THE IMPACT OF APHASIA EDUCATION ON FAMILIES OF STROKE SURVIVORS: A CASE STUDY OF THE STROKE UNIT OF KORLE-BU TEACHING HOSPITAL, ACCRA, GHANA

BY

GLADYS AKOSUA AGBEKO
(10602610)

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

JULY, 2018

DECLARATION

I, **GLADYS AKOSUA AGBEKO**, hereby declare that this dissertation which is submitted in partial fulfillment of the requirements of the Master of Science degree in Speech and Language Therapy, is the result of my own 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 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 will be jointly held between me as the first author and the project supervisors as subsequent authors.

Signed……. Date……

GLADYS AKOSUA AGBEKO (Student)

Signed……. Date……..

DR. GEORGE AKANLIG-PARE (Principal Supervisor)

Signed……. Date……

MS NANA AKUA VICTORIA OWUSU (Secondary Supervisor)

Signed……. Date……

DR. NEAL BOAFO

(Head of Department)

DEDICATION

This dissertation is dedicated to my loving husband, Mawusi, Elorm my son, and my mom, Mrs Florence Agbeko.

ACKNOWLEDGMENT

I thank God Almighty for life and security. God's sovereignty has kept me through all the changing phases of life's struggles and I am humbled and submitted to my Lord.

I would like to thank my supervisors, Dr. George Akanlig-Pare and Ms Nana Akua Victoria Owusu for their kind help in shaping my thoughts and guiding me through the process of dissertation preparation.

I would also like to thank the Head of Department for Speech and Language Therapy, Dr. Samuel Anim-Sampong for his encouragement and help throughout my two-year stay in the department. I give my deepest appreciation to all other lecturers in the department, especially Mr. Clement Amponsah, Miss Josephine Bampoe and Madam Karen Wylie. I thank my friends, Abena Asiedua Owusu Antwi and Malaika Abigail Addai-Sundiata, Mr. Godwin Tettevi and Madam Bernice Brown aka "Auntie Bee" for their immense help.

To the nurses at the Stroke Unit of Korle-Bu Teaching Hospital and all those I interviewed for the study, I express my deepest appreciation and gratitude.

I am profoundly grateful to my beloved husband, the Rev. Fred Mawusi Amevenku of Trinity Seminary, Legon, who funded the programme and my siblings, especially Kwame and Ivy for their financial, moral and spiritual support. God bless you all.

CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ACRONYMNS

ASHA	American Speech-Language-Hearing Association
GHF	Ghana Heart Foundation
IARC	International Aphasia Rehabilitation Conference
ICF	International Classification of Functioning and Health Disability
KBTH	Korle Bu Teaching Hospital
NHIS	National Health Insurance Service
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech and Language Therapist
WHO	World Health Organization

ABSTRACT

Background: Aphasia is an acquired language impairment which is the result of a scratch of the focal brain even when other cognitive, motor or sensory impairment is not present. It often follows a stroke. Globally, about 30-35% of stroke patients suffer aphasia after they have been hospitalized for stroke. The resulting aphasia leads to difficulties with reading, writing, and expressive and receptive language. The provision of standard education to stroke inpatients, and providing further education support to their caregivers in follow-up home visits after hospital discharge, is standard practice. In Ghana, community awareness of the risk of stroke is unsatisfactory. Nurses at the Stroke Unit at Korle Bu Teaching Hospital (KBTH) educate aphasia caregivers on communication with persons with aphasia. Sometimes nurses counsel caregivers as well.

Aim: The aim of the study is to investigate the nature, effectiveness and benefits of aphasia education, provided to family caregivers of persons with aphasia at the Stroke Unit of KBTH.

Methods: In this study, caregivers of 20 randomly selected stroke and aphasia patients, who previously reported at the Stroke Unit of KBTH were recruited and interviewed, using an interview guide. Questionnaires were administered to elicit data from the Stroke unit of KBTH, about how family caregivers are educated to improve communication with patients.

Outcome: The study has shown that education given to family caregivers at the Stroke Unit of KBTH helps to improve communication for persons with aphasia at home after hospitalization.

Conclusion: A formalized and well-structured aphasia education for patients who report at the Stroke Unit will help facilitate patient communication if aphasia sets in after the stroke.

Key words: Aphasia, education

CHAPTER ONE: INTRODUCTION

1.1. BACKGROUND

Aphasia is a post stroke language and communication impairment resulting from brain damage which makes it difficult for its victims to produce or understand language. Aphasia affects reading, understanding, writing, and signing negatively. This study shows that education given to caregivers of persons living with aphasia, during a patient's hospitalization at the Stroke Unit contributes to subsequent improvement of communication effectiveness between patient and caregivers at home. Even though aphasia rehabilitation goes far beyond language development and communication[1], the work of Speech and Language Therapists (SLTs) concern communication specifically. Professional SLT's therefore need to work with other professionals in an integrated approach to aphasia rehabilitation to ensure that persons living with aphasia fully recover from their conditions.

The incidence of stroke in Ghana is of grave concern to government, health authorities, families and individuals. According to Agyeman et al (2017), stroke is a leading cause of death in the country and it accounted for 13.2% of all "medical adult deaths" at the Komfo Anokye Teaching Hospital (KATH) during the period of January 2006 to December 2007. Deaths from stroke accounted for 11% of autopsies conducted over a five-year period at KBTH (Wiredu and Nyame 2001). In many cases, stroke victims also experience aphasia after the stroke attack. Aphasia drastically reduces their ability to effectively communicate. The difficulty to communicate

[1] Kagan et al (2007) have shown that living with aphasia is a difficult experience that needs an integrated approach from different professionals to manage. They note further that to improve efficiency for persons with aphasia includes the enhancement of the patient's participation in life situations, communication and language development and the mastery of personal identities, attitudes and feelings. The intersection of these various aspects of aphasia rehabilitation defines how holistic the management of the condition becomes, and the progress, success and effectiveness of rehabilitation depends on the severity of the condition.

efficiently with relatives or caregivers can be frustrating for persons with aphasia. The focus of intervention for persons living with aphasia can either be the individual or in groups. Increasingly, training of communication partners has been noted as one of the intervention goals for persons living with aphasia.

1.2. PROBLEM STATEMENT

Aphasia is a major concern around the world because about a third of stroke survivors experience aphasia (Papathanasiou, et al 2017). Aphasia greatly affects patients along with their families as it may bring about, not only communication disability but also social isolation, high care costs or depression among many other conditions. Governments and health authorities are understandably concerned because stroke is responsible for many premature deaths in Ghana (Wiredu and Nyame, 2001). Donkor et al (2014), show that Ghana is currently experiencing a stroke epidemic and that the poor community awareness of the risk factors is probably responsible.

Research into the rehabilitation of post stroke aphasia patients is on the increase in Australia and other parts of the world (Papathanasiou, Coppens, & Bronwyn, 2017). The main approach is behavioral, in that, it is intended to help recipients change their current communication conduct. There are different approaches to this, including one-to-one method with a clinician, group therapy, computer-based approaches or telepractice methods (Papathanasiou et al., 2017). Non-behavioral approaches are also being investigated, including drug therapy and nonaggressive brain stimulation procedures (Papathanasiou, 2017).

The Stroke Unit KBTH reports many instances of stroke-aphasia. Despite this, post stroke aphasia education aimed at helping family caregivers to improve their communication with patients, a standard approach to aphasia therapy, is not structured and enthusiastic enough at the unit.

1.3. RESEARCH QUESTIONS

In addressing this, the following research questions were formulated:

1. Upon discharge, do staff of the Stroke Unit educate stroke survivors and their families?
2. What is the nature of the education and how it is delivered?
3. Do the nurses use the World Health Organization (WHO) framework known as International Classification of Functional and Health Disability (ICF) to educate persons with aphasia and their caregivers?
4. What impact does the chosen approach, make on the families of victims of stroke-aphasia?

This study attempts to answer these questions, using both qualitative and quantitative methods. The research will investigate how helpful the family caregivers find such education.

1.4. SIGNIFICANCE OF THE STUDY

This research investigated the nature, effectiveness and benefits of aphasia education given to family caregivers of persons with aphasia, during the patient's admission at the Stroke Unit. The study has shown that not all stroke patients reporting to the unit are screened for aphasia. Moreover, nurses at the Stroke Unit use their discretion to decide which caregivers to give aphasia education to. Besides, the study found out that there is no standard material available for aphasia education at the Stroke Unit of KBTH.

1.5. AIM OF THE STUDY

The aim of this research was to investigate the nature, effectiveness and benefits of aphasia education given to family caregivers of persons with aphasia at the Stroke Unit of KBTH.

1.6. OBJECTIVES OF THE STUDY

The objectives of the study are:

I. To investigate and explain how nurses at the Stroke Unit of KBTH give aphasia education to caregivers of persons with aphasia and their families, during the time the patients are on admission.

ii. To evaluate, through questioning and observation the effectiveness of education delivered to caregivers and families of persons with aphasia at the Stroke Unit of KBTH.

iii. To assess the benefits of aphasia education delivered at the Stroke Unit of KBTH, by finding out how a caregiver, who has received aphasia education is influenced in communication behavior with persons with aphasia.

1.7. ORGANIZATION OF THE STUDY

The study has been organized into six chapters. Chapter one, the introductory chapter covers the background to the study, statement of the problem investigated, the research questions and the objectives of the study. In chapter two, literature relevant to the study has been reviewed. Chapter three explains the methods used for the study. In chapter four, the data collected has been presented in statistical tables and charts for easy grasp of the information. Chapter five presents the analyses of the data and its discussion. The study draws its conclusions and makes some recommendations in chapter six.

1.8. DEFINITION OF SOME KEY TERMS

Aphasia: Aphasia is an acquired language impairment resulting from a focal brain lesion in the absence of other cognitive, motor or sensory impairments. The brain damage caused leads to the dysfunction of the central nervous system and frustrates language production and comprehension for the victim of aphasia.

Education: It is a process by which a person receives information, instruction, teaching and guidance on a given subject, which leads to a permanent positive change of behavior in that person.

Aphasia education: It is a process by which a caregiver of an aphasia patient receives information, instruction, teaching or guidance to know how to change his or her approach to communication with the patient for greater efficiency in communication.

Caregiver: Someone responsible for helping a person living with aphasia to get by on daily basis in terms of the communication and provision of the aphasia patient's daily needs.

Aphasia rehabilitation: A holistic process involving many health care providers and support groups, by which a person living with aphasia is cared for and managed to be able to navigate his or her life while aphasia persists until he or she is fully cured of aphasia.

1.9. CONCLUSION

In this Chapter, the background, problem, research questions and the objectives of the study, as well as the conceptual framework and a preliminary literature survey are given for the study. In this way, the study is put in its proper context for the main investigation to be carried out. The focus of the study as shown in this introductory chapter is the investigation into the nature benefits and effectiveness of aphasia education for caregivers of persons with stroke-aphasia.

