



Why Me?: A Qualitative Study on the Experiences of Young Stroke Survivors in the Accra Metropolis of Ghana, West Africa

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Abstract

Young stroke survivors are affected gravely when diagnosed with stroke between the ages of 18 to 45 years. The psychological and social effects of young stroke require stringent coping factors geared toward recovery and regeneration of self. A qualitative exploratory design was used to explore coping experiences and purposive sampling technique was employed to recruit 10 participants. Data were collected using tape recorded interviews which lasted between 45 minutes to 1 hour 30 minutes and guided by a semistructured interview guide which was informed by the research objectives and literature review. Thematic content analysis was used to analyze the transcribed data and 6 themes namely: psychological disruption, disruption to social identity, spiritual practices and beliefs, self-determination, support, and herbal medicine were derived. These themes gave insight into how these young stroke victims experienced and coped with physical signs and symptoms which negatively impacted their activities of daily living and resulted in social isolation, fear, anxiety, depression, guilt, and suicidal ideations. Provision of continuity of care for young adults living with stroke is highly recommended.

Keywords

qualitative methods, quality of life, cardiovascular disease, patient perspectives/narratives

Introduction

Stroke refers to a cardiovascular incident that occurs in the brain. It is the principal cause of adult disability and the third foremost cause of death in most of the developed countries in the world (1–3). Sub-Saharan Africa is currently recording a rapid rise in the incidence of stroke in young adults who are affected mainly in their reproductive years (4–8) as a result of epidemiologic and demographic transition and rising cardiovascular risk profile resulting from nutritional and lifestyle changes (9–14). Specific studies have not been conducted in Ghana to ascertain whether or not young stroke is on the increase, but health professional have noted a high among younger age groups of adults less than 45 years; forming greater than 30% of strokes seen and at a higher mortality rate (15).

Many of those who are discharged from hospital after a stroke have tenacious impairments, including weakness, balance difficulty, cognitive impairment, immobility, and dependency in activities of daily living (16,17).

These severe physical, social, and psychological consequences can be devastating and coping with the outcome tends to be extremely difficult with an abundance of adjustments and variations in young adults' physical abilities, social integration, and family roles (3,18–20). The ability to meet specific needs such as parenting, family finances, sexual function, and issues related to the sense of self (ie, self-confidence and self-esteem) is often greatly affected since younger people are still part of the economically active population and live longer to face the impact of stroke on their quality of life (13,21,22). The study is significant to

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Table 1. Demographic Characteristics of the Participants.

Pseudonym	Age (years)	Sex	Marital status	Level of education	Occupation	Employment status	Religion
Kojo	40	Male	Married	Form four	Baker	Unemployed	Christian
Sulley	31	Male	Married	JSS	Mason	Unemployed	Muslim
Rufinah	45	Female	Married	Sixth form	Hairdresser	Self employed	Muslim
Joojo	26	Male	Single	Tertiary	University graduate	Unemployed	Christian
Delali	28	Male	Married	Tertiary	Engineer	Unemployed	Christian
Bonsu	39	Male	Married	Tertiary	Teacher	Employed	Christian
Atta	40	Male	Married	Tertiary	Banker	Employed	Christian
Serwaa	45	Female	Married	Form four	Trader	Self employed	Christian
Lokko	45	Male	Married	Tertiary	Engineer	Unemployed	Christian
Atakora	38	Male	Single	Tertiary	Building draftsman	Employed	Christian

nursing and health professionals because it is the first to be conducted among young stroke survivors in Ghana to gain knowledge and a deeper understanding into their psychosocial experiences while living with stroke and to identify their coping strategies. Knowledge which the researchers believe could only have been better understood using a qualitative approach. The information provided by this study will not only bridge the existing gap in knowledge but will also form a basis for the development of interventions that are best suited to meet the health needs of young stroke victims in a timely, cost-effective and age-specific manner. It will also provide information for educating the general public on the need for regenerative health to help reduce the alarming increase in stroke incidence among young adults.

