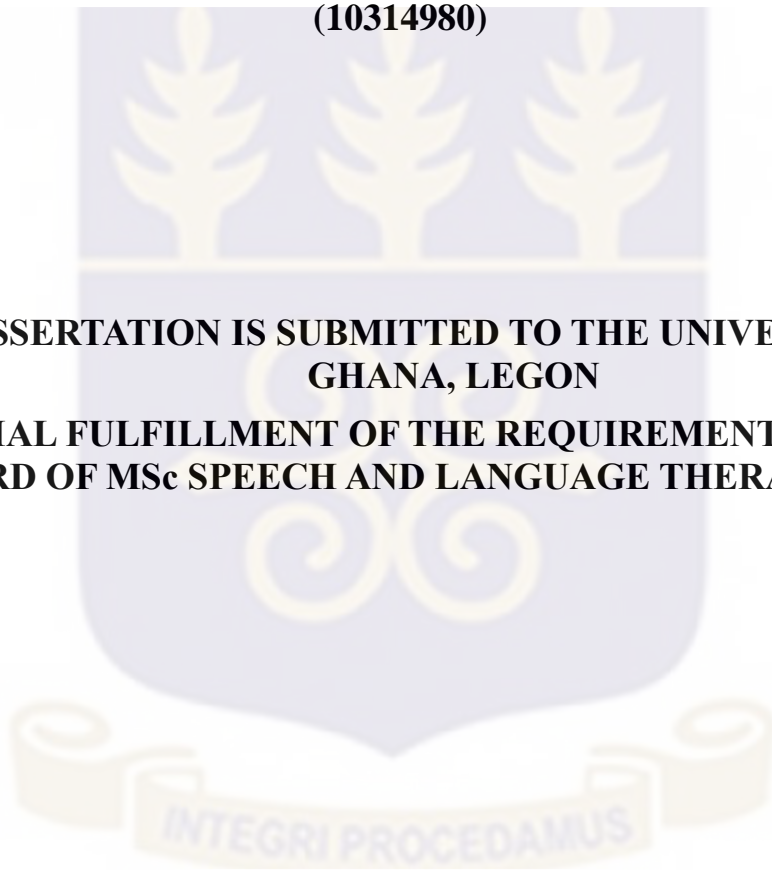


**COMMUNICATION STRATEGIES USED BY FAMILIES OF AN  
INDIVIDUAL WITH APHASIA FOLLOWING STROKE**

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**THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF  
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AWARD OF MSc SPEECH AND LANGUAGE THERAPY DEGREE**



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## DECLARATION

I, **ABENA ASIUEDUA OWUSU ANTWI** do hereby declare that this dissertation which is being submitted in fulfillment of the requirements for the Master of science degree in Speech and Language therapy is the result of my own research performed under supervision, and that except where otherwise other sources are acknowledged and duly referenced, this work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

I hereby give permission for the Department of Audiology, Speech and Language therapy to seek dissemination/publication of the dissertation in any appropriate format. Authorship in such circumstances to be jointly held between me as the first author and the supervisors as subsequent authors.

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## **DEDICATION**

The work is dedicated to the Lord God Almighty.

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## **LIST OF ABBREVIATION**

TMA: Transcortical motor aphasia

TSA: Transcortical sensory aphasia

QOL: Quality of life

## ABSTRACT

**Background:** Aphasia is an acquired communication disability where an individual loses his or her ability to understand and use language in any modality. Gestures, writing and the use of pictures are some examples of strategies which improve communication and interaction with individuals with aphasia. Research shows that adopting communicative strategies and behaviours and establishing positive interactions with individuals with aphasia helps improve their quality of life.

**Aim:** The study was aimed at investigating the strategies and behaviours family members use when communicating with the individual with aphasia.

**Methods:** This research used a qualitative single case study design methodology that explored communication strategies used to support communication between an individual with aphasia and five family members. Two data collection methods were used to explore this topic: an observational method to explore the nature of everyday conversations; semi-structured interviews to describe the range of communication strategies during interactions. Transcripts from the interviews were analysed using thematic analysis based on the six steps process by (Braun & Clarke, 2006). The observational study was analysed using a combination of deductive and inductive analysis. The findings on the two data collection strategies were triangulated to provide a generalising conclusion and to improve rigor and confirm trustworthiness of the processes.

**Results:** The study revealed a description of the strategies and behaviours the family members developed to encourage interactions with the individual who presents with anomic aphasia. Strategies and behaviours such as the use of alternatives, incorporating patience, encouraging one-on-one interactions, stating the topic, body language/the use of objects to communicate were outlined by family members to facilitate communication with the individual with anomic aphasia.

**Conclusion:** This preliminary exploration has illuminated the communication strategies employed by family members to facilitate interactions with the individual with aphasia within one family case. Future research should build on these preliminary findings to explore patterns in strategies within a range of families.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 BACKGROUND**

Communication difficulties are common after stroke and affect about 50% of stroke survivors (Sorin-Peters, McGilton, & Rochon, 2010). Aphasia brings changes to language which affects the uniqueness of everyday conversations to the affected individual (Davidson, Worrall, & Hickson, 2003). People with aphasia consider communication to be a daunting task due to their negative experiences of trying to get their “message across”, which often results in inadequate communication (Gordon, Ellis-Hill, & Ashburn, 2009) .

Due to the importance of communication, changes in communication impact social relationships for many individuals (Brown, Worrall, Davidson, & Howe, 2011). These difficulties in the use of language influence the quality of life of people with aphasia, due to the increased dependence on others and the difficulties they face with communication (Lynch et al., 2008).

In a study conducted by Brown et al (2011; p.541), an individual with aphasia specified that, “Speech is a gift, communication is a gift”. The individual conveyed that, living successfully with aphasia meant being able to communicate extensively without limitations and furthermore noted that, ‘establishing unlimited communication’ implies the help of family members to improve their communication to meet their needs. People with aphasia tend to also depend on family members for companionship, which further increases the responsibility of family members. This burdens the family members and affects their well-being (Davidson, Howe, Worrall, Hickson, & Togher, 2008).

In one study, family members of people with aphasia identified goals for themselves that relate to their participation in rehabilitation and communication (Wallace et al., 2017) and called for the need to overcome barriers of frustration when communicating with people with aphasia (Howe et al., 2012).

The use of strategies such as gestures, pictures, writing and drawing have been observed to optimize the communication abilities of people with aphasia (Sacchett, Byng & Marshall, 1999). Simmons-Mackie, Raymer and Cherney (2016), identified the need for speech and language therapists to work with dyads (i.e., people with aphasia and their respective communication partners) to create improvements in functional and effective communication. Interventions of this type require therapists to identify these communication strategies which are effective in promoting and maintaining social relationships (Davidson, Worrall & Hickson, 2003).

## **1.2 PROBLEM STATEMENT**

Stroke survivors who present with aphasia may have difficulties in comprehending verbal and written information and may not be able to express themselves effectively. This challenges the usual routes of communication (Gordon et al., 2009). Research has deduced the effective use of strategies to facilitate successful communication with people with aphasia (Paul & Sanders, 2009). In Ghana, there has been no research on how family members, who are key communication partners, communicate with people with aphasia. This study provides early research in this area exploring the communicative strategies used by families of people with aphasia in Ghana.

### **1.3 SIGNIFICANCE OF STUDY**

The study will provide information on how family members communicate with people with aphasia, with an emphasis on the methods adopted by communication partners to facilitate their communication. This knowledge will be used to shape local Ghanaian knowledge on communication practices that can be used in therapy with people with aphasia. Speech and language therapists may use this information as stepping stones to help develop local evidence-based resource materials on appropriate and culturally relevant communication strategies when communicating with people with aphasia.

### **1.4 AIM OF THE RESEARCH**

The aim of this study was to investigate the strategies and behaviours family members use when communicating with the individual with aphasia.

### **1.5 RESEARCH OBJECTIVES**

The objectives of the study were;

1. To explore the nature of everyday conversations of family members and the individual with aphasia.
2. To describe the range of communication strategies used within one family case, when communicating with an individual with aphasia.

## **1.6 RESEARCH QUESTION**

What strategies do family members adopt when communicating with the individual with aphasia?

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This chapter reviews literature on aphasia following stroke, types of aphasia, people living with aphasia, communication partners of people with aphasia, the quality of life (QOL) approach to aphasia and aphasia, stroke and culture.

#### **2.2 APHASIA FOLLOWING STROKE**

The sudden change in the functional capability and health status of patients after stroke negatively impacts family relations and leisure activities (Lee, Lee, Choi, & Pyun, 2015). Stroke is a primary cause of aphasia (Howe et al., 2012) and is reported to be a principal cause of long-term disability (Lynch et al., 2008). Stroke survivors typically live with neurocognitive deficits including speech and language impairment. This challenges their ability to communicate effectively due to the difficulties they experience (Sorin-Peters et al., 2010).

According to Tesak and Code (2008), most workers in the field describe aphasia as impairments in the use of language, including the expression and comprehension of language in any modality - whether through writing, speech or linguistic signing - and is caused by some acquired form of damage to the brain. Aphasia does not include impairments of articulation (such as dysarthria) or of voice (such as aphonia).

For most people with aphasia, cortical damage from the stroke is located on the left side of the brain (Potagas, Kasselimis, & Evdokimidis, 2017). Left-handed individuals can present with less

severe aphasia because up to 50% may have bilateral hemispheric representation for language (Code, 1987). Persons who are left-handed with right hemisphere dominance for language have better prognosis compared to right-handed individuals who present with aphasia (Papathanasiou, Coppens, & Davidson, 2017).

