

IMPACT OF SOCIAL SUPPORT ON PERSONS WITH APHASIA

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**THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA,
LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD
OF MSC. IN SPEECH AND LANGUAGE THERAPY DEGREE.**

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DECLARATION

I Zahrah Ibrahim, hereby declare that this dissertation which is submitted in partial fulfilment of the requirements of the Master of Science degree in Speech and Language Therapy, is the result of my independent research project and that, except where other sources have been used and acknowledged with explicit references and are included in the reference list, this work has not previously been accepted in substance for any degree and neither is it concurrently being submitted in candidature for any degree.

I hereby permit the department of Audiology, Speech and Language Therapy to seek dissemination/publication of the dissertation in any appropriate format. Authorship in such circumstances will be jointly held between me as the first author and the project supervisors as subsequent authors.

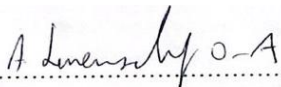
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DEDICATION

The work is dedicated to the Lord God Almighty.

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LIST OF ABBREVIATIONS

- TMA: Transcortical motor aphasia
- TSA: Transcortical sensory aphasia
- PWA: Persons with aphasia
- KBTH: Korle-Bu Teaching Hospital

ABSTRACT

Background: Aphasia is an acquired communication disorder or impairment that is caused by either a stroke, traumatic brain injury (TBI) or a neurological disorder. A person's lifestyle and language changes following the onset of aphasia. This can affect their social, physical, mental and emotional wellbeing. Persons with aphasia need all the support to recover and continue with their everyday activities. Current research is extending our understanding of social support and the influence it has on persons with aphasia.

Aim: The study aims to explore the nature, effectiveness and the impact of social support on persons with aphasia.

Method: Purposive sampling was used in selecting 20 persons with aphasia and their caregivers from the stroke unit and speech and language therapy unit at the Korle-Bu teaching hospital. The instrument used was a semi-structures interview guide for both participants. An audiotape was used to collect the data and was transcribed verbatim and then analyzed using qualitative content analysis.

Outcome: The study has shown that social support from caregivers (family member and friends) helps to improve communication for persons with aphasia at home after hospitalization.

Conclusion: This study showed that social support from caregivers of persons with aphasia contributed significantly to improvement in communication. Family social support play a central role in shaping an individual's well-being across the life course (Thomas et al., 2017).

Keywords: Aphasia, Persons with aphasia (PWA), social support and Korle- Bu Teaching Hospital (KBTH)

CHAPTER ONE

INTRODUCTION

BACKGROUND

In Ghana, according to Agyeman et al (2017), stroke is a leading cause of death and it accounted for 13.2% of all medical adult deaths at the Komfo Anokye Teaching Hospital from January 2006 to December 2007. According to the National Aphasia Association, aphasia as an impairment of language affects the production or comprehension of speech and ability to read and write (National Aphasia Association, 2014). The most common cause of aphasia is stroke, but patients become aphasic following different reasons such as an injury, infection, degeneration, or neoplasm of the brain or intracranial neurosurgical treatment. Aphasia disorders are a common occurrence in any practice where neurological disorders are present. Aphasia brings changes to language which affects the uniqueness of everyday conversations to the affected individual (Davidson et al., 2003).

Persons with aphasia consider communication to be a difficult task due to their negative experiences of trying to get their message across which often results in inadequate communication (Gordon et al., 2009). PWA also tend to depend on family members for social support which further increases the responsibility of family members. The social support family members provide to PWA may be Emotional support, Information support, Tangible support, Affectionate support and Social support (Sherbourne & Stewart, 1991). Research has shown social support is a contributing factor for maintaining and improving good mental health (Semmer et al., 2008). Social support refers to “everyday behavior’s that, whether directly or indirectly, communicate to an individual that she or he is valued and cared for by others (Barnes & Duck, 1994). Social support of high quality can increase resilience to stress, help protect against developing trauma-related psychopathology and decrease the functional consequence of trauma-induced disorders such as Posttraumatic Stress Disorder (PTSD) (Southwick et al.,

2005). Individuals with a strong social network have a low risk of mortality compared to those with a weak social network (L. F. Berkman & Syme, 2016).

PROBLEM STATEMENT

For stroke survivors, more than 50% are left with physical disabilities and at least 15% with aphasia (Wade, 1994). Stroke survivors who present with aphasia may have difficulties in comprehending verbal and written information and may not be able to express themselves effectively. Researches have outlined some significant impact of social support on PWA (Giangrasso & Casale, 2014). Goldney & Schioldann, (2000), reported that suicide rates were lower in societies where individuals were more embedded or integrated into the social group around them. Thus the individual is influenced by the quality and quantity of their social relationships. Social support affects mortality, disease susceptibility and illness. In Ghana very little or no research has been done on the impact of social support family members provide on the quality of life of PWA. This study seeks to address the significance of how social support can improve the health condition of the aphasic patient in Accra Ghana.

SIGNIFICANCE OF THE STUDY

Evidence exists that family members, especially the patient's spouse, may offer important social support, including instrumental help, (Parry, 1987) and emotional encouragement. The family is one of our social support systems and serves a major role in caring for persons with health conditions. Social support from family members plays a central role in shaping an individual's well-being across the life course (Thomas et al., 2017).

Traditionally families have provided support in many developing countries. Families remain pivotal to caring for the elderly and ill members and their lifespans become longer (Bloom et al., 2010). One cannot dismiss the assumption that family members play a specific roles in

caring for their sick members in Ghana, therefore this research sought to provide evidence on how social support can impact the wellbeing on PWA.

AIM OF THE STUDY

The purpose of this study is to explore the impact of social support among Ghanaian families on the rehabilitation process of PWA

RESEARCH OBJECTIVE

The following are the study objectives

1. To understand social support strategies use by families of PWA.
2. To understand how PWA perceive the social support they receive.
3. To understand the effect of social support on the general wellbeing of PWA.

CHAPTER TWO LITERATURE REVIEW

INTRODUCTION

This chapter reviews the literature on aphasia following stroke, types of aphasia, social support and the impact of social support from family members on persons with aphasia.

