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Exploring the Experiences of Family Caregivers in the Management of Stroke  
Among Older Adults in Nigeria: A Qualitative Study

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# **Exploring the Experiences of Family Caregivers in the Management of Stroke Among the Older Adults in Nigeria: A Qualitative Study**

## **Abstract**

**Background:** Stroke, a significant neurological condition, often results in stroke survivors who are older adults relying on family caregivers, including children and spouses, leading to increased challenges for caregivers.

**Objective:** This study investigates the experiences of family caregivers caring for stroke survivors who are older adults, focusing on the context of stroke management.

**Methods:** Participants were purposively sampled, and three focus group discussions involving family caregivers (n=18) of older adults who had experienced strokes were conducted. Conversations were recorded, translated, transcribed, and subjected to thematic analysis utilizing NVivo (version 12 pro) software.

**Results:** Thematic analysis yielded five distinct themes. The first theme illuminated family caregivers' insights regarding the management of stroke in their members or significant others. The second theme emphasized the support and information received at the medical facility. The third theme showcased the perceived value of the information provided. The fourth theme highlighted unmet needs for both information and training in social support. The final theme illuminated the participants' preferences for how they would like to receive information and training.

**Conclusion:** This study highlights family caregivers' experiences, encompassing a range of burdens, stresses, and challenges while caring for stroke survivors who are older adults. Findings emphasize the necessity for formal caregivers to provide adequate information, support, and training to family caregivers, thereby alleviating their burdens and enhancing stroke management in a home environment.

**Conflict of interest:** Authors declared no conflict of interest

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## Introduction

1 Family members have long been involved in caregiving (1). Population ageing, longer lifespans  
2 of older adults with significant morbidities, and poorly coordinated health systems have all  
3 increased the caregiving burden on family members (1). Caregivers' expanded role has also  
4 resulted from the growing trend of early discharge and treatment (2). Stroke caregivers often  
5 face difficulties that arise from caregiving for their loved ones who are stroke survivors, and  
6 these include stress, burden, and a lower standard of living (3).

7 Stroke represents a significant public health concern, standing as a leading contributor to global  
8 morbidity and mortality (4). Reports indicate that 70% of all stroke deaths and 87% of disability  
9 are attributed to low-income and middle-income countries (5,6). Notably, African nations,  
10 including Nigeria, have observed a rising prevalence of stroke (7). Nigeria has a crude  
11 incidence of 27.4 per 100,000 in a year and a 30-day case fatality rate as high as 40% (8). This  
12 is expected to increase as the population ages. Stroke often places survivors in a position of  
13 dependency on family caregivers (9). In the absence of adequate post-discharge management,  
14 the responsibility of caring for stroke survivors frequently falls on family members and close  
15 associates (10). Reintegration into home life after a stroke presents a formidable challenge for  
16 patients, who must adapt to altered life circumstances marked by physical limitations, stress,  
17 depression, cognitive decline, and diminished quality of life (11).

18 There is a growing understanding of the value of family involvement in patient outcomes and  
19 the significance of holistic care for patients undergoing stroke recovery (12). Gaining a  
20 profound comprehension of individuals' encounters with stroke can offer insight into the unmet  
21 needs and challenges faced by caregivers (13). Despite prior experience in caring for those with  
22 chronic illnesses, the demands and vigilance required of family caregivers to ensure adequate  
23 home-based care can prove overwhelming and draining (14). Due to weighty responsibilities,  
24 uncertainties, anxieties, and curtailed social lives, informal caregiving has been identified as a  
25 burden culminating in physical and psychological strain, along with decreased quality of life  
26 for caregivers (3,15).

27 Several scholars in Nigeria have directed their attention towards quantitatively assessing the  
28 quality of life and burden experienced by caregivers of stroke patients (16–18) and there are  
29 documented high levels of caregiver strain, negative caregiver experience, and very low social  
30 support (9,19,20) with little or no information on the lived experiences of family caregivers of  
31 stroke survivors who are older adults. To the best of our knowledge, this is the first study  
32 employing a qualitative approach to gain in-depth insight from the target population in Nigeria.  
33 This we believe will bring about a comprehensive understanding of family caregivers' lived  
34 experiences throughout the stroke care continuum and ultimately guide future interventions  
35 and policy formulation on a holistic approach to stroke care of the older adults. The central  
36 objective of this study was to explore the lived experience of family caregivers in the  
37 management of stroke in older adults in Nigeria.

