




# Caring for a Loved One with Stroke in Lomé, Togo: an Intersectional Framework

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## Abstract

The rate of strokes in Africa, particularly among lower socio-economic classes, is increasing. The impact on long-term, informal caregivers of stroke patients is not known, as most research has focused on acute and discharge care. This study reports on the findings from a study of in-depth qualitative interviews with 20 caregivers to family members with stroke diagnoses in Lomé, Togo. Findings show that social, structural, and relational forces greatly impact the lives of informal caregivers. This study offers an understanding of the caregivers' challenges through an intersectional framework which can be used to inform socio-economic, emotional, and health system supports for caregivers.

**Keywords** Stroke · Togo · Africa · Caregiver · Intersectional approach

Stroke is a debilitating condition that can cause major disabilities to its victims. A stroke happens when a blood vessel going to the brain is blocked or bursts. Without the needed blood and oxygen, brain cells die. When a body region does not receive the blood it needs, it cannot function properly (American Stroke Association, 2020). People

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who suffer from stroke may not be able to perform activities of daily living (ADL) including independently eating, dressing, walking, or bathing (Edemekong et al., 2020); and consequently, may need long-term care. Stroke is estimated to be the top cause of non-accidental chronic disability and leads to higher disability-adjusted life years for survivors (Imarhiagbe et al., 2017). Worldwide, Africa has the highest incidence, prevalence, and case fatality rates of stroke (Agyemang et al., 2012; Ezejimor et al., 2017; Khedr et al., 2014; Walker et al., 2010, 2011). Stroke has significantly increased in Africa among all population groups, and especially among people with lower socioeconomic status (Van de Vijver et al., 2013).

Informal caregiving has been the bedrock of the provision of care to individuals with illness and disability in Africa. Informal caregivers are generally women (Akosile et al., 2009; Badaru et al., 2017; Imarhiagbe et al., 2017; Kangethe, 2010; Lyons et al., 2015; Versey, 2017). The preponderance of women, particularly elderly women, in many developing countries, as informal caregivers is informed by factors such as patriarchal cultures that lead to uneven gender power dynamics (Kangethe, 2010). Caregivers are often much younger than stroke survivors (Badaru et al., 2017). Older caregivers, however, have been found to report worse quality of life than younger caregivers (Badaru et al., 2017).

More than one-third of long-term stroke survivors are functionally dependent (Aziz et al., 2016). Yet, the plight of informal caregivers for stroke survivors has received little research attention in Africa (Aziz et al., 2016; Badaru et al., 2017). Research on stroke has concentrated on acute care and early supported discharge, but paid little attention to longer-term community support for stroke survivors in Africa (Aziz et al., 2016). Further, informal caregiving environments in the developing world often face the challenge of poverty, which is stressful, taxing, and likely to result in burnout (Bessa et al., 2012; Cordes & Dougherty, 1993; Kangethe, 2010).

The complex and multilayered functions of caregiving, in addition to the sheer burden of caregiving, may negatively affect the quality of life among caregivers (Akosile et al., 2011; Anderson et al., 1995; Isaac et al., 2011). Camak's (2015) review of literature of stroke caregiving in the U.S., reported that the abrupt timing of a stroke and the necessary response can land an unprepared caregiver in this role. "The changes that occur due to a beloved family member experiencing a stroke event produce a crisis experience for the caregiver. These changes include role, economic and social adjustments in addition to appropriately meeting the physical and medical needs of the stroke survivor" (Camak, 2015, p. 2379). The Stroke Association of the United Kingdom (2013) and Aziz et al. (2016) reported important post-stroke care related difficulties. Sixty-four percent of caregivers were emotionally drained, more than two-thirds reported being stressed, and about 80% reported frustration or anxiety. Three-quarters of informal caregivers of stroke survivors felt ill-prepared for their caregiving role, and two-thirds reported relational difficulties with the stroke survivor. Badaru et al.'s (2017) review of the literature on informal caregivers in Africa reported that most caregivers carried a severe burden and had a moderate quality of life. The duration and the burden of caregiving were found to affect caregiver quality of life. The caregiver's age as well as the functional status of the stroke survivor were also determinants of caregiver quality of life. The functional status of the stroke survivor as well as having an intimate relationship with

the stroke survivor affect the caregiving burden. Their review also raised questions about the lack of understanding around income, employment status, and financial stress for caregivers (Badaru et al., 2017).

