


ORIGINAL RESEARCH ARTICLE

Open Access



# Exploring the life experiences of stroke survivors in Nigeria using the interpretive phenomenological analysis

Michael O. Ogunlana<sup>1,2\*</sup> , Olufemi O. Oyewole<sup>3</sup>, Ifeoma Blessing Nwosu<sup>4</sup> and Pragashnie Govender<sup>5</sup>

## Abstract

**Background** The consequence of living as a stroke survivor has received significant attention in literature from different parts of the world. Enriching social relations and other factors are reported to influence the post-stroke experience. Differences in health systems, cultural factors and available resources have made it apt to explore the experience of life after a stroke in Nigerian stroke survivors. This study explored the lived experiences of Nigerian adult stroke survivors, with a focus on their concerns, hopes, dreams and daily routine experiences.

**Methods** This qualitative study employed a phenomenological approach based on in-depth interviews with stroke survivors. Interpretative phenomenological analysis was used to analyse the in-depth exploration of the personal experiences of these stroke survivors and the meanings they attached to that experience.

**Results** The participants in this study described their experiences, emphasising both the visible loss of mobility and emotional issues related to their condition. Three superordinate themes were identified: (1) stroke presentation; (2) affect, coping, and adaptation; and (3) social supports.

**Conclusion** The study concluded that the experience of Nigerian stroke survivors is unique as it is a blend of supportive and non-supportive care scenarios, which is greatly associated with environmental and other intrinsic variables. Post-stroke mobility strongly influences the overall stroke experience.

**Keywords** Life experiences, Stroke survivors, Presentation, Social support, Coping

## Background

Stroke is the second most common cause of death and disability worldwide with an obviously increasing African burden [1]. Owolabi et al. [2] reported that the incidence

of stroke in Africa ranges from 25 per 100,000 persons in Lagos, Nigeria, to 250 per 100,000 persons in Al-kharga, Egypt, while the prevalence of stroke ranged from 15 per 100,000 in Ethiopia to 963 per 100,000 in Egypt and 1460 per 100,000 in the Niger delta regions of Nigeria [2]. Stroke constitutes 2.4% of emergency admissions and 17% of medical admissions at a public teaching hospital in Ogun State Nigeria [3]. With increasing sophistication in the medical care of stroke emergencies, there is a gradual increase in stroke survivors with stroke-related morbidities. Many stroke survivors have persistent impairments, such as weakness, balance impairment, cognitive impairment, mobility restrictions and dependency in activities of daily living (ADL) [4]. The sequelae following a stroke also alter the individual's capacity for

\*Correspondence:

Michael O. Ogunlana

opecoluwamic@yahoo.com; ogunlanam@ukzn.ac.za

<sup>1</sup> Federal Medical Centre Abeokuta, Abeokuta, Ogun State, Nigeria

<sup>2</sup> College of Health Sciences, University of KwaZulu-Natal, Private Bag X54001, Durban, South Africa

<sup>3</sup> Olabisi Onabanjo University Teaching Hospital, Sagamu, Ogun State, Nigeria

<sup>4</sup> Department of Medical Rehabilitation (Physiotherapy), Nnamdi Azikiwe University, Nnewi Campus, Awka, Anambra State, Nigeria

<sup>5</sup> Discipline of Occupational Therapy, School of Health Sciences, University of KwaZulu-Natal, Private Bag X5400, Durban, South Africa

social role functioning and can render a vulnerable self-concept in the sense of autonomy and mastery [5].

The impact that a stroke has on the individual is unique and varies widely depending on the injury and the essential functions which are affected, such as cognition, communication and physical abilities [3, 6]. The experience of surviving a stroke is akin to living after being grazed by a deadly bullet. This indeed leaves its mark which initially presents as a one-sided weakness, but later progresses with a series of functional limitations and multiple affectations of the person. Most assessments of post-stroke outcomes still rely on the use of standardised questionnaires comprised of pre-determined questions, presumed to be of importance to the individual, with closed response sets [7, 8]. Within this traditional model of outcome assessment, the healthcare professional, rather than the individual with stroke, is the “expert”. As a result, while much may be known about the impact of stroke on outcomes such as functional ability, for example, less is known about what this means to the individual who has experienced the stroke [9].

Several studies have qualitatively examined stroke survivors’ experiences and surmised that recovery goes beyond functional independence [10–12]. The consequences of living as a stroke survivor have received several attentions in literature from different parts of the world. Stroke survivors in North America reported affectation of social relationships, which is evident in the loss of social support to the extent of home disruption, inability to communicate, which was seen to be more affected than physical functioning and the consequent loss of independence [12]. The stroke survivors in one middle eastern country reported inadequate social and financial support and a lack of access to rehabilitative services leading to functional disturbances [13]. In two Scandinavian countries, it was reported that enriching social relations, successful return to work, and continued presence of professional support during recovery, enhanced the experience of the stroke survivor. At the same time, fatigue and sustained reduced function hindered participation in meaningful activities and influenced the post-stroke experience negatively [14]. Clearly, a hand full of researchers have investigated experiences of recovery and life following stroke [15–18]; however, differences in cultural factors, health systems and available resources [19] have made it necessary to explore the experience of life after a stroke of Nigerian stroke survivors. This present study, therefore, seeks to explore the experiences of Nigerian stroke survivors following a stroke. It is hoped that information from this study will go beyond outcomes from standard questionnaire research [20, 21] to elicit unique information that is essential to the Nigerian stroke survivor. This information, when available, may be

useful in designing specific interventions for stroke survivors to facilitate recovery.

#### **Aim**

The study aimed at exploring the lived experiences of Nigerian adult stroke survivors with a focus on their concerns, hopes, dreams and daily routines.

#### **Method**

The relevant domains of the Consolidated Criteria for Reporting Qualitative research (COREQ) [22] are used to report the methods in this study.

