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Original Article

Therapeutic itinerary of stroke survivors in a Nigerian tertiary hospital

Itinerário terapêutico de sobreviventes de acidente vascular cerebral em um hospital terciário nigeriano

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ABSTRACT

Objective: to analyze the therapeutic itinerary of stroke survivors from stroke occurrence to rehabilitation. **Methods:** therapeutic itinerary - route taken by individuals to solve their health problems, of 12 stroke survivors was explored using in-depth interviews and was thematically analyzed. **Results:** stroke survivors' routes were influenced by type of stroke and the state of the patient at onset of stroke. Lack of capacity facilitates vacillation from private to the public hospital settings. Entry into physiotherapy was dependent on self-referrals and referrals from physicians who often serve as gatekeeper of patients. Stroke significantly affected social life of stroke survivors, and the extent of stroke impairment and unmet expectations promotes medical pluralism among the survivors. **Conclusion:** stroke survivors are involved in intricate and lengthy therapeutic itineraries that are characterized by multiple care seeking practice.

Descriptors: Complementary Therapies; Rehabilitation; Stroke; Physical Therapy Specialty.

RESUMO

Objetivo: analisar o itinerário terapêutico de sobreviventes de acidente vascular cerebral, desde sua ocorrência até a reabilitação. **Métodos**: itinerário terapêutico percorrido por 12 sobreviventes de acidente vascular cerebral para resolver seus problemas de saúde foi explorado usando entrevistas em profundidade e análise temática. **Resultados:** as rotas dos sobreviventes foram influenciadas pelo tipo e estado do paciente no início do acidente vascular cerebral. A falta de capacidade contribuiu para indecisão entre buscar atendimento em hospitais privados ou públicos. A entrada na fisioterapia dependeu da demanda espontânea e de encaminhamentos realizados por médicos que atuam como sentinelas dos pacientes. O acidente vascular cerebral afetou significativamente a vida social dos sobreviventes. A extensão do comprometimento do acidente vascular cerebral e expectativas não atendidas promovem o pluralismo médico entre os sobreviventes. **Conclusão**: sobreviventes de acidente vascular cerebral estão envolvidos em itinerários terapêuticos complexos e extensos, caracterizados pela prática de busca de múltiplos cuidados.

Descritores: Terapias Complementares; Reabilitação; Acidente Vascular Cerebral; Fisioterapia.

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Introduction

Worldwide, stroke is the second leading cause of death and third foremost cause of disability. Studies have shown that 70.0% of all stroke incidences and 87.0% of all stroke-related deaths occur in low-and middle-income countries, which includes Nigeria with stroke prevalence rate of 1.4 per 1,000[1]. The burden of stroke is predicted to increase in these countries due to ongoing demographic changes, such as population ageing and heath transitions[2].

Surviving a stroke can be a long-term process that affects many aspects of survivors' quality of life. Few studies have tracked stroke survivors across continuum of care to understand the quality of care they received and their outcomes[3]. While significant attention in research has been towards epidemiological studies and interventions, the routes traveled in search for solutions to health issues; known as therapeutic itinerary is largely unexplored[4].

Therapeutic itinerary is the search for treatment or paths taken by individuals to solve their health problem. Therapeutic itinerary seems to be influenced by socio-cultural practices, and it is woven in multiple formal and informal networks of support to which a person belongs[5]. Anecdotally, stroke survivors in desperate search for cure, sometimes embark on a number of overt and covert journeys. Considering that engaging in therapeutic itinerary that involves to decide between different types of health systems may lead to possible interactions that may impact patients recovery and outcomes.

Mapping patients therapeutic itinerary may help inform policy and appropriate health education, as well as allow for better understanding of the health and illness behaviour and the undercurrent processes. Therefore, the aim of this study was to analyze the therapeutic itinerary of Nigerian stroke survivors from the point of occurrence of stroke to the period of rehabilitation in order to understand the context-specific facilitators of their health seeking behaviors or path to care.

Methods

12 stroke survivors of at least six months since onset that were attending the Outpatient Physiotherapy Clinic at Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC), Ile-Ife, Nigeria, were recruited in this qualitative study[6]. The study took place between December 2019 and February 2020. Eligible respondents were stroke survivors who had level of cognition of 24 points and above on Mini Mental State Examination scale and without any communication problem.

