Explanatory Models of Stroke in Ghana: Perspectives of Stroke Survivors and their Caregivers

Olutobi Adekunle Sanuade[a], Francis Nii-Amoo Dodoo[b], Kwadwo Koram[c], Ama de-Graft Aikins[b]

[a]Institute of Advanced Studies, University College London, London, United Kingdom
[b]Regional Institute for Population Studies, University of Ghana, Accra, Ghana
[c]The Noguchi Memorial Institute for Medical Research, University of Ghana, Accra, Ghana

Olutobi Adekunle Sanuade (OAS)- o.sanuade@ucl.ac.uk.

Francis Nii-Amoo Dodoo (FND)- fdodoo@psu.edu.

Kwadwo Koram (KK)- kkoram@noguchi.ug.edu.gh.

Ama de-Graft Aikins (AdGA)- adaikins@ug.edu.gh.

Corresponding Author: AdGA
Email: adaikins@ug.edu.gh

Abstract

Objective: This study examines explanatory models of stroke and its complications among people living with stroke, and their caregivers, in two urban poor communities in Accra (Ga Mashie) and Korle Bu Teaching Hospital, Accra.

Methods: Twenty-two stroke survivors and twenty-nine caregivers were recruited from two urban poor communities in Accra and Korle Bu Teaching Hospital (KBTH). Qualitative data were obtained using semi-structured interviews that lasted between 45 minutes and 2 hours. The interviews were audiotaped, transcribed and analysed thematically, informed by the concept of explanatory models of illness.

Results: Participants referred to stroke as a sudden event and they expressed different emotional responses after the stroke onset. Stroke survivors and their caregivers attributed stroke with poor lifestyle practices, high blood pressure, unhealthy diet and dietary practices, supernatural causes, stress, family history, other chronic diseases, and delay in treatment of symptoms. While the stroke survivors associated stroke complications with physical disability and stigmatization, the caregivers associated these with physical disability, behavioural and psychological changes, cognitive disability and death. These associations were mostly influenced by the biomedical model of stroke.

Conclusion: The biomedical model of stroke is important for developing interventions that will be accepted by the stroke survivors and the caregivers. Nevertheless, sociocultural explanations of stroke need to be taken into consideration during delivery of medical information to the participants. This study proposes an integrated biopsychosociocultural approach for stroke intervention among the study participants.

Keywords: Explanatory models, stroke survivors, caregivers, Ghana

Background

Stroke is a significant contributing factor to morbidity and mortality globally (Feigin et al., 2016; Murray et al., 2012). Stroke prevalence is higher in Africa compared to those reported in high income countries and some other low- and middle income countries (LMICs) (Kaul et al., 2009; Awuah et al., 2016). In Ghana, stroke is the second leading cause of death and it represents 8.7% of the proportion of deaths in the country (WHO, 2015). Further, stroke is the leading cause of premature death among the non-communicable diseases between 1990 and 2010 and also a frequent cause of admission to hospitals in Ghana (Sanuade and Agyemang, 2013).

Research has shown that the established risk factors of stroke include high blood pressure, high Body Mass Index (BMI), unhealthy diet and dietary practices, poor lifestyle practices (such as smoking and second-hand smoke, low physical activity, alcohol use), stress, high fasting plasma glucose (diabetes), high total cholesterol, atrial fibrillation, family history, environmental factors (ambient particulate matter pollution, household air pollution from solid fuels, lead exposure) (Truelson, Begg and Mathers, 2000; Feigin et al.,2016). Also, some of the major complications of stroke include recurrent stroke, physical disability (Pains, dysphagia, incontinence), cognitive disability (brain edema), behavioural and psychological changes (depression, anxiety, emotionalism, confusion) (Langhorne et al., 2000; Kumar et al., 2010; American Heart Association, 2015).

Although there are established causes (risk factors) and complications of stroke, research often does not focus on lay explanations of stroke causal theories and complications, and how these converge with and diverge from biomedical models. This is important because differences between medical and lay explanations may undermine biomedical treatment and other interventions on stroke. Previous community studies in Africa, Europe and South America showed low knowledge of stroke among lay individuals with the consequences

being delay in treatment and poor prognosis (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008; Gomes et al., 2017; Kelly-Irving et al., 2010; Pontes-Neto et al., 2008; Yoon et al., 2001).The findings from these studies indicate that while the medical profession perceives stroke to be a biological condition, lay individuals draw on medical, socio-cultural, spiritual and psychological explanations in constructing knowledge about stroke. To date, only a few studies in Ghana have provided information on lay knowledge of stroke. The first study which explored lay knowledge of stroke focused mainly on lay individuals but not illness sufferers (Sampane-Donkor et al., 2014). A study by Okyerefo and Fiaveh (2017) which focused on general illness beliefs provided preliminary insights on stroke beliefs. Another study which explored lay representations of chronic diseases, provided information on lay perspectives on diabetes, hypertension, cancer, epilepsy, sickle-cell, heart disease, asthma, and HIV/AIDS, but not stroke (de-Graft Aikins et al., 2012). There is currently no information on how stroke survivors and their caregivers make sense of this condition in terms of the onset of the illness, its perceived causes, and complications. This study examines explanatory models of stroke and its complications among people living with stroke, and their caregivers, in two urban poor communities in Accra (Ga Mashie) and Korle Bu Teaching Hospital, Accra.

Conceptual framework

The concept of explanatory models (EMs) of illness developed by Kleinman (1980) guided this study. An explanatory model reveals how people make sense of their illness. Kleinman argues that individuals' explanations of illness are shaped by how they perceive, experience and cope with their illness (Kleinman, 1980). Kleinman (1980) provided eight (8) elements of an explanatory model: the definition of the illness, its perceived causes, symptoms, duration, severity, expected consequences, appropriate treatment and anticipated outcomes (Kleiman, 1980).

Explanatory models facilitate effective health communication between patients, their caregivers, and health professionals because they determine patients' adherence, satisfaction and appropriate use of health facilities (Kleinman, 1978). Kleinman (1980) revealed that the EMs of an illness often differ between sufferers and caregivers and in such situations, treatments are sought based on whoever has more dominance. For instance, Sanuade (2016) shows that the illness actions of stroke survivors were mostly influenced by the caregivers; this was because many of the stroke survivors were too incapacitated (cognitively and physically) to make decisions on their treatment option.