## 38 Methodology

39 A cross-sectional qualitative design was employed to address the objective of this study.

## 1 **Study setting and participants**

2 Family caregivers of stroke survivors who are older adults were recruited through outpatient  
3 case notes from the geriatric centre and neurology clinic in University College Hospital, a  
4 tertiary facility in Southwestern Nigeria, following ethical approval and permission from  
5 authorities. Inclusion criteria required participants to be in-dwelling caregivers actively  
6 involved in home-based care of the stroke survivors who are older adults, stroke patients in this  
7 context should be at least 60 years old and should have been previously diagnosed with acute,  
8 focal neurological deficit as a result of vascular injury to the central nervous system with a  
9 neuroimaging evidence of infarct or hemorrhage (21), caregivers must be aged 18 years and  
10 above, and willing to participate. Exclusion criteria involved the denial of potential participants  
11 to provide informed consent. Purposive sampling was used and a total of eighteen family  
12 caregivers participated in the focus group discussion.

13

## 14 **Data collection procedure**

15 Focus group discussion was used to facilitate conversation with participants as it can elicit  
16 extensive information on the subject matter (22). Three focus group discussions were  
17 conducted, with two groups consisting of female family caregivers and the third group  
18 consisting of only male caregivers, each group comprising six participants. The interviews  
19 were conducted in a lounge with a comfortable seating arrangement at Adebutu Kesington  
20 Geriatric Rehabilitation Centre, University College Hospital, Ibadan. Informed consent and  
21 sociodemographic information were obtained before the discussion, covering age, gender,  
22 educational qualification, religion, ethnicity, marital status, relationship with patients, duration  
23 of care, and patient age. A semi-structured interview guide (supplementary file 1) containing  
24 open-ended questions was used to elicit enough information from the participants. The  
25 questions asked were informed by a literature review. The interview guide contained the main  
26 questions and probes. Participants were informed about audio recording and ground rules.  
27 Interviews lasted approximately 60 minutes and were conducted in February 2023.

28

## 29 **Data analysis**

30 Audiotapes were translated and transcribed, with researchers ensuring data quality and  
31 accuracy. Transcriptions were anonymized and underwent further validation, correcting errors  
32 and combining fragmented issues. The researcher and a team of three experienced qualitative  
33 researchers conducted the analysis. NVivo 12 software facilitated coding, sub-coding,  
34 categorization, and theme identification, employing an inductive-dominant approach. The  
35 methods used for data analysis included creating resources, using nodes to code, and running  
36 queries to provide findings that allowed theories to be verified and developed. Codes and  
37 specimens generated were checked carefully for review and critique by the researcher and the  
38 team. Disagreements were resolved among them by reaching a consensus on any conflict  
39 before proceeding to the next phase. Common and peculiar trends, as well as similar and

1 divergent opinions, were noted. Findings were summarized, and relevant verbatim quotes were  
2 provided.

3

#### 4 **Ethical consideration**

5 Ethical approval was obtained from the College of Nursing, Midwifery, and Health research  
6 ethics panel (No.1325) at the University of West London and the University of Ibadan/  
7 University College Hospital Ethics Committee (No. UI/EC/22/0410). Verbal and written  
8 informed consent were obtained, with participants informed of their right to withdraw.  
9 Anonymity was ensured through assigned identity numbers, and strict confidentiality and  
10 privacy were maintained throughout the study.

#### 11 **Results**

##### 12 **Table 1: Socio-demographic Characteristics of Study Participants**

13 Eighteen participants with a mean age of 42.94± 12.04 years were included in the study. The  
14 majority (66.7%) were females, aged between 35 and 59 years, 77.8% were married, and 88.9%  
15 were of Yoruba ethnicity.

##### 16 **Emergent themes across all participant groups.**

17 Analysis of interview data revealed five distinct themes representing the experiences of family  
18 caregivers of stroke survivors who are older adults.

##### 19 Experiences in managing stroke-afflicted family members/significant others:

##### 20 • Challenges Faced by Female Participants:

21 Many female participants in the focus group discussion highlighted the difficulties they  
22 encountered while assisting hospitalized family members with daily tasks like eating,  
23 bathing, and using the restroom. Financial strain emerged. Is a recurrent issue due to  
24 the need for various medications and frequent tests. Participants expressed distress over  
25 the constant financial burden associated with procuring medicines and undergoing tests.  
26 A participant emphasized the challenges: *"The experience I have involves issues with  
27 money and relentless pursuit of acquiring medications. We often lack enough money to  
28 buy certain medications. Another aspect involves the rotation of different doctors  
29 attending to the patients during the hospital stay. Different doctors prescribe  
30 medications, demanding further tests, making it challenging to manage expenses."*