#### **Research design**

This qualitative study employed a phenomenological approach based on in-depth interviews of stroke survivors. Interpretative phenomenological analysis (IPA) was used in this study because it allows for an in-depth exploration of the significance of a personal experience and the meaning attached to that situation or event [23]. The advantage of this approach in relation to the aims was that it enables a detailed analysis of the story and events in each case of a stroke survivor. The cumulative analysis then allowed each case to contribute to the overall account of a stroke survivor’s experience, while retaining a connection to the individual cases [24].

#### **Setting**

The interviews were conducted at different locations selected by the participants. Some interviews were conducted at the hospitals and others at the participants’ homes.

#### **Procedure**

Study participants were stroke survivors listed on the registry of the stroke survivor’s rehabilitation club of Nigeria. They were contacted telephonically after obtaining gatekeepers permission from the club’s coordinators to involve them in this research. The purpose of the research was explained to the participants during the recruitment process, they were assured that participation is voluntary and that they are free to withdraw from the study at any time. Also, their confidentiality was guaranteed. Written informed consent was obtained from participants after obtaining verbal consent from the stroke survivors. Stroke survivors who consented to participate were further scheduled for an interview at their homes or after a visit to the outpatient clinic. Data were collected by one of the authors. This qualitative data was collected using an open interview to explore and understand the experiences of stroke survivors. The interviews were audio-taped and written notes were taken by the researcher during the interview.

### **Sampling procedures**

Study participants were selected using purposive sampling. The researcher selects ‘information-rich cases’ that can provide ‘in-depth understanding’ about life after stroke [25] according to the aims of this study. Potential participants had to have survived one or more episodes of a stroke for not less than two years. The address and telephone numbers of the stroke survivors or their next of kin was obtained from the register of the SSSRCN and used to identify potential participants who met the inclusion criteria.

### **Inclusion and exclusion criteria**

Participants involved in this study were stroke survivors with two years post-stroke incidence, having a score of not more than 3/6 on the modified Rankin scale, required to understand and speak either Yoruba or English, with inclusion age greater than 18 years and able to communicate without serious speech impairment. Potential participants who were severely impaired in their level of functioning prior to the stroke were excluded, for example, an individual who was unable to function independently in ADLs prior to the stroke.

### **Sample size**

The sample comprised as many stroke survivors as possible (saturation sampling) until the data collected became repetitive (data redundancy is reached).

### **Data collection**

#### **Tools and strategies**

An open interview was used during the primary data collection process with a proforma for obtaining sociodemographic information prior to this interview. The data collection proforma sought to obtain information about age, gender, date of the stroke, side of hemiplegia/hemiparesis, duration of hospitalisation, whether rehabilitation was received and how frequent, whether rehabilitation was continuing, education level, and employment prior to and after the stroke. This form had English and Yoruba Language versions and was used appropriately. The open interview contained general questions like ‘How is your life now after the stroke?’ ‘What problems have you experienced after stroke?’ and ‘How has your family experienced life after stroke?’ Interviews began with general and easy questions, and then step by step progressed to more specific and directed questions. Questions were probed based on what each respondent shared to cover themes like their experience in the post-stroke life, the role of family caregivers, and formal caregivers in that situation.

Interviews were conducted at the stroke survivors’ homes or at a neuro-rehabilitation day clinic, based on the participant’s wishes, and lasted 45–60 min.

### **Data analysis techniques**

The analysis was undertaken in six steps following an IPA approach [24]. They are reading and re-reading data, Initial noting, developing emergent themes, searching for connections across emergent themes, moving to the next case and looking for patterns across cases. A consolidated list of superordinate themes was then constructed from the collated cases. The authors undertook the analysis and they jointly reviewed and checked the thematic allocations of the data.

### **Findings**

We interviewed 12 stroke survivors as at data saturation with 75% of them being of the female gender and 66.7% being ischaemic stroke. Their age ranged from 49 to 72 years. Other details of stroke survivors’ demographic profiles are documented in Table 1. The participants in this study described their experiences within the biopsychosocial model, emphasising both the visible loss of mobility and the emotional issues related to their condition. The data analysis resulted in three emergent superordinate themes and corresponding subordinate themes. These are summarised in Fig. 1.

#### **Superordinate theme 1: stroke presentation**

For most participants, the stroke onset was experienced as a dramatic event, with emotive recollections of the events that characterised the stroke incidents. Detailed stories about the cause of the stroke characterised each interview. Most of the participants situated themselves in guilt and procrastinating as a cause of action that may have prevented the incidence of stroke. In the words of Heidegger as quoted by Crooks [26] “every moment is a moment in which both future and past are at stake; every moment is, at least potentially, the decisive moment, the right moment”. The occurrence of the stroke was cited as an event that may have been prevented had they taken better personal choices or had the environmental factors been more favourable.