The burden of informal caregiving with regard to stroke has led to a call for research into the circumstances under which informal caregiving is provided, and also, its effects on the caregivers (Aziz et al., 2016; Brereton et al., 2007; Gaugler, 2010; Greenwood et al., 2011; Kangethe, 2010; McGurk & Kneebone, 2013; Olai, 2010; Rombough et al., 2007; Salter et al., 2010; White et al., 2004). In particular, there is a need for understanding the experiences of African caregivers to survivors of stroke.

This article shares findings from a qualitative study researching the lived experiences of caregivers to stroke survivors in Lomé, Togo. Using an intersectional framework, this qualitative study explored how social, structural, and relational forces impact caregiving and the quality of life of Togolese caregivers.

## Intersectionality Framework

Crenshaw (1988, 1989, 1995) first developed the concept of intersectionality to explain how the discrimination experience of Black Americans was at the intersection of race, gender, and social status. Intersectionality has expanded as a research paradigm (Hancock, 2007; Hankivsky & Cormier, 2009; Simien, 2007) concerned with the simultaneous nature of multiple categories at multiple levels (Hankivsky et al., 2010). According to Brah and Phoenix (2004) intersectionality governs the idea that “different dimensions of social life cannot be separated into discrete or pure strands” (p. 76). This means that all categories of social identity are equally important and no one category is more relevant than another (Hankivsky et al., 2010). It is also important to note that the concept of intersectionality is not just adding categories to one another (gender, race, class, sexuality, etc.) (Brewer, 1993; Hankivsky et al., 2010; Zerai, 2000). Instead, it is concerned with understanding what is created and experienced at the intersection of two or more axes of oppression. This ensures recognition of the multidimensional and relational nature of social locations and places, lived experiences, social forces, and overlapping systems of discrimination and subordination at the center of the analysis (Hankivsky et al., 2010).

Though the intersectional model has gained traction, several studies reported that intersectionality scholarship in general, and specifically methods for developing research studies from an intersectionality perspective, remain at the margins of health research and policy (Hancock, 2007; Hankivsky et al., 2010; Morrow et al., 2007; Weber, 2005). This article uses an intersectional paradigm to address the complexity and diversity of the lives of caregivers studied in Lomé, Togo, “drawing on the analysis of categories” that our study participants reported as “relevant” to their caregiving experiences (Cronin & King, 2010, p. 884).

## Geographic Setting

Located in West Africa, Togo has an estimated population of 7.6 million people with an estimated poverty rate of 55% in 2015 (World Bank, 2018). The state budget allocated to the health sector has been dominated by the small proportion of government expenditure (approximately 5%), low disbursement, and under-mobilization of internal resources as well as an acute shortage of health workers (World Health Organization [WHO], 2014). The density of nurses and midwives per 1000 population is 0.274 while that of physicians per 1000 population is 0.053 (Global Health Observatory [GHO], 2016). Additionally, Togolese health practitioners experience severe emotional distress, which is compounded by their resource-limited settings where weak health systems undermine practitioners' ability to provide quality care (Kpassagou & Soedje, 2017). Another challenge to the Togolese health sector is the limited number of health facilities throughout the country, especially in the rural areas (L'Institut National d'Assurance Maladie [INAM] 2016). Stroke care and rehabilitation services are, generally, nonexistent in low-income countries such as Togo (Pandian et al., 2016).

A study by Assogba (2015), revealed that out of 43,558 Togolese patients sampled in both public and private hospitals, 986 of them were stroke patients. They also reported that over 89% of these 986 stroke patients (89.2%) were found in public health facilities with the remaining in private health facilities. The incidence rate of stroke in Togo is approximately 79.6 per 100,000 inhabitants per year. However, this low figure may be due to the bias in the recruitment of patients and the smaller size of the country's population. Other studies have higher incidence rates, ranging from 170 to 360 per 100,000 inhabitants between ages 55 and 64 years, and from 490 to 890 per 100,000 inhabitants between ages 65 and 74 years (Pickle et al., 1997; Sacco et al., 1998).