Aphasia is characterized by the individual's inability to access language form, content and use and other cognitive processes that interrelate with language such as memory, thinking and attention (Murray & Chapey, 2001). This affects an individual's ability to understand and use language which impairs modalities of language such as speaking, reading and writing (Papathanasiou et al., 2017). People with aphasia can spontaneously recover from it during the first months after stroke but a significant number of people continue to have language disturbances for years (Gialanella, 2011).

Besides being caused by stroke, aphasia may occur as a result of head injury and in some cases slowly develop as a result of brain tumor or a progressive neurological disease (Gillespie & Hald, 2017). As a result of the brain damage, aphasia can co-occur with speech disorders such as apraxia and dysarthria (Murray & Chapey, 2001). A significant negative impact that affects the lives of people with aphasia was determined in a study conducted to assess health-related factors affecting the QOL for over 64,000 hospital in-patients in Canada. Aphasia was shown to have more detrimental effects on health-related quality of life, when compared to that of people with Alzheimer's or cancer (Lam & Wodchis, 2010). People with aphasia face poor quality of life which persists into the long term following stroke (Papathanasiou et al., 2017).

It is estimated that about one-third of strokes result in aphasia (Hilari, Needle, & Harrison, 2012). However, on the basis of data obtained from aphasia following stroke in the developed world, the

incidence rate ranges from 0.02-0.06% and the prevalence rate ranges from 0.1-4% (Code & Petheram, 2011). Currently, there are no records to show the incidence and prevalence rate of aphasic stroke individuals in Africa or in Ghana.

A large global aphasia survey aimed to examine the level of public awareness of aphasia was carried out across six countries: Argentina, Canada, Croatia, Greece, Norway and Slovenia. Findings showed that the public's awareness of aphasia was very low with a significant difference between those who understand what aphasia actually is (6.5%) and those who have only heard of it (40%) (Code et al., 2016).

### **2.3 TYPES OF APHASIA**

Aphasia can be classified into two broad categories: fluent and non-fluent aphasia. These categories comprise different types of aphasia. Broca's aphasia, transcortical motor aphasia (TMA), global aphasia and mixed transcortical aphasia are types of non-fluent aphasia. On the other hand, Wernicke's aphasia, conduction aphasia, anomic aphasia and transcortical sensory aphasia (TSA) are types of fluent aphasia ( Potagas et al, 2017 ).

People who present with non-fluent expressive language in the presence of stronger receptive abilities tend to produce fewer and simpler gestures. Those who present with fluent language with poor receptive abilities tend to produce abundant and complex gestures. However, in spite of damage to the language production system, gestures can remain functional since the production of gestures is not necessarily affected by language impairment (Akhavan, Goksun, & Nozari, 2017). Most aphasia types evolve and change over time; e.g., global aphasia eventually evolves into Broca's aphasia if language production and auditory comprehension recovers. Also, people who

present with Broca's, Wernicke's, conduction and transcortical (sensory, motor and mixed) aphasia tend to resolve towards anomic aphasia overtime (Murray & Chapey, 2001).

An anterior-posterior characterization with a focus on left hemisphere brain damaged patients established that, people who present with anterior left hemisphere damage with non-fluent aphasia characterized by agrammatism and good comprehension present with negative depressive affect whilst those who present with posterior left hemisphere damage characterized by fluent aphasia and poor comprehension often present with positive affect and euphoria (Code et al., 1999).

### **2.3.1 Broca's Aphasia**

Broca's aphasia occurs following damage to the frontal region of the left hemisphere. People who present with Broca's aphasia experience difficulty reading words and sentences and understanding them. They may face difficulties understanding grammatically complex sentences such as "with the pen, point to the book" (Potagas et al., 2017). In their bid to communicate, they tend to sometimes use basic words to get their message across but omit function words such as "is", "and" and "the". They often have a tendency to make mistakes when following directions and say words close to what they intend but not the exact word: "car for truck" (American Stroke Association, 2013). Persons with Broca's aphasia tend to use a lot of gestures which are widely recognized with semantic content, and can co-occur with or replace verbal information (Akhavan et al., 2017). This is the most common form of non-fluent aphasia (Potagas et al., 2017).

### **2.3.2 Global Aphasia**

Large lesions occurring in the frontal (Broca's) and posterior (Wernicke's) regions of the left hemisphere can result in global aphasia which is characterised by severe language expression and comprehension problems affecting all modalities. People who present with Global aphasia

experience difficulty forming words and sentences and difficulty understanding what others say. They are severely nonverbal with impairments in their ability to repeat, to read and to name items. It is the most severe form of aphasia and has a general effect on all other communication abilities (Potagas et al., 2017). Some people with global aphasia may present with very severe aphasia for a short period following stroke then move to a different type of aphasia as they improve. People who continue to present with global aphasia beyond 3 months post-onset tend to have poorer outcomes (Murray & Chapey, 2001).

### **2.3.3 Transcortical Motor Aphasia (TMA)**

TMA, also sometimes called ‘dynamic’ or ‘frontal’ aphasia, occurs following damage to the anterior superior frontal lobe. They present with an apparent lack of the ‘will to speak’. People who present with TMA experience difficulty in initiating and organizing responses when questioned and sometimes there is ‘echolalia’, where they echo what has been said to them and they tend to perseverate on their own utterances (Potagas et al., 2017). They are known to use few gestures when communicating (Akhavan et al., 2017).

### **2.3.4 Mixed Transcortical Aphasia**

Mixed transcortical aphasia is a combination of Transcortical motor aphasia and Transcortical sensory aphasia and is very rare. People who present with this type of aphasia have difficulties with comprehension and are severely impaired in their ability to name, write and read. They tend to repeat words and sentences (Potagas et al., 2017).

### **2.3.5 Wernicke’s Aphasia**

Wernicke’s aphasia is the most common type of fluent aphasia. Lesions occurs in the posterior portion of the left superior temporal gyrus. They produce “empty speech” – that is; they speak in long, complete sentences with little meaning. They have problems understanding the meaning of

spoken words. Since they are not affected with the verbal output, their speech is characterized by phonemic and semantic paraphasias and neologisms. They are anosognosic, i.e. they are often unaware of their language disorder. If the use of paraphasias are particularly extensive and speech appears to have little meaning it is described as ‘jargon aphasia’ (Potagas et al., 2017).

### **2.3.6 Anomic Aphasia**

Anomic aphasia, or anomia, is classically considered to arise following damage to the posterior language area of the left hemisphere, though most types of aphasia can evolve to anomia with recovery. Persons who present with anomic aphasia have fewer difficulties with verbal output but their speech is characterized by word finding difficulties, frequent pauses and circumlocutions. They can often read, understand and repeat words (Potagas et al., 2017). They use fewer gestures when communicating (Akhavan et al., 2017). Due to their word finding difficulty, they experience difficulty accessing the right word when writing and use alternative or substitute words to replace the words they are unable to access when they speak. Approximately half of patients who present with anomic aphasia experience complete recovery by one year post-onset and are expected to have better outcomes (Murray & Chapey, 2001).

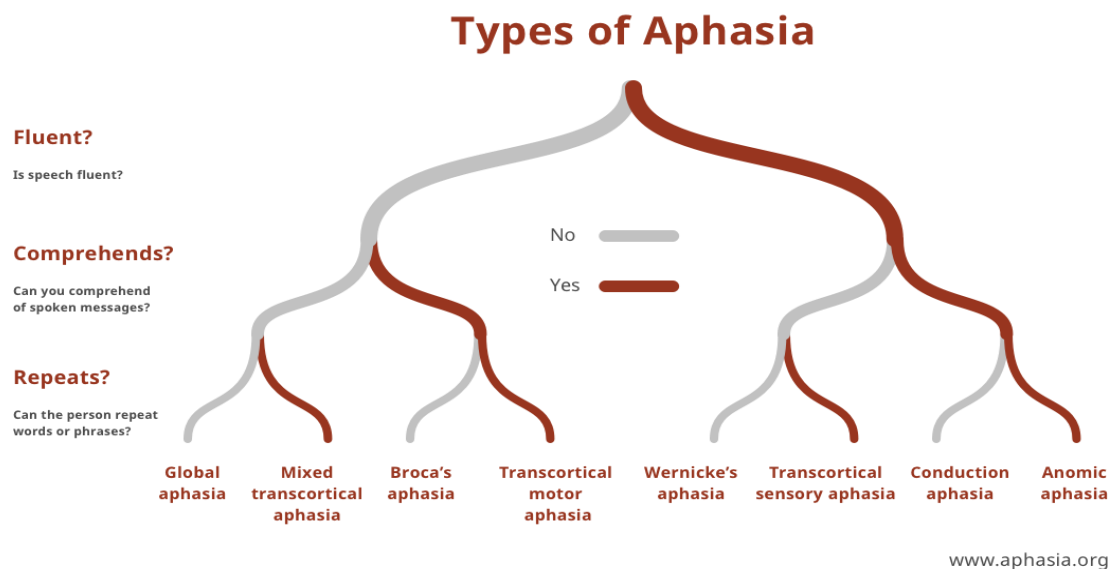
### **2.3.7 Conduction Aphasia**

Conduction aphasia was classically considered to be caused by a lesion to the arcuate fasciculus, the great fibre tract linking Wernicke’s and Broca’s areas. The primary symptom is a repetition deficit. Persons who present with conduction aphasia have relatively fluent speech which is characterized by phonemic paraphasia - (words that sound like the intended word) and anomia (word finding difficulty). Though they sometimes face difficulties understanding complex sentences, they have a tendency to produce phonemic variations in their attempt to correct themselves and are very well aware of their verbal paraphasias (Potagas et al., 2017).

