with others before you had speech language therapy?

- What was the nature of the services? Was it center-based or home-based? Was the family an active part of therapy? Was there a wife/husband or child that participated and supported the sessions? Was homework assigned for practice outside of the sessions with the family?

- Please tell me what the treatment looked like and how long it took? How was the duration of time (30 minutes vs 45 min vs 1 hour), the intensity (once a week vs twice a week vs more), and the total duration of treatment (1 month vs 2 months)?

- Did you think this amount of time was sufficient to treat your aphasia?

- Was the therapy effective?

- Did you understand all the things others said? Can you understand all verbal messages, pictures, objects, gestures?

Social and Environmental Interactions

- Did strangers understand you? For example others at the supermarket, some offices, transports?

- Tell me about the improvements?

- Tell me about your profession before the incident?

- Are you still working in your profession? If not, why not?

- What are you doing now? Are you satisfied with your present job?

- Can you describe your home or workplace environment and share whether you find it supportive or challenging in relation to managing life with post-stroke aphasia?

- How did post-stroke aphasia impact your family members?

- If you feel supported in your home/workplace, could you share the type of support and accommodations that have been beneficial to you in managing post-stroke aphasia?

Social Participation and Relationships

- To what extent has post-stroke aphasia impacted your ability to participate in social activities and interactions?
- In what ways has post-stroke aphasia altered your social relationships and interactions compared to before your stroke?

Broader Perspectives and Suggestions

- What is your perspective with regard to the status of persons with post-stroke aphasia in Ethiopia?
- Do you wish anything would have been done differently throughout the course of your treatment program?
- What do you suggest to be done to improve their quality of life?