Aphasia can be defined in the simplest form as a loss or impairment of language caused by brain damage, resulting in the dysfunction of the central nervous system. About 33% of all stroke cases develop aphasia (Threats, 2012)). Aphasia disrupts the life of patients, family members and the community. People with aphasia find it difficult to read, write, sign, understand and speak. Caring for aphasia victims is demanding in several ways. Much resource is needed because aphasia care and rehabilitation require concerted efforts of many health-related professionals. Unfortunately, low individual and community awareness of aphasia makes it difficult to manage the condition, though aphasia is preventable.

TYPES OF APHASIA

Aphasia can be classified into two broad categories which are fluent and non-fluent aphasia. These categories consist of different types of aphasia. Types of non-fluent aphasia include; Broca's aphasia, transcortical motor aphasia (TMA), global aphasia and mixed transcortical aphasia. On the other hand, fluent aphasia includes; Wernicke' aphasia, conduction aphasia, anomia aphasia and transcortical sensory aphasia (TSA) (Threats, 2012)

People who present with non-fluent expressive language, with 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, despite the damage to the language production system, gestures can remain functional since the production of gestures is not necessarily affected by language impairment (Akhavan et al., 2018). Most

aphasia types evolve and change over time. An example is a global aphasia which eventually evolves into Broca's aphasia if language production and auditory comprehension recovers. People 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 effect whilst those who present with posterior left hemisphere damage characterized by fluent aphasia or poor comprehension often present with positive affect and euphoria (Threats, 2012).

BROCA'S APHASIA

Broca's aphasia occurs following damage to the frontal lobe 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 "near the riverbank, lays a crocodile" (Threats, 2012). 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 the". They often tend to make mistakes when following directions and may say words close to what they intend, but not the exact word such as "car-truck" (American Stroke Association, 2013). Persons with Broca's aphasia tend to use a lot of gestures which is widely recognized with semantics content and can co-occur with or replace verbal information (Akhavan et al., 2018). This is the most common form of non-fluent aphasia (Brookshire, 2015)

GLOBAL APHASIA

Large lesions occurring in the frontal (Broca's) and posterior (Wernicke's) region of the left hemisphere can result in global aphasia which is characterized 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 a general effect on all other communication abilities (Brookshire, 2015). Some people with global aphasia may present with severe aphasia for a short period following a 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)

TRANSCORTICAL MOTOR APHASIA (TMA)

TMA 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 response when questioned and sometimes there is "echolalia". Echolalia means echoing what has been said to them and they tend to perseverate on their utterances (Threats, 2012) They are known to use a few gestures when communicating (Akhavan et al., 2018)

WERNICKE'S APHASIA

Wernicke's aphasia is the most common type of fluent aphasia. The lesion occurs in the posterior portion of the left superior temporal gyrus. They produce "empty speech"- i.e., they speak in long complete sentences with little meaning. They have a problem understanding the meaning of spoken words. Since they are not affected by the verbal output, their speech is characterized by phonemic and semantic paraphasia and neologism. They are anosognosic, that

is, they are often aware of the language disorder. If the use of paraphasias are particularly extensive and speech appears to have little meaning it is described as jargons aphasia (Sinanović et al., 2011)

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 (Sinanović et al., 2011). 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 the patients who present with anomic aphasia experience complete recovery by one-year post-onset and are expected to have better outcomes (Murray & Chapey, 2001).

CONDUCTION APHASIA

Conduction aphasia was classically considered to be caused by a lesion to the arcuate fasciculus, the great fiber tract linking Wernicke's and Broca's area. The primary symptom is a repetition deficit. Persons who present with conduction aphasia have a 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 tend to produce phonemic variations in their attempt to correct themselves and are very aware of their verbal paraphasia (Threats, 2012)

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 paraphasia 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 a similar deficit as in Wernicke's aphasia, but repetition ability is spared and phonemic discrimination impairment are not found (Brookshire, 2015).

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, read and write. They tend to repeat words and sentences (Schoeman & van der Merwe, 2010).

SOCIAL SUPPORT

Social support has recently been recognized as an important component of the recovery process of an individual (Pernice-Duca, 2010). It has been the most frequently studied psychosocial resource and usually refers to the functions performed for the individual by significant others, such as family members, friends, and coworkers. According to Pancoast, (1987) social support is defined as "the sum of the social, emotional and instrumental exchanges with which an individual is involved having the subjective consequence that an individual sees him or herself as an object of continuing value in the eyes of significant others". Family members often present a primary source of social support, especially among people living with a serious mental illness. Evidence exists that family members, especially the patient's spouse, may offer important social support, including instrumental help, (Wellman, 1988) and emotional encouragement. Families have traditionally provided such support in many developing

countries. Families remain pivotal to caring for the elderly and ill member, and their lifespans become longer (Bloom et al., 2010) while in some literature, too much support from family members/ caregivers may lead to overprotection, under-stimulation and patients living alone may recover more favourably compared with those living in a family context (Gauthier, 2008). In a study conducted by Belyea et al., (1993a), several patients voiced complaints about unwanted assistance, smothering attention from relatives, or patronizing attitudes among hospital personnel.

Despite the unwanted assistances from family members towards the patients (Belyea et al., 1993a), family members provided various forms of functional social support which include (Sherbourne & Stewart, 1991);

1. Emotional support: which involves caring for others, showing love, someone with whom to share private thoughts and fears, and showing empathy for another.
2. Instrumental support: referred to by many as tangible support. It is more practical support such as behavioural assistance or material aid.
3. Information support: guidance or feedback that can provide a solution to a problem, it is feeling there is someone whose advice you value, who can offer information, guidance or feedback.
4. Appraisal support: which involves information relevant to self-evaluation.
5. Social companionship /Affectionate support, this concept is also referred to as positive social interaction, 'belongingness', and social integration. It also involves spending time with others in leisure and recreational activities.
6. Spiritual support: believing in higher source for divine healing.

EMOTIONAL SUPPORT

Emotional support involves spending time with another person, listening and talking about problems and concerns in a way that is helpful and reassuring. Emotional support is also essential for the adjustment of relatives. Emotional support received from family members and friends are important (Elina Eriksson & Lauri, 2000).

However, many relatives need to have emotional support from health care professionals as well because they have first-hand knowledge about the patient's situation. Relatives do not always wish to discuss their concerns with anyone outside the group of people caring for the patient;

Emotional support involves elements of supportive psychotherapy, which may range from dealing with issues actively to simply being close to relatives. Usually, the most important thing is that relatives can feel that someone cares about them. Even though relatives have expressed a desire to receive emotional support, several studies indicate that health care professionals rarely provide such support (Semmer et al., 2008). Emotional support has been described as behaviour which assures the individual that he is loved and valued as a person regardless of achievement. It has also been defined in terms of physical presence, empathy, expressed concern and affection. It also involves special understanding (Martin et al., 1994) love concern, reassurance, encouragement (Dunkel-Schetter, 1984) and closeness with another person in whom the recipient can confide.