In addition, Kleinman shows that patients and health professionals have different sets of EMs (Kleinman, 1980: page 106). Research has shown that people living with a particular illness and their families do not often volunteer their EMs to the health professionals; even when they do, "they report them as abridged explanations because of fear of being ridiculed or criticised by the health professionals" (Kleinman, 1980).

For instance, previous research on stroke in Ghana showed that many of the stroke survivors seeking treatment from the largest tertiary hospital in the country used both biomedical treatment and herbal treatment in managing their stroke; however, they did not disclose this to the health professionals due to fear of rebuke (Sanuade, 2016). Similar results have been published regarding hypertension and diabetes communicative practices in Ghana (Kretchy et al., 2014; de-Graft Aikins, et al., 2014). Understanding the EMs of stroke from the perspectives of the stroke survivors and their caregivers can enhance tolerance by the health professionals and this can create an atmosphere where stroke sufferers can freely discuss their treatment options with health professionals.

In sub-Saharan Africa, a few studies in Tanzania and South Africa have used the concept of EMs of stroke, and the distinct elements examined by these studies include the causal

theories of stroke and health seeking behaviour (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008). With respect to the causal theories of stroke, these studies showed that people attribute the causes of stroke to: hypertension (Mshana et al., 2007; Mshana, 2008); stress (due to physical demand of work) (Hundt et al. 2005; Mshana et al., 2007; Mshana, 2008); lack of sleep (Hundt et al., 2004); family history (Mshana et al., 2007); spiritual disruption (witchcraft, demons, evil spirits, angry ancestors, curses) (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008), predestination (God's will) (Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008); psychological disruption (unhappiness, worry, frequent thinking) (Hundt et al., 2004); social conflicts (jealousy of property and during work promotion) (Mshana, 2008), and; imbalance between hot and cold in the body (Bham and Ross, 2005). These studies showed that there are rural-urban differences as well as variations among different social actors (lay individuals, stroke survivors, caregivers, health professionals, religious leaders and traditional healers), regarding causal theories of stroke. These studies however have some limitations. First, all the studies did not distinguish between the EMs of stroke survivors and that of the caregivers. Also, with the illness onset element of EMs, Kleinman (1980) only focused on how illness starts and ignored the emotional responses of the sufferer. Within the fields of sociology and social psychology of health and illness, emotions are integral to the meaning making process and, by extension, patient-centred interventions (Crossley, 2000; Wetherall, 2012). Therefore we included an examination of emotional responses to stroke within our EM framework.

In Ghana, the concept of EMs has been used to explore how people living with type 2 diabetes in urban poor communities 'make sense of' and respond to their illness (de-Graft Aikins et al., 2014). de-Graft Aikins et al. (2014) showed that people living with diabetes associated diabetes and its complications with diet, family history, lifestyle factors (smoking, excessive alcohol consumption and physical inactivity), psychological stress and supernatural

factors (witchcraft and sorcery). The study further showed that the participants drew on biomedical and cultural models, as well as their subjective experiences, to describe diabetes complications. No stroke study in Ghana has used the EMs framework. For this study, the concept of EMs was used in three ways: 1) to describe the onset of stroke and the emotional responses after the stroke onset; 2) to explore the pre-diagnosis awareness and causal theories of stroke, and; 3) to describe the causal theories of stroke complications, from the perspectives of the stroke survivors and their caregivers.

Methods

Study design and setting

Qualitative interviews were conducted with 22 stroke survivors and 29 caregivers, recruited from two urban poor communities in Accra (Ga Mashie)and two Units from the Korle Bu Teaching Hospital, Accra (Stroke Unit and Physiotherapy Unit) (Table 1). Some of the participants recruited from the Physiotherapy Unit were interviewed in different residential areas in Accra. A total of 11 dyads (i.e. stroke survivors and their corresponding caregivers) were part of the sample; 11 stroke survivors and 18 caregivers were interviewed alone. The initial sampling plan was to select 10 stroke survivors and 10 caregivers at each of the three study sites, with the assumption that meaning saturation may be reached with this number. Based on this design, we were hoping to interview 30 stroke survivors and 30 caregivers. However, we arrived at the current sample size (22 stroke survivors and 29 caregivers) due to meaning saturation.

Ga Mashie is located in Ghana's capital, Accra and characterised by low income, low level of education, lack of access to improved sanitary facilities, low access to healthcare services and double burden of communicable and non-communicable diseases (de-Graft Aikins et al., 2014). Korle-Bu Teaching Hospital, also located in Accra, is the largest tertiary hospital in Ghana. Participants were recruited from a hospital facility because it was expected that the

experiences of stroke survivors and caregivers from the hospital would be different from those in the communities. In addition, it was expected that those at the Stroke unit would probably have more serious complications compared to those at the Physiotherapy Unit because many of the stroke cases at the Stroke Unit are acute in nature.

The research participants

Due to the nature of the study population, purposive and snow-ball sampling strategies were adopted in recruiting the participants. Respondents were included in the study once they gave their informed consent. The process involved reading the general information about the study and potential benefits/risk (in the consent form) to people with stroke (and their caregivers). The consent form also outlined the rights of participants including confidentiality and the right to withdraw from the study or from answering a question. Participants gave their verbal consent before starting the interviews and this was tape-recorded. Stroke survivors with speech impairments and cognitive dysfunctions were excluded from the study. Ethical approval was provided by the Ethics Committee for the Humanities (ECH), University of Ghana.

Data collection

The fieldwork was carried out between March 2014 and December 2015. Two interview guides were developed for the stroke survivors and their family caregivers. The interview guide for the stroke survivors and that of their family caregivers covered 4 broad sections (Table 2).

The first author and three research assistants were involved in the data collection. Each of the research assistants helped at each of the three sites (Ga Mashie, Physiotherapy Unit and Stroke Unit). The one who assisted in Ga Mashie was fluent in English and four (4) local languages (Ga, Twi, Ewe and Hausa). The second and third research assistants who worked

during the data collection at Physiotherapy Unit and Stroke Unit respectively were fluent in English, Twi and Ga. All the research assistants received training on the interview guides so that they could get familiar with the questions. All the interviews in Ga Mashie, except one, were conducted in Ga, the native and predominant language of the community. The last interview was conducted in Twi because the stroke survivor was Akan. About half of the interviews at the Physiotherapy Unit and Stroke Unit were conducted in local languages (Twi and Ga) and the rest were conducted in English language. The interviews lasted between 45 minutes and 2 hours. Table 3 presents the summary profile of the participants.