### 2.3.8 Transcortical Sensory Aphasia (TSA)

In many cases, individuals with TSA often produce fluent but unintelligible speech. They may repeat words and sentences and their speech is characterized by paraphasias and neologisms. They are impaired in their ability to read, write and name objects and have difficulty understanding oral and written language. Some may be echolalic and tend to repeat words and sentences said to them. TSA presents similar deficits as in Wernicke’s aphasia, but repetition ability is spared and phoneme discrimination impairments are not found (Potagas et al., 2017)

A summary of the eight (8) main types of aphasia is shown in Fig 2.1.



**Figure 2.1: Types of aphasia** (Source: National Aphasia Association)

## 2.4 OTHER TYPES

There are other rarer types of aphasia which do not specifically fall within the categories of fluent or non-fluent aphasia.

### **2.4.1 Crossed Aphasia**

There are rarely cases of right-handed individuals who suffer from aphasia after right hemisphere lesions. Most types of aphasia have been described following a right hemisphere lesion in right-handed people (Coppens, Hungerford, Yamaguchi, & Yamadori, 2002). People who present with right hemisphere lesions may also present with deficits in extra-linguistic aspects of language such as processing nonliteral verbal stimuli, verbal jokes, idioms and prosody but perform well on traditional aphasia tests (Code, 1987; Potagas et al., 2017).

### **2.4.2 Sign Language Aphasia**

Deaf people who use sign language can acquire aphasia as a result of lesions in the left hemisphere affecting the same areas of the language system as hearing individuals. This affects their ability to gesture and pantomime which alters their mode of communication due to the deficit in the language areas of the brain (Potagas et al., 2017).

### **2.4.3 Subcortical Aphasia**

This type of aphasia is often as a result of damage to the subcortical regions of the brain such as the thalamus, internal capsule and the basal ganglia (Potagas et al., 2017).

## **2.5 PEOPLE LIVING WITH APHASIA**

Aphasia creates an atmosphere of negative outcomes for social activities that often leads to social segregation, loss of autonomy, role changes and stigmatization (Simmons-Mackie et al., 2016). The experience of living with communication difficulties after stroke limits meaningful interactions (Gordon et al., 2009) and functionally masks inherent competence (Papathanasiou et al., 2017). This affects the individual's ability to contribute ideas (Davidson et al., 2003), which impacts on the quality of interactions and nature of communication (Davidson et al., 2008).

Individuals with aphasia are undermined with teasing (Parr, 2007), excluded in communications (Howe, Worrall, & Hickson, 2008) and socially isolated when compared with their peers. They experience restriction in participating in activities (Gialanella, 2011), which often results in occupational frustrations and a reduced involvement in daily activities (Code, 2003).

It is never the wish of people with aphasia to not communicate. Instead, they have branded themselves as incapable in the environment in which they find themselves (Lyon, 1989). People with aphasia themselves describe the importance of the communication environment, as they perceive that the communication environment has the ability to foster their participation in activities, express themselves, and also to comprehend others (Garcia & Connor, 2011). Negative attitudes such as being impatient (Howe et al., 2008) and talking about the individual rather than acknowledging them (Braun & Liechty, 2014) have a drastic toll on their confidence and identity (Shadden, 2017).

In light of this, people with aphasia identify that important issues that impact their ability to communicate are the behaviour and responses of families and people within the community (Parr, 2007). People with aphasia further stated how “broken speech” is not tolerated readily by listeners and silence in such situations creates an atmosphere of discomfort (Le Dorze & Brassard, 1995). These attitudes and behaviours of others affect them emotionally as they may grieve through stages of denial, anger, depression and acceptance (Code et al., 1999). This, however, leads to a deterioration in health (O’Halloran, Carragher, & Foster, 2017). Many people who have been devastated with aphasia, spend a significant amount of time with family and friends and sometimes in churches and other community activities (Code, 2003). One distressing factor that people with aphasia reported as a barrier was the lack of knowledge about aphasia and stroke and the specific communication difficulties they present with (Howe et al., 2008). They expressed that these

negative effects are present because the relative or friend is unable to maintain conversation (Le Dorze & Brassard, 1995). People with aphasia do, however stress, the need to include family members in communication rehabilitation (Howe et al., 2012) so as to promote positive “supportive” relationships to help facilitate communication, strengthen self-esteem and improve confidence (Simmons-Mackie, 2008).

In light of facilitating successful communication within families, individuals with aphasia together with speech and language therapists have highlighted the important role family members play in facilitating communication with regards to living successfully with aphasia (Brown et al., 2011).

## **2.6 COMMUNICATION PARTNERS OF PEOPLE WITH APHASIA**

The most important communication partners to people with aphasia are the family members (Johansson, Carlsson, & Sonnander, 2011). Family members of people with aphasia tend to cope with new responsibilities by taking on new roles in addition to other responsibilities and also serve as a translator for the individual with aphasia (Howe et al., 2012). Spouses are affected more than other relatives (Le Dorze & Brassard, 1995). Though they have little or no knowledge about aphasia and stroke, (Avent et al., 2005), spouses noted the frustration felt by the individual in an attempt to help the individual with aphasia (Müller, Code, & Mugford, 1983) and perceived them to be demanding, immature and anxious (Le Dorze & Brassard, 1995).

Though the family is considered to be one of the most valuable resources to people with aphasia (Johansson et al., 2011), relatives are, however, ill-prepared to deal with the unexpected and permanent changes caused by aphasia (Avent et al., 2005). They tend to experience a psychological separation from the individual with aphasia (Code et al., 1999) laying emphasis on the effect of aphasia and describing the situation as irritating, tiring, stressful and discouraging

(Le Dorze & Brassard, 1995). They sometimes saw these communication difficulties spill into anger and sometimes violence (Parr, 2007). In spite of this, their emotions and feelings were overlooked because the person with stroke was regarded as a 'patient' (Anderson & Marlett, 2004).

Positive effects of aphasia on family members were reviewed in a study and its findings, mapped to the International Classification of Functioning and Disability (ICF), marked improved relationships of family members with people with aphasia. This was characterised by hopefulness, appreciation of life, improved relationship with other family members, demonstration of physical attraction, engagement in social events, amongst others (Grawburg, Howe, Worrall, & Scarinci, 2012).

## **2.7 THE QUALITY OF LIFE (QOL) APPROACH TO APHASIA**

Globally, QOL has been used to determine the impact of diseases from a patient's perspective. This encompasses behaviours and attitudes towards people who present with disability that can either facilitate or hinder functionality (Mattevi, Bredemeier, Fam, & Fleck, 2012). There is an increasing interest in the use of well-being as a measure of QOL to effectively reflect client outcomes and service provision in the field of healthcare and health interventions (Cruice, Worrall, & Hickson, 2011). A shift in social roles of the stroke survivor impacts on his or her QOL as they depend on others for everyday activities (Lynch et al., 2008). This however shows the significance of self-help groups to support people with aphasia to empower them to establish new identity, where their own disability is recognized (Code et al., 2003). In order to better understand the social activity of people with aphasia, it would be better to target socially relevant therapy and raise public and professional awareness to reduce communication barriers in the community (Code, 2003). The circumstances surrounding aphasia are more complex than simply a language disorder.

To improve on the QOL of family members and individuals with aphasia, it is necessary to understand the functional limitations with regards to communication so as to develop effective rehabilitation programmes (Le Dorze & Brassard, 1995). This involves supporting individuals and families in creating a positive post-stroke identity (Anderson & Marlett, 2004).

Intervention in the lives of people with aphasia focuses on the social approach, which addresses the ability of people with aphasia to communicate effectively in his or her environment (Paul & Sanders, 2009). These approaches are marked by enhanced life participation and improved QOL (Simmons-Mackie et al., 2010). This addresses the means through which communication partners in the aphasic individual's environment modify their communication to successfully transmit thoughts (Paul & Sanders, 2009). This is successfully carried out by paying attention to the "nature of the place", putting into consideration the content of the message with the purpose of ensuring that they are communicatively accessible (Parr, 2007). Communication partners are people in the environment with whom people with aphasia interact. This is not restricted to healthcare providers, volunteers or friends, but embraces family members as well. These partners exhibit some characteristics such as an increase in the use of effective strategies to reveal the communicative competence of people with aphasia (Simmons-Mackie et al., 2016).

Healthcare providers play a vital role in providing an enabling environment in promoting meaningful interaction in hospital rehabilitation. This involves providing information and emotional support to help the patient come to terms with their stroke (Gordon et al., 2009). Healthcare providers may not know, and most often do not know, how best to communicate with people who present with communication disability. As a result, people with communication disability face a higher risk of compromised healthcare and poorer long-term outcomes than people without communication disabilities. However, people with communication disability describe the

knowledge and skill nurses use during interactions that helped to achieve communication success (O'Halloran, Hickson, & Worrall, 2008). These positive interactions between caregivers and residents in long term care institutions have been documented to not only improve the QOL of residents and their psychological and social well-being, but even to contribute to increasing life expectancy (Simmons-Mackie et al., 2016).

O'Halloran, Hickson and Worrall (2008) examined environmental factors that affect communication between healthcare providers and people with aphasia. They explored the barriers or attitudes that facilitated or hindered communication between healthcare providers and people with aphasia. The barriers faced included frustration when communication was unsuccessful and the lack of knowledge of other alternative communication systems. Certain attitudes and behaviours facilitated more successful communication, including kindness, patience and the willingness to keep trying when the communication was unsuccessful. Adopting the incorporation of written information in ways which could be easily understood was also useful to assist communication for people with aphasia. Thus, the ultimate goal for people with aphasia and professionals working with them is to dismantle barriers which frustrate and disable people (Code et al., 2003).

The family members, who are regarded as stakeholders into providing insight to living successfully with aphasia, express their need for information on aphasia, to develop effective means of communicating with the individual with aphasia and establish better relationships with their family (Brown et al., 2011).