INFORMATIONAL SUPPORT

Informational support involves giving information to relatives about medical and nursing care as well as organizational information (E. Eriksson & Lauri, 2000). Information support also involves guidance, offering of advice, or feedback that can provide a solution to a problem. Family members who remain at the hospital provide vital information about the patient, and their presence increases communication and the continuity of care (McCabe, 2014). The

sources of information vary in different situations. Physicians mainly tell relatives about the current state of the illness, the current treatment, and about the expected length of stay in the hospital (this could be called 'medical information'). Nurses usually talk about the nursing information which is related to nursing action. However, the role of nurses in giving information is not always clear and straightforward.

SOCIAL COMPANIONSHIP

Scientific evidence shows that involvement in social companionship benefits health. The most striking evidence comes from prospective studies of mortality across industrialized nations. These studies consistently show that individuals with the lowest level of involvement in social companionship are more likely to die than those with greater involvement (House et al., 1988). For example Lisa F. Berkman and Syme, (1979) showed that the risk of death among men and women with the fewest social ties was more than twice as the risk for adults with the most social ties.

Moreover, this finding held even when socioeconomic status, health behaviours, and other variables that might influence mortality, were taken into account. Social ties also reduce mortality risk among adults with documented medical conditions. Generally speaking, there are three broad ways that social ties work to influence health: behavioural, psychosocial, and physiological.

SPIRITUAL SUPPORT

Medical ethicists have reminded us that religion and spirituality form the basis of meaning and purpose for many people (Foglio & Brody, 1988). Spiritual patients may utilize their beliefs in coping with illness, pain, and life stresses. Some studies indicate that those who are spiritual tend to have a more positive outlook and a better quality of life. For example, patients with advanced cancer who found comfort from their religious and spiritual beliefs were more

satisfied with their lives, were happier, and had less pain (Balboni et al., 2007). Nevertheless, people long for their physicians as well as their families and friends to sit with them and support them in their struggle.

In stroke context, Strong spiritual connection could help with a person's acceptance of their new situation post-stroke, retaining hope, increasing motivation to work harder during rehabilitation, and encourage patients to fight through challenges post-stroke (Chow & Nelson-Becker, 2010). In a study by Arafat et al., (2018) prayer is a way to communicate with Lord. When stroke patients felt hopeless due to their paralyzed, they are prayed thru shalat and zikr to acknowledge their needs. This spiritual connection, emerged to provide a sense of confidence about the future for stroke survivor.

THE IMPORTANCE CAREGIVERS ON APHASIA PATIENTS

One common disabling disease is, stroke and therefore requires the involvement of family caregivers for patients' successful rehabilitation (Low et al., 1999). A family caregiver is a person who lives daily with the patient providing assistance with hygiene care, giving comfort, feeding, encouraging rehabilitation activities, and interacting with the therapeutic team ("Caregivers' Conception of the Care Provided to the Elderly," 2014). Family caregivers play a key role in the recovery of aphasia stroke survivors. Aphasia patients need additional support from family or friends to live independently (Strudwick & Morris, 2010).

However, caring for stroke patients can be a stressful task with caregivers reporting a considerable burden for several years after the initial event (Greveson et al., 1991). Many caregivers encounter various challenges such as financial difficulty, social isolation, lack information and poor physical and mental health (Dennis et al., 1997). Despite the stress that caregiver encounter, research shows that patient outcomes are impacted greatly by family

presence. Patient- and family-centered care represents the future model of healthcare (McCabe, 2014).

CHAPTER 3 METHODOLOGY

INTRODUCTION

Research methodology is the specific procedures or techniques used to identify, select, process, and analyze information about a topic. It allows the reader to critically evaluate a study's overall validity and reliability. Methodology answers two main questions: How was the data collected or generated? And, how was it analyzed? The qualitative research method was used to collect data. In this chapter, the study design and procedure for data collection and the theoretical framework is defined. The research instrument, data management plan of the research, research ethics and the dissemination of the research findings were conclude in this chapter.

STUDY DESIGN

The study employed a qualitative design in data collection. The qualitative research design is an exploratory research that allows for in-depth exploration of a phenomenon. It involves data that can only be described with words.

STUDY SITE

Study location/ site was the KBTH Stroke unit and the Speech and Language Therapy clinic. KBTH is the only public tertiary hospital in the southern part of Ghana. It is a teaching hospital affiliated with the medical school of the University of Ghana. The hospital has specialization in various field such as Neuro-surgery of which the Stroke Unit can be found, Ear, Nose and Throat (ENT) of which the Speech and Language Therapy Clinic is found, Dentistry, Eye, Dermatology, Oncology, Psychiatry etc.

SAMPLING METHOD AND SIZE

In qualitative research, only a sample of the population is selected for a given study. The study's research objectives and the characteristics of the study population (such as size and diversity) determine which and how many people to select. A purposive sampling method was used to select twenty (20) families made up of 20 caregivers and 20 PWA for the study. Purposive sampling, is one of the most common sampling strategies used for groups' participations according to preselected criteria relevant to a particular research. Purposive sampling amounts to selecting participants well informed on the topic and who will subsequently lead to answering the research questions

According to (Tongco, 2007) purposive sampling is a sampling method in which researchers intentionally chooses participants based on their knowledge of a particular subject. He further describes it as a non-random method which does not need any latent theories or a specific number of respondents. The responsibility lies on the researcher to decide on what information to seek and who is ready to avail themselves to provide such information. This sampling method allowed the researcher to careful select participants' base on their age, the type of aphasia and the onset of the stroke.

The twenty families selected for the study included, the caregivers (spouse (husband or wife), siblings, children, aunties and a nurse) and their PWA in the KBTH Stroke and Speech and Language Therapy Units. A sample size of 20 families (20 caregivers and 20 PWA) is sufficient to obtain data saturation as Creswell (1998) recommended that a sample size ranging between 20 and 30 was adequate to reach data saturation. Caregivers interviewed consisted of (19) nineteen family members (spouse, children and other family members) and one professional nurse. Seven (7) patient had slurred speech while 13 patients used gestures in communicating due to sever expressive language deficits.