#### **Subordinate theme 1.1: “It was like a disconnection”: dramatic onset of the stroke experience**

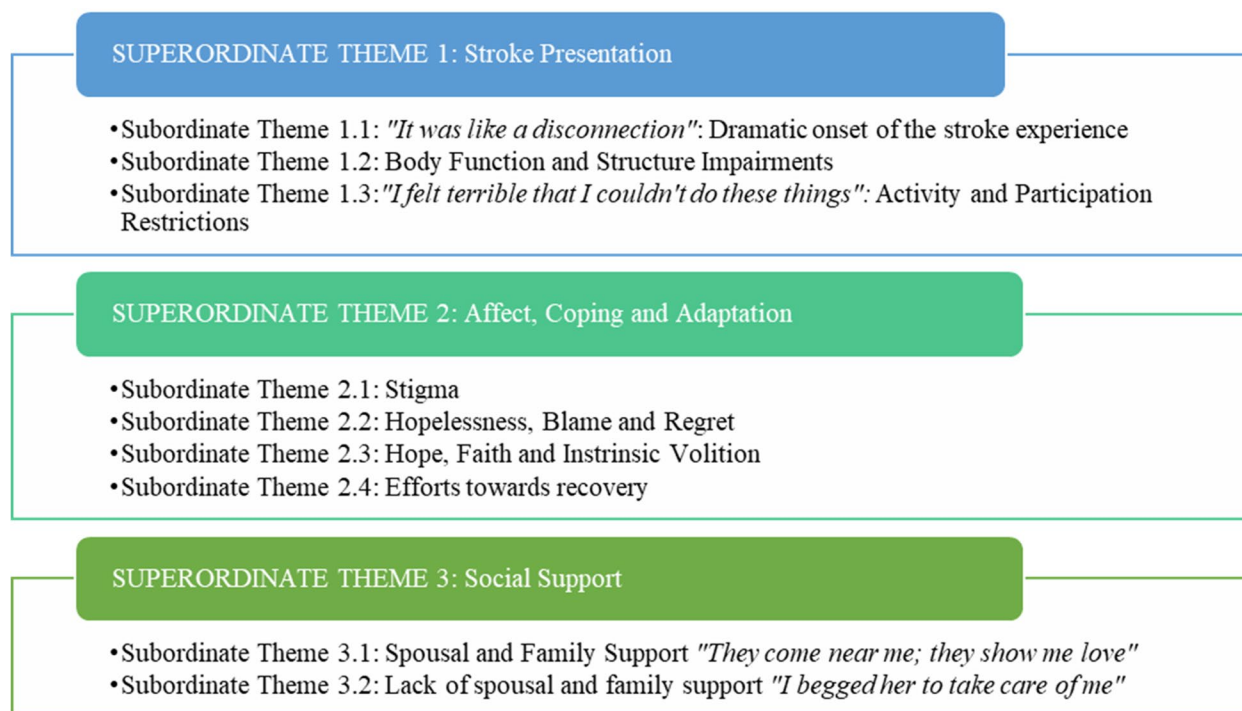
Several participants described the occurrences of these events during ADL tasks, such as ablution, eating, rest and sleep.

*It was as if something was disconnecting at that part, I had to call my daughter to help me massage my mouth and after that, I was carried to the hospi-*

**Table 1** Profile of Nigerian stroke survivor participants (n = 12)

Identifiers/ characteristics	Pseudonyms	Occupation	Employed before stroke	Employed after stroke	Type of stroke	No. of stroke incidences	Age	Gender	Highest education	Year of stroke incidence	Years living with stroke	Side affected	Type of hospital attended
<b>Survivor 1</b>	S1	Lecturer	Yes	Yes	Haemor- rhagic	1	54	Female	PhD	2017	3 years	Left	Private & Public
<b>Survivor 2</b>	S2	Teacher	Yes	No	Ischaemic	1	58	Female	NCE	2017	3 years	Left	Private
<b>Survivor 3</b>	S3	Mechanical Engineer	Yes	No	Ischaemic	1	49	Male	HND	2018	2 years	Left	Private
<b>Survivor 4</b>	S4	Businessman	Yes	Yes	Ischaemic	1	64	Male	SSCE	2013	7 years	Right	Tradio-medical and public
<b>Survivor 5</b>	S5	Retired teacher	Yes	No	Haemor- rhagic	2	66	Female	B.Ed	2017	3 years	Left	Private and public
<b>Survivor 6</b>	S6	Retired Account officer	Yes	Yes	Haemor- rhagic	1	69	Male	OND	2014	6 years	Right	Public
<b>Survivor 7</b>	S7	Teacher	Yes	No	Ischaemic	2	62	Female	BSC	2017	3 years	Left	Public
<b>Survivor 8</b>	S8	Health Atten- dant	Yes	Yes	Ischaemic	1	49	Female	SSCE	2016	4 years	Right	Public
<b>Survivor 9</b>	S9	Trader	Yes	No	Haemor- rhagic	1	60	Female	SSCE	2019	2 year	Left	Public
<b>Survivor 10</b>	S10	Trader	Yes	No	Ischaemic	1	72	Female	No formal Education	2016	4 years	Right	Public
<b>Survivor 11</b>	S11	Trader	Yes	No	Ischaemic	1	50	Female	SSCE	2016	4 years	Left	Tradio-medical and public
<b>Survivor 12</b>	S12	Trader	Yes	No	Ischaemic	1	61	Female	SSCE	2019	4 years	Right	Public

PHD Doctor of Philosophy, NCE National Certificate of Education, HND Higher National Diploma, SSCE Senior School Certificate Exam, B.Ed. Bachelor of Education, OND Ordinary National Diploma



**Fig. 1** Overview of superordinate and sub-ordinate themes

*tal in the morning...It was like a disconnection in my body... Everything just stood still. (S2)*

S2 woke up in the night to use the rest room and suddenly felt an urgency to do some exercises at night, she started feeling a disconnection in her body, and for her, it appeared as if everything stood still, which may be a tacit reference to her loss of mobility and or disconnection with the sense of time as occasioned by the stroke incident.

There appeared to be an immediate awareness of mobility loss among some participants, that is, in their hands and feet, while others experienced speech deficits, dizziness and headaches.

*By 10 pm, I started stooling, coming from bathroom to toilet and back to the toilet till around 6 am in the morning...my husband took me to the medical centre in my place of work ... We were about to enter Babcock (hospital) when my speech became blur ... It was only hand that was affected when we wanted to leave the (medical centre) ... It was when we wanted to enter that I noticed that I could not lift my leg again...(S1)*

For S1, the associated non-specific occurrences like stool frequency throughout the night increased the drama of the stroke incident experience. It portrayed the stroke

incident as a plethora of events that gradually culminated in mobility loss. The nocturnal onset of the stroke events adds to the strangeness described by the research participants. S1, S2, S3 and S8 who reportedly experienced 'wake-up' strokes (strokes situation where a patient awakens with stroke symptoms that were not present prior to falling asleep) while S4, S6, S9, S10 and S11 reported strokes while awake. Again, survivors that had a stroke episode while awake were able to relate the occurrence with the performance of certain activities of daily living. For example, S6 had the episode while writing, S9 had the episode while walking from a religious meeting, S10 had the stroke episode after a meal, and S11 had the stroke episode during prayer while using ablution facilities. Below are verbatim quotes from these stroke survivors.