Methods

Design

A qualitative exploratory design was used for the study. This design was appropriate because it affords the opportunity to study what has not initially been studied and seeks to highlight new knowledge, new insights, new understandings, and new meanings and to explore factors related to the topic. It allowed for the researchers to avoid using predetermined categories. Instead, the categories and their names were generated directly from the data collected. As such, the need to use open-ended interviews in the development of codes using conventional content analysis approach was possible (23–26).

Participants

Overall, 10 young stroke survivors took part in the study from the Greater Accra region of Ghana, using purposive sampling technique as a guide for sample selection. Ages ranged from 18 to 45 years and those who participated all met the inclusion criteria; which was that participants could be either a male or female who had lived with stroke for at least 1 year and are undergoing rehabilitation or recovering at home. Someone who could communicate verbally in, understand and speak English and had the ability to give

informed consent. A summary of participant's demographic characteristics is presented in Table 1.

Data Collection

Participants were recruited from the stroke and physiotherapy units of a teaching hospital in the Greater Accra Region of Ghana. Individuals were eligible for participation if they were between the ages of 18 and 45 years and had lived with stroke for at least 1 year and undergoing rehabilitation or recovering at home. Those who could give their consent to participate were expected to be able to communicate verbally in, understand and speak English and Twi. Formal permission to conduct the research at the Teaching Hospital was first sought and potential participants who gave permission to do so, were referred to the principal investigator by the nurse in charge of the stroke unit. The study was further explained and consent was sort to conduct interviews. Individuals were taken through confidential semistructured interviews by the principal investigator, who is well vexed in qualitative methods.

Data were collected using a semistructured interview guide which was designed with focus on the objectives of the study which sort to explore the psychosocial impact of stroke on young adults and identify their coping strategies for surviving their stroke experience. Preliminary guiding probes for the interview included the following questions: "When were you diagnosed with stroke?," "Can you tell me what happened when you first starting experiencing symptoms, what were they?," "How do you feel as a young adult living with stroke?," "How are you coping with your symptoms now?." They were prompted with various follow-up questions to elicit more information on their experiences, the impact of the stroke on their relationships and their coping strategies.

Analysis

The qualitative conventional approach to content analysis was specifically use for this study to ensure that data gathered from participants were unfiltered and analyzed systematically for the generation of codes, themes, and categories

as identified (24,25). Audio-taped data were transcribed verbatim by one of the researchers and assessed by all 3 researchers to ensure the data generated was accurate. Data were then entered into NVivo 10 (QSR, 2012) for data management after validating the accuracy and analysis was done concurrently with data collection (25) by reading transcripts and plunging into data in order to acquire in-depth knowledge into the topic (24). Initial categories were decided on after coding 7 transcripts, and new categories were added when data did not fit into already developed categories. Interviews stopped after 10 participants because no new information surfaced (23). Codes were then examined to gain more insight into recurring categories that adequately reflected the psychosocial experiences of the affected young stroke sufferers and their coping strategies. The “umbrella theme” was then addressed after developing indexing categories and thematically sorting and assessing relations between categories and subcategories (23,24).

Trustworthiness

Rigor was ensured through the choice of study design, selection of participants, approach to data analysis, and scope of interviewing (26). The researcher ensured credibility by recruiting only participants who gave consent and those who met the inclusion criteria. Investigators were knowledgeable in quantitative research, and piloting was done to ensure the meaningfulness of interview questions and to identify researcher bias and minimize error. Member checks were done by verifying all patterns and statements observed by the researcher from participants and throughout the coding and data analysis. To address confirmability, regular discussions were held throughout the data analysis process to allow for a good assessment of all conflicting explanations of the various categories. The researcher made sure that the research process especially the research design and the data gathering procedure, was documented in detail, leaving an audit trail to make replication of the research easy and enhance dependability of findings (23,25). To ensure transferability, a clear and accurate description of the phenomenon under study was given in order for other researchers to make meaning of it. The researcher also gave a thick description of study setting, sample size, study design, and inclusion and exclusion criteria (23).