CHAPTER TWO: LITERATURE REVIEW

2.1. INTRODUCTION

Aphasia is a language disorder that results from brain damage, resulting in the dysfunction of the central nervous system. Stroke causes aphasia. About 33% of all stroke cases are followed by aphasia (Papathanasiou, et al 2017). Aphasia disrupts the life of its victim, 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 requires concerted efforts of many health-related professionals to manage. Unfortunately, low individual and community awareness of aphasia makes it difficult to manage the condition, though aphasia is preventable. Aphasia education for patients, caregivers and communities holds the key to the effective control of the disease.

2.2. APHASIA

Like other health conditions, aphasia does not lend itself to a single definition. Nor is it easy to define aphasia, since scholars tend to examine the condition from different perspectives.[2] Many researchers have defined aphasia differently as a result. According to Brookshire (2007), aphasia is an impairment which frustrates one's ability to comprehend and produce language because of brain hemisphere damage. From the perspective of neurology, aphasia has been defined as an acquired language impairment resulting from a focal brain lesion in the absence of other cognitive,

[2] According to Papathanasiou, Coppens and Davidson (2017) Aphasia can be approached from different perspectives such as neurology, linguistic, neuropsychology and psychosocial. This is the result of the theoretical underpinnings that investigators rely upon when seeking understanding of aphasia, therefore no single approach to aphasia can be said to be final in any definite sense.

motor or sensory impairments (Papathanasiou, Coppens and Davidson, 2017). This latter view is sufficient as an operational definition for the purposes of this study.

Aphasia often follows a stroke and it can affect all components of language, such as phonology, morphology, syntax, semantics and pragmatics. Subsequently, persons with aphasia tend to have difficulty speaking, reading, writing and signing (Papathanasiou, Coppens and Davidson, 2017). In other words, aphasia affects its victim's ability to read, write, speak, sign, and understand. Without the appropriate functioning of the human brain, these activities stall. Since the human brain is made up of cells and nerves that control the above activities and more, when a brain vessel bursts or is blocked, the result will be that the brain cells no longer receive the amount of oxygen they require to function normally, therefore some are damaged and some die altogether (Scottish Intercollegiate Guidelines Network 2011) resulting in dysfunctions in the body. The changes, apart from those already mentioned include difficulty in walking and the use of a person's arms, inefficiency in bladder and bowel control, seeing, eating and swallowing, balancing, emotions and confidence levels among many others (Scottish Intercollegiate Guidelines Network 2011). The combined effects of these dysfunctions are massive and very devastating to the patient, whose life is drastically distorted and disorganized suddenly at the onset of aphasia.

Aphasia devastates its victim, the patient's family, the community and society as well. This is more so with the immediate family. For instance, when aphasia strikes a young spouse with children, the other spouse will immediately be confronted with serious adjustment issues. Since the spouse living with aphasia will no longer be able to communicate with the family in a manner as previously done, this would also mean that the spouse with aphasia will not also be able to

understand or make sense of many of the activities that happen around, the patient is bound to feel neglected and distanced from the rest of the family. In the same way, the young spouse whose partner has been affected with aphasia might become disappointed, frustrated, angry and bitter because of the situation. Some spouses even blame the aphasia victim for not taking their diet and exercise more seriously leading to the disease (Aphasia Guide, 2007). Such blame only serves to worsen the plight of both victim and family hit by aphasia.

The immediate family of a person with aphasia is devastated because they are the ones at the receiving end of the disorganized life of their relative. To take care of a person with aphasia is difficult and involving because many professionals, including dieticians, social workers, doctors, nurses, occupational therapists, physiotherapists and speech and language therapists (SIGN, 2011) need to come on board for holistic rehabilitation. All these professionals have different and specialized contributions to make to the management and care of the person with aphasia. Since caring for a person with aphasia involves rehabilitation of the person and management of the condition, family caregivers need to work with the various professionals to plan the process effectively. According to the American Speech-Language-Hearing Association (ASHA), aphasia intervention principles are based on evidence-based practice which includes the employment and deployment of cutting edge research evidence with practitioner expertise and client preferences and values in an integrated way to make clinical decisions (ASHA, 2005). Family members need information to be able to cope with the condition, deal with it or adjust appropriately to the devastating changes that the disease brings to the family.

2.3. FAMILY CAREGIVERS OF PERSONS WITH APHASIA

Family need of information is crucial to enhance aphasia management and care for persons with aphasia. Yet the process of care and management comes at high cost. For aphasia victims who are fortunate to have a supporting family capable of finding the resources required for comprehensive care, improvement becomes rapid. According to Salter et al (2006) many aphasia patients can see drastic improvement within a year following the onset of aphasia, provided they get the right kind of care. In situations where persons with aphasia receive effective, intensive regular aphasia therapy, receptive and expressive language begins to improve within two to three months (Salter et al, 2006). If families cannot find the resources needed for holistic care for persons with aphasia, then recovery will be slow. This probably connects economic power with the enjoyment of effective health care delivery, and the more money and other resources the family of a person with aphasia can raise to care for the victim, the better.

This is because family members are often the caregivers of persons with aphasia. To do so effectively, they need knowledge. They are, therefore, given education to help them. McAllister, Wylie, Davidson and Marshall (2013) have observed that to be effective, aphasia-related education must target public awareness-creation to function as a community intervention strategy even though most interventions, as far as they are aware, centre on individuals. Yet both individuals and the community will benefit from aphasia education when they receive it. Individuals constitute families and families come together to form bigger social groups such as clans, ethnic groups and communities. Some communities form groups to create the environment for the effective participation of aphasia patients, their family caregivers and other community members, to enhance aphasia management. Education of persons with aphasia and their family caregivers helps,

not only to improve the management of aphasia, but also to avoid further relapse (Cawood & Visagie, 2015). Relapse occurs when the right intervention is not available. Where caregivers are ignorant and misunderstand the effects of aphasia on a victim's life, patient deterioration may result. Such misunderstanding might lead persons with aphasia and their caregivers to neglect best intervention practices leading to tragedy.

2.4. APHASIA EDUCATION

Like many social concepts, the meaning of education defies precise, universal definition because of its nature and form as well as the context in which it is delivered. Education could take place formally or informally, in a school setting or some other environment. Homes, families, clans and communities often provide informal education for socialization of their members. This includes the acquisition and development of language, a powerful tool of human communication. It is also universal practice now, that in addition to informal education, families also strive in collaboration with governments around the world to provide formal education in school settings. Education has many benefits, because effective education primarily causes a positive change in behavior. These benefits are associated with aphasia education as well.

Education on the causes, prevention and management of aphasia falls within the category of specialized health education for patients and caregivers. It is aimed at getting people to change their behavior to respond appropriately to the sudden attack of aphasia on their family members. Aphasia education around the world is given mostly at the Stroke Unit of hospitals, just before people with aphasia are discharged for subsequent home care (Marissa et al., 2016). This approach often involves the presentation of written information to patients and their caregivers, but a 2009

study in Australia found that, the goal for giving the educational information was not being met (Worrall et al., 2009). The main issue here was that, persons with aphasia surveyed in the study preferred to receive written aphasia information at several stages of post onset, ranging from one day after the stroke attack, to the period of hospitalization up to more than a year after the stroke. It was evident that majority of the respondents wished that memory should be restored before written aphasia education information is received.

2.5. SOME PROBLEMS WITH APHASIA EDUCATION

Aware of some of the problems associated with ineffective stroke-aphasia education for victims and family caregivers, health workers themselves meet frequently to discuss how to improve upon the education they give out to patients and families (Navarro, Alejandro, Baroquell, and Lokin, 2013). Since aphasia disrupts the lives of victims and family physically, mentally and emotionally, aphasia education helps to prepare persons with aphasia and their caregivers to deal with the new struggles associated with the victim's incapacitation (Cameron, 2013). Giving aphasia education aims to improve function and quality of life, and to prevent possible deterioration of the condition of the persons with aphasia (Rodhrock et al., 2006). Specialized, patient-specific education leads to effective patient rehabilitation. Each member of the family needs to understand the educational information, because whatever changes that occur takes place within the family system (Visser-Meily et al, 2006). This calls for multiple learning and teaching techniques, consistent with the needs of the patients and the family.

2.6. FAMILY CAREGIVER APHASIA EDUCATION FOR APHASIA

The American speech-language-hearing association (ASHA) has observed that family members may also feel strong emotions – anxiety, anger, confusion, depression, despair. The situation of marriage changes and partners may feel a sense of loss. It is natural to go through a grieving process when a family member develops aphasia, and family members need to be helped through this process (ASHA, 2007).

Most often, close family members elect themselves as caregivers of aphasia patients. To succeed in their service to the patient, caregivers need useful information which can be provided through effective aphasia education. In most jurisdictions, the medical staff is responsible for providing such education. According to Marissa et al (2016), many hospitals around the world recommend to their staff to give their specific stroke education packet to the patient or caregiver prior to hospital discharge. Furthermore, the nurses are advised to give oral education to review the packet, but since in many cases this is not required, many institutions do not practice it consistently.

Aphasia education enables family caregivers to understand the patients and to know how best to communicate with them for effective and efficient care. Providing an already prepared brochure to family caregivers just before patient discharge is standard practice in many other places yet challenges arise to this approach where patients, caregivers, and healthcare providers misunderstand themselves (Marissa et al., 2016). When they are given, the education packet often includes information about the nature of stroke, its effects and after management (Marissa et al., 2016). Probably mindful that there could be misunderstanding of aspects of the stroke education material, the authorities encourage nurses to review the education material orally but this is often

not done. The oral review would hopefully clarify portions of the material that caregivers find difficult to comprehend. Only 37% of caregivers of stroke survivors in the Free State of the Republic of South Africa receive family education just before the victim is discharged from the hospital (Cook, 2017), yet educating caregivers and families of stroke patients ought to be included in stroke management. Indeed, it is important for governments to adopt a multi-sectoral approach to stroke rehabilitation to ensure holistic service to stroke survivors (Cook, 2017).

2.7. COMMUNITY INTERVENTION AS APHASIA EDUCATION

Papathanasiou, Coppens and Davidson (2017), quote McAllister et al (2013)[3] as having observed that to be effective, aphasia-related education must target public awareness creation and function as a community intervention strategy even though most interventions, as far as they are aware, centre on individuals. The point is that while aphasia afflicts individuals, the changes that come with the onset of the disease go far beyond the individual. To mention that the family is drastically affected is to state the obvious. Beyond the family, aphasia results in changes that affect the entire community, so while education for the immediate family members, especially the caregivers ought to be the starting point, this is not an end, it is a means to an end—total community awareness that ensures almost total prevention of the condition is equally desirable. Where there is widespread aphasia awareness, prevention measures will prove effective.

Thus, both individuals and the communities will benefit from aphasia education. Community groups create the environment for the effective participation of aphasia patients, their family

[3] Papathanasiou, Coppens and Davidson (2017) do not give the title of the source from which they took the information from McAllister et al. Nor do they acknowledge the source in their select bibliography. Attempts to find the title of the work by McAllister et al were unsuccessful, hence the decision to rely on Papathanasiou, Coppens and Davidson for the information attributed to McAllister, Wylie, Davidson and Marshall (2013).

caregivers and other community members, to enhance aphasia management. Education of persons with aphasia and their family caregivers, helps to improve the management of the aphasia condition and to avoid further relapse (Cawood, J. & Visagie, S., 2015). When used, "sophisticated computerized communication devices are not always effective for aphasic clients with cognitive impairments" (Cawood & Visagie 2015: 7), but basic graphic communication panels (Cawood & Visagie, 2015) could improve expressive language. Aphasia education with follow-up counseling support has proven more effective than aphasia education without follow-up counseling, in getting families to adjust to changes which accompany the onset of stroke in a family (Evans et al., 1988).