An in-depth interview guide was used to collect data in this study. The interview took place in a room dedicated for this study at the Physiotherapy Department. The interview was conducted by two of the authors using an interview guide that sought information on therapeutic itinerary of patient seeking care, stages and experiences with therapy, and the undercurrent for choices of therapy (Figure 1). The interviews were tape recorded and lasted for mean period of approximately two hours for each respondent, as rest intervals were allowed for the respondents. Interviews were conducted in either English or Yoruba depending on respondents' language of best proficiency. Yoruba language is the most widely spoken indigenous Nigerian language in the setting where this study was conducted. Translation of interviews conducted in Yoruba language into English was done by experts at the Department of Linguistics and African Languages of Obafemi Awolowo University, Ile-Ife, Nigeria.

Data was analyzed in steps following Graneheim and Lundman protocols on qualitative content analysis[7]. These protocols include manifest and latent content, unit of analysis, meaning unit, condensation, abstraction, content area, code, category and theme content analysis. The tape-recorded interviews were transcribed verbatim and were reviewed by authors to guarantee accuracy. Short descriptive codes were allocated to sections of the text, and codes expressing similar concepts were grouped together to form themes. Thematic content analysis of key themes and

phrases were used to organize data and narrations in all, quotes considered representative of themes were chosen for illustrations and to ensure readers can evaluate the transferability of the results. In order to protect the anonymity of the respondents, pseudonyms were used. Descriptive statistics of frequency and percentages were used to summarize data on the socio-demographic variables of the respondents.

Informed consent was obtained from each respondent and ethical approval for the study was obtained from the Research Ethics Committee of OAUTHC No. ERC/2019/12/20. Additionally, permission was sought from the respondents to tape record the interviews.

1. Stroke Incidence (sudden/insidious)
2. Immediate action after stroke (Call for help/observed/self-help/hospital/sought advice/ignored)
3. Hospital's action after admission (Immediately/ Delayed/ Not specific)
4. Hospital visitation experience (poor, fair good experience/ improvement following hospital's visit
5. Referral (another hospital/reason for referral/physiotherapy referral/source of physiotherapy referral)
6. Outcome after physiotherapy (Pain relief/mobility/functional improvements/return to work)
7. Social impact (interference of condition with social life/ interference with family function/interference with religious practice)
8. Sough care from alternative source (improvement from alternative source/perceived effectiveness between hospital, alternative and combination)

Figure 1 – Questions contained on the interview guide. Nigeria, 2019

Results

The socio-demographic and clinical characteristics of the respondents are presented in Table 1. The mean age of the informants was 56.4 years. The respondents were mostly traders and retirees. Most of the respondents were Christians (83.3%), had ischemic stroke (83.3%), and had no co-morbidities (83.3%). Analysis of the respondents' comments yielded six themes: point of acute care, clinical care experience, physiotherapy referral, outcome, social impact, and medical pluralism. The qualitative analysis results from the study are presented in italics. At acute stage stroke survivors end up in a public or private hospital, however, they enegage in medical pluralism at chronic stage. The path taken by the respondents while seeking care for stroke is presented in Figure 2.

Table 1 – Socio-demographic and clinical characteristics of the respondents (n=12). Nigeria, 2019

Variable	n (%)
Age Mean: 56.4	
Sex	
Male	8 (66.7)
Female	4 (33.3)
Religion	
Christian	10 (83.3)
Muslim	2 (16.7)
Occupation	
Retiree	4 (33.3)
Trader	4 (33.3)
Typist	1 (8.3)
Lawyer	1 (8.3)
Driver	1 (8.3)
Pastor	1 (8.3)
Duration Mean: 42.9	
Co-morbidities	
No	10 (83.3)
Yes	2 (16.7)
Type	
Ischemic	10 (83.3)
Hemorrhagic	2 (16.7)