INCLUSION CRITERIA

Criteria for inclusion as a person with aphasia included:

1. Persons must be diagnosed with aphasia.
2. The participant must be able to provide informed consent.
3. Family members or caregivers of PWA following a stroke.
4. The type of aphasia was non-fluent aphasia/ Broca's aphasia/ expressive aphasia.
5. Aphasic patients between the ages of 45- 80 years of age.
6. The aphasic patient should be living with family members (spouse, children (son/ daughter) or any significant other)

EXCLUSION CRITERIA

Criteria for exclusion include the following;

1. The individual with aphasia was excluded if they experienced a significant hearing loss which impacts his/her ability to respond to conversational level auditory stimuli.
2. People who use hearing aids who can respond to conversational stimuli were not excluded.
3. If aphasia type is fluent aphasia/ Wernicke's aphasia/ receptive aphasia.
4. Family members/ caregivers who were unable to give informed consent.
5. Caregivers below 18years.

INSTRUMENTATION

The instrument used in the study was a semi-structured interview guide (**Appendix I**). The semi-structured interview guide consisted of both close and open ended questions. Questions allocated to caregivers were open ended questions while questions allocated to the patient included both open and close ended question. The audio recorder was used to collect information during the interview sessions of both caregivers and the PWA, together with a one-

page summary of relevant information that was passed by the caregivers about the research topic members. Family members and PWA consented to the use of audio recorder for the research purpose as part of the consents processes

PROCEDURE FOR DATA COLLECTION

A semi-structured interview was conducted with twenty (20) families at the KBTH. These twenty families consisted of both caregivers and PWA. A brief introduction of the researcher and the research was provided to the family members. Family were also assured full security and confidentiality of their information. Families who showed interest in the study were given a consent forms to fill out. For PWA who could not write and sign, their caregivers served as third party to sign on their behalf after the consent had been read and explained to them. A period of twenty to thirty minutes was spent with each participant (caregivers and patients) because the participants were either exhausted or had to attend other duties. Most of the caregivers had to return back to the various duties after seeing the doctor. For this reason the interviewers was unable to spend enough time with participants. 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 caregivers and it allowed for new ideas to be brought up as a result of the responses from the caregivers on each caregiver perceptive on the question asked (Tellis, 1997). A brief and explanation were given to both participants as an introduction to the study. For patients who were not verbal the use gestures to communicate such as shaking and nodding the head, a thumbs up 👍 /down 👎 was used to represent their responses.

An audio recorder was used to store responses of both participants during the interview sessions, together with a one-page summary of relevant information that was passed by the caregivers about the research topic members. Family members and PWA consented to the use

of audio recorder for the research purpose as part of the consents processes. The researcher received relevant information about participants from the nurses and therapist on duty about their age, type of aphasia and the onset of the stroke.

The researcher visited the KBTH three times in a week to interview caregivers and their patient at both the Stroke Unit and the Speech and Language Therapy Unit. One month was used to gather information. Nurses and therapist from the two Units assisted with selecting participants but some reluctant in taking part in the study due to COVID-19. Their folders were given to help with the selection of the participants. Outward patients came to the Stroke Unit only on Mondays because Mondays were review days for patients but for inward patients there wasn't any specific day for admitted.

DATA MANAGEMENT

All electronic devices used to store the data collected were secured with a password. Data generated from the study was treated with confidentiality.

DATA ANALYSIS

The languages spoken during the interviews session was Twi, Ga and English. The audio recorded data were transcribed verbatim. Respondents were given coded names to keep their identity safe. The data was analyzed thematically using the recurring themes from the responses of the caregivers. The thematic analysis allowed the researcher to see and make sense of collective or shared meanings and experiences. Identifying unique and idiosyncratic meanings and experiences found only within a single data item is not the focus of thematic analysis (Braun et al., 2019). The themes for the study were predetermined from literature (Sherbourne & Stewart, 1991). Sherbourne and Stewart, (1991) distinguish five categories of functional social support, they include;

1. Emotional support: for example, feeling that there is someone to confide in who will be empathetic, someone with whom to share private thoughts and fears.
2. Informational support: e.g., feeling there is someone whose advice you value, who can offer information, guidance or feedback.
3. Tangible/ instrumental support: more practical support such as behavioural assistance or material aid.
4. Social companionship: the availability of other people to do fun things with you. This concept is also referred to as positive social interaction, ‘belongingness’, and social integration.

The study also developed a few themes and these were generated based on six steps outlined by (Braun et al., 2019) ;

1. Familiarizing yourself with the data. This is the first step and it’s important to get a thorough overview of all data collected before the analysis of individual information
2. Generating initial codes; highlighting sections of the text usually phrases or sentences and coming up with shorthand or codes to describe their content.
3. Searching for themes, these themes are generally broader than codes.
4. Reviewing potential themes; the themes are compared against other themes.
5. Defining and naming themes;
6. Producing the report/writing up.

ETHICAL CLEARANCE

Ethical clearance was obtained from the Ethical and Protocol Review Committee of the School of Biomedical and Allied Health Sciences of the University of Ghana. Permission was sought from all the relevant authorities of the KBTH before the onset of data collection. Patients and their family caregivers were given assurance that the data was gathered for research purposes

only. The purpose of the study and procedure for the data collection were explained to participants. All 20 families who consented were included and were informed they could withdraw from the research at any time. Data gathered from the study was treated as anonymous and confidential. To protect the identity of the respondents, the researcher kept every data collected for the study, strictly confidential and in line with the ethics policy that guided the research.

DISSEMINATION OF RESULTS

The research findings will be submitted as a Master of Science degree in Speech and Language Therapy dissertation to the University of Ghana, College of Health Sciences, and the Department of Audiology, Speech and Language Therapy, School of Biomedical and Allied Health Science. Portions of the work which are of scientific importance will be published in peer-reviewed journals.

CHAPTER 4 RESULT AND FINDINGS

INTRODUCTION

This chapter presents the results of the study. The study adapted Sherbourne & Stewart, (1991) functional social support which include emotional, informational, instrumental, and social companionship. These functional social support were categorized into themes and from the researchers findings identified spiritual support as a type of support given. Responses from the interviews were transcribed from the interviews and findings deduced from the study and field notes analysis. It describes the social support family members give to the persons with aphasia and how these supports affected the patients' wellbeing. Comments for patients who were not verbal and used gestures to communicate such as shaking and nodding the head, has been presented using a thumbs up 👍 /down 🙇 .