Data analysis

The interviews were transcribed into English by a team of transcribers with Ga, Twi and English language competence. The data were analysed using thematic approach (Attride-Stirling, 2001), with the aid of ATLAS. Ti developed by ATLAS.ti Scientific Software Development GmbH, Berlin, Germany. The analysis was guided by a coding frame which included a mix of deductive and inductive codes.

The coding process started with identification of the deductive codes. The deductive codes were derived from previous qualitative studies in sub-Saharan Africa (SSA) which highlighted the EMs of stroke (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008), and a survey on stroke awareness in Ghana (Sampane-Donkor et al., 2014). The deductive coding stage was followed by identification of inductive codes. The inductive codes included new themes which emerged outside the existing literature as well as those within existing literature. The entire coding process was informed by attention to consensus, conflict and absence in the participants' narratives (de-Graft Aikins, 2005).

At the second stage of the analysis, we focused on interpretive analysis of the data by developing a linkage between codes, themes, and appropriate participant quotes, existing

empirical data and conceptual framework. First, we identified the lay causal theories of stroke. Second, we compared the lay causal theories with that of established biomedical theories of stroke and stroke complications listed in Table 4.

For instance, the deductive and inductive coding for the stroke survivors yielded eleven (11) causal theories of stroke. In order of dominance, these causal theories were: poor lifestyle practices, high blood pressure, unhealthy diet and dietary practices, supernatural causes, stress, heredity, psychological disruption, other chronic diseases, contagiosity, predestination (fate) and delay in treatment of symptoms. Coding for caregivers (in order of dominance) yielded nine (9) causal theories and these included: poor lifestyle practices, high blood pressure, non-adherence to biomedical care, stress, supernatural causes, delay in treatment of symptoms, unhealthy diet and dietary practices, other chronic diseases and heredity (Figure 1). At the interpretive stage, the contents of each biomedical-aligned theme were examined to identify the extent to which lay explanatory models were similar or diverged from established biomedical models (Tables 5 and 6).

Results

The results are presented in three sections: (1) themes generated on illness onset and emotional responses after the stroke onset; (2) pre-diagnosis awareness and causal theories of stroke, and; (3) themes generated on causal theories of stroke complications. The results are presented in order of dominating themes.

Illness onset and immediate reactions after diagnosis

When the stroke survivors were asked to narrate how their illness started, their narratives centered on the sudden nature of stroke.

> *I went to the market and came back. I went to prepare 'klakla akala'… I finished preparing it and I went to call my friends to come and eat with me. When I got to the veranda, I got struck by the sickness and fell to the ground and they came to lift me up* ***(Female, 46 years)***

I am a pastor. I pastor in the church before the sickness came. One day as I just came back from my work and I decided to have a little rest at home. It was in the evening like this around 6 or 7 so when I woke up from sleep, I saw that my body has changed and I could not understand. That time my wife was lying by my side. She was very surprised, to see me that way. She said what is the problem and I told her I don't know what was happening to me, my body was twisting ***(Male, 52 years)***

With regard to the immediate reactions after the illness onset, the emotional responses of the stroke survivors from the three study sites were similar. The emotional responses included: worry ('*naagba'*), sadness ('*aweleho*'), crying/weeping ('*yaafo*'), fear ('*gbeye*'), shock ('*tsui famↃ*), and dismay ('*naakpe'*). For stroke survivors who experienced worry, their worries centered on what to eat and how they would take care of their families. Some of them felt sad because they knew they could not do the things they used to do any longer. In addition, many of those from the hospital facility mentioned that they were shocked about the diagnosis because they did not expect someone of their (young) age to have stroke.

When I was taken to Korle Bu, the doctor told me that I had stroke. I was wondering how I would work to take care of my children, I was very sad, I cried so much; but when my church members came to visit me, they encouraged me and told me not to cry, and that God is on my side ***(Female, 57 years)***

I didn't know it as stroke; I thought it was some sickness that has befallen me. It wasn't until I went to the consulting room and the doctor told me it was a stroke. I was sad, so I started weeping and the doctor asked me why I was crying. I asked him whether I would ever get the strength to get up again. Because that day, I had to be supported before I could even get up. He told me if God should intervene, everything would be fine ***(male, 44 years)***

…I felt that I was going to die because this illness, I have never experienced it. Some people say it has no cure and that any person that this illness is going to die. I think that was what I had in mind but I know that God can do all things and God has saved me from that time till today. I know that I cannot die again ***(male, 52 years)***

…when I was told that I had stroke, I was not sad because I knew that God would heal me ***(female, 48 years)***

The emotional responses of the caregivers included: sadness, worries, fear, and devastation. Three categories of emotional responses emerged from their narratives. Firstly, for some of

the caregivers, the emotional responses were as a result of the sudden nature of stroke. For others, they expressed those emotions because they were aware of the numerous disabilities associated with stroke.

> *Honestly I was really sad, because someone with whom we were living normally, he just complained of malaria and went to buy the drugs himself then all of a sudden getting stroke, it was really disturbing* ***(female, 41 years)***

> *Well, initially because I haven't experienced it, I only heard of it and I didn't know what it is. I was a bit afraid that my wife is going to be bed ridden. It was a bit difficult for me and more importantly for people around who used to see her as someone who was strong and going about her business…all that they see now is that she is in her wheelchair and all that. It was something difficult for me to bear* ***(male, 47 years)***

In addition, some of the caregivers expressed different emotions because they felt their care recipients were too young to be diagnosed with stroke. One caregiver from Ga Mashie particularly mentioned that she cried because her care recipient still had little children to take care of. Some of the female caregivers were worried because with the household head being diagnosed with stroke meant a disruption in the families' livelihood.