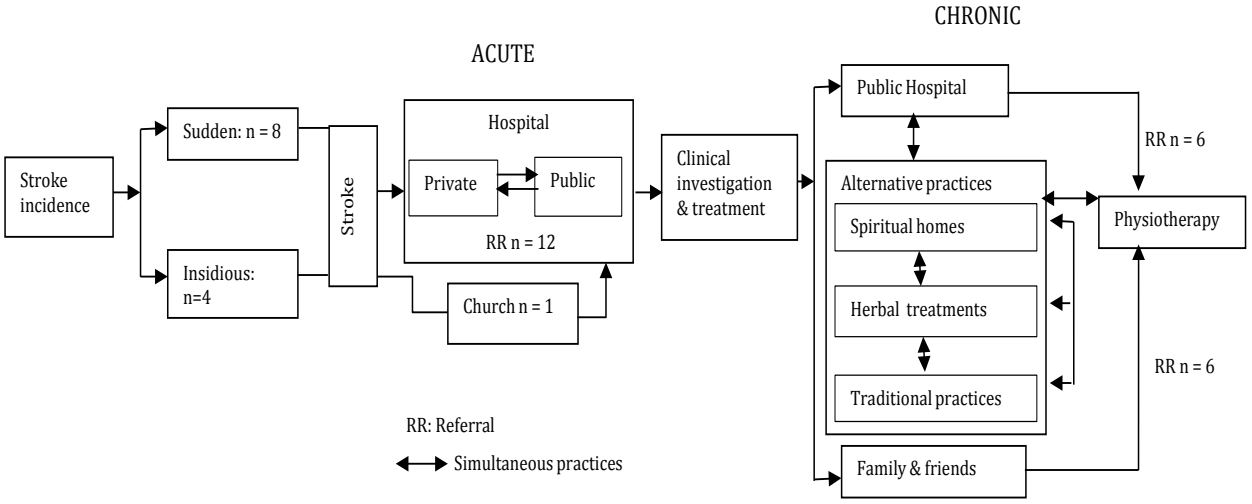

Figure 2 – Path taken by the study respondents while seeking care for stroke. Nigeria, 2019

Point of acute care

Owing to the nature of stroke, it's being sudden or insidious influenced initiation of care and preferences. Eight respondents described the onset of their stroke symptoms as sudden. One of the informants narrated that: *As a matter fact, initially I was feeling the pain on the left hand side, but I didn't know that it was stroke. All of a sudden the thing just happened, I just fell down in the toilet and I was taken to the hospital unconscious* (P6). Another informant recounts: *I'm a truck driver, I was carrying out my duty when I felt the need to ease myself, I came down and went to do so, on my return to the truck, I discovered my arm stopped moving, that was how it started* (P10). Consequently, these stroke survivors had no strong influence on the first point of call. One of the informants revealed saying: *They rushed me to a General Hospital...* (P6). One other informant said: *I didn't know anything; I later learnt I was carried from that place to one clinic* (P11).

Informants who reportedly had insidious onset of stroke to some degree had influence on where to initiate their care. Some of the informants expressed: *When it happened, I went to church...* (P1). *I called a friend who took me to the hospital* (P3). *I observed till 12 noon, then I called my child, and he took me to he teaching hospital* (P9). Overall, hospitals were the first destinations for initiation of care for stoke victims in this study, except for few instances among persons with insidious onset of stroke with mild to moderate symptoms.

For those who could take steps in the early phase of the accident to seek care, they largely patronized at hospitals, especially the private settings. Teaching hospitals often receive referrals from the private hospitals in serious cases, especially when the sufferer is unconscious. An excerpt reveals: *... I was there for 18 days and there was no improvement, later I was referred to the Teaching Hospital...* (P7). In exploring steps taken after the incident of stroke, another informant reported: *I sought advice from people who have had similar experiences either personally or it happened to someone related to them, which led to my using both medical and traditional medications* (P9).

Clinical care experience

Considering that almost all the informants began their path of care of stroke through the hospitals. Their hospital experiences with acute stroke clinical care were varied. For example, one of them retorted: *I was taken to the hospital the same day, but I wasn't attended to until after about 12 hours* (P1). Similarly, another informant narrated his hospital experience, thus: *After the stroke I was taken to the hospital that night. My wife appealed to the doctor because he was rejecting me... it took a while but they attended to*

me... (P4). In contrast, some other informants relished their positive hospital experiences involving immediate care or referrals as expressed in the following excerpts: *...went to the hospital before 24 hours and was continuously given Augmentin® injection, immediately, I was only referred to go for X-ray in another hospital* (P12). *I was referred from the emergency hospital to another hospital...* (P3).