2.8. FRAMEWORK AND CHALLENGES

In 2001, the World Health Organization (WHO) developed a framework known as International Classification of Functioning Disability, and Health (ICF). For a person with aphasia, the ICF model has two categories — activity[4] and body functions and structure[5] (Papathanasiou, Coppens and Davidson, 2017). These modalities have been developed to facilitate assessment and intervention for people with aphasia. For persons with aphasia, as has been noted, functioning normally is a daily struggle because the condition restricts their capacity to act and participate in daily engagements.

Since majority of stroke patients do not retain a memory of their hospitalisation (Marisa et al., 2015), the ICF recommends that caregivers take the responsibility to help patients change their

[4] Activity refers to "tasks or actions that involve the four language modalities — listening, speaking, reading or writing — as well as the daily functional communication tasks, such as conversing with family members and friends, reading a newspaper, writing an e-mail, and the like." (Papathanasiou, Coppens and Davidson 2017).
[5] Body functions and structure refer to how the brain function and impairment activities (Papathanasiou, Coppens and Davidson 2017).

behaviours to prevent recurrence of stroke. The framework is aimed at holistic education for effective care delivery and interaction between impairment and environment, which affects the participation and quality of life of the victim. The ICF approach redefines functioning and disability as a strategy to achieve its goal of ideal care for victims. The whole process, as recommended by WHO therefore, hinges on education and knowledge management for effective therapy.

Many stroke-aphasia patients receive education from the hospital which aids them in the post-stroke period, as a significant source of information after discharge from acute hospitalization. Unfortunately, as has been indicated already, many persons with aphasia do not remember being given education on their condition while on admission at the hospital. It is argued, as a result that since most stroke survivors do not remember being admitted at hospital and cannot recall being given education on stroke-induced aphasia while still on admission, the timing of education interventions is important. (Marissa et al., 2015). It might be necessary for the hospital staff to investigate the presence of memory of the victim before undertaking the task to educate them on the post admission management of the condition.

Stroke patients and their caregivers often do not know what to do to prevent stroke recurrence (Merissa et al., 2015) even though caregivers are given general education about post-stroke care and prevention of recurrence. In the state of Hawaii, caregivers receive a brochure just before the patient is discharged (Marissa et al., 2015) as it is in other jurisdictions such as Australia, Canada and the US. In Hawaii, the brochure does not address specific conditions of stroke-aphasia victims and their family care plans (Marissa et al., 2015). Beyond formal education, there are concerns for

the recurrence of comorbid stroke, for instance (Marissa et al., 2015), so that the more knowledge caregivers have about the aphasia the easier their task becomes. In getting messages across to aphasia patients from caregivers, gestures and facial expression prove to be among the most effective methods (Aphasia Guide, 2007). A knowledgeable and well-educated caregiver would know this and be able to apply the skills learnt to ensure better care for the patient.

In Ghana, efforts to manage the menace of stroke-aphasia are ongoing. According to Donkor, (2014) though most people can appreciate that stroke is very serious but preventable, even in the capital Accra, "community awareness of the risk factors and warning signs" is unsatisfactory. This means that most people indulge in health-compromising behaviors without realizing how they endanger their lives. Subsequently, it stands to reason that when people are educated at the community level about the risks and management of stroke, it encourages people to report to the hospital in the event of an attack, and decreases stroke attack for others (Donkor, 2014).

This community aphasia awareness drive is crucial for Ghana as a developing nation because even the developed nations of the world still report low levels of aphasia awareness among their citizens. For instance, in a 2016 survey conducted by the National Aphasia Association (NAA) in the USA, less than 9% percent of respondents were "aphasia aware", and of this group nearly 35% were aware because either they had the condition themselves or someone they knew had the condition (US, NAA 2016). The need for awareness education is even more urgent in Ghana because the country has a high stroke mortality rate (Donkor, 2014) and a health service system with numerous challenges. Increasing awareness rates would enable citizens to take better care of themselves and when disease strike they would know what to do and quickly too. The Ghana Heart Foundation

(GHF) has been engaged for some time now in the promotion of knowledge through constant health education on cardiovascular diseases, including stroke. As a non-governmental organization, the GHF also raises funds to promote free or subsidized heart related surgeries for needy people at the cardiothoracic center of KBTH.

2.9. OTHER APPROACHES TO APHASIA EDUCATION

According to Tanya et al (2012) stroke victims without aphasia remember receiving information from health professional but only slightly more than half of persons with aphasia recall being given information at the hospital. Moreover, health care providers in hospitals communicated more extensively with stroke patients without aphasia during their admission than with stroke-aphasia victim (Tanya et al 2012). This is unlikely to be deliberate yet, health care providers spending less time to give education information to persons with aphasia than with stroke victims who have no aphasia, further limits the functioning ability of persons with aphasia. It is possible that this happens because of the difficulties in communicating with persons with aphasia, which health professionals need to overcome to effectively educate persons with aphasia. If persons with aphasia become disadvantaged compared with stroke patients who do not have aphasia, because it is relatively easier to communicate with stroke persons who do not have aphasia, then aphasia management becomes a very tall order. To minimize such a challenge, there is the need to modify written aphasia educational information sufficiently before giving it to persons with aphasia (Aleligay, Worrall & Rose, 2008).

2.10. CONCLUSION

Aphasia is a language disorder that affects a person's ability to speak, write, read, sign, and understand due to a grave dysfunction of the victim's central nervous system. Aphasia is the result of a stroke. Over the world, about a third of stroke cases result in aphasia. Aphasia devastates its victim, family members of the patient and the rest of the community. Because of its disorganizing effect, managing aphasia is very challenging. Many professionals, such as nurses, doctors, physiotherapists, speech and language pathologists, counselors, social workers and dieticians are involved. The cost of aphasia care and rehabilitation is obviously high because of the concerted effort required.

Both caregiving and rehabilitation of persons with aphasia require education. Aphasia education aims at getting the caregiver, members of the victim's family and the community to appropriately change their behaviors as a response to the drastic changes that the disease makes to the life of its victim. Since, aphasia is preventable, education and awareness creation for both family and community will go a long way to control the incidence and effect of the disease

CHAPTER THREE: METHODS

3.1. INTRODUCTION

This chapter explains the method by which the study is conducted. The method falls within the methodology of mixed methods research, which is a research process in which both qualitative and quantitative approaches are applied. The chapter also presents the study design in which the target population as well as the sample is defined. The procedure for data collection and the theoretical framework behind it is also explained. The issue of the validity and reliability of the research instrument, the data management plan of the research, the research ethics and the dissemination of the research findings conclude the chapter.

3.2. METHODOLOGY AND METHOD

According to Walliman (2011), research methods are tools and techniques required for research. Different ways of reasoning lead to different methods of investigation to discover new facts or shed light on known facts. Just as it is necessary to find the appropriate tools and equipment to undertake a specialized job, so also research methods provide suitable techniques and tools for investigating a specific problem. In research, the nature of the problem under investigation tends to determine the type of method to apply to the study.

Research methodology, on the other hand, is a system of how to do, study or teach something (McIntosch, 2013). In other words, methodology is the scheme or structure by which a research is organized, classified and arranged to ensure that the findings of the research are sufficiently scientific and objective. This study has proposed to use a mixed method approach because its data collection plan combines both qualitative and quantitative approaches. The difference between the two types of research methods is mainly based on the nature of reasoning behind them.

While qualitative research designs are based on inductive reasoning, quantitative research methods are based on deductive reasoning. In qualitative research methods and reasoning, research results in the development of theory, such that research findings are deployed to explain and clarify theories for further study. In quantitative research method and reasoning, the process begins with a theory (or theories) which the research process might disprove or confirm. Theories connect ideas with one another to establish relationships between or among concepts. Concepts are ideas. A research design functions to explain how relationships among ideas or concepts being studied in each research are established or explained.

3.3. STUDY DESIGN

This study used a mixed method. Mixed methods research uses qualitative and quantitative approaches to data collection for a single study or a series of studies (Suleman and Hopper, 2014). Quantitative research technique involves data that can be reduced into numbers, such as the number of patients reporting at the Stroke Unit within a given period of the year 2018. Quantitative research procedures on the other hand, involve data that can only be described in words, such as how effectively a respondent considers aphasia education given by nurses.

This study randomly selected twenty family caregivers of persons with aphasia for the study. It is the nature of the present study that demands this approach. The study is qualitative because data in the form of ideas, opinions and feelings was collected from randomly selected respondents. The twenty randomly selected caregivers and their families constitute the sample. In random sampling, every item has an equal chance of being selected. To ensure that there are no biases to affect the selection of the 20 respondents, two conditions were laid down at the onset. First, the researcher

decided to visit the Stroke Unit of KBTH in the months of February, March and April 2018 every Tuesday of each month when the unit received patients. A record of all the stroke cases reported during the period was kept along with the statistics of the caregivers. Second, out of 163 patients 47 were diagnosed as persons with aphasia with the help of the nurses at the unit. Of the 47 persons with aphasia, 20 were selected to constitute the sample. Each of the 47 cases were coded with a unique label and deposited in a bowl. The researcher then randomly selected 20, looking away from the bowl each time a selection was made. The caregivers of the 20 persons with aphasia constituted the sample for the study.

The study is quantitative because it involves empirical data to be collected at the Stroke Unit of KBTH. While the main purpose for collecting data from the Stroke Unit is to find out how persons with aphasia and their caregivers are educated to improve communication after patient discharge from the hospital, the data has been counted in figures, because it involved determining the number of post stroke aphasia patients who visited the Stoke Unit over a three-month period. As already mentioned, the study investigated the nature, effectiveness and benefits of aphasia education, for caregivers of persons with aphasia and their families receive during the time their family members. Thus, it involved multiple respondents-post stroke patients with aphasia and their caregivers. By effective aphasia education, we mean the type that helps the family caregiver to know what to do to facilitate communication with the person with aphasia, to help the aphasia patient function more easily.

3.4. STUDY POPULATION AND ITS DELIMITATION

The population of a research project is a group of people, objects or events with identifiable characteristics defining them (Walliman, 2011). Since this research investigates aphasia education

for family caregivers, the target population of this research covers caregivers of all post stroke aphasia patients who report to the Stroke Unit of the KBTH. The Stroke Unit attends to the needs of stroke patients every Tuesday, therefore a study with a limited time span, such as the current one cannot possibly sample the entire population. The study is further delimited by the fact that it cannot even study persons with aphasia reporting to the unit throughout the year 2018, let alone the other years. Sampling an entire population is nearly impossible in most research works. This study is no exception to this general principle.