Results

The 3 major categories that emerged from the data analysis were outlined as (a) psychological disruption, (b) disruption to social identity, and (c) coping strategies. “Why me?” was the overarching theme that linked the categories and subcategories together in this study.

Psychological Disruption

All 10 participants were impacted psychologically and disclosed that they were surprised when diagnosed with stroke.

This was because they were not sick in any way before the onset of the signs and symptoms of the disease. The physical effects of the condition on their daily lives were overwhelming. Uncertainties about the recovery process and the possible outcome of the disease caused most of them to be afraid of possible death and disability. This fear of dying and disability led to feelings of guilt, depression, and eventually thoughts of suicide because they felt responsible for their stroke due to bad lifestyles, not listening to advice and failure to go for regular checkup in the hospital.

Like I said initially it came as a surprise. I was a physically active person . . . I had to argue a little with the doctors because I didn't believe that I had stroke. (Bonsu)

I never knew I was hypertensive so the whole stroke thing is a disappointment . . . I have let myself down by not going for regular checkups. (Bonsu)

I really feel like ending it all . . . just to kill myself . . . because I sometimes felt if I had even died it would have been better. (Delali)

Disruption to Social Identity

Participants disclosed that some members of their communities and social groups considered stroke as a disease for older people, and perceived young stroke sufferers as witches, having been bewitched or being punished by a deity for a sin they had committed. All these negative perceptions made them feel stigmatized and unable to interact with other people or disclose their condition for fear of stigmatization. Most of them had to keep to themselves and ended up feeling very lonely.

I can meet someone and they would ask what has happened to me and I will say stroke and they will say you young boy and you have had a stroke. (Sulley)

Some think you are a witch or that you are paying for a particular sin . . . They think we have gone to do something bad or gone for something from a fetish priest . . . I feel lonely, all my friends have left me. (Serwaa)

Sometimes I wonder if my daughter has a boyfriend . . . since the stroke affected us, I have observed that some people are scared. Some of the boys might even say this family has stroke cases and that if you marry from it the person might get a stroke. (Serwaa)

Coping Strategies

Coping strategies were one of the main categories described by the participants. This referred to the practical routines that participants initiated and managed in order to cope with or overcome the negative psychosocial impact of the stroke experience. The subcategories that made up this category were spiritual practices and beliefs, support, self-determination, and herbal medicine.

Spiritual Practices and Beliefs

Christian and Muslim alike attributed their recovery, source of encouragement, and hope to the worship of God or Allah whom they expressed their gratitude to. Praying, reading the bible or the Quran along with the encouragement they got from people gave them courage and a reason to keep on living. They felt that only God could take them out of their predicament.

As Muslims, Allah has thought us that in everything whether good or bad we should give it to Him. If He wills, he will allow me to be strong again. (Sulley)

I'm just praying to God that he will take me out of it . . . with the encouragement from my fellow Christians . . . with the help of the bible I really got this courage to keep trusting in Jehovah than ever. (Delali)

Support

Support in the form of financial and special assistance from family, friends, colleagues, and employers was evidently a great source of support for participants. They were able to cope with upkeep, high cost of treatment, and work fatigue as a result. Spousal support was also mentioned as very key to recovery and it was emphasized that every stroke patient needs a companion to ease the burden of the condition.

I have been assured by my directors that I should recover fully I shouldn't worry myself . . . my salary is paid me and they take care of my medical costs, the drugs, physiotherapy or review . . . my colleagues at work have also been very supportive. They visit and have taken up my teaching assignments. (Bonsu)

The hospital bills, drugs, my senior brother took care of that, it was not a problem. Everybody was fighting for me to survive so then everybody was ready to do everything for me. (Lokko)

Every stroke patient should have a companion, if you have a wife or husband . . . they should be there for each other. It's a big relief and a big remedy. (Bonsu)

Furthermore, though support was received from family, friends, and colleagues at work and employers who contributed immensely to paying of medical bills, giving encouragement, and providing other forms of assistance; health personnel were seen not to offer enough support after discharge from hospital and completion of the 6 months stipulated review.