However, the first point of call hospitals seems to be limited in capability to handle stroke accidents because outright referral for tests or for onward care were common practices: *I was referred from the emergency hospital to another hospital to do a brain test* (P3). *...I was just taken to the hospital. I took tests at this hospital and at another place* (P7). Also, another informant recounted: *I spent three days in casualty and did various tests; I was* (then) *referred to another hospital for Computed Tomography scan* (P9). Overall, the informants expressed diverge opinions on their visits to the hospitals. Specifically, some said: *The experience was bad because action was not taken immediately, hence causing further deterioration in health* (P1). *The first private hospital I went to they couldn't do much*... (P8). *When I got to the teaching hospital* [name withheld] *initial there was no bed space, I had to sit on the floor...* (P10). Some others expressed fair views on their hospital visits experiences, as cost of care seem to be what has robbed them of an otherwise good experience. For example, someone said: *My experience there was fair, the doctors did their best, the treatment so far was pleasant, just that the drugs we are meant to be given in the hospital because they are expensive and they tell us it's out of stock* (P9). *They attended to me on time but the test was too much, I mean too costly* (P4). On the positive, some expressed outright satisfaction with their hospital visits experiences. The following excerpts captured the experiences: *Honestly, I am satisfied* (P11). *It was good; I was attended to immediately* (P12). *I was immediately attended to and was satisfied with the treatment* (P3). *...The doctors tried in the other hospitals* [names withheld], *I was attended to properly* (P8). By and large, 11 informants attributed significant improvement in their conditions to visits to the hospital. The following excerpts succinctly describe the feelings: *It was helpful and my health has improved a little bit* (P1). *There was improvement from this hospital* (P6). *It improved my health, there was a difference* (P4).

Physiotherapy referral

In the journey to recovery from stroke, physiotherapy plays a significant role and it is an important route to return to normal or near normal and to work. The route of entry of stroke survivors into physiotherapy for rehabilitation care was explored in this study. One of the informants revealed: *I was for several years going to the hospital clinic, then my wife said to the doctor can't you refer my husband for physiotherapy. Then a woman working here* [at the clinic] *referred me to this place* [physiotherapy clinic]. Generally, physicians (6 respondents; 50.0%) and friends and relative (6 respondents; 50.0%) were instrumental in all referrals for physiotherapy. Some of the informants stated: *I was referred by a friend* (P1). While others said: *I was referred by the doctor* (P2). This study explicated on what the informant did after being referred. Among some of the survivors, there were no significant wait times between referrals and first and subsequent appointments. Some of the informant recalls: *I started early* (P8), *it was immediately I was referred* (P12), *it took about seven days before I started* (P3). However, some others presented for physiotherapy late. As seen in the following excerpts: *It took one and a half months after the incident* (P10), *it was not immediately because I didn't know there was such a thing as physiotherapy* (P1), *...Physiotherapist didn't come see me when I was in the ward* (P4). Still for the patients who presented for physiotherapy after referral did not receive therapy immediately, as they were either schedule for a future appointment or put on a wait list. For example, one of the informants stated: *It was 3 days after presenting, that I was given appointment to come for treatment...* (P5).

Outcome

This study also explored the usefulness of physiotherapy to functional outcome among the informants. Seven of the respondents, reported that physiotherapy was helpful in regaining mobility, four respondents reported pain relief, while two of them reported functional improvement, and only one respondent was able to return to work. The excerpts be-

low reveal the informants' accounts: *Physiotherapy has been helpful in my moving and walking around* (P1). *The pain has reduced too because they recommended analgesic gel* (P6). *Yes, I can do most things myself; I can even prepare amala* [local diet made from cassava]*, which I couldn't do before* (P6). Furthermore, an informant excitedly expressed return to work having received physiotherapy: *Can you see me now* (laughs). *I have been able to work better; my pain has also reduced* (P11). However, regaining hand function was reported only by few of the informants, and it is a bother for some of them as an aspiration that is yet to be achieved. Account of one informant reads: *There have been improvements in my legs, but it remains my hands. There has been no pain* (P7).