3.5. SAMPLING METHOD AND SIZE

The random probability sampling method was used in this research to select 20 post stroke aphasia patients, who the researcher contacted for further data collection. The researcher visited the Stroke Unit of KBTH every Tuesday for three months between February and April 2018 and recorded all the stroke-aphasia cases reporting to the unit. To gather the appropriate quantitative data in this regard, a 6-item questionnaire (see appendix 2) was developed and administered at the unit. The first item sought to find out how many patients reported to the unit each Tuesday for a period of three month between February and April 2018. The second item inquired about the number of reported stroke cases for the selected period that were followed by aphasia. The responses were recorded and later analyzed. The study also investigated whether the principal caregivers of the stroke-aphasia patients reporting to the unit over the period are members of the patients' family. From the research visits to the Stroke Unit of KBTH, it emerged that there were 47 aphasia cases which the Stroke Unit diagnosed. Though there were 173 stroke cases reported during the period, not all of them were screened for aphasia. 20 out of the 47 aphasia cases were randomly selected along with their caregivers. The researcher contacted the caregivers to explain the purpose of the

research and interviewed the family caregivers relating to the research questions and objectives. The findings were recorded for analysis.

There was a self-introduction to the family caregivers to explain the purpose of the research. Once this was done, the researcher interviewed the family caregivers. The interview questions (appendix 3), among other things, attempted to find out how effective the persons with aphasia communicated after being attacked by stroke-aphasia. The interview further investigated whether the relatives of the aphasia patients who give care at home received education from nurses at the Stroke Unit, and how the application of the information received in turn helps them improve upon communication with their relative with aphasia. Subjects were also asked to evaluate the relevance of the aphasia education given to the caregivers and the patients.

3.6. INSTRUMENTS AND PROCEDURE FOR DATA COLLECTION

A semi-structured questionnaire was used to interview 20 selected family caregivers. These caregivers are from families whose relatives have been affected by a stroke resulting in aphasia. The caregivers of the 20 aphasia-after-stroke patients were contacted and interviewed to find out if they received education while their aphasia victim relatives were on admission. Some of these caregivers granted interviews at the Stroke Unit. For those caregivers who received education on aphasia, the study further sought to determine, whether, among other concerns, the education covered how they might communicate with a person living with aphasia.

The respondents were 20 caregivers. For 19 of these caregivers, their relatives had been affected by a stroke resulting in aphasia. One respondent was not a family member of the aphasia victim but a professional nurse caregiver hired to help the person living with aphasia. 20 caregivers responded to questions aimed at finding out whether they received education while their family

members (and patient), affected by stroke were on admission. The study investigated whether, among other concerns, the education covered how to communicate with a person living with aphasia. The number of patients who developed aphasia after the stroke attack was noted from February 2018 to April 2018.

This aspect of the data has been counted and recorded and displayed in statistical diagrams in chapter four. This is the quantitative part of the study. Since the basis of knowing, in a quantitative study, is empirical, the data collected is objective. Empirical data is observable, measurable and factual and the logic of empirical research method is based on deductive reasoning. In deductive reasoning, an argument is claimed to be true, based on the truth of the premises that lead to the argument (Copi and Cohen 2009). The factual, empirical data from the observation made at the Stroke Unit showed that, the nurses educate persons with aphasia and their caregivers in some cases only. Most of the caregivers however, got the knowledge they have of aphasia elsewhere, including other hospitals and from the internet.

The nurses indicated that they only gave aphasia education to caregivers, where they found difficulty communicating with the stroke patient. The reason for this is obvious. Aphasia after stroke is quite a common phenomenon. Both stroke and aphasia make significant and lasting adjustments to their victims' lives, mostly for the worst. For this reason, victims of stroke-aphasia require sufficient support to navigate their lives after an attack. Caregivers play an indispensable role in delivering the needed care, therefore if they know what to do to help persons with aphasia; it goes a long way to alleviate the difficult plight of the patients. On the other hand, what caregivers may claim to know and use to assist the patient may not be appropriate and as supportive as is expected.

3.7. CONCEPTUAL FRAMEWORK

To measure outcomes, the current researcher observed, recorded and statistically represented incidences of aphasia after stroke over three-months at the Stroke Unit of KBTH. Since qualitative research methods are generally subjective and the reasoning behind them inductive, the basis of finding knowledge is by discovery. Respondents were interviewed about the education they received at the unit, intended to help them manage communication with the patients at home after discharge from the hospital effectively.

The 20 respondents were all willing to participate in the study, thereby enhancing the value of the study. To maximize reliability, respondents were assured of utmost confidentiality regarding information they gave out. They were further told that the data was being collected for education purposes only. Where respondents disclosed their names and contact numbers, only the principal investigator had access to the information provided, as those identity markers never got mentioned in the dissertation.

3.8. DATA MANAGEMENT AND ANALYSIS

Since the study used both qualitative and quantitative data collection methods, the data was analyzed accordingly. Descriptive statistical charts and diagrams, such as pie charts and histograms were used to present and analyze the quantitative data. The research used statistical tables and charts to present and interpret the quantitative data collected during the period of observation and investigation at the stroke unit of KBTH.

After gathering data from the 20 family caregivers of stroke-aphasia patients, the researcher interpreted the data in line with the key themes and concepts (discussed in chapter five) associated with the education of the families of stroke-aphasia victims. The results were evaluated, using the objectives of the study and the research questions as benchmarks and conclusions drawn. The analyses of the results relate to how nurses at the Stroke Unit of KBTH educate caregivers of stroke-aphasia patients during the time the patients are on admission at the unit. The results were evaluated, using the objectives of the study and the research questions as benchmarks.

3.9. ETHICAL CONSIDERATION

Stroke is a devastating disease whose victims are often traumatized along with their families, therefore to collect any kind of data from them for a study needs care. One of the most important considerations in this regard is confidentiality. Patients and their family caregivers were given assurance that the data was being gathered for research purposes only. Permission was sought from all the relevant authorities before the onset of data collection. The University authorities gave ethical clearance for the study.

Due care was exercised during interaction with the respondents to ensure confidence. 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. The investigator replaced all identity markers, such as names and contact numbers of participants with codes. The investigator alone had access to the codes and the identities they mark. These have not been disclosed in the report.

3.10. LIMITATIONS OF THE STUDY

The success of the research depended on some factors, such as the willingness of respondents to participate, the quality of the methods and research experience of the investigator. A larger sample size than 20, effectively managed would have given better, more representative results, but time and resource constraints did not make it possible for the current study. The researcher assured respondents of confidentiality to minimize the limitation of respondent hesitance to reveal certain information. The integration of qualitative and quantitative research methods also aimed at achieving results that either approach may not reveal when used alone.

3.11. 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 Sciences. Portions of the work which are of scientific importance will be published in peer reviewed journals.

3.12. CONCLUSION

This chapter discussed how the research was conducted. It started with the explanation of the method for the study as a mixed method approach. Next, the population and sample of the study were described, indicating the study's interest in education of stroke-aphasia patients and their caregivers, for effective communication between them. It has also outlined the procedure for collecting the desired data and explained how the data so collected was managed.

CHAPTER FOUR: RESULTS

4.1. INTRODUCTION

This Chapter presents the data using statistical tables and charts, as well as percentage representations. The table below shows that 53, 54 and 56 patients reported to the Stroke Unit of KBTH in February, March and April 2018 respectively. The average visit in those three months is therefore approximately 54.

4.2. STROKE PATIENT VISITS TO THE STROKE UNIT

The frequency of visits by the stroke patients to the study site is presented in Table 4.2.

Table 4.2: Frequency of visits to study site

Month of visit (2018)	Frequency	
	Number of patients	Percent %
February	53	32.51
March	54	33.13
April	56	34.36
Total	163	100.00

There were more visits to the Stroke Unit in April (*n*=56, 34.36%). The frequency of visits in February (*n*=53, 33.51%) and March (*n*=54, 33.13%) were almost the same. The nurses at the Stroke Unit did not specifically record the aphasia cases that were among the stroke cases reported during the period of data collection because no policy obliged them to do so. The nurses, therefore did not specify on monthly basis which of the cases were persons with aphasia. However, through

interaction with the patients and their caregivers the nurses identified 47 suspected aphasia cases and offered additional intervention assistance. Not all caregivers were members of the patient's family. There were 19 family caregivers and 1 caregiver who was hired as a nurse from outside the family to give care to the patient. The 19 caregivers included parents and siblings, as well as a brother-in-law.

4.3. CAREGIVERS' EXPERIENCE WITH VICTIMS IN COMMUNICATION

The number of caregivers stated that they were educated at the Stroke Unit on how to communicate with their clients and the various methods the nurses taught them to use are presented in Table 4.3. Caregivers who were not given aphasia education is also indicated in the Table 4.3.

Table 4.3: Aphasia education at the Stroke Unit

Number of caregivers	Aphasia education at Stroke Unit	
	Number educated (%)	Number not educated
20	13 (65%)	7 (35%)

Most (65%) of the caregivers said the nurses at the Stroke Unit gave them "verbal" education regarding how to communicate with the person living with aphasia. Thirty-five percent (35%) indicated that no education was given to them at the Stroke Unit. However, thirteen respondents (65%) noted that they had earlier visited other hospitals where they received "verbal" aphasia education from the staff. The hospitals were not specified. One caregiver reported having read about aphasia from the internet.

Respondents learnt different non-verbal communication strategies such as the use of signs and gestures, written communication on plain sheets for persons with aphasia to read, use of

demonstration and the application of visual aids to help convey information to persons with aphasia. Respondents noted further that the verbal (oral) education they received at the Stroke Unit provided useful information about the causes, effects and management of aphasia.

From the data, it was revealed that from the time of stroke attack and first time visit to the Stroke Unit as against the time of interview, varied periods between one month and 8 years of stroke-aphasia attacks were recorded. Ninety percent of caregivers reported difficulty in communication with patients after the stroke attack. All twenty respondents indicated that their clients visited the Stroke Unit after the stroke attack. In all, 18 caregivers reported difficulty in communication with patients to the hospital.

4.4. DEMOGRAPHICS

Besides the questions and responses mentioned above, the study also collected demographic data on the respondent caregivers. Demographic data gathered included the level of formal education, age and gender of caregivers and the onset and incidence of stroke-aphasia of the patient. Table 4.4 presents the age and gender distribution as well as the frequency of the age distribution of the 20 caregiver respondents who participated in the study as follows:

Table 4.4: Age and gender distribution of caregivers.

Age (years)	Mid-point age (x)	Freq (f)	Fx	Gender	
				Male	Female
< 19	19	1	19.0	1	-
20 - 29	24.5	6	147.0	2	2
30 - 39	34.5	7	241.5	3	4
40-49	44.5	1	44.5	1	1
50-59	54.5	4	218.0	-	5
60-69	64.5	0	0.0	-	-
70-79	74.5	1	74.5	-	1
		$\sum f$ =20	$\sum fx$ = 744.5	7	13

There were 13 female caregivers (65%) and 7 male caregivers (35%) involved in the study. Their ages range between 19 and 73 years. The mean age of caregivers was approximately 38 years. A pictorial representation of the age distribution is given in Fig. 4.1.