> *It disturbed me that he had stroke, because he is not old, and his children are still very small. When the doctor broke the news that day, honestly, I cried because his children are very small* ***(female, 41 years)***

> *I was worried. I was worried because a man who was heading the house, now look at him. So I told myself that the Lord is my strength* ***(female, 42 years)***

> *I was so devastated, everything…everything was…, I don't know the words to use* ***(female, 30 years)***

Pre-diagnosis awareness of stroke

This focused on participants' awareness of stroke before their diagnosis. Five stroke survivors, mostly from the hospital facility, had pre-diagnosis awareness of stroke. However, many of the stroke survivors from Ga Mashie did not have pre-diagnosis awareness of stroke.

While some of the participants who had pre-diagnosis awareness of stroke knew the causes of stroke, some did not and others had misconceptions about stroke. For instance, one stroke survivor recruited from the hospital facility mentioned that even though he had prior awareness of stroke, he did not know it could happen to someone younger than 50 years old.

> *I have heard about it, but I didn't expect it to happen to someone of my age. I expected it to happen to old men and women. I am not even 50 years old* ***(male, 44 years)***

> ***Interviewer:*** *when you went to the hospital and the doctor told you that you had stroke, what did you do?*
>
> ***Respondent:*** *I started crying*
>
> ***Interviewer:*** *before then, have you heard of stroke?*
>
> ***Respondent:*** *NO, NO, NO. I didn't even know that there was any illness like that* ***(female, 46 years)***

On the other hand, many of the caregivers mentioned that they had pre-diagnosis awareness of stroke before their care recipients were diagnosed with the illness. Out of the six caregivers who did not have pre-diagnosis awareness of stroke, four were from Ga Mashie. Among those who had pre-diagnosis awareness of stroke, some had comprehensive knowledge of stroke (that is, knowledge on causes, complications and preventions) while others did not until it happened to their care recipients.

> *Uhhh…. Yeah I know a little bit about stroke and because I am a nurse, I know* ***(elderly male)***
>
> *I… have a limited knowledge but I didn't know so much about it until it happened to my wife* ***(female, 53 years)***

Causal theories of stroke: Stroke survivors

Stroke survivors attributed stroke to 11 causes: poor lifestyle practices, high blood pressure, unhealthy diet and dietary practices, supernatural causes, stress, heredity, psychological disruption, other chronic diseases, contagiosity, predestination (fate), and delay in treatment

of symptoms. We present a comparison of biomedical and lay theories of causes of stroke and stroke complications in Tables 3 and 4.

Poor lifestyle practices

Poor lifestyle practices were the dominant causal theory of stroke mentioned and discussed by 13 participants. Participants identified lifestyle practices such as smoking, alcohol consumption, being physically inactive and 'womanizing' as causes of stroke.

> *...people claim drinking, smoking, or womanizing cause stroke. I hardly drink. I don't smoke and womanize* ***(male, 45 years)***
>
> *... hmm, elderly people have stroke. When I went to the hospital they told me that when you are drinking alcohol and smoking and a lot of things you can get stroke. I know at the hospital* ***(male, 69 years)***

High blood pressure

Nine participants from the hospital facility associated stroke with high blood pressure/hypertension. Some of them were already living with hypertension before they were diagnosed with stroke and so they were able to link their stroke condition to high blood pressure. Some further said that untreated hypertension or non-adherence to anti-hypertensive medications could lead to stroke.

… They said my BP (hypertension) had gone up. They said it was because of the blood pressure…. I don't know so much about stroke but what I think I know is only the BP that causes stroke. That is all I know ***(male, 43 years)***

Unhealthy diet/dietary practices

Six participants from the three study sites mentioned unhealthy diets as causes of stroke. This theme focuses on two dimensions: 1) unhealthy foods, and; 2) unhealthy dietary practices. With respect to the unhealthy foods, participants mentioned that intake of fatty and oily foods could lead to stroke. With regard to the dietary practices, participants mentioned that poor timing of meal (eating late), eating too much of chicken and beef could result in stroke.

> *...As for stroke, those who usually get it are those who like eating oily foods a lot* ***(male, 44 years)***

…it (stroke) can affect anybody, but it usually affects people from 40 years and above, because of their eating habits…. ***(female, 50 years)***

Supernatural causes

Supernatural causes emerged across the narratives from Ga Mashie and Physiotherapy Unit, but was mostly dominant in Ga Mashie. There were three sub-themes to this: 1) witchcraft; 2) devil, and; 3) spiritual means. While some of the stroke survivors said that stroke could be caused by witchcraft, others mentioned that it could be invoked on an individual through spiritual means or could be caused by the devil. The narratives of these participants were drawn from lived experiences and common sense knowledge.

After they told me at the hospital that I had a stroke, we took it as the work of witches…this is because I was not sick and I was even planning to travel the following day when it happened ***(male, 52 years)***

*…some people say it is transferred to a person through spiritual means, others say it is the disease in town now****(female, 68 years)***

At first, elderly people used to have it a lot, but now it is different, young people and little children are also getting it. Where is this coming from, it is all the work of the devil. Even if you don't think evil of anyone, someone is wishing evil for you ***(female, 57 years)***

Stress

Four participants mentioned stress as a cause of stroke. The dimension of stress included: hard work and lack of sleep. The narratives of these participants were based on lived experiences. For instance, a Pastor who was recruited from the hospital facility mentioned that his condition was caused by too much stress. He regretted his limited knowledge about the association between stress and stroke. As a result, he had made a decision to educate his fellow Pastors not to indulge in too many activities but rather take resting very seriously.

I think it is stress (respondent referring to causes of stroke). It is stress because I must confess, I am always stressed due to the nature of my work. We pastors, we don't know that sometimes we can be in this condition. They will call you to go here and you will go and they will call you to go there and you will go. That day I wanted to travel to the village where I do missionary work and I got the sickness, since that day I have not gone again ***(male, 52 years)***

Family history

Two participants mentioned family history as a cause of stroke. They drew their narratives from lived experience of family history of stroke as well as knowledge from health professionals. For a participant who had experienced family history of stroke, she mentioned that her mother and aunt had stroke: her mother got a stroke two months before hers.

> *…I know because as for hypertension even in my mother's side a lot of them have the hypertension. Even this stroke they normally get it. Even my mother had the stroke two months before me* ***(female, 43 years)***

Psychological disruption

The participants mentioned that psychological disruptions such as thinking and worrying could cause stroke. These explanations were mainly drawn from participants' experiences.