Social impact

While appreciable improvements in impairment variables were associated with receiving physiotherapy, all the informants were affirmative that their condition still interferes with social participation. For example, one of the informants narrated thus: *It has affected it* [social participation] *very seriously. Since this* [stroke] *happened, I have not gone to work, party or anywhere. All my girlfriends have run away including my wife, only my children come to visit me* (P4). Another said: *It has interfered with most of the things that I'm supposed to do as a father; I could not do it, because there is no work. Most of my friends visit me often. Just that I cannot visit them as I used to. Yes, I think a lot. Before I have a lot of money to spend but now, I am begging for money* (P6). Some others retort saying: *A lot! ... The places I go to regularly I can't regularly again; the activities I participate in actively I had to reduce my participation* (P9). *My social participation has reduced drastically, although sometimes some situation arises and wants to make me depressed, but I don't allow the thought of it* (P10).

A significant concern to the informants is the limitation in religious participation: *It has really affected my social life because I couldn't go to church regularly* (P1). *It has restricted my going out and praying posture* (P3). *I have to pray at home and not in the mosque as before* (P5). In addition to the foregoing, stroke was reported to significantly affect family life by nine of the informants. In the words of the informants, they recount that: *I used to play with my children, but I can't anymore. I used to buy something for them but I can't again* (P4). *My daughters don't talk to me as much...*(P5). *... My children don't talk to me like before* (P7). *I had to withdraw my children who were going to a private secondary school to a public school* (P10). *The condition interfered with my family because of the problems I put them through as a result of the illness* (P1). *...They still come to me; they didn't run away* (P3). *...They are always worried about my health* (P2).

Medical pluralism

Empirical and anecdotal evidence indicate that stroke survivors are engaged in multiple complex trajectories in seeking treatment upon stabilization in the hospital. Assertions from the informants show these practices: *I have used so many things I must not lie, when they said the hospital wasn't helping again I resulted to traditional medicine. Some people around me said it needed herbal attention so I had to go with using herbal concoction and medicines* (P9). *My brother in Lagos took me to Ijebu-Ode to one Indian doctor, as a matter of fact the man tried but when I could not cope with money, I quit. They gave me herbs; it works at Ijebu-Ode. It has helped me* (P6). *I have taken herbs* [laughs], *I am an African. Yes, I always go to church and herbal home* (P11).

Some of the informants tend to play down on some of the alternative practices like there is nothing to them. For example, someone said: *I have not sought any other place except the hospital here. But I have used soap* [soap in this context refers to a wide range of herbal formulations or concoction believed to have medicinal values] *but it's nothing at all* (P4). In addition, the patients embarked on spiritual healing itinerary: *I use avocado care, which I saw on facebook and my Imam comes to pray for me at home* (P5). *...My pastor comes to pray for me at home* (P7). *Prayers were offered for me in the church and my house* (P1). *...Water and oil from church* (P8). *Prayers from the mosque...* (P3). However, only two informants claimed to have other alternative practice: *Just the hospital, no other place* (P10, P12).

A follow up probe on the experiences with alternative practices with respect to suffering stroke revealed that one out of every two believed that it was helpful. The following excerpts captured the informants' feelings: *The herbs given to me were very helpful* (P6). *It made me feel better* (P1). *There were improvements because of my*

Pastor's prayers (P7). *It was good and helpful ...the herbal treatment helped me to start standing* (P9). *...Going to church and this (herbal home), ...Have been helpful*, [laughs]... (P11). But some engaged in these practices disclaimed that they give any benefits. Specifically, they said: *I didn't see any difference* (P3). *Did not notice an improvement with it* (P4).

Discussion

This study assessed the stage-to-stage journey of stroke survivors from the point of occurrence of stroke to rehabilitation period and to understand the context-specific undercurrents of their health seeking behaviors or path to care or cure. The search for therapy begins with the realization something is not right and by severity following stroke patients are more likely to consider urgent contact with emergency medical services[8]. The routes were influenced by type of stroke and the state of the patient at onset of stroke. Lack of capacity facilitates vacillation from private (which served as initial point of entry) to the public hospital settings. Entry into physiotherapy was dependent on self-referrals and referrals from physicians who often serve as gatekeeper of patients. Stroke significantly affected social life of stroke survivors, and the extent of stroke impairment and unmet expectations promotes medical pluralism among the survivors. These findings are discussed in turn in this section.

First, the finding of this study indicates that 75.0% of the stroke survivors had stroke of sudden onset and they eventually received hospital services especially in private settings. Conversely, those who reportedly had insidious onset of stroke to some degree influenced where to initiate their point of care. The level of severity of symptoms and loss of consciousness dictate preferences for health care seeking in stroke[9]. In this study, for those who could take steps in the acute phase of stroke in seeking care, they largely patronized or reported at hospitals, especially the private settings. Reasons for not seeking care from public hospital have previously been stated[10] and those seek care in public hospital teaching hospital largely because they are reputed to provide high-grade care.