31

##### 32 • Challenges Faced by Male Participants:

33 Male participants echoed similar financial challenges and stressors related to the  
34 hospitalization of family members due to stroke. They also noted behavioural shifts and  
35 mood swings in the affected individuals, including increased irritability and reduced  
36 ability to perform tasks. A participant expressed the challenges faced: *"My experience  
37 is undoubtedly challenging, especially the considerable stress within the hospital  
38 setting. The lack of basic amenities such as water makes it hard for me. I had to descend  
39 to the ground floor to fetch water for cleaning at the hospital."*

##### 40 • Home Treatment and Positive Aspects:

1 A smaller subset mentioned that their stroke-affected family members received  
2 treatment at home under a doctor's care and utilized massage equipment. Some  
3 participants highlighted positive aspects, including the importance of balanced dietary  
4 intake, regular exercise, and adherence to prescribed medications.

5  
6  
7 Information and support received at the facility:

8 Insight from female focus group discussion participants shed light on the information and  
9 support received at the healthcare facility. Most articulated receiving guidance on dietary  
10 preferences for stroke patients, emphasizing the avoidance of sugary and processed foods.  
11 Additionally, recommendations for supervised walking sessions to promote mobility were  
12 highlighted. However, some participants expressed that the information during visits focused  
13 primarily on tests and adhering to prescribed medications. One participant recounted her  
14 experience, revealing challenges and financial strains associated with medical procedures and  
15 medication procurement. In contrast, two participants mentioned not receiving any  
16 information. One anticipated guidance related to the National Health Insurance Scheme  
17 (NHIS), while another received assistance through reduced admission fees, complimentary  
18 medications, and massage therapy. The proactive approach of seeking information questioning  
19 was emphasized.

20 Male participants conveyed receiving various forms of information at the healthcare facility,  
21 including adherence to prescribed medications, dietary choices, stress reduction, and patient  
22 exercises. The transformative effect of this guidance was highlighted, leading to a shift in  
23 perceptions and stroke.

24 • Usefulness of the information:

25 Participants overwhelmingly expressed the usefulness of the information received.  
26 Many credited following the guidelines for tangible improvements in the patient's  
27 condition. Positive changes were noted in family members' health, with a shift in  
28 perception about stroke leading to the adoption of beneficial practices. A participant  
29 highlighted the transformative effect of this guidance:

30 *"The information helped us because we initially thought it was a*  
31 *spiritual problem and we were contemplating traditional remedies until*  
32 *the medical expert clarified that it was a stroke and could be addressed*  
33 *through exercises. This revelation prompted us to embrace exercises*  
34 *earnestly."*

35  
36 • Unmet information and Social Support Needs:

37 Several female participants voiced unmet needs for information and training,  
38 particularly regarding post-stroke complications. Dissatisfaction with the  
39 physiotherapy services and the desire for comprehensive drug usage guidance were  
40 highlighted among male participants. They expressed a need for awareness of potential  
41 side effects and the expected duration of recovery. One of the participants elucidated  
42 her expectations:

43 *"What I hoped to gain here is the insight into the eye treatment we initially*  
44 *sought. My father had glaucoma, and we were directed to the general outpatient*

1            *department for his health evaluation. Following consultation with the doctor,*  
2            *we were referred to the geriatric unit, where several tests were prescribed and*  
3            *conducted. However, my anticipation was for the doctor to expound on the test*  
4            *results, elucidate my father's condition, and provide a comprehensive*  
5            *understanding. Instead, the doctor merely collected the test results, prescribed*  
6            *medications, and assigned the next appointment."*

7  
8        One participant emphasized the disparity between medical practitioners' efforts and the  
9        insights captured in medical literature. Beyond the hospital environment, participants sought  
10       guidance on machines and practices to aid recovery. The uncertainty surrounding medication  
11       continuity prompted attendance at the session to seek clarity. One participant elucidated this  
12       perspective:

13            *"Notably, the medical practitioners are indeed making efforts, but their delivery*  
14            *falls short of the insight captured in the medical literature. Those outside with*  
15            *the experience of the illness know what the patient will use for them to recover.*  
16            *Like in the hospital now, there are physiotherapy resources; however, certain*  
17            *critical details are occasionally left unaddressed. Beyond the hospital*  
18            *environment, those with experience will tell us the kind of machines and things*  
19            *we should buy, and it is helping the patient. Another thing is doctors prescribe*  
20            *drugs for us; I don't understand how the patient will be using it for life or if it*  
21            *has a stopover for some time, and maybe some drugs will be added or removed.*  
22            *The uncertainty prompts me to attend this session today, seeking clarity on the*  
23            *continuity of the medication"*.