Self-Determination

Majority of participants insisted that only the person having the stroke could describe the experience and knew what to do to hasten recovery and make the condition bearable. Some decided to pursue higher education in order to be assigned more sedentary roles that would limit movement, and others were also motivated to make the necessary adjustments such

as diet management, exercise, and strict adherence to treatment regimen in order to live healthy and complete their physiotherapy.

With stroke when it affects you, initially that is where the problem is but if you are out of danger the rest of the recovery depends on you so I realized I have to help myself. (Lokko)

I was determined to move on so I pursued a master's degree and I'm currently doing a professional course in banking . . . I would rather be trained and use my brain than do operations and move around because moving around is a problem. (Atta)

Herbal Medicine

A few participants resorted to herbal medication for treatment because they believed it would help them recover faster and because they couldn't afford their drugs and physiotherapy. Although effective for some others did not benefit from herbal medicine. They rather ended up disappointed and claimed that they had severe side effects.

I used to limp initially but I did herbal treatments and within three months I improved . . . when I was discharged my hand wasn't strong but the treatments helped. (Sulley)

The herbalist gave me medicine, each time I took it I felt dizzy and cold. So, after studying it for a while I was like no I won't do it again. (Serwaa)

Why Me?

"Why me?" was the overarching theme that linked the categories and subcategories together in this study. Majority of the participants admitted that the sudden nature of the stroke event was frustrating, shocking, overwhelming, and debilitating. Although they sort varied ways of coping with their condition and had some form of support, there was no denying that their physical inabilities had also disrupted their ability to work as before in order to meet financial some obligations.

They take care of me from the office, but the whole of this year it hasn't been so. So, when I made my enquiry my boss was telling me that its better, I go on early retirement, because he doesn't know when I'll be well to come back. Lokko

I can walk but because of the pain in my back I am unable to do anything else. I should have been able to sell at my shop . . . if it wasn't the stroke that affected me. I would have been able to work. (Serwaa)

The inability to carry out simple activities of daily living as before and the ripple effect of financial constraint contributed to the negative psychological impact that led to suicidal tendencies and feelings of despair. They often asked themselves why and also wondered why they were going

through so much within what they described as a short space of time.

Like I said initially it came as a surprise. I was a physically active person... I could not believe that I had stroke... why me?... I had to argue a little with the doctors because I could not believe it. (Bonsu)

I felt I was going to die... I was wondering how the disease was going to go away... so much had happened within a short space of time. (Sulley)

Discussion

Demographic Characteristics

The ages of all the young adults who took part in this study were between 18 and 45 years; with the youngest participant been 26 years old and the oldest participant been 45 years old. Only 3 of the participants were employed and of these 3, only 2 were physically present at work. The other participant was still receiving salary from his workplace and had his name on the staff list but was not fit to go to work because of a left-sided hemiparesis which he was now recovering from. The 5 young adults who were unemployed was as a result of existing physical disabilities and the length of time spent in the recovery process. The 2 women who participated in the study were the ones who were self-employed and were managing their own small-scale businesses but though self-employed, only one, was able to work, the other was unable to work because of pain in her back. Studies have shown congruence with these findings and have indicated that inability to return to work and unemployment are directly linked to stroke and occur by virtue of the accompanying emotional, social, or physical impairments that associate with stroke acquisition; which tend to reduce the quality of life of affected persons (27,28). However, most of the young adults in this study were married and appeared happier than unmarried participants who conveyed that they wished they had spouses and emphasized the importance of spousal support and companionship as key features and remedies for recovery. This finding is in line with a study done in Norway which indicated that those who were unmarried had lower health-related quality of life as compared to married patients (29).