> *As for me, I think stroke is brought about by thinking or worrying. Maybe life is not going the way you plan it therefore, when think too much, it can trigger stroke.* ***(female, 57 years)***

Other chronic diseases

Even though 16 participants had comorbid conditions (hypertension, diabetes, high cholesterol and kidney failure), only two participants associated stroke with diabetes and high cholesterol.

> *For mine, it is a complication. I know I had diabetes, then pressure came in (BP), but the pressure is on and off. So I went to the hospital, they said I have cholesterol. So finally I had it (respondent referring to stroke)* ***(male, 52 years)***

Contagiosity (social infection)

Majority of the stroke survivors from the three study sites said that stroke is not contagious. When participants were asked whether stroke could be contagious or infectious, only one stroke survivor from Ga Mashie mentioned that stroke could be contagious.

> *It (stroke) is a sickness that can be transferred to another. If someone around you has it, you can also get it* ***(female, 86 years)***

No, I don't think so, because as I have stroke now, there are people around me, but none of them has had it. So, I know that stroke is not contagious ***(female, 57 years)***

..*the reason why I think stroke is not contagious is that, it's not a cough or anything of that sort. Stroke is a matter of inability of the blood to penetrate the veins properly. That's what I know brings about stroke* ***(male, 44 years)***

Predestination

One stroke survivor from the hospital facility mentioned that stroke could be caused by life's own determination. This theme came out of the fact that the respondent could not identify or explain the cause of his stroke condition.

....stroke can be caused by life's own determinations ***(male, 42 years)***

Causal theories of stroke: caregivers

Caregivers attributed stroke to nine causes: poor lifestyle practices, high blood pressure, non-adherence to health care, stress, supernatural causes, unhealthy diet/dietary practices, other chronic diseases, family history (heredity), and other cases (such as lack of knowledge about health issues, not being sociable, and not paying attention to patients' complaints).

Poor lifestyle practices

Caregivers in all the three study sites linked the causes of stroke to poor lifestyle practices such as: alcohol consumption, smoking, and physical inactivity. Their narratives were drawn mainly from the experiences of the care recipients (stroke survivors). The caregivers particularly laid emphasis on smoking as a poor lifestyle that put their care recipients at risk of stroke.

The doctor told her not to drink alcohol but she continued to take it. If the doctor advises you to refrain from something and you don't listen, you will face the consequences ***(female, 48 years)***

..*I can't really say, because I wasn't living with him. But he was smoking both cigarettes and marijuana before he got stroke. He wasn't going to the hospital too* ***(female, 17 years)***

High blood pressure/hypertension

Hypertension formed the dominant theme on the narratives of the stroke caregivers on causal theories of stroke. Since many of the stroke survivors had high blood pressure before stroke diagnosis, the participants were able to identify hypertension as a cause of stroke. Hence, the participants' narratives were based on care recipients' experiences and information from the health professional.

> *In my mother's case, it was the BP (hypertension) that caused her to get stroke. So if someone has BP, the person should take care of him/ herself so that it doesn't affect other things which could bring the stroke* ***(female, 32 years)***

Non-adherence to health care

Non-adherence to health care entails not following professional medical advice on health issues. Participants mentioned that irregular blood pressure check, non-adherence to anti-hypertensive medications, not medicating when sick, and not seeking biomedical treatment early after onset of symptoms could result in stroke.

> *Since it is BP which causes it, so if you don't take medications and check your BP you can get stroke* ***(female, 41 years)***

> *My father's friend is a doctor, he used to tell us that if you're the kind who doesn't go to the hospital to check your blood pressure, you can get stroke* ***(female, 41 years)***

> *…and she was not taking her medicine. According to her, it was only on that day that she failed to take her medicine on time* ***(male, 52 years)***

Stress

Some of the caregivers mentioned stress as the cause of their recipients' stroke. The dimension of stress included lack of rest or not having enough rest after involvement in too much work. This knowledge was based on the experiences of the care recipients.

> *My mom is a trader and works very hard. She brought us up single-handedly and she wasn't having enough rest. You know most of these traders work so much and just take a little rest when they feel headache from too much working* ***(female, 20 years)***

Supernatural causes

Stroke caregivers in all the three study sites mentioned that stroke could occur through spiritual attack or it could be invoked on an individual by someone else. Some of the participants drew on this knowledge because they could not offer explanation to the cause of their care recipients' illness (stroke). Some also mentioned that stroke could be spiritually caused as a way of implying that living with stroke is not based on individual's actions.

> *However, sometimes, it may be given to you spiritually* ***(female, 17 years)***

> *I don't know. I feel it is an attack (spiritual attack I guess) because we have gone to check for any heart problem, kidney, liver, all are normal. He is not diabetic* ***(female, 60 years)***

> *I think it is somebody who sent it to him because how can somebody who came back and went to sleep in the evening time as siesta come out like this* ***(female, 60 years)***

Unhealthy diet/dietary practices

Participants from Ga Mashie and Physiotherapy Unit associated the cause of stroke to dietary imbalance such as poor diet and poor eating habits.

> *…they say it's partly caused by our eating habits. So we have to watch our eating habits* ***(female, 41 years)***

Other chronic diseases

Participants mentioned that other chronic diseases such as diabetes and multiple sclerosis could result in stroke. They also mentioned that untreated diabetes, non-adherence to medication and indulgent in poor lifestyles as a diabetes patient could lead to stroke.

> *If you have diabetes and you're not checking it, it leads to stroke. You're having diabetes but you're taking alcohol, which has sugar in it. When you come back, then you also go and buy 'hausa koko' which also has sugar in it. After that, then you sleep. So I feel the diabetes is what caused the stroke* ***(elderly female)***

> *I don't know. I feel it is an attack (spiritual attack I guess) because we have gone to check for any heart problem, kidney, liver, all are normal. He is not diabetic* ***(female, 60 years)***

Family history

Family history appeared within the narratives of participants from the Stroke Unit. The participants mentioned that the existence of stroke in a family could put an individual at risk of stroke. Participants' knowledge was drawn from personal observations as well as lived experiences of their care recipients.