24  
25        The preferred manner of receiving information and training:

26        The majority of female participants expressed a strong willingness to receive comprehensive  
27        training and information related to stroke and its management. One participant explicitly stated  
28        her openness to learning from stroke experts, expressing a desire for more insights into the  
29        disease, particularly given her mother's absence of high blood pressure:

30            *"I am wholeheartedly open to receiving such training. Stroke experts can*  
31            *lecture us to learn more about the disease. What baffled me is that my mother*  
32            *does not have high blood pressure. After all, I've heard that someone with high*  
33            *blood pressure can easily develop a stroke. Her recent blood pressure readings*  
34            *were 100 and 110. She has never nursed high blood pressure or diabetes."*

35  
36        Both male and female participants expressed enthusiasm for participating in training programs  
37        aimed at aiding their family member's recovery. One participant emphasized the need to  
38        comprehend the ailment and methods to prevent potential recurrences. A few male participants  
39        suggested that prior notice, ideally three to four days before training, would facilitate their  
40        participation. However, some participants shared that if essential information is provided when  
41        needed, formal training might not be essential. One participant advocated for more accessible  
42        consultations by augmenting the number of available doctors:

43            *"Having more doctors accessible for consultations would be advantageous.*  
44            *This way, ample time could be allocated to addressing queries and concerns."*

## 1 Discussion

2 Our study revealed a preponderance of female family caregivers in 12 out of 18 of the  
3 participants This finding is similar to several studies which reported a higher percentage of  
4 female family caregivers (23–26). This may be a result of a belief system that places the burden  
5 of caregiving of family members on the female gender (27,28). Female caregivers are likely to  
6 combine stroke caregiving with domestic activities and job demands which could result in  
7 increased stress and burden (9,26). These hurt their financial strength and purchasing power  
8 which may result in financial dependence and low self-esteem. Therefore, a formulation of  
9 policy that provides favourable socioeconomic inclusion of female caregivers, educational  
10 empowerment, and paid time for service provided are important to improve caregiver and  
11 stroke survivors' quality of life.

12 The identification of five key themes, covering stroke management, information, and support  
13 reception, utilization of provided information, unmet information, and training delivery,  
14 provides valuable insights into the multifaceted challenges within the caregiving domain.

15 The narratives from our study participants underscore the substantial role played by family  
16 caregivers in assisting stroke-affected individuals with their daily living activities which often  
17 lead to significant burdens. This is similar to existing literature that highlights the demands and  
18 stress placed upon informal family caregivers in stroke scenarios as a considerable proportion  
19 (25 -75%) require assistance for daily activities from family caregivers (29–31). This  
20 emphasizes the pivotal role these caregivers play (32). Our study resonates with prior research,  
21 exemplified by Jika *et al.*, (33), which illuminated the physical, financial, and psychological  
22 strains endured by family caregivers in a similar context. Several studies carried out in different  
23 geographical regions in Nigeria highlighted high levels of caregiver strain as a result of a lack  
24 of social support and strain on family income (9,19). Additionally, studies conducted in  
25 different countries including Denmark and Italy gave an exposition on the caregivers'  
26 emotional tolls emanating from difficult communication and memory deficits with stroke  
27 survivors (34–37). Similarly, a study conducted in Brazil revealed detrimental changes in  
28 different domains such as overall quality of life, physical, emotional, social, and environmental  
29 of family caregivers of stroke survivors (38). This indicates that family caregivers of stroke  
30 survivors across various parts of the world undergo similar burdens and experiences. Hence  
31 personalized interventions focusing on improved overall quality of life are needed to reduce  
32 the associated stress of caring for stroke survivors who are older adults.