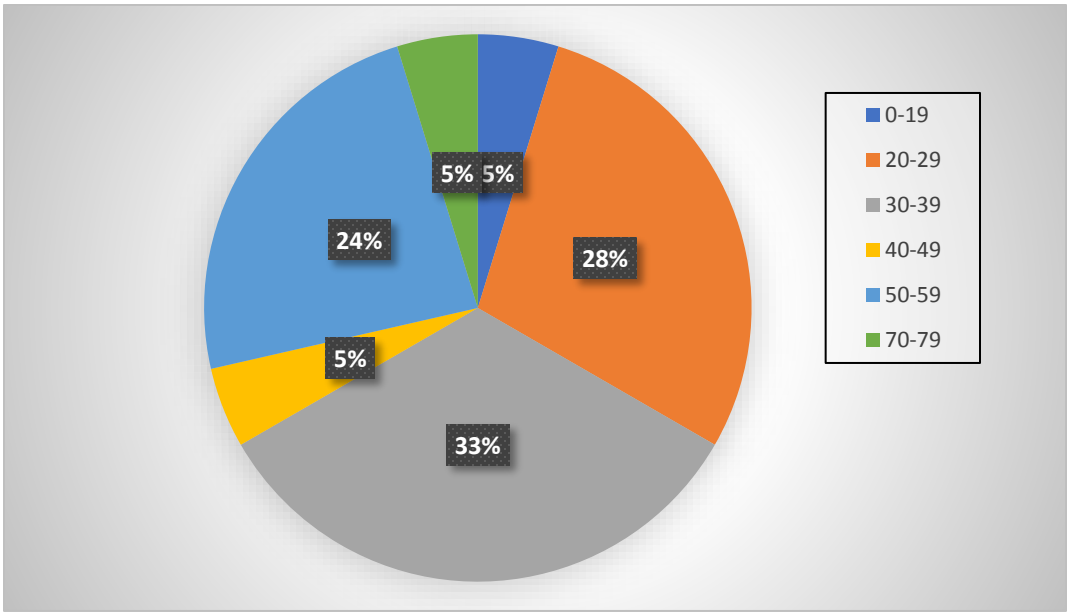

Figure 4.1: Age distribution of caregivers

The duration of the stroke incident for the victims ranged between one month and 128 months. The frequency table for the duration distribution is as follows:

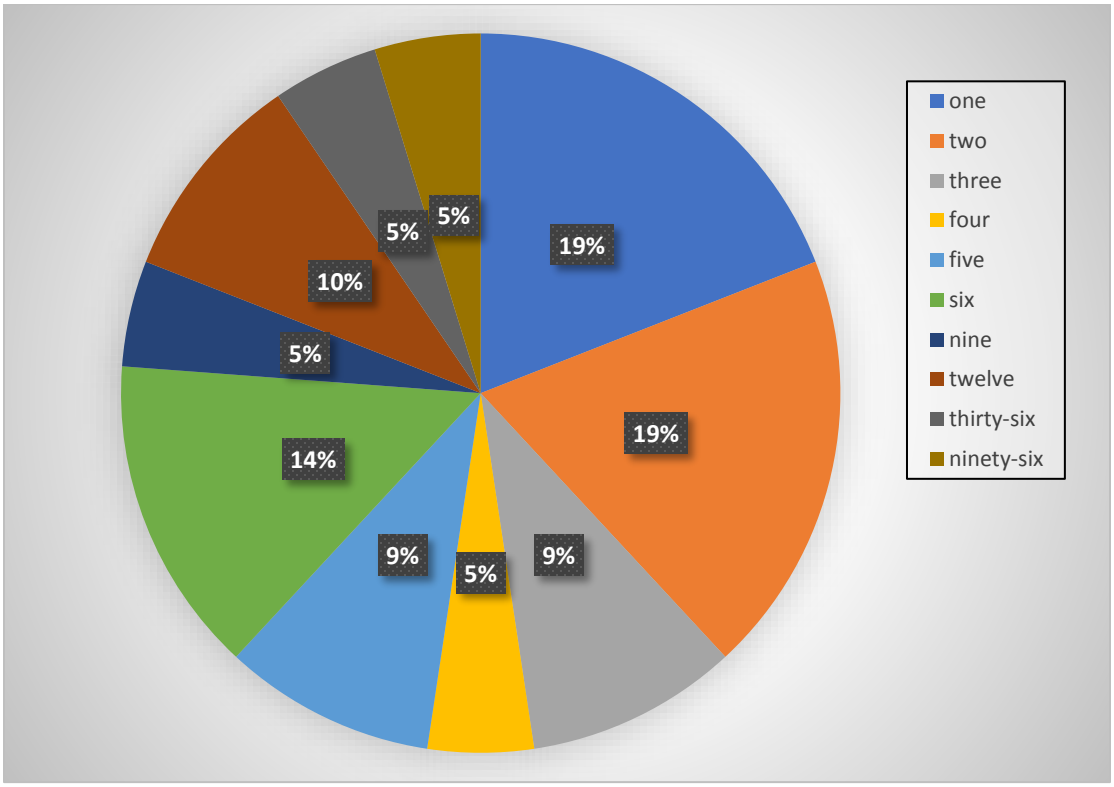

Figure 4. 2: Duration of stroke incident (in months)

4.5. FORMAL EDUCATION LEVEL OF RESPONDENTS

Respondents had formal education at the basic (2), secondary (6) and tertiary (12) level. Majority (60%) of caregivers had tertiary education. Those who had secondary and basic education were respectively 30% and 10%.

4.6. RELATIONSHIP OF CAREGIVERS TO PATIENTS

Most of the caregivers interviewed were family members of the aphasia patients. There were 19 family caregivers and 1 non-family care giver (nurse) who participated in the research. The pie chart (Fig. 4.3) represents the data above.

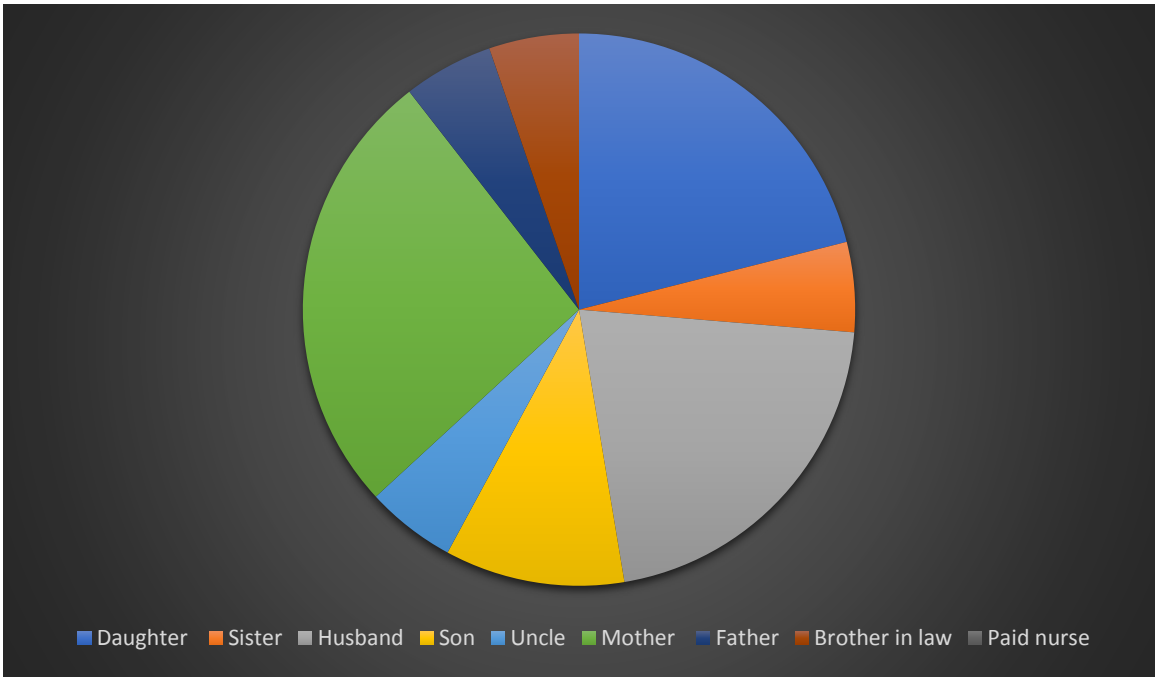

Figure 4. 3: Caregiver relationship to patient

4.7. CAREGIVER KNOWLEDGE OF APHASIA

As shown above, the Stroke Unit of KBTH was the main source of caregiver education on aphasia. However, not all caregivers who visited the unit with their clients were educated at the Stroke Unit of KBTH. The unit educated 13 caregivers among the 20 respondents. 7 out of the 20 respondents did not receive aphasia education at the Stroke Unit of KBTH. 2 respondents had not been educated on aphasia anywhere at any time, while 4 participants, including a nurse said they got to know of aphasia education during the interview. One respondent had read about aphasia education on the internet, 1 learnt about it at school and 1 participant still was educated on the disease in another hospital.

The study found that 55% got to know about aphasia only when their relatives became victims of aphasia. 5% reported that they got their knowledge of aphasia from the internet; another 5% acquired knowledge about aphasia through formal science education at school, while 10% only

got to the knowledge during the principal investigator's interview with them. One respondent, representing 5% of the sample was a nurse but had not heard of aphasia until the day of the interview. Another 5% received their aphasia education in a different hospital. These results corroborate the conclusion (Wiredu & Nyame 2001) reached that community awareness of stroke-aphasia is low even in Accra. This is worrying because Accra is the capital, comparatively where there are well-educated and highly trained individuals and communities of persons than the other areas, against the inaccessible remote communities of Ghana.

Out of the 13 respondents educated on aphasia at the Stroke Unit, 7 reported that the nurses at the unit presented the material verbally; 4 said the nurses wrote the materials for them. Respondents who reported having received written materials indicated that the nurses wrote the items themselves. The nurses had no prepared, handy materials to give to the caregivers.

4.8. CONTENT OF THE APHASIA EDUCATION GIVEN

Out of the 20 respondents, 7 reported that the content of aphasia education they received focused on how the caregiver could communicate with the patient, while 13 said the education centered on general knowledge about stroke and aphasia. Majority of caregivers (13 of 20) indicated that they were educated on causes, effects and general management of aphasia, which also included the rejection of traditional superstition associated with aphasia. For 7 out of 20, the education addressed how to develop personal skills and strategies to communicate efficiently and effectively with the patient. The most emphasized skills were non-verbal gestures (n=17) and the development of the non-verbal communication (n= 9), while written was least (n=4). Verbal communication still applied in most cases (14) as shown in Fig.4.4.