In light of this, family members tend to develop their own communication materials to encourage communication with the aphasic individual if they are not given directions on how to facilitate

communication (Howe et al., 2012). These strategies may be either positive: where the spouse or relative accompanies his/her speech with a gesture, or maladaptive: where the spouse or relative 'pretends' to understand the individual with aphasia, and this eventually leads to a breakdown in communication (Murray & Chapey, 2001). They experience difficulties in the process of facilitating communication with people with aphasia that can be distressing because of their constant interaction with the individual with aphasia (Paul & Sanders, 2009).

There is often a disruption in communication without the use of these strategies, which can be traumatic for individuals who communicate with people with aphasia frequently (Paul & Sanders, 2009). In view of this, family members called for the need to be included as key members of the rehabilitation process, stating the need to prioritize their need to communicate, as that of the people with aphasia can establish better relationships (Brown et al., 2011).

Communication interventions in the lives of individuals with aphasia after stroke requires an expansion of research and management efforts to include communicative skills of communication partners of people with aphasia (Simmons-Mackie, 2008). This involves formally providing information or educational interventions that may successfully improve patients and caregivers knowledge about stroke and communication (Anderson & Marlett, 2004).

People with aphasia reveal that the use of communication strategies is a key component of living with aphasia (Brown, Worrall, Davidson & Howe, 2010). They feel that having access to visual information, such as the use of pictures and verbal information, assists them in communicating (Brown et al., 2010). A study conducted by (Rose, Worrall, & McKenna, 2003) investigated the comprehension ability of people with aphasia, when aphasia-friendly principles, such as the use of visual and written information, were adopted in printed health education materials. The study

found that people who present with aphasia felt that these principles aided them during interactions and indicated the preference for aphasia-friendly materials. Notable amongst them is the use of pictures, which was regarded as helpful and useful in aiding memory. Incorporating written information such as using short and simple language, bolding important information and the use of common everyday words proved to be of benefit to the individuals with aphasia.

Akhavan, Goksun and Nozari (2017) addressed the significance of the use of gestures in facilitating conversations with people with aphasia. They emphasized the significance of the use of gestures by people with aphasia which compensates for their verbal deficits and facilitates the production of words. People with aphasia further emphasize that people's awareness of aphasia creates opportunities in society that facilitate participation (Howe et al., 2008). In this regard, it is expected of the communication partner to maintain the communication exchange by taking time to listen, paying attention to what the person with aphasia is saying, and also ensuring that others will speak to the person with aphasia in spite of his/her withdrawal from communication (Le Dorze & Brassard, 1995). Also, they appreciate it when the communication partner acknowledges communication breakdown and together with the individual with aphasia decide to proceed or continue conversation at a later time so as to achieve success (Clarkson, 2010). Most relatives and friends of people with aphasia identify the need to be trained in the practical skills to support communication (Parr, 2007). In light of this, most clinicians called for the need to train communication partners since communication partner training serves as "communication ramps" to minimizing communication disability (Simmons-Mackie et al., 2016).

## **2.8 APHASIA, STROKE AND CULTURE**

There has been insightful contributions in the field of aphasiology in majority world countries such as South Africa; addressing the need to explore the cultural context of aphasia and stroke. It is suggested that, this exploration can eventually shed light on how people who present with aphasia and their communication partners perceive the condition and the strategies they adopt in the process of seeking help (Legg & Penn, 2017). These studies addressed the need to engage people who present with aphasia in their cultural context with careful considerations to the diversity of the language and culture. This will provide functional ways to developing culturally relevant and appropriate tools for assessment and intervention (Penn & Armstrong, 2017).

Further studies showed participants narrate their shared experiences with aphasia from a sociocultural context. They linked their beliefs about the cause of aphasia to spirituality, particularly; ancestral reprisal and agencies of witchcraft (Legg& Penn, 2014). This brings to light the importance of beliefs and perception in relation to culture. Beliefs, educational background and socio-economic factors can influence how individuals perceive the difficulties they present with (Penn & Armstrong, 2017). Thus, depending on their beliefs and perception, people explored avenues that could help with their misfortune through traditional rehabilitation, biomedicine, making offerings to ancestors, amongst others (Legg& Penn, 2014).

## **2.9 RESEARCH GAP**

There is little research on the structure of informal interactions between aphasic people and their families (Anderson & Marlett, 2004). There are no published studies on this subject in Ghana. This research adds to the evidence base in this field by exploring the everyday communication of

family members and the individual with aphasia, to consider the type of communication patterns and strategies used in a family setting.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter presents the methods and techniques used in collecting and analyzing data in this study.

#### **3.2 STUDY DESIGN**

Specifically, a qualitative single case study design was used. Case studies are a qualitative methodology which seeks to explore a phenomenon within its context using a variety of data sources to allow for multiple facets of a phenomenon to be revealed through a variety of lenses (Baxter & Jack, 2008). This design was aimed at examining real-life and natural phenomenon through detailed contextual analysis (Zainal, 2007). An instrumental case study was adopted with two data collection strategies: semi-structured interviews and nonparticipant observation to examine how family members interact with an individual with aphasia (Baxter & Jack, 2008). This design was suitable to the research question because case studies enable an early exploration and insight into the studied phenomena. Case study approaches are useful in the first steps of research seeking to provide a deeper and nuanced understanding of a phenomena (Sepehr, Goodarz & Aghapour, 2012).

### **3.3 STUDY SITE**

This study was conducted in the home of the participants, in Accra, so as to examine detailed communication activities of the everyday life of family members and the individual with aphasia.

### **3.4 PARTICIPANTS**

The study participants included an individual with aphasia and five (5) of her family members who live with her. The individual with aphasia, “BJ”, was recruited by contacting speech and language therapists and asking them to act as gatekeepers. Speech and language therapists identified potential participants based on inclusion and exclusion criteria and provided them with information about the study. Interested families were contacted by the researcher and one family was chosen for this study. The individual with aphasia’s family was chosen because of the larger family size she has. The study focused on five participants who were primary communication partners of the individual with aphasia. A day and time was scheduled with the family that agreed to participate. The participants were required to give their consent before proceeding with the study. The participant information sheet and assent/consent form is included as Appendix.

The participant in the case study, identified in this thesis as BJ, is a female who has a diagnosis of anomic aphasia following stroke. BJ was 66 years of age and, 1-year post-stroke at the time of the study. BJ had normal hearing and lived with her family members (husband, two sons, two daughters and a carer - who is considered as family by the participants). BJ’s primary language is Twi and BJ is also fluent in English. BJ together with her family, have a high-level educational background, all having completed University education. Prior to her stroke, BJ was employed as a teacher. She was reported by her family to spend a lot of time at church and had the support of her church members. BJ is hypertensive, diabetic and was then on herbal medication.

### **3.5 INCLUSION AND EXCLUSION CRITERIA**

#### **3.5.1 Inclusion Criteria**

Criteria for inclusion as a person with aphasia included:

- having a diagnosis of aphasia following stroke
- Being between the ages of 45-66 years
- Being within 6 months to one-year post-stroke
- living with family members (husband, daughter, son or a significant other)

Criteria for inclusion of family members of BJ in the study included:

- Being recognized as frequent and regular conversation partners of BJ by other family members since the onset of aphasia.
- Being at least 18 years of age.

#### **3.5.2 Exclusion Criteria**

The individual with aphasia was excluded if they experienced significant hearing loss which impacts his/her ability to respond to conversational level auditory stimuli. People who use hearing aids who are able to respond to conversational stimuli were not excluded.

Family members were excluded if:

- He/she is not a primary conversation partner of the individual with aphasia
- He/she is not 18 years and above

### **3.6 INSTRUMENTATION**

The instruments used in this study included an audio recorder and an audio-visual-recorder. The audio recorder was used to record the interview session together with a one-page summary of an

interview guide to address questions pertinent to the research topic. An audio-visual recorder was used to record everyday interactions between the individual with aphasia and family members. Family members and the person with aphasia consented to the use of an audio recorder and audiovisual recording for research purposes, as part of the consent processes.

### **3.7 PROCEDURE FOR DATA COLLECTION**

Data was collected in two phases. The first phase involved semi-structured interviews with open-ended questions. Field notes were taken during interviews with the participants in their homes.

The second phase took the form of an observational study.

#### **3.7.1 Semi-structured interviews**

Semi-structured interviews were conducted with five (5) family members of BJ. The intention was to conduct individual semi-structured interviews within a maximum of 25 minutes to 80 minutes, but based on the preference and wishes of the family members, the interview was carried out with each participant in a group setting with all the family present. Open-ended interviews were adopted with follow-up or clarifying questions which emerged from the dialogue. This was aimed at collecting detailed and person-centred information from the participants and it allowed for new ideas to be brought up as a result of the responses from the participants on each participants perceptions on the questions asked (Tellis, 1997). The interviews lasted approximately an hour and 45 minutes and an audio recorder was used to record the session (DiCicco-Bloom & Crabtree, 2006). An interview guide consisting of a one-page summary of topics was used to explore the research questions pertinent to the topic. The interview was carried out in English and in Twi (a Ghanaian local language largely spoken by Akans), as BJ and her family frequently used both languages. The following topics were used to guide the interview: 1) Is there enough information

about aphasia available to them? 2) what is the hardest part about communicating with BJ? 3) how do they help best when BJ communicates her basic needs (hunger, pain, discomfort) – do they incorporate gestures, drawing, writing or pointing?, 4) how do they help when BJ makes routine requests (asking for light to be turned on, asking for directions)? and 5) how do they communicate new information to BJ?, 6) if they switch topics during conversation or speak too quickly or if they all talk at once when speaking to BJ. The topic guide is included as Appendix.