DEMOGRAPHICS

The study collected demographic data on the respondent caregivers. Demographic data gathered included the level of formal education, age and gender of both the caregiver and the patient and the onset and incidence of the stroke-aphasia of the patient.

Table 4.1

<u>VARIABLES</u>	<u>CATEGORIES</u>	<u>No of families: 20</u>	<u>Percentages</u>
Gender of patients	Males	13	65%
	Females	7	35%
Gender of caregivers	Males	8	40%
	Female	12	60%
Educational level of patients	Basic	–	–
	Secondary	6	30%

	Tertiary	14	70%
Educational level of caregivers	Basic	–	–
	Secondary	11	55%
Age of patients	Tertiary	9	45%
	40-60	15	75%
	61-80	4	20%
	81 and above	1	5%
Ages of caregivers	18-25	2	10%
	26-40	12	60%
	41-60	5	25%
	61 and above	1	5%

THEMES DERIVED FROM THE INTERVIEW

The study set out to answer three main questions: To understand social support strategies use by families of PWA, to understand how PWA perceive the social support they receive and to understand the effect of social support on the general wellbeing of PWA.

In exploring the social support strategies used by families of PWA, five (5) main forms of support strategies were identified these included Emotional support, Information support, Instrumental/Tangible support, Spiritual support and Social companionship. It was noted that each caregiver provided more than one type of social support.

EMOTIONAL SUPPORT

Emotional support involves spending time with another person, listening and talking about problems and concerns in a way that is helpful and reassuring. Emotional support is also

essential for the adjustment of relatives. Each caregiver demonstrated various ways of showing love and care for their love ones. The following stated that;

Family A, caregiver's report *"I am always with him. I don't want him to feel because of the stroke we have ignored him. He sometimes complains about been ignored"*.

Family C, caregiver's reported *"my mother worries a lot when she is alone, and that makes her B.P go high. So I am always with her at home. I make sure if I am not home with her I will call the children living in the house to come around her to keep her occupying. This is how I show my love and care. She feels her condition (aphasia) was caused by someone in the family so I always encourage her"*.

Family B, caregiver's report *"with the emotional support I am not doing well on that. My work is demanding and I don't get time to spend with my father, but that does not mean I don't care about him. He knows I care"*.

Family D, caregiver's report, *"My father gets excited when he sees my mother and me at the hospital. I want to see my father always happy so we are here every morning and evening during visiting hours"*.

Family O, caregiver's response, *"I am always advising her and always visiting her in the hospital because of that she feels much secured talking to me although her speech is not clear"*.

INFORMATIONAL SUPPORT

Informational support involves giving information to relatives about medical and nursing care as well as organizational information. Interestingly only one caregiver reported providing this form of support.

Family N, caregiver's report: *"when my wife had the stroke, she could talk but after a while, her speech became slurred then she finally lost her speech completely. This got me worried so I began seeking help. We were then referred to see a speech therapist. After a while, I noticed significant improvement until COVID 19 set in then we had to stop going but have been doing what I learnt from the speech therapist and then telling her other helpful things I found online"*.

INSTRUMENTAL SUPPORT/ TANGIBLE SUPPORT

Instrumental support/ tangible support referred to by many as tangible support. It is more practical support such as behavioural assistance or material aid. Caregivers expressed their support to PWA by showing instrumental support. Other also reported that the PWA felt entitled to providing the basic needs for the home despite their condition. PWA show appreciation for the support their family members displayed. Some caregivers reported that,

"My uncle is still the breadwinner of the family despite his condition. He said since he's not dead then he is responsible for the families basic needs. My uncle's speech is not clear so when we are talking we both use gestures. Example when he gets a call I illustrate the symbol of a phone" (Family A, caregivers report).

Family B, caregiver's response; *"Because I do not spend quality time with my father, what I can do to support him is to do this he cannot do for himself such as bathing, dressing, bring him to the hospital"*.

Family D caregiver's response *"I am the one providing for my children and husband since he had the stroke"*. I also use gesture when communicating with him. He doesn't say much but also responds using gestures such as shaking the head for NO and nodding for YES.

Family E caregiver's response *"All the children are always present to take care of all her needs. We have hired a nurse to assist with her health condition"*.

Family J, caregiver's response: *"My husband's stroke affected only his speech. He's able to move around and do things for himself. For financial support he does not appreciate my support he prefers I spend more time with him"*.

Family K, caregiver's response: *"I come every day to the hospital to clean him up and change his clothes because he can't do it himself. We communicated using gestures. He doesn't talk but use gestures such as point or shaking or nodding his head to respond to questions"*.

Family O caregiver's response *"My daughter is been abused by her husband and because of that, she lost her job. He is even the reason why she cannot talk because this is a second stroke. My brother and I are the ones taking care of her financially. We have promised her to open a business for her to earn her income"*.

Family Q, caregiver's response: *My father doesn't want anyone to know he has a stroke. My mother and I are the once catering for him financially.*

Family F, G, H, N, and M provided similar responses, as they were the once responsible for the patient's financial needs.

SOCIAL COMPANIONSHIP

This concept is also referred to as positive social interaction, 'belongingness', and social integration. It also involves spending time with others in leisure and recreational activities.

Caregiver expressed more support in the area of social companionship. Others acknowledge the need to provide such support but due to agendas, they are unable to so. The following are their responses,

Family A, caregiver's response; *"I am always at home with my uncle because there is no one else at home"*.

Family C caregiver's response *"I like to watch television with my mother because it makes her happy. I try to entertain her by cracking jokes to make her laugh and forget about her worries. She seems excited when people come round her"*.

Family D, caregiver's response: *"Anytime my mother and I come to the hospital to visit my dad. We chat with him as if everything is ok with him. As a side, my mother and I other family members also come and visit"*.

Family G, caregiver's response: *"..... This outcome is as a result of our constant visitation by not just family members but friends, work colleagues and church members"*.

Family E, caregiver's response: *"We do not live with our mother but we visit her every other week. My mother has had a stroke for a while now but two days ago she had another attack and can't talk well. I feel sad because she has been complaining we don't visit her lastly. I know if we have been around this wouldn't have happened"*.