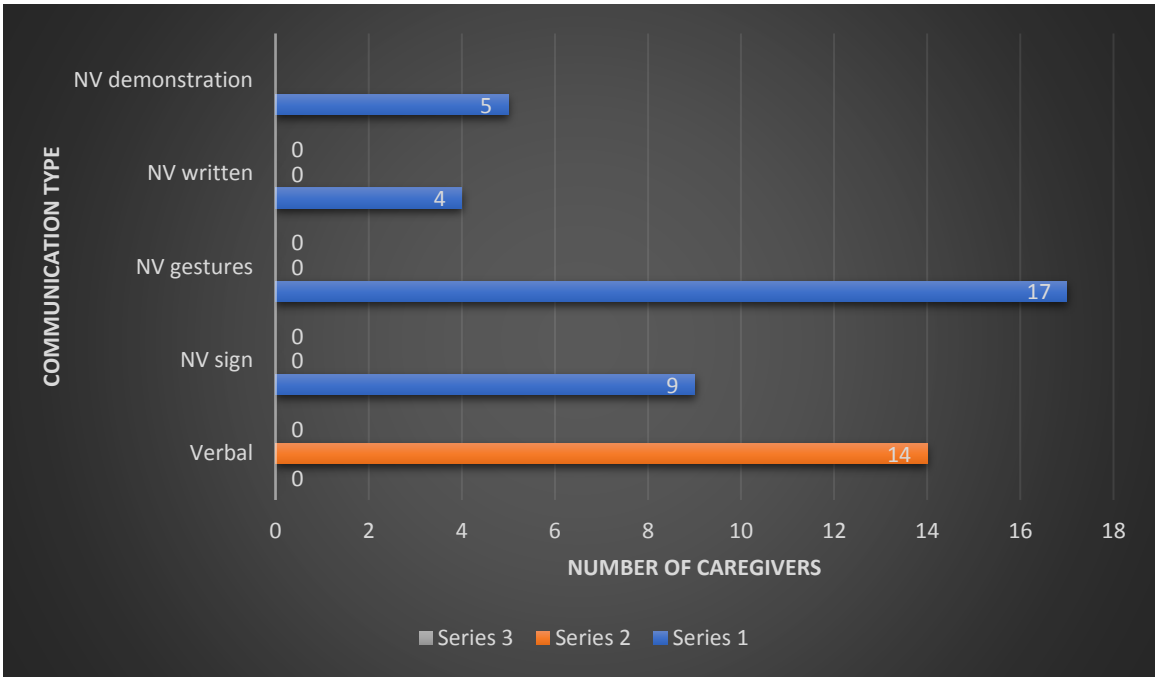

Figure 4.4: caregiver communication with aphasia patient after education

4.9. RESULTS AND BENEFITS OF APHASIA EDUCATION FOR CAREGIVERS

Respondents reported difficulty in communication between caregiver and patient. Even though 2 respondents said communication with their clients was "easy", the majority reported was that communication with aphasia patients was either quite difficult (16) or very difficult (4) despite having been taught orally at the Stroke Unit, how to communicate with persons with aphasia. Thus, the caregivers readily endorsed the suggestion for further, intensified aphasia education. The chart shown in Fig.4.5 represents caregiver opinions about the difficulty of communicating with aphasia patients.

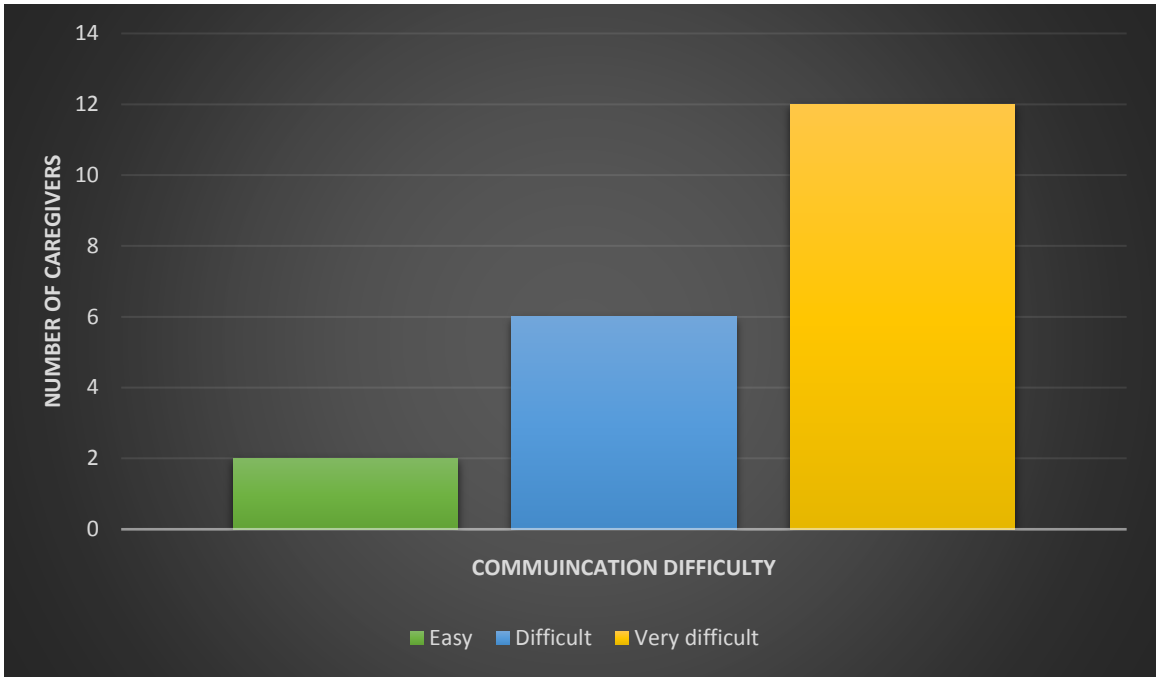

Figure 4.5: Communication difficulty with aphasia patients

Caregivers assigned various specific reasons for the need for additional aphasia education. For most (14 or 70%), additional education about aphasia for effective communication with the patient is key to understand the patient as shown in Fig.4.6.

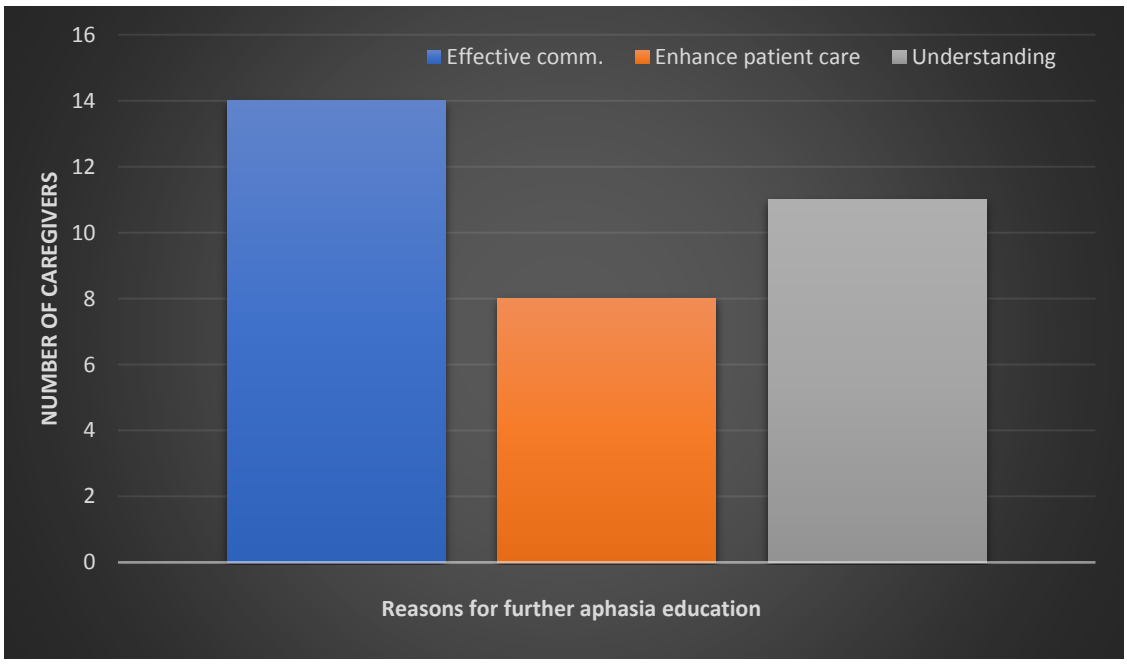

Figure 4.6: Additional aphasia education

Eleven (55%) noted that they needed more aphasia education to enhance patient care and 50% (10) said further aphasia education would enable caregivers to help the patient relearn expressive language and speak well (Fig.4.6). Those who dismissed the need for additional aphasia education said it is because there is understanding between client and caregiver. This constituted 10% of the respondents. There were overlaps as well in the reasons that caregivers assigned for requiring additional aphasia education: 10% percent of the entire sample (20) caregivers, however indicated that they were satisfied with the nature of communication that goes on between them and the patients, therefore there was no need for them to receive further aphasia education.

There were overlaps as well in the reasons that caregivers assigned for requiring additional aphasia education: 10% percent of the entire sample (20) caregivers, however indicated that they were satisfied with the nature of communication that goes on between them and the patients, therefore there was no need for them to receive further aphasia education.

4.10. THEMATIC ANALYSIS OF THE RESULTS

"Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes… data set in (rich) detail" (Braun & Clarke 2006:79). Scholars do not always agree on how thematic analyses should be done but generally, the method takes into consideration and examines patterns or themes that emerge from a given study. The importance of a theme borders on how crucial a data entry is in addressing the main research question of the study. Thematic analysis could be pragmatic, constructionist or contextual depending on the underlying theoretical assumptions of the study (Braun & Clarke, 2006).

If a pragmatic approach to thematic analyses is taken, it reports the realities, experiences and meanings of respondents; if a constructionist approach is adopted, thematic analyses studies how meanings, experiences and events are results of societal discourses; contextual thematic analyses takes a medial approach between realist and constructionist methods, and recognizes how individual members of society make sense and meaning of their own life experiences and how the social context influences the making of such meanings. By the nature of this study, a combination of pragmatic and contextual thematic analyses is adopted. Since this study investigated the impact of aphasia education on families of stroke survivors, the three main themes of stroke survivors, aphasia education and caregiver communication with persons with aphasia have been identified from the data collected.

4.8.1. Stroke Survival

From the study, an average of 54 stroke cases are presented to the Stroke Unit of KBTH each month. Out of this, an average of 4 fatal cases are recorded each month, suggesting that there are about 50 stroke survivors that are recorded each month at the Stroke Unit. Caregiver respondents of this study unanimously rejected any suggestion that evil spirits are responsible for aphasia. They probably took this position because of the good educational background that their bio-data reflected as people who benefitted from secondary and tertiary level schooling.

4.8.2. Aphasia Education

Being a specialized knowledge, aphasia education as the study showed, was not readily available to the respondents. Most of respondents got to know about aphasia at a hospital, even though there was also a case in which a respondent read about aphasia from the internet. The study found that there is no policy on aphasia education applicable to those who visit the Stroke Unit of KBTH.

Since the staff of the Stroke Unit of KBTH is under no management policy obligation to screen every stroke case for aphasia, the nurses at the unit use their discretion to judge whether a specific stroke case requires aphasia education to enhance communication or not. Moreover, the study found that following oral aphasia education given by the nurses of the Stroke Unit of KBTH, caregivers reported how they adopted various non-verbal communication methods.

4.8.3. Caregivers Communication with Persons with Aphasia

The study has shown that most caregivers have difficulty communicating with persons with aphasia. Caregivers find it frustrating that persons with aphasia struggle to communicate their needs, making it challenging for caregivers provide the required service. The difficulty in communication with persons with aphasia lessoned when caregivers began to apply the various non-verbal communication methods they were taught at the Stroke Unit or what they learnt from other sources.