*It happened in the midnight... I discovered that I was moving on the bed, but I couldn't stand up, so I shouted. (S3)*

*I can't really say how it happened. I didn't really know stroke before until it happened to me, I just used to hear about it...I noticed that my hand and leg were getting weak. (S4)*

*I was ready to start writing, as usual, then, I discovered that my leg was just shaking for about 5 min-*

utes, I couldn't move it again, so I called my wife, and we went to FMC immediately. (S6)

It was in the morning, I just woke up, I wanted to go to the toilet but couldn't stand up, so I forced myself to stand up and I fell. I can't remember how I got to the hospital (S8)

I just finished eating. I wanted to throw away the leaves of the food I ate but I couldn't throw it away with my hand, so I called my younger brother to come and take me to the hospital. I told him that stroke has started though he told me that it can't be stroke but I knew it was stroke and we confirmed it at the hospital. (S10)

S9 and S11 reportedly felt a push and feelings of dizziness. This is a layman's description of the loss of balance which is a significant indicator of the occurrence of a stroke. Again, a loss of balance was only reported among stroke survivors who had their experiences while awake.

I was coming from the mosque in the morning. I was almost at home when I felt a push. I had to struggle to get home... I discovered that my hand and leg became cold, and I was having consistent headache at that time. (S9)

I was doing ablution, I wanted to pray, then I noticed that my body was going down, and I was surprised, I held the wall and I prayed. I called someone that checks my blood pressure, and she said my blood pressure is high. ... That day I went to the toilet and noticed my hand was stiff so I went to lie down on a chair and my eyes starting turning, I started feeling dizzy... so, I told my child to go and buy me malt and milk but when she came back, I couldn't stand up again. When that happened, my left hand died, it wasn't working well, the vein stopped too. (S11)

#### **Subordinate theme 1.2: body function and structure limitations**

Participants expressed a loss of body functions that impaired their activity and restricted participation. Participants expressed mobility impairments, pain and sexual dysfunction.

When they started treating me my hand will be paining me so much, so I told a doctor that I want it to be amputated, sometimes I can't sleep (S10)

I can't lift my right hand; it is not responding. My right leg too, I have to drag it. I walk with a walk-

ing stick. My other body organs are weak, my penis is weak. (S4)

I have the best handwriting. Not being able to use my right hand is the major problem (S7)

I can't use my left leg like before. My walking is now slow...(S1)

Moreover, participants indicated cognitive limitations that affected their overall functional ability.

My brain has been affected. I can be talking to someone and forget what we were talking about (S8)

I am a very detailed person; I take note of every detail and present it when it is needed or when I am asked any question, but I can't do those things anymore. I was so detailed; People are now saying they don't know who can take that place now. I have done my best. (S7)

#### **Subordinate theme 1.3: "I felt terrible that I couldn't do these things"**

Several participants expressed not being able to participate maximally in their religious practices. Some activity restrictions were reported, including attendance at prayer sessions, fatigue, mobility restrictions, inability to drive, impairments, and maintaining specific postures for prayer.

It is painful to me. Stroke stopped me from praying and going for programs (asalalatu) in the mosque (S11)

Assuming I can walk well, it would have been good. Not been independent makes life difficult for me. I walk around the house little by little, and my children drive me around the community. I go to church despite the stroke. I trust God for healing. I don't do much in church. I used to go for preaching before, but it is difficult now, I have to be driven around because I get tired. (S2)

Now, I can't observe my prayer as a Muslim because I can't stand alone. I go for programs in the mosque 2 times in a week, but I don't go now because I can't walk like before. (S12)

Social restrictions were illustrated by narratives that expressed decreased satisfaction due to social exclusion, stigma, impairments in skills and ability that influenced prior social participation.

I can't go out. I don't have friends again. There is (stigma) but I try not to take it to heart so that it doesn't affect my mood (S2)

*I was a choir member and a poet. I render poems at work too whenever we have parties but I can't do much now (S3)*

*I discuss and joke, I don't have friends. I go for events, we sing and come back home but I can't do most of these now (S10)*

Vocational consequences, limitations to career progression, and financial limitations were additional barriers faced by these participants. One participant described his experience of being dismissed from work, with no opportunities for reasonable accommodation or realignment at work as a person with disability.

*No, I am not working anymore. I was sacked when my employers saw that I was not fit anymore. Before I went to see my employers, they were giving me salary but after they saw the state of my body, they sacked me. Before the stroke, I was working 7 a.m-4 p.m., though we used to have a break by 12-1 pm but I was sacked since I can't work after the stroke. (S3)*

This participant expressed how his career aspirations were thwarted due to the stroke.

*No, no good thing. It spoilt things for me because I was working in an oil and gas company. I would have been able to travel abroad for training if not for this stroke. My colleagues were able to enjoy this benefit, but I could not because this stroke happened around the time I was supposed to travel. (S3)*

Even voluntary vocational tasks were reportedly restricted for one participant,

*I was an usher. We welcome people to church, count offerings, and tithe, arrange the church and ensure a smooth running of the church but I can't do those things now (S5)*

Several participants experience financial restrictions related to purchasing medication and accessing travel as a person with a disability.