Family F, caregiver's response: *"I live in a family house with my grandmother and the grandchildren are always around her. We wait for television together, sit on the compound to chat and laugh about old times with my uncles and aunties"*.

Family J, caregiver's response: *"Because of the COVID 19 my children are always home with their father. Their father's speech is slurred so when he gets a call the children answer the call and repeats what their father tell them to say"*.

Family Q, caregiver's response: *"It is the only family member that comes to visit my father. He doesn't want anyone aside from family to come to visit him. Anytime I come visiting, I talk about football because he likes football. I do this to get his mind off what is happening to him. He gets happy when he sees his grandchildren that are my children but due to the COVID I can't bring them to the hospital so I do a video call"*.

SPIRITUAL SUPPORT

Spiritual support is believing in a higher source for divine healing. Some family provided spiritual support to their client as they appreciated the importance of such support to the PWA.

Family A, caregiver's response; *"I always pray for my uncle. My grandfather always sends him bibles scriptures"*.

Family C, caregivers report *"The support I give more to my mother is spiritual support. I believe the doctors will do their part but healing comes from God"*.

Family G, caregiver's response: *"My husband worked at Action Chapel until he had the stroke. His colleagues from church always pray for him". I have seen improvement in my husband speech. When he first had the stroke he couldn't talk my now he attempts to talk when his colleagues from church come around.*

Family H, caregiver's response *"My father doesn't respond when he's been speaking to but when he's alone at homes he tunes in to prayer sessions on the radio"*.

Although all the various social support provided impacted the patients' quality of life, one type of social support lacked attention which is informational support. Caregivers and PWA lacked knowledge of aphasia (E. Eriksson & Lauri, 2000). They didn't understand what was happening to the patient speech and therefore generated their mode of communication because they lacked information. One caregiver stated, "Daddy is talking like he is drunk". Healthcare professional in the stroke did not inform patient and caregivers of where they could get help.

PWA'S PERCEPTION OF SOCIAL SUPPORT PROVIDED BY FAMILY

Most of the PWA appreciated the various support their caregivers provided. Patients with slurred speech expressed the taught verbally while patient who had expressive language deficit

expressed their thought and opinions through gestures. The thumps-up is a representation of their responses.

Emotional support

Patients C report 👍, *this represent her appreciation to the emotional support provided from her son*

Family B patient's report 👍

Family D patient's report 👍

Family O patient's report *"I appreciate all she is doing for me"*.

Instrumental support/ tangible support

Family B Patient's report 👍

Family D Patient's report 👍

Family E Patient's report *" my children are the onces taking care of me. They pay for my hospital bills and other bills in the house.*

Family K patient's report 👍

Family O Patient's report 👍

Social companionship

Family A Patient's report: *"the nephew does so much for me, he is always with me anywhere I go"*

Family B Patient's report 👍

Family C Patient's report 👍

Family D Patient's report 👍

Family G Patient's report 👍

Family F Patient's report 👍

Family G Patients report 👍

Family Q Patients report: *I wish I will see my grandchildren, I have missed them.* 👍

Spiritual support

Family A Patient's report; *I always pray. If not for the prayer I would be dead by now*".

C Patients report 👍

G Patients report 👍

Informational support

Family N Patient's report 👍

Overall PWA appreciated the support they receive from family, however, some of them wished their families could provide more support or other forms of support they were not receiving;

Patients A report; *"I wish my wife will encourage me in my situation....."*

Family A, Patient's report, *"Although I am sick it is still my responsibility to provide for the family"*.

Family E Patient's report: *"I wish they will spend more time with me"*

One respondent further expressed his concern over not being able to provide instrumental support for his family due to his condition.

He reported that; *"Now I am not working so my wife and brother are the ones taking care of me. This doesn't make me happy. As a man of the house, you should provide for the family but because of my condition I am not in the right position to do so"*.

EFFECT OF SOCIAL SUPPORT ON THE GENERAL WELLBEING OF THE PATIENT

Social support from friends, community, and a close personal relation has a protective effect (Hyman, 1972) against PWA. Family members reported significant improvements in the lives of the patient's.

Family B caregiver's response *"my father appreciates it when people come round him, so my grandmother is always around to engage him in conversation although he doesn't respond, we know he can hear us and understand us"*.

Family C caregiver's response *.....She seems excited when people come round her"*.

Family D, caregiver's response: *"..... I notice he becomes cheerful and makes a conscious effort to say something....."*

Family G, caregiver's response: *"my husband's recovery rate is faster than we assumed. When he got the first attack he lost his speech completely but now he has few words....."*

ADDITIONAL FINDINGS

CAREGIVERS' KNOWLEDGE OF APHASIA

It was noted that majority of caregivers had no or very little knowledge on aphasia and most importantly only had information the primary diagnosis of PWA. Eighteen (18) caregivers had no knowledge or education on what aphasia was even after their relatives were diagnosed. When asked "do you have any knowledge of aphasia?" their responses were no. Two (2) caregivers had some knowledge or education of aphasia after they had been referred to the Speech and Language Therapy Clinic in the KBTH.

SUMMARY OF FINDINGS

Social support provided for PWA contributed to their levels of recovery. Some participants recorded to have observed a fast rate of recovery in the patients' speech due to the social support they provided. Some patients further recorded progress from using gestures to using single words or learned phrases to communicate. Some caregivers also wished to have provided more support but couldn't due to some circumstances beyond their control and some PWA reported having expected emotional support instead of social companionship.

Caregivers did not reflect on the type of social support they provide and how it's impacted the patient until they were asked by the researcher. They also reported having no or very little knowledge on aphasia.

CHAPTER 5 DISCUSSION

INTRODUCTION

This chapter discusses the results of the present study concerning the relevant literature using the research questions and the objectives of the study as benchmarks. Implications of the findings as well as limitations of the study are also discussed.

To gain insight into how social support impacts PWA, information was obtained from caregivers on what type of functional social support they frequently provided to their patient that represents multiple dimensions of support; emotional, informational, tangible, spiritual and social companionship support. The literature review suggests that families who provide social support facilitate healthy behaviours in both a direct way (e.g., giving information about healthy habits) and an indirect way. Among healthy elderly adults, Kahn et al., (2003) found that the perception of one's available social support is a strong predictor of well-being in terms of depressive symptoms and life satisfaction.