4.11. CONCLUSION

This study used two different instruments to collect data: a questionnaire to gather quantitative data from the Stroke Unit and an interview guide to gather information from 20 caregivers of aphasia patients. The data collected was analyzed and presented in statistical tables and charts to enhance easy communication. Of the 20 caregivers who responded to the interview questions, 19 were family members and 1 was a paid nurse who was not related to the patient. Most of the family caregivers were close relatives such as spouses, siblings and children who were aged between 19 and 73 but the mean age was approximately 40 years.

Some respondents reported having received verbal aphasia education from nurses at the Stoke Unit of KBTH. Others had gathered some information either from the internet or from another source. Most respondents admitted that communication with the patients was either difficult or very difficult so they needed more skills through additional aphasia education to ensure effective and efficient communication with patients

CHAPTER FIVE: DISCUSSION

5.1. INTRODUCTION

Chapter Four presented the results of the study in statistical charts and figures. Chapter Five discusses these results, using the research questions and the objectives of the study as benchmarks. The Chapter discusses the nature, benefits and effectiveness of aphasia education which nurses give caregivers of persons with aphasia during patient hospitalization at the Stroke Unit. For stroke cases in which nurses at the Stroke Unit do not suspect aphasia, caregivers are not given the regular oral education the unit carries out because there is no policy to screen all stroke patients reporting to the Stroke Unit for aphasia. The WHO, ICF framework is not used and there is no predetermined aphasia education toolkit to give to caregiver just before persons with aphasia are discharged. The respondents themselves did not know that doctors in some jurisdictions are required to screen every stroke patient for aphasia.

5.2. THE NATURE OF APHASIA EDUCATION AT THE STROKE UNIT OF KBTH

This study investigated the nature, effectiveness and benefits of aphasia education given to caregivers of persons with aphasia at the Stroke Unit of KBTH. Effective education is that which leads to permanent and desirable change in behavior. The study revealed that at the Stroke Unit of KBTH nurses give verbal aphasia education to 65% of caregivers of persons with aphasia. From the study, 35% caregivers are not given aphasia education at the Stroke Unit. This happens when the nurses suspect aphasia, after observing that communication between a patient and his or her caregiver is becoming difficult. The nurses do not use any structured, standard aphasia education pack, such as the WHO-recommended ICF. Unlike what pertains in other jurisdictions, the nurses at the Stroke Unit have no special kit, including education material and fliers to give to the caregivers to help them communicate well with the patients.

Numerous stroke patients report to the Stroke Unit of KBTH every Tuesday for attention. These patients are treated and given medication. Some of them are admitted for further attention but there is no deliberate hospital policy to screen each of the stroke cases for aphasia. Aphasia screening for each reporting patients would have been helpful, since aphasia affects about one third stroke patients the world over.

5.3. BENEFITS OF APHASIA EDUCATION AT THE STROKE UNIT

The study showed that caregivers and patients, who were given aphasia education at the Stroke Unit of KBTH during the patient's hospitalization, overcame superstition about aphasia and accepted to undertake several activities to help the patient to communicate well. Caregivers learnt from the Stroke Unit that non-verbal means of communication, such as signs and gesture, demonstration and written transmission of information and the use of visual objects are effective means of communicating with persons with aphasia.

Despite this benefit, only 10% of caregivers claimed that communicating with persons with aphasia was easy; 90% said communication with persons with aphasia is either difficult or very difficult. It is for this reason that all but one respondent desired further aphasia education to enhance efficiency and ease of communication between caregivers and persons with aphasia.

5.4. EFFECTIVENESS OF APHASIA EDUCATION AT THE STROKE UNIT

The study revealed that the education given to caregivers of the Stroke Unit of KBTH is satisfactory but not completely efficient, as most caregivers called for further aphasia education to improve upon their communication with persons with aphasia. The call to additional aphasia

education further indicates the inadequacy of the education arrangement at the Stroke Unit, though respondents did not say that the education was ineffective.

To increase the effectiveness of aphasia education, intervention should target not only persons living with aphasia and their caregivers, but also communities and the entire society. This is because the study found that Ghana is experiencing stroke epidemic and since one third of stroke cases are followed by aphasia, intensifying stroke-aphasia education for both affected families and entire communities will go a long way to promote good health in the country.

5.5. APHASIA EDUCATION AND REHABILITATION

The study has shown that caregivers are mostly very well educated, meaning that most of them would be gainfully employed prior to taking up the caregiving role, even though the study further reports that 10% of caregivers were retired workers. Even though some caregivers were as young as 19 years old and others were as old as 73, the average caregiver respondent was in the prime working age of 40 years (mean age). This confirms that most of these caregivers had to abandon their jobs to care for persons with aphasia.[6]

Moreover, some had to give care for long periods. The study revealed that the duration for stroke-aphasia varied from one month to 8 years. Considering that some of the persons with aphasia had

[6] Aphasia rehabilitation requires comprehensive effort from many care providers because aphasia disrupts the lives of its victims, families and communities. Not only does aphasia leave a patient, suddenly unable to communicate, apart from the stroke effect of inability to move around, work or take care of oneself, it also leaves most victims frustrated and depressed. Since persons with aphasia are not able to work, the resulting loss of income brings drastic disruption to both the patients' lives and those of their families. Loss of income for a person with aphasia who was previously the breadwinner of the family reduces or even erodes family income at a time when more resources than before are needed to care for the person with aphasia. Insufficient family incomes in the face of these challenges make some children drop out of school and many caregivers lose their job. Caregiver job loss is because persons with aphasia rely completely on caregivers for their needs.

just been admitted to the Stroke Unit, it can be argued that their caregivers could not be sure of the duration of caregiving that would be required of them. Through education at the Stroke Unit, caregivers became aware that persons with aphasia were not under a curse or suffering from mental illness, and that the patients could fully recover. The problem, however, is how to find the extensive resources needed for holistic care for persons with aphasia.

Even families that are fortunate to have the needed resources may not be aware of what to do. For instance, the study found out that majority of caregivers (and other members of the family) got to know about aphasia only after their relative had been affected by the condition. It is the nurses who educated them on aphasia.

5.5.1. Difficulties with Communication

Most respondents reported difficulties in communicating with persons with aphasia. This is a grave challenge which is consistent with recent research findings. Difficulty in communicating with persons with aphasia is a very serious concern because it affects negatively the enthusiasm of caregivers to help persons with aphasia (Tanya et al 2012: 12). Tanya et al (2012) investigated the amount of time health care providers spend with stroke patients and found that nurses spent more time interacting with stroke patients without aphasia than with stroke-aphasia victims. Though trained to help persons with aphasia, there is a sense in which it can be argued that the nurses interacted more with stroke patients without aphasia because it is easier, compared with persons with aphasia, to get patients to speak, read, write, sign and comprehend.

5.5.2. Additional Aphasia Education

From the need expressed by the respondents of additional aphasia education, it can be argued that the education delivered at the Stroke Unit needs to be stepped up. One way of doing this is to adopt standard education toolkits that are in use in other jurisdictions (such as ICF, ASHA and IARC models) for use in Ghana. The content of such aphasia educational material obviously needs to be adapted to the Ghanaian situation. It will be appropriate to develop and include evaluation questions in the kit, to enable beneficiaries of such aphasia education to give their impressions about the effectiveness of the material to the health care providers for future improvement.

5.6. CONCLUSION

Close relatives of persons with aphasia take care of the patients when they are affected by stroke-aphasia. Unfortunately, most caregivers quit their job to take care of persons with aphasia, leading to loss of income for both persons with aphasia and the caregiver. These losses of income lead to dwindling in family resources in the face of debilitating illness, therefore rehabilitation of persons with aphasia becomes very difficult. With their shrunk income, families are unable to hire diverse health care providers, such as dieticians, nurses, doctors, clinical psychologists and SLT to give holistic care to their members affected by aphasia. The low community awareness of aphasia worsens the already bad condition, as community members who have no idea what aphasia is about, speculate based on superstition.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

This study has shown that aphasia education provided at the Stroke Unit of KBTH improves subsequent communication between persons with aphasia and caregivers at home after the patient's hospitalization. The study argues that since the nature, effectiveness and benefits of aphasia education determines the success of aphasia rehabilitation, Ghana needs an integrated, holistic and concerted effort of all relevant caregivers in both aphasia rehabilitation and community awareness education to manage prevalence and prevent spread.

6.2. CONCLUSIONS

Aphasia family caregivers do not receive any standard aphasia education package at the Stroke Unit of KBTH, even though nurses at the unit educate caregivers on how to communicate with persons with aphasia just before discharge from the hospital. Nurses give verbal education to the caregivers on how to improve communication with persons with aphasia upon discharge from the hospital. When a caregiver is taken through aphasia education at the Stroke Unit of KBTH during the patient's hospitalization, caregiver communication with persons with aphasia at home improves to facilitate aphasia patient recovery.

This research discovered that nurses the Stoke Unit of KBTH did not give aphasia education to some of the caregivers of stroke patients (see page 30). It can be explained that nurses did not give aphasia education to some of the caregivers because they did not suspect that those patients had aphasia.

Those who the nurses educated at the unit reported that the process was "verbal", that is, the nurses interacted with the caregivers using words only. Caregivers who received verbal education from the Stroke Unit before the discharge of their aphasia patients reported several nonverbal methods of communication, including gestures, pictures, signing and facial expressions as strategies for personal communication with the patients. Despite this, most respondents expressed the desire to receive more education on measures for effective communication with people with aphasia.

Since the WHO, ICF framework for aphasia education is not used at the Stroke Unit and no predetermined aphasia education toolkit is available at the Stroke Unit for distribution to caregivers, as the study has shown, it will be necessary for management to consider using the ICF approach. Besides, the Stroke Unit does not keep specific records of stroke attacks that are followed by aphasia. Making it a policy to keep such records will help enhance aphasia treatment. Nor are community awareness programs organized to widen the scope of public knowledge about aphasia and what to do when it affects them or their relatives. Community programs could be employed to create public awareness. This corroborates the research findings of Donkor et al (2014).

Moreover, from the study, there is no evidence that stroke caregiving, as planned and executed from the Stroke Unit of KBTH, adopts an integrated approach involving many professionals. A few professions—Doctors, nurses and physiotherapists are mostly involved, leaving a discrepancy for other health care professionals, such as clinical psychologists, social workers, dieticians and especially, SLTs. Current best practice in aphasia rehabilitation around the world involves many

professionals, including SLTs (Cook, 2017). The Stroke Unit could consider intensifying its intervention programs to include the involvement other professionals which are yet not involved.

Most caregivers, especially females have benefited from formal education to the tertiary level and most of them were females. This means that expanding aphasia education programs will quick and successful if the background of caregivers is anything to go by.