Stroke survivors that began their care in hospital have varied hospital experiences. Some patients expressed delay in medical treatment at arrival, which maybe related with low-income settings. In contrast, some of the stroke survivors expressed positive hospital experiences, including immediate treatment. Patient experience of healthcare provision, including patient satisfaction, has become an important outcome measure for healthcare organizations and a mechanism to monitor quality advancement[11]. Ultimately, many of the respondents reported improved condition after hospitalization. It should be noted that patient's experience either good or bad is subjective, as there are a number of undercurrents beyond the surface.

Physiotherapy has a significant role in stroke rehabilitation and often starts within the first days and continuing into the chronic phase post stroke[12]. Prompt physiotherapy is considered as one of the most important aspects of acute treatment in a Stroke Unit[13]. The route of entry or referral of stroke survivors in physiotherapy as explored showed that physicians, and friends and relative were involved in the referrals. Authors postulated several factors for the low level of utilization of physiotherapy among physicians[14].

This study also explored the usefulness of physiotherapy to functional outcome among the patients. More than 50.0% of the respondents reported that physiotherapy was helpful in regaining mobility, 25.0% reported pain relief, while less than 20.0% of them reported functional improvement. However, only few informants reported regaining hand function and it is a bother for some of them as aspiration that is yet to be achieved. Recovery of upper extremity (UE) functions to practical level has been considered difficult in many patients with stroke[15]. Despite appreciable improvement in impairment following physiotherapy, all the respondents claimed that their condition still interferes with social participation. This phenomenon experienced by stroke survivors, though said not to be solely explained by activity limitation[16] or

motor or cognitive dysfunction, still hampers dynamics of family interaction[17].

It is noteworthy that hospitals were the first point of call for stoke sufferers but upon stabilization they embark on multiple complex practices that are typically undisclosed to the health care providers. Communication regarding alternative medicine between patients and carers may imbibe the culture of shared decision[18] about therapeutic options for patients since it promotes patient satisfaction and active patient involvement in their care. Traditional medicine is used largely and it has rapidly growing health system and with economic relevance. In Nigeria, there is dearth of information about traditional medicine use but available data put the use of conventional nutritional supplements and alternative medicine mostly in the form of herbal products, at an estimate of about 31.9%[19].

Concurrent use of herbal and orthodox medicines[20] causes interactions between these two forms of medicines which can lead to undesirable pharmacokinetic and pharmacodynamics effects. Till date, there is an apparent dearth of investigation on alternative practices among patients receiving rehabilitation. A follow up probe on the experiences with alternative practices with respect to suffering stroke revealed that one out of every two believed that it was helpful. Advocates of alternative medicine hold that the various alternative treatment methods are effective in treating a wide range of major and minor medical conditions, and contend that some published research proves the efficiency of specific alternative treatments[19].

The participants in this study consisted of volunteers and they were recruited conveniently. These respondents might have different itinerary compared to those who were not interested in the study and this may limit the transferability of our findings. Also, we could not evaluate respondents' therapeutic itinerary to their socio-demographic variables. It is possible that level of income, for instance, may influence therapeutic itinerary of stroke survivors.

Conclusion

From this therapeutic itinerary study, it was found that stroke survivors transitioned from the private to the public health sectors. The primary point of care that may be close enough to the patients seem not adequately equipped to care for stroke thus necessitating referrals and all its consequences. It was found that physiotherapy was not a compulsory stereotype for stroke survivors in the acute phase, possibly due to late referral from medical practitioners with first contact. It was also seen that the therapeutic itineraries of stroke survivors included alternative medicine practices combined with conventional medicine. Conclusively, stroke survivors are involved in intricate and lengthy therapeutic itineraries that are characterized by multiple care seeking practice.

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Collaborations

Mbada CE contributed to the conception and design of the study. Mbada CE, Ogunleye OM, Ogundele AO, Oyewole OO, Ademoyegun AB, Obembe AO and Fatoye F contributed to the analysis and interpretation of data, drafting the manuscript or revising it critically for important intellectual content and final approval of the version to be published.

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