> ***Interviewer:*** *You said stroke exists in his family. Amongst his siblings, is he the only one with stroke?*
> ***Participant:*** *No. some of them have even passed on*
> ***Interviewer:*** *How many siblings has he got?*
> ***Participant:*** *Two*
> ***Interviewer:*** *And they have both passed on?*
> ***Participant:*** *Yes*
> ***(Elderly female)***

Other causes of stroke

Caregivers mentioned that stroke could be caused by other factors such as: lack of knowledge about health issues and not being sociable. A participant from the hospital facility mentioned that stroke could be caused by unsociability. This narration was based on the experience of a care recipient who was living with stroke. According to the participant, the sister liked to be alone all the time and that was why it was difficult for anyone to help her when she experienced the stroke symptoms because she always locked herself in the room. Hence, when she (care recipient) fell down in the room, she was helpless for four days before she could get to open the door for people to come to help out. By that time, her condition had become worse. The caregiver mentioned that the stroke could have been prevented if his care recipient was more sociable.

Causal theories of stroke complications: perspectives of the stroke survivors

Stroke complications focus on the disabilities that could result from living with stroke. Stroke survivors from the three study sites were asked to list the complications of stroke as well as

the complications they have experienced as stroke survivors. Their knowledge on stroke complications fell under two interrelated themes: 1) Physical disability; 2) cognitive disability, and; 3) Stigmatization.

> *Honestly, within three years I realized a lot had changed about my body, a lot of drugs... When it started at first, I couldn't get up; if I wanted to do something, I will tell my mother (the old lady you met the first time) and my sister would carry me. If I am going to the hospital, I am carried* ***(female, 57 years)***

> *Because what I see is that when you think so much about the disease it makes you forgetful concerning a lot of things. Even when you are holding glass, you may let go of it for it to crash on the ground without noticing it* ***(male, 44 years)***

> *... yes, I am feeling if I went out people (...) even now when we went out to Korle Bu to come back, a lot of people when they see me they are looking at me. That is why I can't go anywhere* ***(female, 43 years)***

Participants from the hospital facility mentioned that stroke could cause physical disabilities such as immobility, severe pain, inability to walk properly, total body shut down, and paralysis. A participant mentioned that stroke could lead to stigmatization as a result of the physical disabilities associated with the illness. Two out of the three participants that could not identify the complications of stroke were from the Physiotherapy Unit.

> *...as you are sitting down and you can't move your leg, those are some of the things and the changes it brings to your life..because of this now I cannot walk properly. I cannot move out. Even when I am staying out I don't feel okay. When I am among people I cannot stay with the people. It is a lot of things* ***(female, 43 years)***

Causal theories of stroke complications: perspectives of the caregivers

Caregivers were asked to list the complications of stroke as well as the complications of their care recipients. The knowledge of the participants centered on four main themes: 1) physical disability; 2) behavioural and psychological changes; 3) cognitive disability; and; 4) death.

Physical disability

Physical disability formed the dominant theme on the knowledge of caregivers on stroke complications. The participants mentioned that anyone living with stroke would experience physical disabilities such as: inability to eat alone; immobility; loss of limbs; numbness in limbs; inability to work; inability to do things; not being active as before; pain in "manhood", and; other forms of physical disabilities. Participants' narratives came from their care recipients' experiences.

> *…she could no longer walk by herself because her right side is paralysed, but she can reason and speak well* ***(male, 17 years)***
>
> *..his body is bent to one side, he cannot move his hands anymore, and even the right hand is affected a little* ***(female, 58 years)***
>
> *…the person will not be able to support himself, cannot walk, and not even eat by himself. It is dangerous. If you don't have money, you can curse the sick person because it is not easy at all. You need to have the love in you* ***(elderly male)***
>
> *…yes, sometimes when he urinates he experiences pains in his manhood* ***(male, 30 years)***
>
> *It affects a lot of things, there are things you wish you could do yet you cannot do them again* ***(female, 32 years)***

Behavioural and psychological changes

Participants mentioned that stroke could bring about behavioural and psychological changes in an individual living with stroke. The behavioural changes mentioned by four participants included: being easily annoyed, getting angry easily and not wanting to be helped. These narratives were based on caregivers' experiences with their care recipients.

> *She gets angry very quickly, she is very quick tempered. But when she is angry, I am the only one who can calm her* ***(female, 32 years)***
>
> *…he doesn't calm down to be helped. He wants to do everything on his own* ***(female, 17 years)***

Psychological disability refers to the effect of stroke on the thinking pattern of the stroke survivors. Only two participants mentioned that stroke could result in psychological disability such as consistent thinking and worry.

> *He is always been thinking more than he should. Thus, worries a lot about things he shouldn't even be bothered about* ***(female, 32 years)***

Cognitive disability

According to the participants, stroke could result in cognitive dysfunctions such as: inability to remember things, forgetfulness and brain damage. The explanations of the participants were drawn from their care recipients' lived experiences. These complications were mentioned by caregivers recruited from the Stroke Unit.

> *He forgets what he has been doing in the church. Sometimes he forgets to do it. If I remind him then he will do it* ***(female, 60 years)***

> *He cannot even remember anything. All he remembers is the meetings concerning his business and other appointments* ***(male, 52 years)***

Death

One participant from Ga Mashie mentioned death as an end point reality of living with stroke.

> *The end result of such a case is that you will die. Because you would also think a lot; and with this kind of situation, you don't have to think a lot. Because when you have stroke, it comes with BP, so you don't have to think too much****...(male, 20 years)***

Discussion

The discussion focuses on three conceptual aims of the study: 1) onset of stroke and immediate reactions after diagnosis; 2) pre-diagnosis awareness and causal theories of stroke and stroke complications, and; 3) implications of the findings for research and policy.

Onset of stroke and immediate reactions after diagnosis

The participants in this study described stroke as a sudden event. This is not surprising because research has shown that stroke is a sudden condition which frequently affects people

who are not aware of their risk (DiGiovanna, 2017). Therefore, when stroke 'strikes', both the sufferers and their family caregivers are often not prepared to deal with the multifaceted disabilities that comes with it (Lutz et al., 2011). Further, irrespective of the socioeconomic status of the household, the sudden nature of stroke causes interruption in the economic circumstances of the household and which changes the family dynamics. This economic burden is even higher for individuals with low income prior to the stroke onset because they face greater risk of experiencing subsequent post-stroke disability (Bettger et al., 2014). This study showed that the emotional impact of stroke was strong and varied due to the sudden nature of the condition, coupled with the multifaceted disabilities, uncertainty about rehabilitation, fear of how to cater for family, and the young age of stroke onset. In addressing the suddenness of stroke, there is a need to develop enhanced health services that target the physical and psychological disruptions that stroke survivors and their caregivers experience after diagnosis.