The “stroke experience” is described as a “psychological transition” because it occurs suddenly and changes the ability of the affected person to function effectively in a social setting (27). Participants in this study faced different psychological disruptions and although the intensity of these psychological disruptions had reduced overtime because of adopted coping strategies, traces of such emotional responses were identified as these young adults had to contend with existing physical impairments on a daily basis.

Kuluski et al identified that the emotional impact of stroke was difficult to predict because many people were likely to pendulate from a state of grieve to normality

throughout the disease process; more consistently in individuals with persisting impairments (28).

Stroke survivors admitted to been surprised about their stroke diagnosis, particularly because they were not sick before the incident and considered themselves physically active. Some remained in a state of denial for a while and silently or confrontationally challenged health personnel about the accuracy of their diagnosis. Studies confirm that stroke survivors, particularly young adults are taken aback by the sudden nature of the stroke event and shaken to the core in a state of shock (21,29). Participants also experienced fear and anxiety which was because they were not sure about the outcome of the disease and feared possible death and disability. This state of fear and anxiety was probably because young adults live longer, have more responsibilities and obligations and in the advent of physical impairments may remain impacted over a longer period of time (30,31). The resultant effects of such fears and anxiety was guilt because young stroke survivors blamed themselves for causing their disease through certain habits such as excessive drinking and smoking which are known risk factors for hypertension and subsequently stroke as well as not going for regular hospital checkups. There is paucity of studies to assess the prevalence of self-blame among stroke survivors; however, a study by Santos et al (32) on suicidal plans of patients with acute stroke has established a direct link between self-blame and depression which may lead to suicide.

Participants who showed the most signs of depression were those who had hemiparesis of either the left or right sides of their body, who were physically handicapped and had experienced dizziness and imbalance. Deductively, this manifestation of depression was probably because they were lonely. Studies disclose that depression is common among stroke survivors as a result of social, cognitive, and physical dysfunction decreasing the quality of life of affected persons (33-35). The direct link between physical impairment and depression probably explains why those participants, in this current study who showed signs of depression, also showed signs of frustration. This argument corresponds with a study done by Regen et al (36) which found that depression is rooted in extreme feelings of frustration (37,38).

Furthermore, participants contemplated committing suicide. These thoughts were attributed to the anticipation of an inability to cope with physical disabilities, pain, and depression. In congruence to this finding, studies found that stroke, depression, and pain increased the risk for suicidal ideation and attempts, independent of other factors that are known to be associated with suicidality, suggesting that stroke per se may be an independent risk factor for suicidality (38-46).

Our findings also established the impact of stroke on the social identity of the affected individuals and how they were perceived by people in their community or social group. Stroke was viewed as a disease for the elderly or witchcraft or a punishment by a deity for a sin that had been committed. Stroke for many years was apportioned as a disease of the

elderly (47) possibly because, in past years, stroke affected mainly the elderly populace and was uncommon among younger persons. This perception seems to have long caught up with the Ghanaian society and rendered stroke among young persons, below the age of 45 years as unheard of, even in the light of recent studies that indicate a rise in young stroke (29).

Studies done by Aikins (26) and Atobrah (48) in the Ghanaian context support the findings related to superstitious beliefs regarding having chronic illness. In the study by Atobrah (48), it was discovered that young adults diagnosed with certain chronic illnesses ascribed supernatural interpretations to their disease condition. The study by Aikins (26) also highlighted findings in relation to society members seeing chronic illness sufferers as bringing their condition upon themselves through their own powers of witchcraft; giving some weight to the social perceptions society members hold with regard to chronic illness sufferers. As a result, there were also some indications, however small, about feelings of been stigmatized because of the social perceptions that were attributed to stroke among young adults. Studies assert that in order to avoid been stigmatized most stroke sufferers were likely not to disclose their condition because of the likelihood of been viewed in a negative manner (49–53) by members of a social group.