### **3.7.2 Observational study**

An audio-visual recorder was used to observe everyday interactions between family members and BJ so as to capture natural conversations as the family members and BJ went about their normal activities. Arrangements for recording, such as times and situations, were mutually decided with the participants and the person with aphasia, on the basis of interactions BJ has with the family members. The intention was to have the audio-visual recording undertaken within a maximum of 10-15 minutes every other day for two weeks. Time constraints experienced by the family resulted in shorter video recordings, than those originally planned and agreed on. With the help of a family member as a collaborator, the audio-visual recording was undertaken across two weeks within a minimum of 5 minutes. The collaborator sometimes placed the audio-visual recorder in an unobtrusive position in their home and at other times followed the participants in their everyday activities to observe their interactions. The 2<sup>nd</sup> daughter and the carer were not available during the video recording.

### **3.9 DATA MANAGEMENT PLAN**

The relationship status between the family members and the individual with aphasia was used to identify each participant. Data collected was only able to be accessed by the researcher and supervisors.

### **3.10 DATA ANALYSIS**

Semi-structured interviews: Audio recorded data was transcribed verbatim. The interview data in Twi was transcribed verbatim and translated in English by the researcher. A process of immersion in the data was used, with interview data repeatedly listened to and transcription read and re-read, so as to ensure accuracy during interpretation of findings (DiCicco-Bloom & Crabtree, 2006). Interview data was analysed using thematic analysis based on the six (6) steps outlined by (Braun & Clarke, 2006). Following a period of immersion in the data, including repeated review of audio recordings, transcripts of the interview and field notes, the researcher followed the steps outlined in Table 3.1 to analyse the data:

*Table 3.1 Six steps of data analysis used in analysis of the transcripts (Braun & Clarke, 2006)*

Step 1	Familiarization and review of transcripts and notes taken outlining initial observations.
Step 2	Initial were generated and collated to describe content within the transcripts.
Step 3	Codes were refined and sorted into “preliminary themes”
Step 4	“Preliminary themes” were reviewed
Step 5	Themes were refined and named
Step 6	Extracts from the data were identified which illustrated the key themes.

Observational study: Data obtained from the audio-visual recording of family interactions was coded in detail by observing the interactive behaviour patterns of the family members and the individual with aphasia (Pepler & Craig, 1995). As per the wishes of the family, video recordings were deleted after they were coded by the researcher. The video recordings were repeatedly reviewed by the researcher prior to deletion. Video recordings were analysed using a combination of deductive analysis and inductive analysis (Fereday & Muir-Cochrane, 2006). This research used a mix of deductive and inductive analytic approaches. Strategies identified in a previous study (Paul & Sanders, 2009) were applied to the findings derived from the observations and interviews in a deductive approach to analysis. The study by (Paul & Sanders, 2009) sought to investigate the communicative strategies used by nine communication partners to facilitate effective communication with people who present with aphasia. The use and exploration of data, using predetermined categories, or testing a theory is representative of research that is deductive

in nature (Ritchie, Lewis, Nicholls, & Ormston, 2013). Additionally, I recognised that the Ghanaian culture and background of participants was different to the Paul and Sanders (2009) study, there was a need to examine if new or different patterns of communication strategies were evident. An indicative process supplemented the pre-existing observational checklist. The research made field notes of behaviours and processes the family members used as communication strategies which were not already on the observational checklist. Drawing themes directly from the data, is reflective of an inductive approach to data analysis (Ritchie et al., 2013). Inductively, by observing and reflecting on communication patterns within the family, the analysis attempted to build upon the checklist of commonly identified communication strategies (Paul & Sanders, 2009) by adding key themes derived directly from the interview, which may have been specific to this family or this cultural context.

### **3.11 REFLEXITIVITY AND RIGOUR**

Triangulation is used when more than one method is used in the data collection process. Specifically, within this study, methodological triangulation was used to compare the qualitative data from the field notes, observation study and the semi-structured interviews. This method helped to provide confirmation of findings and also enhance trustworthiness of the study conducted. (Jones & Bugge, 2006).

### **3.12 ETHICAL CONSIDERATIONS**

Ethical clearance was obtained from the Ethical and Protocol Review Committee of the Korle-Bu Teaching Hospital. Permission was sought from the individual with aphasia to indulge her family

members in this study and from family members themselves. The purpose of the study and procedure for data collection were explained to participants. Only those who consented were included in the study. Data gathered from the study was treated as anonymous and confidential.

## **CHAPTER FOUR**

### **RESULTS**

#### **4.1 INTRODUCTION**

This chapter presents the results of the study. It explores the themes derived from transcriptions from the interviews and findings deduced from the observational study and field notes analysis. It describes the strategies and behaviours the family members use when communicating with the individual who presents with anomic aphasia.

#### **4.2 PHASE 1**

##### **4.2.1 Interviews**

The interview was conducted with five (5) participants who were primary communication partners of the individual with aphasia. Analysis of the interviews revealed seven (7) emergent themes relating to communication strategies used in interactions between family members and the individual with aphasia. These themes are summarized in box X and described in the following section. Discussion of themes includes the use of direct quotes from the data to represent the direct voice of participants and support the interpretation of the research. Prior to the interview, the researcher observed that, details of the participant information sheet and the assent form was explained to BJ by her husband in Twi and English. He carefully and in a calm manner explained the contents to BJ and waited for BJ to give her consent for the research work.

**Box X:** Summary of the themes derived from the interviews

Theme 1: Lack of knowledge on aphasia: “We know she has aphasia but we know nothing about it”

Theme 2: Alternatives: “When she is provided with options, she is able to say what she wants”

Theme 3: Stating the Topic: “...narrow down to the area of discussion...”

Theme 4: Verbal communication/words: “We do talk about everything”

Theme 5: Patience: “We wait for her to say what she wants to say”

Theme 6: One-On-One Interaction: “We all do not rush in to talk to her”

Theme 7: Body language/using objects to communicate: “she gets hold of the cutlass to let us know she wants to weed”

**4.2.2 Theme 1: Lack of knowledge on aphasia: “We know she has aphasia but we know nothing about it”**

Communication partners of BJ expressed their concern about not having enough knowledge about aphasia available to them. They reported that they knew BJ presents with aphasia but have no idea about what it means to have aphasia. A statement is illustrated below:

“Hmm, I think so. We do not have information. We need more information.

I believe it’s not the whole brain affected? Would she need a psychologist?” (Husband)

“We know she has aphasia but we know nothing about it. This is why we want to see a neurologist so he can explain it to us”. (1<sup>st</sup> daughter)

#### **4.2.3 Theme 2: Alternatives: “When she is provided with options, she is able to say what she wants”**

Frequently noted comments by the family members were around the benefits of using alternatives when communicating with BJ:

“When we got to a shop, she asked if I will not buy “it”. So, I decided to give her alternatives- that’s how we mainly communicate with her. I picked a few things. The shop is full of items. I decided then to give her alternatives from the things we have at home. I was trying to find out what she meant by “it”. I tried but she asked us to leave and come back to it later when she remembers. Sometimes it is difficult”. Most of the time, she can’t say what’s on her mind and it’s very difficult for us because we do not know what she is talking about. We feel bad when she is unable to find the words and I know sometimes she feels uneasy”. (Husband)

“Even with alternatives, it is difficult”. (1<sup>st</sup> daughter)

“When am with her at home or talking to her, she is unable to tell me she is hungry. So I go to her and ask her if she is hungry. Then, I start to provide options of what she would want to eat”. (Carer)

Family members expressed giving BJ choices sometimes facilitated interactions with the individual with aphasia, although giving choices did not always result in an effective communication exchange.

#### **4.2.4 Theme 3: Stating the Topic: “...narrow down to the area of discussion...”**

Family members expressed that stating the topic by narrowing down to the area of discussion seemed to facilitate communication with BJ:

“When you narrow down to the area of discussion and state exactly what you want to talk about, she gets it and is able to say what she wants to say. (Son).

“We inform her about everything and make her aware of every situation. As soon as we state the topic, she knows what she wants to say and the conversation flows”. (2<sup>nd</sup> daughter)

This idea of funneling the conversation down to a narrow topic appeared to aid in both comprehension and expression and improve the consistency of communication.

#### **4.2.5 Theme 4: Verbal communication/words: “We do talk about everything”**

Family members identified that, despite the aphasia, the most frequent mode of communication with BJ was through the use of words:

“We do talk about everything. We use words. Even though sometimes she mixes up her words and has difficulty with her nouns and verbs. Though she uses gestures sometimes, we communicate mainly by talking to her”. (Husband)

Family members stated this modality as one of the principal ways that communication occurs within daily routine and that facilitated conversation with the individual with aphasia.

#### **4.2.6 Theme 5: Patience: “We wait for her to say what she wants to say”**

Family members the issue of time and waiting in communicating with the individual with aphasia:

“We wait for her to say what she wants to say. We help her at her own pace, we do not change the topic no matter how painful it is! Initially, her carer did not understand her actions since the onset of aphasia. We then advised her to be patient, help her instead of confronting her”. (Husband)

“When she gets in the middle of a conversation, she gets stuck. You have to wait. we wait for her and after thinking through for a while she tells us what she wants to say” (1<sup>st</sup> daughter).

The word wait was used extensively by family members in describing their interactions with their family member. Communicating at the pace of the person with aphasia was seen to facilitate interaction, which meant incorporating patience, time and allowing more in conversations.