## Methodology

### Data Collection and Sample

The first author, along with an experienced and trained research assistant, conducted in-depth qualitative interviews with 20 caregivers to family members with stroke diagnoses in Lomé, the capital of Togo, from October to December, 2012. To be included, the participant had to be the primary care provider for the person with a stroke. Snowball sampling was used to recruit participants. To ascertain the experiences of caregiving to a person with stroke diagnosis, a series of open-ended questions asked the caregivers to elaborate on topics such as: why they were the ones providing caregiving, their daily caregiving activities and challenges, how they overcame these challenges, and what, if anything, they had acquired as caregivers. They were also asked about how their loved-ones became a victim of stroke and factors that they believed caused the stroke. These

open-ended questions were created based on the literature on caregiving to people with stroke as well as some of the findings from the first author's past caregiving research (Bessa et al., 2012).

In-depth interview questions were chosen because of their ability to produce "thick" descriptions by which an observer is able to interpret the "conceptual structures" of the motivations and influences' underlying behavior (Geertz, 1973). Interviews lasted for an average of 75 min and were done in either Ewe or French by the first author with the assistance of a trained Togolese research assistant. Interviews were separately transcribed in French by the research assistant and the first author. They were back-translated into English, and were analyzed for recurrent themes by the two first authors. Recurrent themes, phrases, and explanations were classified and frequency of occurrence tabulated. Interviews were coded for ease of textual content analysis. To protect confidentiality of participants, pseudonyms were used throughout this paper. This study was approved by the Internal Review Board of the first author's institution.

## Data Analysis

The first two authors, each separately coded the data and created the recurring categories and themes. They then discussed the categories and themes together and came to a consensus on the interpretation of the data. The small size of the sample allowed for each of the coders to independently code 100% of the data. Also, quality assurance in the form of inter-coder reliability was achieved through meetings in which consensus was achieved. An intersectional framework was used to understand how multiple dimensions of inequality interlock to impact the lives of caregivers. The authors drew on the analysis of categories that participants made relevant through their interviews (Cronin & King, 2010; Taylor, 2009).

Analysis followed an inductive content strategy whereby emic analytical patterns that emerged from the data were analyzed instead of predetermined analytical approaches (Patton, 1990). The data were read several times and initial codes were generated by identifying categories and themes within participant transcripts by each the first and second authors. Then they created relationships within the categories and themes (Charmaz, 2006), based on the analysis of what study participants reported as relevant to their caregiving experiences. As recommended by Miles and Huberman (1994), relationships between themes as well as trends that emerged across the sample were examined. Patterns were organized into thematic typologies that reflect the emic understandings of the constitutive structures that are important to the lived experiences of the caregivers. The lived experiences of participants, including caregiving contexts, challenges, and forces that shaped the caregivers' ability to provide daily caregiving activities are presented in the following section.

## Findings

Demographic findings from the study indicate that the caregivers were mostly women. The mean age of the caregivers was almost 46 years (45.80). On average, they had been providing care for about 5 years (4.61). They had a mean of about 5 years of education (5.40). Most of the caregivers were providing care to their husbands (40%), followed by their parents (35%). Almost all the caregivers were Christian (19); one was a Muslim. The stroke survivors were mostly male (55%). The average age of the stroke survivor was about 64 years. The mean monthly expenses was about 30,000 FCFA which was equivalent to US \$60 (see Table 1).

Findings from the lived experiences of caregivers were generated and organized into four categories: gender roles and expectations; socioeconomic status; sociopolitical status of country and healthcare; and religious beliefs and resilience.

**Table 1** Characteristics of caregivers and persons with stroke

Caregivers				
	N	%	Mean	Range
Age	20		45.8	26–73
Number of years of education	20		5.4	0–17
Number of years of care provision	20		4.61	0.25–10
Sex				
Male	2	0.1		
Female	18	0.9		
Religion				
Christianity	19	0.95		
Muslim	1	0.05		
Relationship to person with stroke				
Husband	8	0.4		
Wife	1	0.05		
Mother	6	0.3		
Father	2	0.1		
Brother	1	0.05		
Sister	1	0.05		
Daughter	1	0.05		
Person with stroke				
Age	20		64.15	46–85
Expenses (monthly)	20		\$12	\$5–\$24
Sex				
Male	11			
Female	9			

## Gender Roles and Expectations

Gender roles in Togo are generally based on traditional gender division of labor whereby men are expected to perform the instrumental roles and women, the expressive roles. Participants were mostly women (18 women, 2 men) as caregiving falls in the domain of women's roles. It is important to note that one of the men caregivers reported having a hired worker to provide care with daily activities to his wife who was a stroke survivor. He only managed these activities by making sure that the helper met his wife's needs and demands. Also, as indicated by participants' accounts, their status as poor and women heightened the caregiving challenges. While female caregivers were expected to do household chores, some of the husband stroke survivors expected their wives to also promptly attend to their needs. When the women failed to meet these demands, the husbands became belligerent as articulated in the following paragraphs.