33 Financial concerns emerge as a salient issue, with participants expressing varying perspectives,  
34 ranging from support such as subsidised admission fees and free medication, to unmet  
35 expectations, such as the absence of the National Health Insurance Scheme (NHIS) provision.  
36 Out-of-pocket payment is a major challenge in Nigeria as health insurance is limited to only  
37 5% of which the majority are government employees. This has made individuals and families  
38 incur catastrophic expenses further impoverishing them because of their health challenges (39).  
39 This aligns with findings by Gott *et al.*, (40) underscoring the financial strain endured by  
40 family caregivers due to the direct and indirect costs of care, significantly impacting both the  
41 quality of care received by patients and the well-being of caregivers. Providing a

1 comprehensive support system, including financial assistance and health counselling, becomes  
2 imperative for mitigating these challenges (41). The healthcare system in Nigeria is still largely  
3 underdeveloped with poor facilities and inadequate staffing of skilled personnel especially in  
4 the rural area (42). Our study was carried out in the urban centre of Ibadan, Oyo State in one  
5 of the leading teaching Hospitals in Nigeria, University College Hospital. The care received by  
6 the patients and their family caregivers while on admission and after admission is suboptimal  
7 as expressed by our participants. However, the scope of our study is limited to the experiences  
8 of stroke survivors and their respective family caregivers. It is imperative to explore the  
9 institutional or health system capacity in stroke management.

10 The need for general information support was highlighted by our study participants as it reveals  
11 gaps in knowledge of stroke and its management. A noteworthy finding is the perception of  
12 stroke as a spiritual affliction by one of our study participants which could hurt the care of  
13 stroke survivors who are older adults. Recognizing the importance of providing accurate  
14 information and support for effective stroke management is paramount (43). Hence  
15 collaboration between formal carers and family caregivers is a crucial support system, offering  
16 valuable insights and knowledge that positively impacts stroke management. A study by  
17 Mackenzie *et al.* (44) reveals caregiver strain during the active phase of stroke prompting active  
18 seeking of essential information. This underscores the pivotal role of coordinated efforts  
19 between formal and family caregivers in enhancing the understanding and implementation of  
20 appropriate care practices (45,46).

21 While the study shed light on the information and support landscape, it also underscores  
22 existing gaps. A prevailing unmet need for specific information and social support training is  
23 evident, encompassing areas such as stroke awareness, seizure management, physiotherapy  
24 approaches, and the interpretation of diagnostic test results. The importance of appropriate  
25 information and support has been identified especially during the early stages of stroke  
26 incidence (43).

27 This underscores the significance of bridging these knowledge gaps, as an informed caregiver  
28 is better equipped to provide optimal care and address survivors' needs (44,45,47). Caregivers'  
29 enthusiasm for knowledge acquisition does not always align with successful fulfilment (45),  
30 emphasizing the need for effective communication and tailored educational interventions.

31 Overall, our study underpinned the complex interplay between caregiving challenges,  
32 information dissemination, and support dynamics. This study not only offers valuable insights  
33 into the existing landscape but also highlights the critical need for targeted interventions that  
34 encompass comprehensive support, knowledge enhancement, and effective coordination  
35 between formal and family caregivers. By addressing these dimensions, the study has the  
36 potential to significantly enhance stroke management outcomes and alleviate the burdens borne  
37 by both caregivers and patients in Nigeria.

### 38 **Conclusion**

39 Beyond formal caregivers, family caregivers emerge as pivotal stakeholders significantly  
40 contributing to stroke management and its associated complexities. This study provides a

1 profound understanding of family caregivers' encounters in Nigeria's stroke management  
2 realm. Their journey is marked by a continuum of burdens, anxieties, and challenges arising  
3 from tending to stroke-affected older adults during their recovery. Importantly, the study  
4 reveals an eagerness among informal caregivers to acquire enhanced knowledge concerning  
5 stroke prevention and effective management of its repercussions. Considering these findings,  
6 it becomes imperative for formal caregivers to extend substantial support and comprehensive  
7 training to family caregivers. Such interventions should ideally commence during the acute  
8 care phase at the hospital and persist into the post-discharge period. This proactive approach  
9 can alleviate caregiver strain, enhance the quality of home-based stroke management, and  
10 subsequently contribute to more favourable patient outcomes.

### 11 **Strengths and Limitations of Study**

12 The strength of this study is rooted in its thorough exploration of the experiences encountered  
13 by family caregivers attending to stroke-affected older adults in Nigeria. Our sample size was  
14 considerably adequate for the methodology employed. However, this study, conducted within  
15 the southwestern region of Nigeria, may have limitations concerning its generalizability to  
16 other geographical areas. Additionally, it is acknowledged that recall bias might be inevitable,  
17 considering the reliance on participants' subjective recollections as the basis for the study's  
18 findings and translation of local languages to English. Purposive sampling employed could  
19 introduce selection bias thereby eliminating potential participants. The preponderance of  
20 female participants could have limited gaining extensive insight into male experience in stroke  
21 caregiving to older adults.

22

23

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