#### **4.2.7 Theme 6: One-On-One Interaction: “We all do not rush in to talk to her”**

Communication partners of the individual with aphasia indicated that communicating with the person with aphasia one-to-one, rather than in a group conversation was helpful in promoting effective communications. The concept of taking turns was noted to help to facilitate communication:

“We all do not rush in to talk to her. We do not clamp on her to frustrate her. (Husband)

“We all take turns one after the other”. (1<sup>st</sup> daughter)

#### **4.2.8 Theme 7: Body language /using objects to communicate: “she gets hold of the cutlass to let us know she wants to weed”**

Communication partners of the individual with aphasia stated that, being able to read BJ’s movements helped to facilitate communication. It was apparent that BJ was able to use her body language to control her environment and initiate requests or give instructions which the family complied with:

“She takes the initiative in everything, put on the light, if she wants to bath, she takes the kettle, fills it with water and brings it to the electrical point. We then help her out. She will bring her things and begin to put it in the washing machine. (Husband)

Gets hold of the cutlass to let us know she wants to weed”. She is used to doing things on her own so when she starts by picking things up to communicate with us, we follow up! (Son)

The researcher observed that, BJ tried to open a bottle of water herself but she had difficulty opening it. Her husband asked if she needed help with it and she nodded yes and gave him the bottle of water.

### **4.3 PHASE 2**

#### **4.3.1 Observational results**

Phase 2 addressed the aim of determining the nature of everyday conversations of family members and BJ through observing interaction. Data was analysed using a checklist, field notes and observations, using a process which incorporated both deductive and inductive analysis.

Table 4.1 and table 4.2 summarize the strategies observed in interactions between BJ and family members, using both inductive and deductive processes.

**Table 4.1** *Deductive analysis*

*A table showing the comparison of communication strategies and behaviours used by nine communication partners of people with aphasia as generated by (Paul & Sanders,2009) to communication strategies and behaviours adopted by family members of an individual with anomic aphasia.*

<i>Strategies/behaviours used by families in communicating with persons with stroke</i>	<i>Yes</i>	<i>No</i>	<i>Examples and comments</i>
<b>a) Visual Information: uses pictures to communicate intent and to show what she’s talking about /eye contact/pointing</b>	✓		(Husband, son and 1 <sup>st</sup> daughter) were noted to not use pictures when communicating with BJ. Her 1 <sup>st</sup> daughter however made use of pointing when trying to help BJ find her phone. - “What are you looking for? Your phone? It’s in the bag - points to the bag and BJ reaches for it. Her 1 <sup>st</sup> daughter-maintained eye-contact whilst communicating with her but BJ looked away most of the time. Son maintained eye contact during interactions with BJ as they were getting ready to leave for a party.
<b>b) Uses gestures, facial expression and a calm voice to communicate intent.</b>	✓		1 <sup>st</sup> daughter used a calm and soft voice to facilitate conversation with BJ when asking BJ about her phone. However,1 <sup>st</sup> daughter did not make use of gestures or facial expression when communicating with BJ. Husband and 1 <sup>st</sup> daughter used a calm voice whilst communicating with BJ when he tried to use alternatives to facilitate conversation with BJ. Husband started to mention the names of her children but she shook her head and said no! 1 <sup>st</sup> daughter then agreed with BJ to leave the conversation as it is and return to it when she remembers what she wants to say. Husband however was not noted to use any facial expression or gestures to facilitate interactions.

		<p>Son also used a calm voice whilst interacting with BJ as they were preparing to leave for a party by asking BJ “who’s party are we going to”? However, Son did not use gestures or facial expressions to facilitate his interactions.</p>
<b>c) Written information: uses writing to supplement verbal communication /routines</b>	✓	<p>None of the participants were noted to use written information to support or supplement verbal communication. They were however not observed to incorporate routines in their interactions.</p>
<b>d) Allows time for person with communication difficulty to communicate/not rushing them/slow pace</b>	✓	<p>1<sup>st</sup> daughter allowed time for BJ to respond as they were preparing to leave for a funeral. This incident occurred as BJ could not find her phone. She did not rush the conversation and waited till the individual responded.</p> <p>As Husband and 1<sup>st</sup> daughter were communicating with BJ about family matters, though they experienced difficulty trying to understand what she was saying, they allowed time for BJ to communicate and did not rush her. Husband spoke at a slow pace during interactions with BJ over lunch.</p>
<b>e) Provide context: signals a change of topic/states the topic</b>	✓	<p>During family discussions in the hall, the communication partners 1<sup>st</sup> daughter and Husband facilitated communication by stating the topic. This did not help facilitate communication since what they said was not what BJ had in mind to convey to them.</p>
<b>f) speaks clearly/uses short clear sentences/asks one question at a time/targeted questions/repetitions</b>	✓	<p>1<sup>st</sup> daughter spoke clearly and was noted to use short sentences with BJ when asking her about her phone.</p> <p>Husband used short clear sentences during interactions with BJ and</p>

		also asked one question at a time. Son used short sentences and asked one question at a time during interactions with BJ. Though the participants were noted to ask one question at a time, they were not noted to encourage repetitions or the use of targeted questions during their interactions.
<b>g) Patience/active listening</b>	✓	1 <sup>st</sup> daughter, Son, Husband were patient and waited for BJ to respond before continuing with their conversation. They maintained attention during interactions with BJ and listened to her and maintained the conversation.

**Table 4.2** *Inductive analysis*

*A table showing the comparison of the reported communication strategies of the family members from the semi-structured interviews to observed strategies from the observational study.*

<i>Strategies/behaviours family members of the individual with aphasia reported to use when communicating with the individual with aphasia.</i>	<i>Yes</i>	<i>No</i>	<i>Examples and comments</i>
<b>a) Alternatives</b>	✓		Communication partners were noted to use alternatives during their interactions with BJ as early on stated during the interviews. During a family discussion, Husband and 1 <sup>st</sup> daughter used alternatives to know what BJ was trying to convey to them. They took turns in asking what she wanted to say. “Is it the food, medicine, pomade, provisions? BJ replied by nodding no.

<b>b) Patience</b>	✓	1 <sup>st</sup> daughter was patient and waited for BJ to respond before continuing with their conversation. As the interactions was ongoing during their family discussions, the communication partners Husband and 1 <sup>st</sup> daughter exhibited patience and asked the individual with aphasia if it will be alright to wait and return to the subject when she remembers what she wishes to convey.
<b>c)One-on-One interaction</b>	✓	Son and Husband all took turns during interactions with BJ. Conversation was at a slow pace as they each took their time in communicating with BJ. 1 <sup>st</sup> daughter and husband also took turns individually as they discussed family matters whilst watching tv.
<b>d) State the topic</b>	✓	During family discussions in the hall, the communication partners 1 <sup>st</sup> daughter and husband facilitated communication by stating the topic. This however did not help facilitate communication since what they said was not what BJ had in mind to convey to them. They both agreed together with BJ to leave the conversation as it is and return to it later.
<b>e) Verbal communication</b>	✓	1 <sup>st</sup> daughter, husband, son all adopted verbal communication by talking with BJ. 1 <sup>st</sup> daughter and Husband made direct references when BJ was not able to say clearly what was on her mind. They started by mentioning the names of BJ's children but the response was a "no" from BJ.
<b>f) Body language</b>	✓	There were no video opportunities to see this strategy used by family members.

#### **4.4 Triangulation of data collection and analytic methods within one family case:**

These extracts help build a more comprehensible picture that suggests that the family members developed their own strategies even though they had no knowledge of aphasia and that, there may be occasions during daily interactions where there is “incomplete communication” because of the family members inability to understand BJ.

The first data extract is taken from the semi-structured interviews.

##### **Extract 1: Interview data – family members describe the strategies and behaviours used when communicating with the individual with aphasia.**

This extract gives insight into a situation where the family members developed the use of alternatives as a strategy and the perceived difficulty of facilitating interactions with BJ.

The family members reported their use of alternatives as the main means of communicating with BJ. Her husband gave insight to the difficulty he faced when BJ could not say what she needed at the shop and replaced the word with “it”. He described the situation as ‘difficult’ as he could not tell what she was talking about. “I tried but she asked us to leave and come back to it later when she remembers. Sometimes it is difficult”.

The second data extract is drawn from video recordings between BJ and her communication partners where they discuss family matters whilst watching tv.

##### **Extract 2: Video-recording data – to determine the nature of everyday conversations between the individual with aphasia and family members.**

During interactions with the individual with aphasia whilst watching tv, the communication partners (Husband and 1<sup>st</sup> daughter) tried to maintain the conversation by giving alternatives: is it

the food or pomade? She remains silent for a while and responds by nodding no. They continue to give further alternatives each taking turns; is it the tin tomatoes, the soap, the things our son brought? The things my brother brought? They then start to mention the names of her children. She responds and says that's not it. She agrees with her 1<sup>st</sup> daughter and husband when they suggest they wait till she remembers.

After the video was coded in detail, the researcher noticed the strategies the family members adopted whilst communicating with the individual. Though they used alternatives, made direct references to the names of her children and talked at a slow pace to help facilitate interactions, they agreed together with BJ to leave the conversation as it is and return to it later when they realized the difficulty BJ had in conveying her information.

The third data extract is drawn from the researcher's observations during the semi-structured interviews.

**Extract 3: Field notes – illuminate behaviours and strategies adopted by family members**

BJ's husband explained details of the participant information sheet and the assent form to her. In a calm manner, he explained the contents to BJ and waited for BJ to give her consent before proceeding with the research.

Combining the methods of interviews, observations and field notes, helped gain a deeper understanding of the communication strategies of the family members and BJ which reinforced findings gathered from interviews than would have been achieved if only one method was used.