6.3. RECOMMENDATIONS

Based on the main objective of this study to find out the nature, benefits and effectiveness of aphasia education given at the Stroke Unit of KBTH to caregivers of persons with aphasia, the following recommendations, measured against the major findings of the study are made:

1. Each case of stroke reported at the Stroke Unit of KBTH should be screened for aphasia.
2. Education at the Stroke Unit should be structured and standardized, if possible using the WHO, ICF recommendation.
3. Authorities of the Ghana Health Service (GHS) should consider preparing aphasia education toolkits for caregivers to take along to their homes, besides the verbal education given at the Stroke Unit.
4. Aphasia education should also target communities because Ghana is experiencing a stroke epidemic while stroke-aphasia awareness among citizens remains minimal.
5. Deliberate efforts should be made to integrate other health professionals, such as SLTs, dieticians, clinical psychologists and physiotherapists in the treatment and management of stroke-aphasia to ensure efficiency and effectiveness of the rehabilitations.
6. Since aphasia rehabilitation requires a lot of resources, taking preventive measures is the best approach to the problem, but since awareness levels are currently low and the disease

common, government should strengthen the NHIS and extend its benefits to complete rehabilitation for aphasia victims, to help reduce the financial burden families of persons with aphasia carry. This intervention should not be decoupled with an aggressive community awareness and preventive aphasia education program for Ghana.

7. The logic of the previous recommendation leads to the next. Since aphasia education needs to be multifaceted to be effective and efficient, it should be accurate, simple, available, obtainable and appropriate (IARC, 2012). Aphasia education should be appropriate in terms of its content, media, format and timing (IARC).

6.4. LIMITATIONS

The purpose of this research is to explain the aphasia education phenomena and to prescribe solutions to the problem investigated. Having established a positive benefit of aphasia education for communication between caregivers and persons with aphasia, it would be desirable to generalize the results to the entire population. In doing this, limitations exist. The fact that some of the stroke cases reported at the unit are not screened for aphasia is one of the limitations of this study. This means that, some of the stroke cases which could have an equal chance of being chosen for the sample were missed. Besides, the study investigated 20 aphasia cases only, even though there were 47 cases which the Stroke Unit had diagnosed out of 173[7] stroke cases reported from February to April 2018. The study needed to be completed on time for submission to the - University of Ghana therefore, a manageable sample size for the limited period was chosen. However, both the population and sample in the current study were scientifically chosen, making the result considerably reliable.

[7] There were 54, 54 and 66 stroke cases reported at the Stroke Unit in February, March and April 2018 respectively. Out of these, the authorities at the unit labelled 13 as "fatal", by which they meant the chances of survival of those 13 cases were slim.

REFERENCES

Agyeman, C, et al (2012). Stroke in Ashanti region of Ghana. *Ghana medical journal*, 46 (2): 12–17.

Aleligay, A., Worrall, L., & Rose, T. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*, *22*(4), 383-407.

American speech-language and hearing association. *Aphasia Guide* (1997-2007).

American Speech-Language-Hearing Association (2007). *Aphasia guide*. Stroke of hope club, Inc. www.strokeofhope.com

Brady, M.C., Kelly, H., Godwin, J., & Enderby, P. (2012). Speech and language therapy for aphasia following stroke. *Cochrane database of systematic reviews. Issue 5*

Brookshire, R. H. (2007). *Introduction to neurogenic communication disorders* (7th ed). St Louis, Missouri: Mosby Elsevier.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. Doi.org/10.1191/1478088706qp063oa

Cameron, V. (2013). *Best practices for stroke patient and family education in the acute care setting, a literature review*. MEDSURG nursing, 22(1): 51-55.

Cawood, J. & Visagie, S. (2015). Environmental factors influencing participation of stroke survivors in a Western Cape setting. *African journal of disability*, 4(1): 198-9 http://dx.doi. org/10.4102/ajod.v4i1.198.

Cook PJ. 2017. *Participatory Outcomes, Quality of Life and barriers faced by Stroke Survivors in the Rural Eastern Free State.* Unpublished MSC dissertation: University of Stellenbosch.

Copi, I. M and Cohen, C (2009). Introduction to Logic. Custom edition. New Jersey: Pearson Education, Inc.

Donkor, E. S., et al (2014). Community awareness of strike in Accra, Ghana. *BMC public health, 14:196.* http://www.biomedcentral.com/1471-2458/14/196

Evans, R. L., Anne-Leith, M. D., Bishop, S., Susan, S., & Pederson, C. (1988). Family intervention after stroke: does counseling or education help? *Stroke,* 19(10): 1243-1249. doi: 10.1161/01.STR.19.10.1243

Fifteen international aphasia rehabilitation conference of Australia, October 2012. University of Queensland.

Kagan, A, Simmons- Mackie, Alexandra R. N, Huijbregts, M, Shumway, E, McEwen, S, Threats, T, & Sharp, S. (2008) Counting what counts: A framework for capturing real- life outcomes of aphasia intervention, *Aphasiology*, 22:3, 258-280, doi: 10.1080/02687030701282595

Marissa M., Kristen, F. Linton, Megan A. Vento, S. B., & Kazuma, N. (2015). Investigation of stroke needs (INVISION) study stroke awareness and education. *Hawaii journal of medicine and public health,* 74(4): 141-145.

McIntosch, C (2013). Ed. *Cambridge Advanced Learner's Dictionary*. Fourth Edition. Cambridge: Cambridge University Press.

National Aphasia Association (2016). *National Aphasia Awareness Survey.* Aphasia.org.

Navarro, J. C, Alejandro, L., Baroquell, C., & Lokin, J. K. (2013). Stroke education in the Philippines, Manila. *International journal of stroke,* 8: 114-115. Doi-10.1111/ijs. 1205.

Papathanasiou, I., Coppers, P., & Davidson, B. (2017). Aphasia and related neurogenic communication disorders: basic concepts, management, and efficacy. In I. Papathanasiou, & P. Coppers (2017). *Aphasia and related neurogenic communication disorders.* Burlington: Jones & Bartlett, 3-61.

Report of the 15th International Aphasia Rehabilitation Conference. (2012). University of Queensland, Australia

Ron, L. E., Anne-Leith, M., Duanne, S. B., Stranahan, S., & Pederson, C. (1988). *Family intervention after stroke: Does counseling or education help?* Dallas: American heart association (AHA). 1243-1249 Doi: 10.1161/01. Str. 19.10.1243

Salter, K, Jutai, J, Foley, N, Hellings, C and Teasell R. (2006). Identification of poststroke aphasia: A review of screening assessment tools.

Sampane-Donkor, E. (2014). *A Study of Stroke in Southern Ghana: Epidemiology, Quality of Life and Community Perceptions*. Unpublished Phd Thesis: University of Iceland.

Sampene-Donkor, E. S., et al (2014). Community awareness of strike in Accra, Ghana. *BMC Public Health, 14:196.* http://www.biomedcentral.com/1471-2458/14/196

Scottish Intercollegiate Guidelines Network (SIGN). (2011). *Rehabilitation after stroke. A booklet for patients and their carers and families.*

Suleman, S and Hopper, T (2014). "*Mixed Methods Research and its Use in Speech-Language Pathology and Audiology Research", Canadian Journal of Speech-Language Pathology and Audiology,* Vol. 38, No. 4, Winter, 386-389

Tanya A. R, Worrall, L. E, Hickson L. M, & Hoffmann, T. C (2012). Guiding principles for printed education materials: Design preferences of people with aphasia, *International Journal of Speech-Language Pathology,* 14:1, 11-23, doi: 10.3109/17549507.2011.631583

Walliman N (2011). *Research Methods: the basics*. Abingdon & New York: Routledge.

Worrall, R. T. A, McKenna, L. E, Hickson, K. T, & Hoffmann, T.C. (2009). Do people with aphasia receive written stroke and aphasia information? *Aphasiology, 23*(3), 364-392

World health organisation (2001). *International classification of functional and health disability.*

Wiredu, E. K. & Nyame, P. K. (2001). Stroke-related mortality at Korle Bu teaching hospital, Accra, Ghana. *East African medical journal*. DOI: 10.4314/eamj.v78i4.9059

McAllister, Wylie, Davidson and Marshall (2013). The world report on disability: an impetus to reconceptualise services for people with communication disability. *International journal of speech and language*, Pathol, 15 (1):118-126. DOI: 10.3109/17549507.2012.757804.

APPENDICES

APPENDIX 1

PARTICIPANT INFORMATION SHEET

I **Gladys Akosua Agbeko**, a graduate student of the University of Ghana, Legon write to obtain your consent to participate in a research study. Participation in the study is entirely voluntary, so you may choose to participate or not.

My interest in the research is to find out the impact of aphasia education on families of stroke survivors. I will ask you a few questions in an interview. This will last for 15 minutes. All the information will be kept anonymous and confidential. This means that your name will not appear anywhere and no one, except me, will know about your specific answers. I will assign a number to your responses and only I will have the key to indicate which number belongs to each participant.

The benefits of this research are that you will be helping me to understand or find out if nurses at the stroke unit at KBTH give caregivers of aphasiacs education, and if so what impact the education makes on the families of aphasia patients. Your responses will also help me to know how the education is delivered.

If you do not wish to continue with the interview, you have the right to withdraw from the study at any time or stage without any penalty or negative implication on you.

The study has received clearance from the University of Ghana, and KBTH.

This form is for you to keep. If you have any questions about the research, please contact 0201747530

APPENDIX 2

STROKE UNIT DATA COLLECTION QUESTIONNAIRE

1. **Questionnaire for data collection at the stroke unit, KBTH**
2. How many patients reported to the Stroke Unit from February-April 2018?
3. How many of the reported stroke cases were followed by aphasia?
4. How many reported cases in the period were fatal?
5. Were all the principal caregivers of the stroke-aphasia patients reporting to the unit over the period, members of the patients' family?
6. If no, how many of them were family members?
7. How were the family caregivers related to the patients?

APPENDIX 3

INTERVIEW GUIDE FOR FAMILY CAREGIVERS

Interview guide for data collection from family caregivers of stroke-aphasia patients

1. When did your relative experience a stroke attack?
2. Was your relative able to communicate well with you after the stroke? Did you have difficulty understanding him/her?
3. If yes, did you report the situation to the hospital staff? [If no, the interview ends here, thanks].
4. If yes, what help did the nurses at the Stroke Unit of the hospital give you?
5. Have you been able to apply the information you received at the hospital to improve upon your communication with your relative?
6. In what ways has the assistance given you been helpful to you?
7. Did the help include education on how to communicate with the patient?
8. If yes, how was this education delivered to you?

APPENDIX 4

INFORMED CONSENT FORM

I ……give my consent to be a part of

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, Accra, Ghana

this research project titled **THE IMPACT OF APHASIA EDUCATION ON FAMILIES OF STROKE SURVIVORS. A CASE STUDY OF KORLE BU TEACHING HOSPITAL.**

I confirm that;

1. I have read and understood the information about the project, as provided in the Information Sheet dated.
2. I have been given the opportunity to ask questions about the project and my participation
3. I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.
4. The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymity of data, etc.) to me.
5. The use of the data in research, publications, sharing and archiving has been explained to me.
6. I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have specified in this form.
7. I, along with the Researcher, agree to sign and date this informed consent form.

_____	_____	_____
Name of Participant	Signature	Date

Researcher:

_____	_____	_____
Name of Researcher	Signature	Date