*Also, it has not been easy on my finances though I get pension, I buy drugs every month and the drugs are expensive (S2).*

*Not happy. I don't feel okay about it. For instance, before the stroke whenever I want to go out, I can board taxi anywhere but now I have to order taxis, especially when I want to come to see the doctor and it is expensive. I am not happy about it. (S3)*

#### **Subordinate theme 1.4: efforts towards recovery**

Despite the impairments, concomitant limitations and restrictions inflicted by the stroke, participants were generally motivated towards their recovery with illustrations of their attempt highlighted below, especially in self-care tasks:

*I cook, mop the floor and sweep with the hand that is not affected by stroke. If I want to bath, my children help me to pour water on my body sometimes, I go to toilet by myself. I exercise myself too. I do my chores little by little unlike before when I could do it with speed. I still do them now but not like before. I cook now too but just once in a while. When I need to get something done sometimes, I tell my children to do it. (S8)*

*I do things. I bath myself; I even wash my bedspread. Things are not that difficult. The only thing I can't do now is to wash my back, I carry empty bottles and pick things myself. I do my chores but that I don't stress myself, I clean the shelf, I sweep too, my children wash the plates. I wash my underwear. Washing has helped in making my hand unfold. (S11)*

*I bath myself, wear my cloth, go to the toilet by myself. Though it takes me time. The difference is that it is not so fast as before. (S7)*

#### **Superordinate theme 2: affect, coping and adaptation**

Participants expressed a range of emotions, including grief, hopelessness, blame and regret, and hope, faith, and intrinsic volition. A number of adaptive mechanisms related to their coping and acceptance were also noted.

##### **Subordinate theme 2.1: stigma**

Stigma emerged as a significant concern for participants as described.

*My neighbours say a lot of things. There was a time they said I am smelling because of the stroke. Some of them still greet me but they stay away from me. (S8)*

*Yes, people think once you have stroke, you can't be alright again (S3)*

Surprisingly, two participants expressed how stigma was enacted "stylishly" on the one hand, and how it was received as positive on the other.

*No, they don't stigmatise me. They do it stylishly, but I don't count it. ... Before the stroke, I go out with*

*my friends in the evening, we joke and play together. After the stroke, I still go out with them. Some make jest of me. (S4)*

*The stigma is not on a negative side, I think it is on a positive side though I don't like a pity party. There was an experience I had, someone saw me and was crying ... I have learnt caring for people, showing compassion, love, bringing out love I don't know exist, I enjoy those things but not with a pity party. They come near me. They feel I need their help. They show me the love I didn't know was there until stroke happened (S1)*

#### **Subordinate theme 2.2: hopelessness, blame and regret**

Most participants experienced blame and regret following the stroke and related this to heeding to their comorbidity of hypertension.

*I should have taken care of myself. I should have paid attention to my high blood pressure. I should have taken the High BP medications (S3)*

*I caused the stroke. I went to the hospital some time ago. I was told I have hypertension, but I did not believe it. If I had believed and taken drugs to bring the blood pressure down, this wouldn't have happened. (S11)*

*I wasn't wise enough to go to the hospital... Maybe if I had gone to the hospital there could have been a difference. (S10)*

Anxiety and unhappiness accompanied the realisation that a premorbid level of functioning was not possible.

*I felt bad that I didn't go back to my former state. I was anxious and unhappy. (S2)*

*I am not happy now; I am praying to God that it will return to normal (S10)*

#### **Subordinate theme 2.3: hope, faith, acceptance, and intrinsic volition**

There were some participants, however, who demonstrated a level of acceptance enveloped in expressions of hope, faith, and intrinsic volition to continue despite limitations.

*I don't have anything doing. I sleep and eat but I want to send someone to go and restock for me so that I can start going to my shop. Before the stroke, I go to Lagos to restock twice in a month, but I have adjusted, I believe if there is life there is hope. I am planning to start going (S9)*

*To stroke patients, they should not give up, they should rest, this thing will go in Jesus name (S8).*

*I don't feel bad about it. I am grateful for life. I have accepted it. I accepted that this stroke may not go away. I am close to 70, it is not likely it will be okay before I die' (S6)*

*No, I know I will be well. The day I stood up; everyone was happy. When I was in the hospital, they cry each time they come to visit me and that makes me sad, but my husband used to tell me not to worry (S5)*

#### **Theme 3: social support**

Spousal and family support were reported as both; present for some of the participants and lacking for others.

##### **Subordinate theme 3.1: spousal and family support: "They come near me; they show me love"**

Participants' community, spouse and children were cited as being essential to their recovery and reintegration.

*They come near me. They feel I need their help. They show me the love I didn't know was there until stroke happened (S1)*

*My husband does all the work now. He cooks for me, he does everything (S9)*

*They helped me, they also gave me money. My friends and family did that for me. (S12)*

*My children did not let me feel anything as they stood by me. My children take care of me, so I don't suffer much. They buy my drugs. They play humorously with us; they don't shout at us. (S7)*

*No people don't run away, they take care of me (S10)*

##### **Subordinate theme 3.2: lack of spousal and family support: "I begged her to take care of me"**

Contrastingly, some participants expressed being abandoned by their spouses and family in their most vulnerable situations.

*I have no wife that can come with me. I have a wife, but she is not doing her duties as a wife. I have a woman, she gave birth to a boy and a girl for me, I begged her to take care of me, I gave her money and some other things but she said she can't take care of me, that I should go and meet other women. She left me, all my efforts to persuade her fell on deaf ears. (S4)*



*Don't mind my family, they left me. They don't even care about me... (S3)*

*Some of my family members didn't care, it even caused a fight, but I thank God for sending me help. Those I trusted disappointed (S11)*

## Discussion

High rates of disability and mortality have been cited due to the increasing public health concern of stroke incidences [27]. With this, is the need to strengthen the service provision for stroke survivors within the health-care system and in their communities into which they are expected to reintegrate. For service provision to be suitably implemented, an understanding of the needs of stroke survivors' barriers and enablers to reintegration is required.