## **CHAPTER FIVE**

### **DISCUSSION**

#### **5.1 INTRODUCTION**

As described in Chapter 1, studies have illustrated that communication strategies can be used to effectively facilitate communication between people with aphasia and their communication partners. This study explored the communication strategies and behaviours of the members in one family when communicating with an individual who presents with anomic aphasia.

#### **5.2 RESEARCH QUESTION**

The research question that guided the study was:

What strategies do family members adopt when communicating with the individual with aphasia?

The findings from this study illuminated the perceptions of the things that communication partners of the individual with aphasia perceived to facilitate communication. This study described the specific communication strategies and behaviours family members used when communicating with the individual with aphasia through two major phases of research. The first phase described the family's reported range of communication strategies used within a single-family case, when communicating with the individual with aphasia. The second phase addressed the nature of everyday conversations of family members and the individual with aphasia. The aim of the study was deduced by adopting the method of triangulation whereby findings from different approaches were compared within one family case to enhance the trustworthiness of the study.

The individual presents with anomic aphasia. Anomic aphasia is characterized by word-finding difficulties, the use of fewer gestures and frequent pauses when communicating as reported by (Potagas et al., 2017; Akhavan et al., 2017). These characteristics are evident in the data, where the individual experienced difficulty in expressing herself during interactions with her family members. An instance is when she substituted the word she was unable to access with the word “it” when they went out for shopping. This is reported by (Murray & Chapey, 2001) which suggests that, people who present with anomic aphasia experience difficulty accessing the right word and substitutes words for words they are unable to access when they speak. The individual’s communication difficulties were identified by the family as limiting meaningful interactions, consistent with the findings of (Gordon et al., 2009). Her loss of words affected her ability to contribute ideas which impacted on the nature of communication and the quality of their interactions as reported by (Davidson et al., 2003; Davidson et al., 2008). However, the members of the family had developed various strategies to effectively communicate with the individual with aphasia. This highlights the importance of family members in enhancing communication with individuals with aphasia. This research finding supports the notion that building family awareness of aphasia, and capacity for interaction, are important elements of helping families build communication success with people with aphasia. This is consistent with findings by (Brown et al., 2011) who reiterated the need to include family members as key members of the communication rehabilitation process, prioritizing their need to communicate so as to establish better relationships. Creating public and professional awareness on aphasia is vitally important, to make people in the community aware of what aphasia is, and in building community knowledge of how best to interact with persons with aphasia. Interventions of this type offer the potential to reduce communication barriers for people with aphasia in the community. This can be effectively

carried out by formally providing information or educational interventions that may successfully improve the knowledge of patients and caregivers about stroke and communication which will eventually create opportunities in society that will facilitate participation as suggested by (Anderson & Marlett, 2004; Howe et al., 2008).

Findings from this research revealed the significance of the communicative environment in facilitating or hindering communication, consistent with findings by (Paul & Sanders, 2009). Similar to the findings of (Brown et al., 2011), the members of the family were concerned about their lack of awareness of aphasia and expressed their need for information on aphasia. Despite this perceived lack of awareness of aphasia, the family in this case altered their communicative environment by developing their own strategies to help facilitate daily interactions with the individual with aphasia, supporting the work of (Howe et al., 2012). This finding reinforces the perception of people with aphasia as stated in (Garcia & Connor, 2011) about the significance of the communication environment which enables them to express themselves. The communication partners portrayed an increase in the use of effective strategies to establish meaningful communication as suggested by (Simmons-Mackie et al., 2016). On the other hand, the family's lack of knowledge on aphasia, prompted them to seek help from a neurologist to satisfy them with information on aphasia because they needed it. They wanted to seek help through biomedical intervention. This resonates with studies done by (Penn & Armstrong, 2017; Legg & Penn, 2014) which was suggestive of the fact that one's beliefs, educational background and socio-economic status has an influence on how the condition is perceived and the avenues of help the individual relies on.

Strategies and behaviours outlined by the members of the family to facilitate conversations with the individual with aphasia in this case included the use of alternatives, developing one-on-one

interactions, being patient, stating the topic during conversations, using verbal communication by just talking to the individual and the use of body language. Studies in other countries and cultures have also shown that families adopt a range of strategies., (Paul & Sanders, 2009; O'Halloran et al., 2008). This research supports the idea that, adopting strategies when interacting with family members with aphasia is apparent in Ghanaian families. This is early research that requires further extension.

Though they developed their own strategies, the members of the family indicated that they faced barriers when communication was unsuccessful and demonstrated their lack of knowledge of other alternate communication systems to facilitate communication. O'Halloran et al., (2008) claimed that families faced barriers during interactions with people with people with aphasia when they had no knowledge of other alternate means of facilitating communication.

Comparing results of this study, to the work of Paul and Sanders (2009), family members in Ghana used similar communication strategies when interacting with their family member with aphasia. Specifically, they adopted different manners of interactions such as establishing eye contact with the individual with aphasia, talking calmly at a slow pace, allowing time for the individual to respond, asking one question at a time and using short clear sentences whilst making direct reference to what they talked about. However, the communication strategies such as the use of gestures, pictures, written information, targeted questions, encouraging repetitions, incorporating routines in their interactions and behaviours such as the use of facial expression as described by (Paul and Sanders, 2009) was not observed in this study. This may be as insufficient time was available to observe the use of this strategy or may represent a cultural difference in the use of communication strategies.

Data obtained through observation, when compared to strategies deduced from literature (Paul & Sanders, 2009), revealed some similarities in their mode of communication. They adopted different manners of interactions such as establishing eye contact with the individual with aphasia, talking calmly at a slow pace, allowing time for the individual to respond, asking one question at a time and using short clear sentences whilst making direct reference to what they talked about.

This research compared reported communication strategies of the family (from semi-structured interviews) with observed strategies (from the observational study) to consider whether the communication partners enacted the strategies they reported. This comparison revealed similar results. Family members made extensive use of alternatives during their interactions, were patient, had individual turns (one-on-one interactions) with the aphasic individual, stated the topic during interactions. However, no examples of how they followed the aphasic individual's lead by reading her body language were observed. This may be a limitation of time and contexts for the video recordings. There, however, was a display of positive strategies, since they did not "assume" to understand the aphasic individual but instead, in addition to their verbal communication, incorporated various cues which helped to facilitate conversation with the individual as stated in a study by (Murray & Chapey, 2001).

Strategies observed in the video recordings, occasionally led to "incomplete communication" but the communication partners-maintained communication exchange by listening and paying attention to the individual with aphasia which is acknowledged in works done by (Le Dorze & Brassard, 1995). In relation to this, they decided together with the aphasic individual to continue or leave the conversation as it is and come back to it later (Clarkson, 2010).

During the observational study, the use of gestures, writing, pictures, targeted questions, encouraging repetitions, incorporating routines and facial expressions were however not used by

the communication partners during their interactions with the individual with aphasia. These contrasts the findings of (Akhavan et al., 2017; Paul & Sanders, 2009), which report that people with aphasia emphasized the importance of gestures in their rehabilitation process which compensates for impaired speech and also in some circumstances serves as a cue in the production of speech increasing the effectiveness of communication. They significantly addressed the use of visual information and the use of written information to facilitate conversations which is acknowledged in works done by (Brown et al., 2010; O'Halloran et al., 2008 ). In light of this, the use of written information and the use of visual information; particularly pictures, can be adopted to create evidence-based resource materials on appropriate and culturally relevant communication strategies to help facilitate communication between communication partners and individuals with aphasia. These principles can be used by speech and language therapists for assessment and intervention in clinics. People with aphasia regarded the use of pictures to aid with memory and saw it as a very helpful tool. Also, the use of short, simple language and the bolding of important information can be carried out by incorporating these aphasia-friendly materials in brochures that will provide information on aphasia and the strategies that can effectively facilitate communication acknowledged in works done by (Rose et al., 2003).

The use of gestures can be equally adopted by developing culturally, relevant and appropriate use of gestures with visual cues and spoken word to effectively facilitate communication since the use of gestures has been examined to be functional since the production of gestures is not necessarily affected by language impairment consistent with findings by (Akhavan et al., 2017) . As part of the communication partner training suggestive in works done by (Simons-Mackie et al., 2016), communication partners of people with aphasia can be trained to adopt the use of various strategies such as incorporating routines and keeping to a schedule in their daily interactions, adopt

the use of targeted questions to understand the individual with aphasia's speech and encourage repetitions to aid in comprehension as reported by (Paul & Sanders, 2009) to effectively facilitate communication with people with aphasia.

It is therefore worthy to note, that, the data gathered on the strategies and behaviours identified and described in this study is representative of behaviours and strategies within only one family case. The aim of this study is not to generalize but to provide an early qualitative exploration of some of the communication acts engaged in dyads when one of the communication partners has aphasia. Future research should build on these preliminary findings to explore patterns in strategies within a range of families.

## **CHAPTER SIX**

### **CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS**

#### **6.1 INTRODUCTION**

This study investigated the communication strategies used by families of an individual with aphasia. The study was carried out using semi-structured interviews which were audio recorded and an observational study which was video-recorded to observe everyday interactions between the individual with aphasia and family members. Field notes supported the data collection process.

#### **6.2 CONCLUSION**

The following are the key findings:

- The family members reported having limited knowledge of aphasia.
- The family members modified their communicative environment by adopting strategies to facilitate effective communication.
- Strategies and behaviours such as the use of alternatives, being patient, encouraging one-on-one interaction, stating the topic and gaining information from the aphasic individual's body language were outlined by the members of the family to facilitate communication.
- Family members play a major role in support and ongoing interaction with people with aphasia. Supporting family members to develop effective strategies to promote communication is an important priority in aphasia rehabilitation as it will impact the communicative success and quality of life of their family member.