Akofa, a 45-year-old married woman who was providing care to her husband for a little over a year, provided the following comment when asked about her challenges that she encountered as a caregiver:

*"... sometimes, I get so upset, but what can I do? I just tell myself that it is God's will for me to be in such a situation. I get upset because sometimes, he (husband) will be scolding me for not helping or attending to his needs on time, especially, when he wants me to get him something but I am in the middle of something else, and cannot get to him right away. This truly upsets me a lot. I tell myself that if he was in a good health condition, he would be going by his daily activities and I will be doing mine without interruption. Sometimes, even when I am cooking, he would want me to come and get whatever he needs right away. He is not cognizant of the fact that the food will be burned if I do not pay attention to it. But ironically, he is the one who gets mad if the food is burned. He will not eat it.*

Almost all of the participants (16 out of 20) mentioned this type of conflict as one of the challenges that they had to manage on a daily basis. Only two of the wives were able to hire inexpensive young maids (paid 5,000 FCFA about US\$10 per month) who assisted them and helped manage some of the conflict. However, there were some other duties that could not be substituted, as shared by Sophia. Sophia, a 66-year-old caregiver whose husband accused her of making him sick in order to remarry another man, explained: "My husband has become very bitter toward me because I refuse to sleep with him (have sexual relation). He gets sicker each time we sleep together. So, I stop having sexual relationship with him. ... He has become so mean toward me. But before he got sick, we were very, very close. People even thought we were siblings. He was very loving before he got the stroke. But now, he is really mean. We used to go out together, eat together. We did almost everything together. But now, not anymore".

The male caregiver who hired a maid for his wife also shared some thoughts about his caregiving challenges. He stated: "I hired a young girl who helped me to meet my wife's needs. She helps with daily activities such as cooking, bathing, feeding, etc. But I gave my wife all her medications. However, whenever she is

upset with me (this happens at times), I just tell myself that it is difficult to please women”.

### **Socioeconomic Status**

Another factor that adds to the intersecting identities of the study participants is their socioeconomic status. The Republic of Togo has a high poverty rate. Over half of the population lived below the poverty line in 2015 (55%) (World Bank, 2018). All of the study participants had difficulty making ends meet and providing adequate care for their loved ones. They all mentioned that they needed help buying medicines for the stroke victims. Also, having enough food was a significant challenge for most. The following accounts described some of participants' challenges due to their disadvantaged socioeconomic status. Esse, a 45 years old married woman described their problem as follows:

*“... We try hard to get something (food and medications) as we do not have money. We spend about 1,000 FCFA to 1,500 FCFA (about \$2 to \$3) daily on food ... When we were released from the hospital after spending a month there, we spent almost everything that we had. We even had to have the medicine changed because we could no longer afford it. But now, as we no longer have enough money, he (husband) will eat whenever we have something. Otherwise, he understands that our funds have been depleted. Our major problem is financial. Sometimes we do not have money for his medications. He also needs a massage therapy but we cannot afford it.”*

Some of the respondents compared stroke to ‘a disease of the rich’ because of its chronic and resource-driven nature. Dabea, simply stated: “This should be a disease for the rich, not for us poor people. We have used up all of our resources. Sometimes, it is difficult to find food to eat. So, you can imagine that getting him medicine daily is not easy at all.”

The lack of resources also prevented the caregivers to provide complementary and alternative medicine believed to help people with stroke such as massages and kinesiotherapy. The following statement ran throughout almost all the interviews (17 out of 20): “We lack money to hire a kinesiotherapist” or “we need money for a massage therapist.” It is important also to note that family (especially adult children), friends and people in the community contributed most for money and foods to help the caregivers and their loved ones with stroke as these people no longer had meaningful ways to gain income.