SOCIAL SUPPORT STRATEGIES USED BY FAMILIES OF PWA

Finding from the study showed that caregivers demonstrated different ways of showing support. Social companionship was seen as the most common type of support provided for PWA. Social companionship, involves spending time with people to do fun things with them (Sherbourne & Stewart, 1991). This concept is also referred to as positive social interaction, 'belongingness', and social integration (Hilari & Northcott, 2006). Family C, a caregiver in the family observed that as he spent more time with his mother watching television and cracking jokes, there were no episodes of high blood pressure. Family G, a caregiver in the family reported that, her husband's recovery rate was faster than she assumed. She believed that her presence and the presence of his friends led to his faster recovery of no speech to speech all be slurred. Other caregivers from different families also reported that, during visiting periods, the

patient gets excited whenever they came around to visit. Studies have shown that family members who remain at the hospital provide vital information about the patient, and their presence increases communication and the continuity of care (Olding et al., 2016). Patients from these various families confirmed that receiving social companionship support from caregivers has led to some significant improvement in their health. Most patients appreciated the support that their caregivers provided and associated that to their recovery. Meanwhile in Family G, the patient expected longer hours with her elderly children while in family A, the patient complained of unwanted services (social companionship) from his wife. He complained of frequent argument with her anytime they were involved in a conversation or sitting together. He stated “I wish she will support me emotionally. All I want is for her to encourage me”. In a study conducted by (Belyea et al., 1993b) they found out from their interviews that, several patients voiced complaints about unwanted assistance.

However, family caregivers did not only provide social companionship support but also provide emotional support and to their PWA. Emotional support is expressed differently by every individual. Emotional support goes beyond saying I love you. It involves both the verbal and non-verbal communication of caring and concern (Giangrasso & Casale, 2014). Emotional support has been described as behaviour which assures the individual that he is loved and valued as a person regardless of their achievement (Bloom, 1982; Cobb, 1976). It has also been defined in terms of physical presence, empathy, expressed concern, affection, special understanding (Dakof & Taylor, 1990) love/ concern, reassurance, encouragement (Dunkel-Schetter, 1984) and closeness with another person in whom the recipient can confide (Schaefer et al., 1981). Family C, a caregiver, expresses emotional support by encouraging his mother with aphasia due to a stroke. He reported his mother gets depressed when she is alone and encourages her to make her fine better and to give her hope for recovery. Other family caregivers encouraged their patients by celebrating or reward them when the patient try to make

verbal request or responses. Some literature has identified that emotional support may reduce distress and provides some purpose or meaning for an overwhelming experience through the improvement of interpersonal relationships with patients and caregivers (Giangrasso & Casale, 2014). In Family A, a patient expected emotional support from his wife but his wife assumed social companionship support was what he needed, this led to constant argument with his wife during conversations. Studies have shown that a low level of emotional support may cause depression and decrease motivation (Elina Eriksson et al., 2006).

Spirituality refers to the experience of a deep inner feeling and belief arising from the cognizance of the existence of the sacred, which in turn, promotes personal meaning, purpose, from the value of life. It is an inner peace as well as love and harmony with others (Fisher, 2011). Available data also indicate that over 90 per cent of Ghanaians are identified as religious with the majority (71.2%) being Christians, 17.6% Muslim, 5.2% traditional, 5.2% none and 0.8% being other (Ghana Statistical Service, 2014) while in a 2018 and 2019 survey, 65% of American adults describe themselves as Christians when asked about their religion. The statistics show that Ghanaians are more spiritual and include spirituality in their day-to-day activities. Findings of the study showed how spirituality was significant factor in healing and was seen as a type of support given to PWA. In Family B, a caregiver reported, he believes that the doctor can do all that he needs to do but healing is from God. He also stated that his mother believes her condition (aphasia) has spiritual implications and always prays for him. According to a study conducted by Oxman et al., (1995), they found religion or spirituality to be associated with a recovery advantage. This was also seen in Family G, the caregiver confirmed she had seen improvement in her husband speech due to the prayers from family members and church members. There is some evidence to support the hypothesis that being prayed for improves recovery from acute illness (Powell et al., 2003). Family A, caregiver stated that he always

prays for his uncle and his grandfather also sends scriptures to the patient. The patient confirmed that the progress in his speech is the doing of God.

Another area where caregivers provided support to their patient with aphasia was instrumental support. Instrumental/ tangible support refers to help with concrete needs such as aid in kind, money, or labour. A meta-analysis conducted by Schwarzer and Leppin, (1991) showed that instrumental support was the strongest predictor of physical health. Östberg and Lennartsson, (2007) also found economic support to be the most predictive of health. Historical men are seen as the breadwinner of the family but sometimes the role changes due to some circumstances such as illness. Male patients who have had aphasia due to a stroke seek for support from their immediate family members such as spouse, children or siblings. In Family E, the caregiver stated that, his wife and brother are currently supporting him financially and he was not happy about that. He stated “As a man of the house, you should provide for the family but because of my condition I am not in the right position to do so”.

Instrumental support does not just involve monetary gains but labour or assisting in performing a difficult task (Semmer et al., 2008). Some caregivers used words or gestures such as pointing or actions to communicate with the PWA. Family D, the caregiver stated, “I am the one providing for my children and husband since he had the stroke. I also use gesture when communicating with him. He doesn’t say much but also responds using gestures such as shaking the head for NO and nodding for YES”. Caregivers from the various families used gestures as a means of communication, this was because verbal communication was a difficulty for them. Caregivers’ provided financial support to all the patients and it was one of the major support provided which the patients appreciated also.

Informational support was the least of the support given. Patients were not given the necessary health information they needed because the caregivers did not have any knowledge on aphasia

and if there was any treatment for it. This was in line with a study conducted by E. Eriksson & Lauri, (2000), who identified that relatives received very little information about the needs of patients. He recommended that the family member must be given enough information about the patient's health. Aphasia may make it difficult for patients to read information leaflets, find out about and fill in benefits forms, write letters, make phone calls, or understand verbal information that is given rapidly in complex language (Hilari & Northcott, 2006). Therefore there is the need for detailed information to the family members and the PWA. Although health providers do not provide detailed information about the client's health condition, patients and caregivers do not also seek detailed information about their health in Ghana. Older adults with very low incomes mostly sought information on diets, drug intake and causes of diseases. Factors such as inadequate knowledge about the benefits of seeking health information, perceived poor attitude of healthcare providers and communication/language problems remain barriers to their health information-seeking behaviour (Agyemang-Duah et al., 2020). Amongst the twenty caregivers, only one caregiver provided the patient with enough information regarding the conditions which is aphasia. Studies have shown that inability to secure the right information could worsen their health status (Agyemang-Duah et al., 2020).