### **6.3 RECOMMENDATIONS FOR PRACTICE**

Based on the findings of this study, it is recommended that:

1. Family members be included in communication rehabilitation of people with aphasia so as to help facilitate communication, improve the quality of life and confidence of people with aphasia.
2. Public and professional awareness on aphasia must be created to reduce communication barriers in the community.
3. Aphasia support-groups must be established to help empower people with aphasia and their communication partners.
4. Communication partner training must be encouraged to train communication partners of people with aphasia on how to use communication strategies to facilitate effective communication.

### **6.4 RECOMMENDATIONS FOR FUTURE RESEARCH**

1. Future research should be carried out on a larger sample size to explore the interactions of individuals with aphasia who present with the different types of aphasia and their respective communication partners taking into detail, the influence of the communicative environment has on his/her ability to participate. This will provide in-depth comprehensive understanding of the variation of language use. Insights from this study will help train communication partners of the aphasic individuals in relation to the type of aphasia they present with.
2. Future research should be carried out to explore the socio- cultural perspectives of aphasia in the Ghanaian context.

## **6.5 LIMITATIONS**

1. There were challenges faced with the video recordings and shorter videos were obtained than the allotted time. Thus, it did not give the opportunity to observe in detail the communication interactions with regards to the influence of the physical environment by the communication partners and the individual with aphasia.

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## APPENDIX I



UNIVERSITY OF GHANA

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Department of Audiology, Speech and Language Therapy  
School of Allied Health Sciences  
College of Health Sciences  
The University of Ghana  
PO Box KB 143  
Korle Bu  
Accra, GHANA

### INTERVIEW GUIDE

1. Is there enough information about aphasia available to you?
2. What is the hardest part about trying to communicate with the aphasic individual?
3. Do you use specific strategies to help you communicate?
  - How do you help when the person communicates about basic needs?  
(gesturing, pointing, writing, drawing)-hunger, pain, discomfort
  - How do you help when the person makes routine requests?  
(e.g. asking for light to be turned on, asking for directions)
4. How do you communicate new information to the person?
5. Do you switch topics during conversations, speak too quickly?
6. Do you all talk at once when speaking to the person?

## APPENDIX II



Department of Audiology, Speech and Language Therapy  
School of Allied Health Sciences  
College of Health Sciences  
The University of Ghana  
PO Box KB 143  
Korle - Bu  
Accra, GHANA

### **PARTICIPANT INFORMATION SHEET FOR FAMILY MEMBERS OF THE INDIVIDUAL WITH APHASIA**

My name is Abena Asiedua Owusu Antwi, a postgraduate student of the University of Ghana, Legon. I am asking family members of an individual with aphasia to consider participating in a research study which aims to find out how family members interact with individuals with aphasia. Participating in this study is voluntary. If you participate, you have the right to withdraw at any time and for any reason. If you choose to participate, you will be asked to take part in an interview to provide information on how family members communicate with individuals with aphasia following stroke. You will partake in an observation study, in which you may be video-recorded or have the student researcher spend time with you and your family member with aphasia to observe how you interact.

If you have questions before, during and after the study, they are welcomed.

#### **Please read details of the research study below:**

The research will be in two parts. The first part will involve an interview with you about the individual with aphasia. The interview will last for 25 to 80 minutes and will be audio-recorded for this interview. The second part will be an observation session. If you and your family member with aphasia agree, an audio-visual recorder will be used to record everyday conversations with

the help of a collaborator. This will take approximately 10-15minutes every other day across two weeks. Alternatively, a non-participant observation will be conducted by the student researcher in the home of the individual with aphasia. This will take up to 8 hours for 3 consecutive days. This is to observe the strategies and behaviours family members use when communicating with an individual with aphasia.

Information about you and your family will be confidential and anonymous. Your responses and identity will be known to the investigator and not disclosed. Your name will not be associated with any responses conducted in this study. There are no possible risks in participating in this study. This study will help further research and also help other people with aphasia in the community and hospitals.

**Participant**

I agree to participate in this research study. My questions and concerns have been addressed.

I certify that I am at least 18 years of age.

.....  
Name of participant                      Date                      Signature/thumbprint of participant

.....  
Name of investigator                      Date                      Signature of investigator

### APPENDIX III



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Department of Audiology, Speech and Language Therapy  
School of Allied Health Sciences  
College of Health Sciences  
The University of Ghana  
PO Box KB 143  
Korle- Bu  
Accra, GHANA

#### **CONSENT FORM FOR FAMILY MEMBERS OF THE INDIVIDUAL WITH APHASIA**

The nature of the research project “Communication strategies used by families of individuals with aphasia following stroke” has been explained to me. I understand I will be interviewed and asked to partake in an observational session which may be video-recorded. I agree that the interview will be audio-recorded. I understand the student may wish to pursue publication at a later date. It has been explained that, information gathered will be used for educational and research purposes only.

Information sought will be confidential and anonymous. I may discontinue participation at any time. The benefits, risks and procedures for this study has been explained to me. My concerns and questions have been addressed to my satisfaction. I agree to participate in this study.

---

**Date**

---

**Signature/thumbprint of participant**

I have explained details of the project and believe the participant is informed. The participant understands the implications of participation.

---

**Date**

---

**Signature of investigator**

## APPENDIX IV



Department of Audiology, Speech and Language Therapy  
School of Allied Health Sciences  
College of Health Sciences  
The University of Ghana  
PO Box KB 143  
Korle- Bu  
Accra, GHANA

### PARTICIPANT INFORMATION SHEET FOR THE INDIVIDUAL WITH APHASIA

This study seeks to find out how **family members communicate** with **the individual with aphasia**.



In this research, you will have to give your **consent** so your **family members** will be **interviewed** which will be **audio-recorded** and also take part in an **observational session** which may be

**video-recorded**. You can talk to your family members to help you decide.



**Your name and personal details will not be disclosed in the report on this study. Only the researcher** will listen to the audio recording and see the video. In other words, **information about you** will be treated as **confidential**.

However, **the report on this study** may be shared with researchers in this **country** and other



**countries.** This will help advance **research** about **aphasia.**

Do you want to take part?



**Yes, I want to**



**No, I don't want to**

Name of researcher

Date

Signature

**Name of participant**

**Date**

**Signature**

**If participant is unable to sign:**

**Name of witness**

**Date**

**Signature**

**Relationship of witness to individual with aphasia .....**

*The participant information sheet was adapted using aphasia- friendly materials. Aphasia- friendly materials help individuals with aphasia understand written information better. This can be achieved through the use of short simple language, bolding of important information and the use of pictures to enhance understanding.*

***Source:** The effectiveness of aphasia- friendly principles for printed health education materials for people with aphasia following stroke (Rose et al., 2003).*

## APPENDIX V



Department of Audiology, Speech and Language Therapy  
School of Allied Health Sciences  
College of Health Sciences  
The University of Ghana  
P .O Box KB 143  
Korle- Bu  
Accra, GHANA

### ASSENT FORM FOR THE INDIVIDUAL WITH APHASIA

Information about this study has been **explained** and **read aloud** to me.

 Yes

 No

I understand that I can **stop** the study at **any time** and **do not** have to give a reason for it.

 Yes

 No

I understand that the study will **primarily** involve my **family members**.

 Yes

 No

I understand a **video** will be made of **me** during the study.

 Yes

 No

I **agree** to take part in this study and have been given a **copy** of this form.

 Yes

 No

I understand this will help **other people with aphasia** in the community

 Yes

 No

I understand **information gathered** will be treated as **confidential**

 Yes

 No

**Date**

**Signature of researcher**

**Date**

**Signature of participant**

**If participant is unable to sign:**

**Date**

**Signature of witness**

**Relationship of witness to individual with aphasia .....**

*The assent form was adapted using aphasia- friendly materials. Aphasia- friendly materials help individuals with aphasia understand written information better. This can be achieved through the use of short simple language, bolding of important information and the use of pictures to enhance understanding.*

**Source:** (“ACT NoW Study aphasia friendly consent form,” 2007)

APPENDIX VI



**UNIVERSITY OF GHANA**  
**SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES**  
30<sup>th</sup> January, 2018.

Ref. No.: .....  
Ms. Abena Asiedu Owusu Antwi  
Dept. of Audiology, Speech and Language Therapy,  
SBAHS,  
Korle Bu.

Dear Ms. Owusu Antwi,

**ETHICS CLEARANCE**

Ethics Identification Number: SBAHS – ASLT. /10314980/AA/5A/2017-2018.

Following a meeting of the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences held on Tuesday 30<sup>th</sup> January, 2018. I write on behalf of the Committee to approve your research proposal as follows:

**TITLE OF RESEARCH PROPOSAL: COMMUNICATION STRATEGIES USED BY FAMILIES OF AN INDIVIDUAL WITH APHASIA FOLLOWING STROKE**

This approval requires that you submit three-monthly review reports of the protocol to the Committee and a final full review to the Committee on completion of the research. The Committee may observe the procedures and records of the research during and after implementation.

Please note that any significant modification of the research must be submitted to the Committee for review and approval before its implementation.

You are required to report all serious adverse events related to this research to the Committee within seven (7) days verbally and fourteen (14) days in writing.

As part of the review process, it is the Committee's duty to review the ethical aspects of any manuscript that may be produced from this research. You will therefore, be required to furnish the Committee with any manuscript for publication.

This reviewed report is valid till 31<sup>st</sup>. August, 2018

Please always quote the ethical identification number in all future correspondence in relation to this protocol.

Thank you.

Yours sincerely,

  
**Dr. S. D. Amanor**  
(Chairman, Ethics and Protocol Review Committee)

Cc: Dean  
School Administrator  
Head, Dept. of Audiology, Speech and Language Therapy

**COLLEGE OF HEALTH SCIENCES**

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