### **Sociopolitical Status of Country and Healthcare**

While Togo appeared to be politically stable in 2012, when data were collected, a lot of Togolese were frustrated with the political conditions and how public resources were being used. Public health facilities and centers were not properly equipped and staffed. Healthcare providers, especially those who were working in the public sector were also exasperated with the government non-engagement and financing of

healthcare. Most of the healthcare providers, thus, were aloof toward patients. Lilivi, for instead, did not mince her words when she described her experiences with the health system in Togo: “We are in a country where nothing is working for ordinary people, unless you are members of RPT (the ruling party). We need health clinics and hospitals where our loved ones who are sick can be promptly cared for. We are pleading with our political officials, we are begging them to help us.” Another caregiver, Akoss, expressed her frustration as follows: “we need healthcare providers who will provide proper care, show interest in patients, and treat them promptly”.

Other study participants did not accuse the government but shared their beliefs of a better situation if they had been living in other countries, mainly developed countries. Fafato, a 48-year old caregiver with 5 children who was providing care to her husband for almost 4 years shared: “Right now, in Togo that we are living in, money is a big issue. It is hard to come by. If you do not have money and you are sick, you can die from the sickness, even if it is not a deadly sickness. In the West, things are much better. People with stroke and caregivers are helped in different ways.” This caregiver also shared that she got very exhausted at times and felt as if she was having a stroke too. She would then take some of her husband’s medicine. This made her feel better. That was how she was able to continue providing care to her husband all of these years.

### Religious Beliefs and Resilience

Studies have reported that informal caregivers rely on religion or spirituality to cope in times of difficulty (Pearce, 2005; Pearce et al., 2016). This study’s respondents also reported that their religion and faith informed their caregiving challenges and aided them in difficult times. Tasivi, a 40 year old respondent who had been providing care to her husband aged 49, for four years expressed how she had been able to overcome her difficult moments as follows:

*Through God’s grace, all will be well. I felt a lot of pain about our situation. When you see me right at the time when my husband fell ill, you would not want to look at me again. I lost a lot of weight and was not myself. It is through God’s grace that I am alive and looking good today. The Bible says that when bad events happen, we must accept them. When good things happen, we must accept them as well. This is my cross. Only Yahweh can help me carry it. This is the only way I find grace and I am now what you see. It is only through prayer that I found grace to carry on with caregiving duties ... When I cannot support it anymore, I just cry and cry. My husband is no longer who he was. He is deformed. At the beginning, his face was deformed too. ... I am just a body with flesh and blood. I don’t have any power. Without the Holy Spirit, I can do nothing.*

One of the only two male caregivers, who was caring for his wife also shared how he has been able to continue in his caregiving activities. He stated:

*Being a Jehovah Witness, we know the origins of problems in this world, we understand why there is sickness. We know that we are living in a difficult*

*world and that we have to patiently bear all these challenges, knowing that one day, the Kingdom of God will reach us. It will come down to earth and all the world's problems will be solved. Being sick is part of the world in which we live. So, when a person is ill, this person must be helped. So, I don't see it as a burden. I am her spouse. I have to provide support for her because she is my wife."*

Fafato, the 48-year-old caregiver with 5 children whose husband had a stroke almost 4 years prior to the study expanded on how her religious belief had aided her to accomplish her caregiving demands as she had once sworn not to ever take care of any ailing person because of her prior experience of providing care to her aunt. She explained:

*... I know the burden of providing care to a sick person. I provided care to my aunt and swore to God that I would never care for another sick human being, even if this person is my mother. My siblings will care for her if need be. ... But God has challenged me and now my husband had stroke. There is no one to care for him. Who I am going to abandon him to? ... To be able to carry on, every morning, I go to church and pray for strength. I give my burden to the Lord. This is a too heavy burden. I cannot carry it on my own. I have no one to carry it with me but the Lord. This is why I go to church every day.*

Two of the caregivers also mentioned that their husbands' families did not appreciate the care that they were providing and had to pray a lot in order not to strike out against these family members. Rachelle simply stated: "I always tell myself, God will reward my efforts even though my husband's family members always complain that I am not properly caring for their son."

## Discussion

By looking into the self-reported burden issues through an intersectional framework that included the social, structural, and relational forces as they impact the caregiving, the findings from this study offer a clearer picture of how the caregiving affects the informal caregiver's quality of life and ways caregivers are able to mitigate the challenges.