Pre-diagnosis awareness and causal theories of stroke and stroke complications

There was poor pre-diagnosis awareness of stroke among the stroke survivors and their caregivers, particularly among those recruited from the urban poor communities. This finding is similar to the previous studies on stroke awareness in Accra (Sampane-Donkor et al., 2014; Okyerefo and Fiaveh, 2017). However, this finding is contrary to the situation in a community-based study in Canada and a hospital-based study in India, where stroke survivors and caregivers demonstrated high pre-diagnosis awareness of stroke (Schneider et al., 2003; Pandian et al., 2006). This finding shows the need to develop public education which targets promotion of stroke awareness in Ghana.

This study showed that a good proportion of participants' causal theories of stroke were aligned with biomedical theories, indicating that biomedical care is legitimised. While stroke

survivors attributed stroke causes to eleven (11) factors, caregivers mentioned nine (9) causal theories of stroke. Six (6) out of the eleven (11) causal theories mentioned by the stroke survivors and six (6) out of the nine (9) causal theories mentioned by the caregivers were aligned with the biomedical models (Table 5). In addition, participants drew on sociocultural models of illness. A few participants attributed stroke to supernatural factors and this aligned with socio-cultural beliefs which had been reported in other stroke studies (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008) and diabetes studies (de-Graft Aikins et al., 2014; Hjelm and Mufunda, 2010; Awah et al., 2008) in sub-Saharan Africa (SSA). Participants in this study drew on supernatural causal theories when the stroke occurrence deviated from the biomedical models. This suggests that even though biomedical care is legitimised among these participants, there are some cultural theories that can undermine stroke prevention and care and these need to be taken into consideration when developing intervention strategies for stroke (Airhihenbuwa and Iwelunmor, 2012).

Further, previous research has shown that drawing on supernatural causal theories will lead to seeking herbal treatment or faith healing (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008). Other studies have contradicted this finding. For example, de-Graft Aikins (2005) showed that the 'motivations' determining the illness action of chronic illness sufferers transcend supernatural causal theories; they include affordability and efficacy of medicines, as well as relief from the physical and psychosocial burden of the illness. The findings from this study were aligned with this view. Even though participants in this study subscribed to supernatural theories, this did not undermine their engagement with biomedical treatment. During the acute phase of the illness, biomedical treatment was the primary choice for most of the stroke survivors. However, after the acute phase, many of the participants sought treatment from different sources to address the complex burdens of stroke. The

association between causal theories of illness and health seeking behaviour did not follow a linear trajectory.

Even though contagiosity as causal theory of stroke is new in stroke study in SSA, this has been mentioned in other non-communicable diseases' study such as diabetes. For instance, de-Graft Aikins (2012) found that people living with diabetes in the same community mentioned disclosure of their diabetes as an infectious agent. She referred to this as "social infection"- a situation where people think that diabetes can be passed on to others through speech and interaction. This indicates that it is important to take these beliefs into consideration during health education on stroke in Ghana.

Participants generally had low knowledge of stroke complications. For instance, complications such as recurrent of stroke, epileptic seizures, chest infection, falls with serious injuries, pressure sores and deep venous thrombosis were not mentioned by the participants. In addition, knowledge of stroke complications were not shared equally by the stroke survivors and the caregivers, especially concerning cognitive problems of stroke and the behavioural and psychological changes associated with stroke. This has serious implications for caregiving and in preventing further stroke or minimising post-stroke disabilities.

Implications of the findings for research and policy

This study has several implications for research and policy. First, due to the low pre-diagnosis awareness and poor knowledge of stroke complications among the participants, there is a need to increase public awareness on stroke and its complications. Also, the findings indicate that it is important to develop enhanced health services to address the physical and psychological aspects of stroke after its onset. If these services are in place, they can help the stroke survivors and their caregivers better prepare for the stroke recovery process.

Further, with respect to the causal theories of stroke, there are strong areas of convergence between the lay (stroke survivors and caregivers) models and the biomedical models which are important for developing interventions that will be accepted by the stroke survivors and their caregivers. On the other hand, there are areas of divergence, especially concerning the sociocultural beliefs such as witchcraft, devil and predestination, which present challenges for intervention. This study suggests the need to factor in these sociocultural explanations of stroke during public education and in developing medical intervention strategies.

The findings also show the need to provide adequate support services (financial, education, psychological) for caregivers to address the cognitive, behavioural and psychological consequences of stroke. This can enhance the caregivers' wellbeing and that of their care recipients; this is because while the health of the stroke survivors affect the caregivers, the reverse is also true. Finally, there is a need for future studies to explore the explanatory models of the health professionals in order to capture current nuances in the shared professional ideas on causal theories of stroke and its complications.

Limitations and strengths

This study has three key limitations. First, the views of the participants may not be reflective of all stroke survivors and caregivers in Ghana because we only selected participants from two urban poor communities and one tertiary hospital in Accra. The findings should therefore be interpreted with caution. Nonetheless, the findings aligned with other qualitative studies on explanatory models of stroke in SSA (Hundt et al., 2004; Bham and Ross, 2005; Mshana et al., 2007; Mshana, 2008).

Also, this study did not observe participants day-to-day practices and it is possible that participants did not share some important information during the interview process. However, probes developed during the interview guide were detailed enough to capture participants'

explanatory models of stroke. Furthermore, while we compared stroke survivors' and caregivers' explanatory models to established biomedical models, we did not interview health professionals to understand their explanatory models. There is a possibility that we may have missed out the current nuances in shared professional ideas about the causes and complications of stroke.

Despite these limitations, this study provides useful contributions to stroke research in Ghana. As the first study in Ghana and SSA to explore the explanatory models of stroke from the perspectives of the survivors and their caregivers, the findings provide insights for research and policy in Ghana and other SSA countries.