Phenomenological research, as in this study, was influential in illustrating the lived experiences of the stroke survivors. By an exposition of their narratives, we have been able to gain insight into their particular challenges and successes. The analysis revealed three superordinate themes that described the typical presentation of stroke, the stroke survivors' affect, coping and adaptation and lastly, social supports.

The presentation of stroke is well documented. In this group of stroke survivors, an in-depth exploration into their experiences of stroke occurrence revealed several non-specific events like frequency of stool, waking up to exercise by midnight, feelings of disconnection in the body, loss of sense of time etc. All these culminated in the stroke incident. Studies [28, 29] have documented specific signs and symptoms of a stroke event to include headaches, vertigo, gait disturbance, and convulsions which results in the final event. Still, based on the experiences shared by the participants in this research, there were certain non-specific (strange actions) that preceded the specific signs and symptoms of the stroke event. The authors are not aware of whether these non-specific events have been reported by other studies. However, it may be beneficial to investigate this in a large epidemiological survey. Another predominant impression portrayed by these stroke survivors in the shared experience of their stroke occurrence was the guilt of not taking appropriate steps in managing an existing diagnosis like high blood pressure, postponing a medical consultation or "playing the ostrich" (denial) with obvious realities of an impending stroke because of a popular opinion that stroke affects the elderly population. This guilt emanated from the present discovery that better decisions and actions may have prevented them from experiencing a stroke. Yuki and Kudo [30] also reported that stroke

survivors recognise the likelihood that their previous way of life may be the reason for the stroke and identifying the need for preventing another stroke episode. Further stroke episodes can only be prevented when good health-seeking behaviour [31] is adopted by stroke survivors. In this context, health-seeking behaviour will include adherence to medications, prompt medical consultation and increasing education to debunk myths on the prevention and management of stroke events. The survivors reported two types of stroke onsets — wake-up strokes and strokes while awake. The presentation of wake-up strokes affects the possibility of prompt intervention [32]. It is often emphasised that 'Time is Brain—Compared with the normal rate of neuron loss in brain ageing, the ischaemic brain ages 3.6 years each hour without treatment' [33]. Aside from the apparent fact that wake-up strokes may not receive early intervention like safe and efficacious reperfusion therapy, there are several uncertainties about the stroke severities [32]. One-third of stroke survivors in this population had wake-up strokes and during the time of the interview, their stroke severity was similar to survivors who had strokes while awake. This is not surprising as reperfusion therapy is not readily available even for Nigeria stroke survivors who had stroke events that occurred while awake. Lack of access to brain imaging and pre-hospital delays are significant barriers to prompt intervention after a stroke event and are the main determinants of stroke outcomes [34, 35].

Participants in this research highlighted many impairments that shaped their stroke experience. Among such are balance challenges, central stroke pain, sexual and cognitive dysfunctions that led to social restrictions, vocational and financial limitations. Loss of balance is a common symptom of stroke [36]; some of the stroke survivors interviewed reported dizziness and feelings of being pushed as their way of explaining the inability to maintain a coordinated posture. The human balance control system is sustained by the sensorimotor system (somatosensory/proprioceptive, visual, and vestibular systems) [37]. The onset of a stroke may affect any of these areas depending on the type, severity and area of the brain in which the stroke is affected. The unilateral muscle paralysis that is the conspicuous physical manifestation of stroke events is sufficient to cause loss of balance and unsteady gait. One of the participants in this study expressed excruciating upper limb pain that he believes may be remedied by amputation of the affected limb. Pain in stroke survivors is expected to be neurogenic, but as the stroke becomes chronic, abnormal synergies cause adaptive shortening that may result in nociceptive pain. Hence management of pain associated with a stroke should consider the need to treat the nociceptive and neurogenic components. Alternative methods

of managing pain should also be encouraged, especially in psychological pain overlays like a stroke survivor requesting limb amputation for pain treatment.

Cognitive impairment after stroke was popularly reported by participants in this study. Al-Qazzaz et al. [38], reported that stroke affects the attention, memory, language, and orientation with attention and executive functions mostly affected. Participants in this study complained of memory problems that appeared to get worse as the stroke became chronic. Early intervention by specialist psychologists into stroke-associated memory challenges should be considered to prevent cognitive disabilities. Sexual dysfunction is not often openly discussed in the Nigerian culture; however, one of the participants in this study revealed that he had a sexual organ weakness, possibly referring to an erectile dysfunction. Oyewole et al. [39] reported that stroke survivors had significantly lower sexual functioning with a higher prevalence of sexual dysfunction than healthy controls. This dysfunction is usually a combination of neurogenic and vasculogenic aetiology. This same survivor and a few others expressed social and spousal neglect, which may be associated with decreased sexual functioning.

These impairments led to a series of activity limitations and participation restrictions like stigma vocational and financial limitations. Activity and participation restrictions were highlighted as strongly related to mobility and self-care. Moreover, observance of religious activities was significant for this group of participants. This aligns with some of the participants who experience a sense of hope and faith that aided their overall coping. Vocational restrictions inevitably occurred. Social support was described across both ends of the spectrum depending on the personal characteristics of the stroke survivors, whether they experienced positive or negative social support. In this study, the older females experienced positive social support while the younger males reported negative social support with an emphasis on spousal rejection.

### Conclusion and implication for practice

In conclusion, the outcome of the present study has given credence to the international classification of functioning and health with emphasis on impairment in the brain functioning that progresses to body mobility loss which will result to functioning limitation and participation restrictions in diverse human occupations. We hope that the knowledge of non-specific or dramatic stroke onset presentation may be useful in ensuring early remediation and stabilisation of symptoms during an acute stroke experience. Access

to neuroimaging facilities for any suspected stroke incident will be apt towards reducing morbidity and mortality with a concomitant improvement in the experience of the stroke survivor.