The findings demonstrate how caregiving intersects with gender roles and expectations; socioeconomic status; sociopolitical status of country and healthcare; and religious beliefs and resilience. Furthermore, these factors create marginalizing effects on caregivers as reported in Greenwood et al. (2018). In fact, this study showed how social structures in Togo not only create certain social categories and experiences for the caregivers in this study, but also create different forms of oppression that are unique to the study participants (Weldon, 2008). For instance, as shown by some of the caregivers' accounts, because of their status as poor and female, these caregivers endured oppression from their husbands with stroke when they did not meet expectations. At the same time, they were unable to hire employed assistants to aid them in their caregiving activities.

Because 18 of the 20 caregivers interviewed were female, the category of gender roles and expectations was a focal point of the study and outcomes revealed that female caregivers were indeed expected to layer post-stroke caregiving of their loved one on top of the traditional gender roles they were already carrying. As noted in their shared dialogues regarding this concept, the caregiving role further burdened the women due to the conflict and intersectionality of the roles they were expected to play. These burdens were regardless of the bitterness and negativity shown by some of the male patients the women were caring for. Dealing with being poor or in poverty was described by the participants as having a major effect on those trying to afford the healthcare received for the stroke survivor immediately, as well as the post-stroke medical needs on a long-term basis. The burden of caregiving was further exacerbated by the lack of funds to provide these high cost medical needs on top of basic essentials such as food. These findings support Badaru et al.'s (2017) suggestion that financial stress can be a factor for caregivers; in this study that financial stress is compounded by the intersection of gender roles.

The age of the caregivers in this study is an important consideration. Caregivers were significantly younger (mean age of 46) than the stroke patients (mean age of 64). The findings of this study's relatively young sample highlight the multiple layers of the younger caregiver role. Younger caregivers are in the child bearing and child rearing age. Likewise, they are also in the age range of life's most economically productive years. The challenges of caregiving, child bearing, child rearing, and economically providing all coalesce for caregivers in this younger age range. It is also important to contextualize these struggles within other studies that suggest that older caregivers reported worse quality of life than younger caregivers in Africa (Badaru et al., 2017). It is possible that the struggles highlighted in this study could be even more severe among older caregivers.

Simultaneous frustrations regarding the quality of healthcare facilities and professionalism of the healthcare providers were also found to be intertwined within the dialogues from the informal caregivers interviewed. This lack of quality care combined with wait times, poor facilities, and unprofessional providers was shown to be another significant emic analytical pattern that was part of the intersectionality results. It was also noted that the overall political control of allocating less than optimal resources towards public healthcare for those citizens who were not a member of the ruling party or who were impoverished further compounded the plight of caregivers seeking sufficient medical care and support for their loved ones.

The findings from this study support previous studies which have found religion and spirituality to have strong, protective impact on people in times of adversity (Reed, 1987) and give a sense of hope and resilience (Faigin & Pargament, 2010; Koenig, 2002). Similarly, the findings from this study indicate that the most positive layer of the lived experiences was noted to be about the informal caregivers' resilience and religious beliefs. An expression of faith in God and in the power of prayer was communicated by some of the caregivers and their belief in God was what carried them through these difficult long-term caregiving times. Others noted that their religion helped them realize that sickness is part of life in this world and their job was to support their loved one through the illness.

## Conclusion

This study expands the literature for understanding the outcomes for caregivers of stroke patients by examining the long-term support of informal caregiving for post-stroke patients. The findings from this study suggest that stroke causes not only the patient to have a change in quality of life, but in many cases, the informal caregiver results in a change in quality of life as well. Because informal caregiving is a multilayered function, it can cause the caregiver to have to maneuver through layers of roles needing to be carried out while simultaneously experiencing overlapping emotional feelings. These different dimensions of roles and feelings cannot be separated from one another and are equally important in the caregiving process. Additionally, financial, social and political pressures further exacerbate informal caregiving and can decrease the caregiver's quality of life. Understanding these challenges through an intersectional framework offer a lens for approaching socio-economic, emotional, and health system supports for caregivers.

There is a need for building on this research with further study, including research areas looking at longitudinal data from caregivers to stroke patients, as well as studies with larger and more diverse samples in regard to age. Additionally, studies examining health care provider policies for stroke patients and their caregivers are also recommended.

## Declarations

**Conflict of Interests** All authors declare no conflict of interest.

**Informed Consent** None.

**Ethical Treatment of Experimental Subjects (Animals and Humans)** No experimental treatment was conducted on either human or animal subjects in this study.