Conclusion

This study showed low pre-diagnosis awareness of stroke and lack of comprehensive knowledge on stroke complications among the participants; this raises the need to increase public awareness of stroke. However, participants had comprehensive knowledge on stroke causal theories and this legitimises biomedical care. The emotional impact of stroke on stroke survivors and caregivers is significant and should be included in the illness onset element of EMs. Consequently, there is a need to develop enhanced health care services in Ghana, where sufferers and caregivers can be counselled on the physical, cognitive, emotional, behavioural and psycho-social consequences of stroke. Further, in developing appropriate intervention strategies for stroke, it is important to pay attention to the sociocultural beliefs of the stroke survivors and their caregivers as this has the tendency to undermine biomedical treatment. An integrated biopsychosociocultural approach is proposed for stroke intervention among the study participants.

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Competing interests

None declared

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Table 1 Number of interviews completed

Study Sites	Stroke Survivors	Caregivers
Ga Mashie	8	8
Physiotherapy Unit	9	10
Stroke Unit	5	11
Total	**22**	**29**

Table 2. Key interview areas for people living with stroke and stroke caregivers

Key interview areas for people living with stroke

(1) General life history
(2) Knowledge of stroke
(3) Nature of illness experience, management and health seeking behaviour
(4) Stroke self-care

Key Interview areas for family caregivers of stroke

(1) General life history
(2) Knowledge of stroke
(3) Impact of stroke
(4) Nature of coping strategies

Table 3. Socio-demographic details of respondents

Characteristics	Stroke Survivors Total (N=22)	Caregivers Total (N=29)
Sex		
Female	8	20
Male	14	9
Age		
<50	9	16
51-60	8	7
60+	5	4
No response	0	2
Education		
No education	0	0
Primary	4	5
JHS	6	7
SHS	7	6
Tertiary	3	9
No response	2	2
Occupation		
Unemployed	13	5
Trader	3	8
Retired	2	2
Driver	2	0
Business (private)	0	4
Other	2	10
Monthly Income		
No income	14	4
≤GHC500	3	8
>GHC500	0	4
No response	5	13
Marital Status		
Never Married	1	10
Currently married	15	16
Divorced/Separated	4	2
Widowed	1	1
No response	1	0
Religion		
Christian	20	28
Muslim	1	0
No religion	1	1
Ethnicity		
Akan	7	9
Ewe	3	5

Ga	10	12
Other Nationals	1	1
No response	0	2
Relationship with SS		
Husband/wife	-	10
Mother	-	1
Son/daughter	-	13
Nephew/niece	-	3
Other (cook, friend)	-	2
Comorbidity		
No	6	-
Yes	16	-
Duration of stroke/caregiving		
< 1 year	6	12
1-5 years	11	13
6 years and above	*5*	*4*

JHS- Junior High School; SHS- Senior High School; SS- stroke survivor

Table 4. Established biomedical theories of causes of stroke and stroke complications

Biomedical causal theories of stroke	Biomedical causal theories of stroke complications
1. High blood pressure 2. High Body Mass Index 3. Unhealthy diet and dietary practices (diet high in sodium and sugar-sweetened beverages; diet low in fruits, vegetables, whole grains) 4. Poor lifestyle practices (smoking and second-hand smoke, low physical activity, alcohol use) 5. Stress 6. High fasting plasma glucose (Diabetes) 7. High total cholesterol 8. Atrial fibrillation 9. Environmental factors (ambient particulate matter pollution, household air pollution from solid fuels, lead exposure) 10. Family history	1. Recurrent stroke 2. Epileptic seizure 3. Urinary tract infection 4. Chest infection 5. Falls with serious injury 6. Pressure sores 7. Deep venous thrombosis 8. Pulmonary embolism 9. Physical disability (Pains, dysphagia, incontinence) 10. Cognitive disability (Brain edema) 11. Behavioural and psychological changes (Depression, anxiety, emotionalism, confusion) 12. Diseases (Pneumonia, fever)

***Sources**: Feigin et al (2016); American Heart Association (2015);Truelson, Begg and Mathers, 2000; Langhorne et al., 2000; Kumar et al., 2010.*

Table 5. Comparison between established biomedical theories and lay theories (stroke survivors and caregivers) of causes of stroke

Biomedical theories	**Lay theories**	
	Stroke Survivors	**Caregivers**
Common causes		
High blood pressure	High blood pressure	High blood pressure
High Body Mass Index	-	-
	Kidney failure	Kidney failure
-	-	Liver failure
Diabetes	Diabetes	Diabetes
High total cholesterol	High cholesterol	-
Unhealthy diet and dietary practices (diet high in sodium and sugar-sweetened beverages; diet low in fruits, vegetables, whole grains)	Unhealthy diet and dietary practices (high intake of meat and oily foods and late eating)	Unhealthy diet and dietary practices (poor diet, poor eating habits)
Poor lifestyle practices (smoking and second-hand smoke, low physical activity, alcohol use)	Poor lifestyle practices (smoking, alcohol consumption, physical inactivity, womanizing)	Poor lifestyle practices (smoking, alcohol consumption, physical inactivity)
Stress	Stress	Stress
Family history	Family history	Family history
Supernatural causes		
-	Witchcraft	Witchcraft
-	Devil	Devil
-	Spiritual means	Spiritual means
-	Predestination (fate)	-
Other causes		
-	Psychological disruption (too much worrying and thinking)	Not being sociable; lack of knowledge about health issues
-	Delay in treatment of stroke symptoms	Non- adherence to health care

Table 6. Comparison between established biomedical theories and lay theories (stroke survivors and caregivers) of causes of stroke complications

Biomedical theories	**Lay theories**	
	Stroke Survivors	**Caregivers**
Recurrent stroke	-	-
Epileptic seizure	-	-
Chest infection	-	-
Falls with serious injury	-	-
Pressure sores	-	-
Deep venous thrombosis	-	-
Pulmonary embolism	-	-
Physical disability (Pains, dysphagia, incontinence	Physical disability (severe pains in the body, hemiplegia, total paralysis, impotence)	Physical disability (severe pains in the body, hemiplegia, total paralysis, impotence)
Cognitive disability (Bain edema)	Cognitive disability (inability to remember things, forgetfulness)	Cognitive disability (inability to remember things, forgetfulness)
Behavioural and psychological changes (Depression, anxiety, emotionalism, confusion)	-	Behavioural and psychological changes (emotionalism)
-	Stigmatization	-
-	-	Death

Figure 1. Casual theories of stroke from the perspectives of stroke survivors and their caregivers, based on dominance of themes.