This study has some practical implications. Some of the stroke survivors expressed regret about not complying with solutions to pre-stroke comorbidity. Healthcare professionals should therefore focus on health education and good health-seeking behaviour alongside the quest for functional independence for stroke survivors. This health education should include sexual and cognitive functioning, which are not often the focus of post-stroke rehabilitation. Hope was a strong motivational factor to cope in this study's participants, but this may wane in the face of continued residual impairments. Therefore, stroke survivors must be prepared and equipped with adaptive coping mechanisms during rehabilitation. There is also the need for the establishment of formal social support for improved outcomes and quality of life among stroke survivors [12, 13].

### Study limitation and recommendation for future research

The novel outcome of this present study may be limited in external validity even though the researchers ensured data saturation during participant recruitment. The social and cultural biases of these respondents may account for the study outcome hence more extensive research using a mixed-method design involving participants from different socio-cultural backgrounds may further validate the lived experiences of Nigerian stroke survivors.

#### Abbreviations

IPA Interpretative phenomenological analysis  
COREQ Consolidated Criteria for Reporting Qualitative research

#### Acknowledgements

The authors acknowledge all stroke survivors that consented to the interview for this research.

#### Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

#### Authors' contributions

All authors contributed fully to this research. The authors read and approved the final manuscript.

#### Funding

This research received no specific grant from any funding in the public, commercial or not-for-profit sectors.

#### Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

Ethical clearance was obtained from the Federal Medical Centre Abeokuta Health Research Committee with protocol number FMCA/470/HREC/01/2019/10. Permission was obtained from the Stroke Survivor Support and Rehabilitation Club of Nigeria (SSRCN) for the use of the club's register to identify potential study participants.

### Consent for publication

All authors read and gave consent for the publication of the manuscript.

### Competing interests

The authors declare that they have no competing interests.