PWA'S PERCEPTION ON THE SOCIAL SUPPORT

In a study conducted by Belyea et al., (1993b) they found out from their interviews that, several patients voiced complaints about unwanted assistance or support from family member. Family G, the patient expected longer hours with her elderly children while in family A, the patient complained of unwanted services (social companionship) from his wife. He complained of frequent argument with her anytime they were involved in a conversation or sitting together. He stated "I wish she will support me emotionally. All I want is for her to encourage me".

EFFECT OF SOCIAL SUPPORT ON THE GENERAL WELLBEING OF THE PATIENT

Numerous studies have found that, people with chronic illness who have a strong social relations show greater signs of recovery or survival after illness and better psychological health, well-being and quality of life (Hilari & Northcott, 2006). Family members who show empathy and social companionship support report a progress in stroke rehabilitation (Hyman, 1972). Also family members who remain at the hospital provide vital information about the patient, and their presence increases communication and the continuity of care (Olding et al., 2016). Patients from these various families confirmed that receiving social companionship support from caregivers has led to some significant improvement in their health. Most patients appreciated the support that their caregivers provided and associated that to their recovery.

CONCLUSION

Each caregiver provided more than one social support to their PWA. Patients also reported their appreciation to the support the caregivers provided. This response was obtained by the patient either nodding, shaking their head to respond or a verbal respond.

CHAPTER SIX

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

CONCLUSION

The study aimed at obtaining information on the various types of social support caregivers provided to PWA and how useful the support was to them. The study considered 4 types of functional social support which includes, emotional, instrumental/ tangible, informational, social companionship support while spiritual support was also a type of support caregivers provided to the PWA.

Each caregiver provided more than one type of social support. Caregiver's choice of social support was subjective but some patients admitted to appreciating the support the caregivers provided.

RECOMMENDATION

1. Speech and language therapist, nurses and physiotherapist should guide caregivers to reflect on the type of social support they provide for the PWA. This will help them to readjust their support strategies.
2. Speech and language therapist, nurses and physiotherapist should emphasize to caregivers on the importance i.e., both objective and subjective of support provided to the PWA.
3. Health professionals should create awareness or educate both the caregivers and patients on aphasia and make the necessary referral to reduce communication barriers in the community.
4. Professional such as the speech and language therapist can use these findings as a guide in their practice and encourage the use of social support in the rehabilitation process of the PWA.

5. Speech and language therapist are encouraged work on early identification and treatment of patients with aphasia to aid better outcomes.
6. Future research should be carried out to explore the socio-cultural perspectives of aphasia in the Ghanaian context.

LIMITATION

The success of the research depended on some factors such as willingness of respondent to participate in the study, amount of time during the interview and a larger sample size more than twenty 20. However, some caregivers were hesitant in taking part in the study due to the following factors;

- COVID-19. They did not want close contact with the people in the hospital.
- The environment was not friendly for the interview. Some clients had to stand because there weren't enough chairs.
- Time of interview. The interviews took place in the morning during visiting hours (6:30-7:00 am) and on review days which took place only on Mondays. When visiting was over caregivers were in a heist to go back home/ work.

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APPENDIX I

QUESTIONNAIRE (FAMILY MEMBER)

1. Gender a) Male b) Female

2. Age Group
 - a) Below 20 years b) 21 – 40 years c) 41– 60 years d) 61 years and above

3. Education Level
 - a. Postgraduate
 - b. Graduate
 - c. Diploma
 - d. Certificate
 - e. Other (please specify).....

4. Contact.....
5. What is your relation to the patient?
6. Who was your relation before the stroke?
7. What caused the stroke and how long?
8. Do you know what Aphasia is?
9. What did you do when you realize he/she had aphasia?
10. What are some of the activities you do with him/her when you are at home or in your leisure time?
11. How these activities help/improving his/her condition?
12. How do you support the PWA?
13. To what extent has these support affect the PWA?

QUESTIONNAIRE (PATIENT)

1. Do you know what Aphasia is? **YES** **NO**
2. What is your experiences with aphasia (For patients with slurred speech)
3. How does the family support you? (for patients with slurred speech or the use of gesture)
4. Is the support you get what you need? **YES** **NO**
5. Do you think the support caregivers provide has improved your health? **YES** **NO**
6. What are you able to do now since the onset of aphasia?

Thank you for answering the questions!

APPENDIX II

SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES

COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA

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.

CONSENT FORM FOR CAREGIVERS WITH PERSONS WITH APHASIA

I, _____ [PRINT NAME], give my consent to participate in the research project entitled PROJECT TITLE “GHANAIAN SOCIAL SUPPORT AND THE IMPACT IT HAS ON PERSON’S WITH APHASIA IN ACCRA”.

In giving my consent I acknowledge that:

1. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
2. I understand that being in this study is completely voluntary and confidential.
3. I understand that any research data gathered from the results of the study may be published. However, no information will be used that can identify me.
4. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or The University of Ghana.
5. I understand that if I have concerns about the research at any point I am able to contact the research team to discuss any issues I have:

Name of participant

Signature or Thump print of participant

Date

Name of researcher

Signature of researcher

Date

APPENDIX III

Department of Audiology, Speech and Language Therapy
School of Allied Health Science College of Health Science

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).

APPENTIX IV



UNIVERSITY OF GHANA

SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES

May 16, 2020

Ms. Ibrahim, Zahrah
Department of Speech and Language Therapy SBAHS, Korle - Bu
Dear Ms. Ibrahim,

ETHICSCLEARANCE

Ethics Identification Number: SBAHS/AA/SLT/1041336112019-2020

Following a meeting of the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences held on April 9, 2020, I write on behalf of the Committee to approve your research proposal entitled:

"Social support and the impact it has on persons with Aphasia in Accra".

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 clearance is valid for three years, with effect from the date issued.

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

Yours sincerely,

Jonathan Quartey (PhD)
Chairman, Ethics and Protocol Review Committee

CC: Dean, SBA-IS

Head, Dept. of Speech and Language Therapy, SBAHS School
Administrator, SBAHS

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