However, in the light of these hurdles, participants coped by attributing their recovery to “God’s” help and prayed for complete healing. This goes to show that providing a culture conscious care for patients to needs for spiritual affiliation is essential to them and must be taken seriously by nurses and other health professionals (54,55). Notwithstanding, studies assert that alternative meanings attributed to the causes of stroke that include witchcraft suggest a lack of perceived control and takes the focus off less visible risk factors such as hypertension, familial history, or diabetes (56,57).

Niemi et al reports that it is important for self-help programs and rehabilitation institutions to make sure that stroke patients have the needed encouragement, psychological support, adaptation training, and sufficient neuropsychological information. Such social support would enable patients who are discouraged by stroke to assess themselves more realistically and live healthier and fuller lives (58).

In our study, young adults also hammered on the need for the stroke sufferer to gain control of him or herself and be actively involved in those activities geared toward recovery. This process of self-determination is achieved through self-efficacy which focuses on one’s ability to influence events that affect their lives through a positive mindset (59). This mindset motivated healthier lifestyles through diet management and exercise, sticking strictly to treatment regimen and developing a positive attitude toward the recovery process. In stroke-related cases, self-efficacy has been seen as a major contributing factor to the achievement of positive rehabilitation outcomes and improvement in overall quality of life (60,61). The onus lies on health professionals to encourage

individuals to gain a sense of control to make decisions that would affect their lives positively (62,63).

Coping strategies adopted to help deal with the dynamics of the stroke incident included the use of herbal medicine which some benefited immensely from. Li et al gives evidence that shows good efficacy and safety of herbal medicine use in patients affected by ischemic stroke (64) yet some participants reported that they did not benefit at all from these treatments. Donkor’s study supports these findings by evidently revealing that there has been proliferation in recent times of herbal services that provide nonorthodox medical assistance for wide range of diseases such as stroke (65).

Limitations

The study design chosen helped to provide deeper insight and understanding into the study area; however, the use of a qualitative approach with a sample size of 10 does not support generalization of findings due to the limited the scope of responses solicited. Another limitation is that the present study also focused on the experiences of young stroke sufferers and as such the age limitation siphoned the information that could have been elicited from the elderly stroke affected population. Finally, the physical, biographical, and economic disruption of stroke on the quality of life of participants became an important issue but could not be explored during the study because focus was on the psychosocial impact and identified coping strategies of affected young persons. This gap in knowledge is recommended in further studies.

Conclusions

This study unearthed the overwhelming nature of the effect of the stroke condition on the psychosocial well-being of affected persons. The impact which took the form of surprise, fear anxiety, guilt, depression, and suicidal ideation reinforced the need to develop specific coping strategies to manage these difficulties. As such, young stroke survivors resorted to the comfort derived from spiritual beliefs and practices such as prayer and reading of the bible or Quran, family and external support, self-determination, and the use of herbal medicine. It was however revealed that young adults predominantly lacked information from health personnel on how to effectively cope with the aftermath of the condition after recovery from the acute stages and as a result had a lot of unanswered questions. It is therefore imperative for nurses to spearhead the education of patients on the prevention, treatment, and management of cardiovascular diseases and campaign for the promotion of regenerative health. It has also become necessary per the findings of this study for policymakers to adopt a curriculum that will train cardiac nurses to cater for the comprehensive and holistic needs of stroke sufferers especially Young Adults and their families. This study calls for further research in to the psychosocial

effects of stroke on spouses and children of young adults living with stroke, in order to gain in-depth understanding into what these spouses and children go through during the stroke experience especially when the affected person is the breadwinner of the family. It further calls for research into the prevalence and incidence of stroke among young adults living with stroke in Ghana using a quantitative approach.

Authors' Note

Ethical approval was sought from the Institutional Review Board (IRB) of the Nogouchi Memorial Institute, University of Ghana (Study Number: 058/15-16). Derived data supporting the findings of this study are available from the corresponding author on request.


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