Received: 14 November 2022 Accepted: 6 April 2023

Published online: 20 April 2023

## References

- Akpalu A, Sarfo FS, Ovbiagele B, Akinyemi R, Gebregziabher M, Obiako R, et al. Phenotyping Stroke in Sub-Saharan Africa: Stroke Investigative Research and Education Network (SIREN) phenomics protocol. *Neuroepidemiology*. 2015;45:73–82. <https://doi.org/10.1159/000437372>.
- Owolabi M, Olowoyo P, Popoola F, Lackland D, Jenkins C, Arulogun O, et al. The epidemiology of stroke in Africa: a systematic review of existing methods and new approaches. *J Clin Hypertens (Greenwich)*. 2018;20:47–55. <https://doi.org/10.1111/jch.13152>.
- Ogun SA, Ojini FI, Ogungbo B, Kolapo KO, Danesi MA. Stroke in south west Nigeria: a 10-year review. *Stroke*. 2005;36:1120–2. <https://doi.org/10.1161/01.STR.0000166182.50840.31>.
- Perry SB, Marchetti GF, Wagner S, Wilton W. Predicting caregiver assistance required for sit-to-stand following rehabilitation for acute stroke. *J Neurol Phys Ther*. 2006;30:2–11. <https://doi.org/10.1097/01.npt.0000282144.72703.cb>.
- Palmer S, Glass TA. Family function and stroke recovery: a review. *Rehabil Psychol*. 2003;48:255–65. <https://doi.org/10.1037/0090-5550.48.4.255>.
- Kumlien S. Persons with Stroke and their nursing care in nursing homes. Stockholm: Karolinska Institutet; 2005.
- Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. *J Rehabil Med*. 2008;40:595–602. <https://doi.org/10.2340/16501977-0238>.
- Bayley KB, London MR, Grunkemeier GL, Lansky DJ. Measuring the success of treatment in patient terms. *Med Care*. 1995;33:AS226–235.
- Clarke P. Towards a greater understanding of the experience of stroke: integrating quantitative and qualitative methods. *J Aging Stud*. 2003;17:171–87. [https://doi.org/10.1016/S0890-4065\(03\)00005-7](https://doi.org/10.1016/S0890-4065(03)00005-7).
- Becker G. Continuity after a stroke: implications of life-course disruption in old age. *Gerontologist*. 1993;33:148–58. <https://doi.org/10.1093/geront/33.2.148>.
- Becker G, Kaufman SR. Managing an uncertain illness trajectory in old age: patients' and physicians' views of stroke. *Med Anthropol Q*. 1995;9:165–87. <https://doi.org/10.1525/maq.1995.9.2.02a00040>.
- Lynch EB, Butt Z, Heinemann A, Victorson D, Nowinski CJ, Perez L, et al. A qualitative study of quality of life after stroke: the importance of social relationships. *J Rehabil Med*. 2008;40:518–23. <https://doi.org/10.2340/16501977-0203>.
- Dalvandi A, Heikkilä K, Maddah SSB, Khankeh HR, Ekman SL. Life experiences after stroke among Iranian stroke survivors. *Int Nurs Rev*. 2010;57:247–53. <https://doi.org/10.1111/j.1466-7657.2009.00786.x>.
- Pedersen SG, Anke A, Aadal L, Pallesen H, Moe S, Arntzen C. Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis. *Int J Qual Stud Health Well-Being*. 2019;14:1659540. <https://doi.org/10.1080/17482631.2019.1659540>.
- Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal primary carers of stroke survivors living at home—challenges, satisfactions and coping: a systematic review of qualitative studies. *Disabil Rehabil*. 2009;31:337–51. <https://doi.org/10.1080/09638280802051721>.
- Lou S, Carstensen K, Jørgensen CR, Nielsen CP. Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disabil Rehabil*. 2017;39:301–13. <https://doi.org/10.3109/09638288.2016.1140836>.
- Peoples H, Satink T, Steultjens E. Stroke survivors' experiences of rehabilitation: a systematic review of qualitative studies. *Scand J Occup Ther*. 2011;18:163–71. <https://doi.org/10.3109/11038128.2010.509887>.
- Sarre S, Redlich C, Tinker A, Sadler E, Bhalla A, McKeivitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disabil Rehabil*. 2014;36:716–26. <https://doi.org/10.3109/09638288.2013.814724>.
- Ayis S, Wellwood I, Rudd AG, McKeivitt C, Parkin D, Wolfe CDA. Variations in Health-Related Quality of Life (HRQoL) and survival 1 year after stroke: five European population-based registers. *BMJ Open*. 2015;5:e007101. <https://doi.org/10.1136/bmjopen-2014-007101>.
- Abubakar SA, Isezuo SA. Health related quality of life of stroke survivors: experience of a stroke unit. *Int J Biomed Sci*. 2012;8:183–7.
- Gbiri CA, Akinpelu AO. Quality of life of Nigerian stroke survivors during first 12 months post-stroke. *Hong Kong Physiother J*. 2012;30:18–24. <https://doi.org/10.1016/j.hkpj.2012.01.004>.
- Booth A, Hannes K, Harden A, Noyes J, Harris J, Tong A. COREQ (Consolidated Criteria for Reporting Qualitative Studies). Guidelines for reporting health research: a user's manual. John Wiley & Sons, Ltd; 2014, p. 214–26. <https://doi.org/10.1002/9781118715598.ch21>.
- Smith JA. Qualitative psychology: a practical guide to research methods. Thousand Oaks: Sage Publications, Inc; 2003.
- Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: theory, method and research. Thousand Oaks: Sage Publications; 2009.
- Morse JM. Qualitative nursing research: a contemporary dialogue. 1st ed. Newbury Park: SAGE Publications, Inc; 1991.
- Crooks J. Recovering kairos : toward a heideggerian analysis of procrastination, health, and well-being. Elsevier; 2016, p. 21–41. <https://doi.org/10.1016/B978-0-12-802862-9.00002-5>.
- Tawa N, Rhoda A, Brink Y, Urimumbeni G, Giljam-Enright M, Charumbira MY, et al. Stroke rehabilitation services in Africa – challenges and opportunities: a scoping review of the literature. In: Louw Q, editor, et al., Collaborative capacity development to complement stroke rehabilitation in Africa. Cape Town (ZA): AOSIS; 2020.
- Rathore SS, Hinn AR, Cooper LS, Tyroler HA, Rosamond WD. Characterization of incident stroke signs and symptoms: findings from the atherosclerosis risk in communities study. *Stroke*. 2002;33:2718–21. <https://doi.org/10.1161/01.str.0000035286.87503.31>.
- Rosamond WD, Folsom AR, Chambless LE, Wang CH, McGovern PG, Howard G, et al. Stroke incidence and survival among middle-aged adults: 9-year follow-up of the Atherosclerosis Risk in Communities (ARIC) cohort. *Stroke*. 1999;30:736–43. <https://doi.org/10.1161/01.str.30.4.736>.
- Yuki T, Kudo M. Factors related to continuation of health behaviours among stroke survivors. *J Jpn Phys Ther Assoc*. 2011;14:1–11. [https://doi.org/10.1298/jjpta.Vol14\\_001](https://doi.org/10.1298/jjpta.Vol14_001).
- Oberoi S, Chaudhary N, Patnaik S, Singh A. Understanding health seeking behavior. *J Family Med Prim Care*. 2016;5:463–4. <https://doi.org/10.4103/2249-4863.192376>.
- Rubin MN, Barrett KM. What to do with wake-up stroke. *Neurohospitalist*. 2015;5:161–72. <https://doi.org/10.1177/1941874415576204>.
- Saver JL. Time is brain—quantified. *Stroke*. 2006;37:263–6. <https://doi.org/10.1161/01.STR.0000196957.55928.ab>.
- Lin MP, Liebeskind DS. Imaging of ischemic stroke. *Continuum (Minneapolis)*. 2016;22:1399–423. <https://doi.org/10.1212/CON.0000000000000376>.
- Denti L, Artoni A, Scoditti U, Gatti E, Bussolati C, Ceda GP. Pre-hospital delay as determinant of ischemic stroke outcome in an Italian cohort of patients not receiving thrombolysis. *J Stroke Cerebrovasc Dis*. 2016;25:1458–66. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2016.02.032>.
- Arienti C, Lazzarini SG, Pollock A, Negrini S. Rehabilitation interventions for improving balance following stroke: an overview of systematic reviews. *PLoS ONE*. 2019;14:e0219781. <https://doi.org/10.1371/journal.pone.0219781>.
- Peterka RJ. Sensory integration for human balance control. *Handb Clin Neurol*. 2018;159:27–42. <https://doi.org/10.1016/B978-0-444-63916-5.00002-1>.

38. Al-Qazzaz NK, Ali SH, Ahmad SA, Islam S, Mohamad K. Cognitive impairment and memory dysfunction after a stroke diagnosis: a post-stroke memory assessment. *Neuropsychiatr Dis Treat*. 2014;10:1677–91. <https://doi.org/10.2147/NDT.S67184>.
39. Oyewole OO, Ogunlana MO, Gbiri CAO, Oritogun KS. Sexual dysfunction in a nigerian stroke cohort: a comparative cross-sectional study. *Sex Disabil*. 2017;35:341–51. <https://doi.org/10.1007/s11195-017-9488-6>.

### **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

**Submit your manuscript to a SpringerOpen<sup>®</sup> journal and benefit from:**

- ▶ Convenient online submission
- ▶ Rigorous peer review
- ▶ Open access: articles freely available online
- ▶ High visibility within the field
- ▶ Retaining the copyright to your article

---

Submit your next manuscript at ▶ [springeropen.com](https://www.springeropen.com)

---