## References

- Agyemang, C., Attah-Adjepong, G., Owusu-Dabo, E., Aikins, A. D., Addo, J., Edusei, A. K., Nkum, B. C., & Ogedegbe, G. (2012). Stroke in Ashanti region of Ghana. *Ghana Medical Journal*, *46*, 12–17.
- Akosile, C. O., Okoye, E. C., Nwankwo, M. J., Akosile, C. O., & Mbada, C. E. (2011). Quality of life and its correlates in caregivers of stroke survivors from a Nigerian population. *Quality of Life Research*, *20*, 1379–1384.
- Akosile, C. O., Okoye, E. C., & Odunowo, O. K. (2009). Carers' burden in stroke and some associated factors in a South-Eastern Nigerian population. *African Journal of Neurological Sciences*, *28*, 22–28.
- American Stroke Association. (2020). *About Stroke*. <https://www.stroke.org/en/about-stroke>
- Anderson, C. S., Linto, J., & Stewart-Wynne, E. G. (1995). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke*, *26*(5), 843–849.
- Assogba, K. (2015). Epidemiology, risk Factors, type and outcome of stroke in health care facilities of Lomé, Togo: A prospective study. *Science Journal of Public Health*. <https://doi.org/10.11648/j.sjph.20150301.15>
- Aziz, N. A., Pindus, D. M., Mullis, R., Walter, F. M., & Mant, J. (2016). Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services—a systematic review of the qualitative literature: protocol. *BMJ Open*, *6*(1).

- Badaru, U. M., Ogwumike, O. O., Adeniyi, A. F., & Nelson, E. E. (2017). Determinants of caregiving burden and quality of life of informal caregivers of African stroke survivors: Literature review. *International Journal on Disability and Human Development*, 16(3), 249–258.
- Bessa, Y., Moore, A., & Amey, F. (2012). Caring for a loved one with cancer: It is my job. *Journal of Psychosocial Oncology*, 30, 217–238.
- Brah, A., & Phoenix, A. (2004). Ain't I a woman? Revisiting intersectionality. *International Journal of Women's Studies*, 5(3), 75–86.
- Brereton, L., Carroll, C., & Barnston, S. (2007). Interventions for adult family carers of people who have had a stroke: A systematic review. *Clinical Rehabilitation*, 21, 867–884.
- Brewer, R. M. (1993). Theorizing race, class and gender: The new scholarship of Black feminist intellectuals and Black women's labor. In S. James & A. Busia (Eds.), *Theorizing Black Feminisms* (pp. 13–30). Routledge.
- Camak, D. J. (2015). Addressing the burden of stroke caregivers: A literature review. *Journal of Clinical Nursing*, 24, 2376–2382. <https://doi.org/10.1111/jocn.12884>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage.
- Cordes, C. L., & Dougherty, T. W. (1993). A review and an integration of research on job burnout. *The Academy of Management Review*, 18, 621–656.
- Crenshaw, K. W. (1988). Race, reform, and retrenchment: Transformation and legitimization in antidiscrimination law. *Harvard Law Review*, 101(7), 1331–1387.
- Crenshaw, K. W. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 139–168.
- Crenshaw, K. (1995). Mapping the margins: Intersectionality, identity politics and violence against women of colour. In (Eds.), *Critical Race Theory: The Key Writings that Informed the Movement* (pp. 357–383). Stanford: The Stanford Law Review.
- Cronin, A., & King, A. (2010). Power, inequality and identification: Exploring diversity and intersectionality among older adults. *Sociology*, 44(5), 876–892.
- Edemekong, P. F., Bomgaars, D. L., Sukumaran, S., & Levy, S. B. (2020) Activities of Daily Living (ADLs). *StatPearls*. <https://www.ncbi.nlm.nih.gov/books/NBK470404/>
- Ezejimor, M. C., Uthman, O. A., & Maduka, O. (2017). Stroke survivors in Nigeria: A door-to-door prevalence survey from Niger Delta region. *Journal of Neurological Sciences*, 372, 262–269.
- Faigin, C., & Pargament, K. (2010). Strengthened by spirit: Religion, spirituality and resilience through adulthood and aging. In B. Resnick, L. Gwyther, & K. Roberto (Eds.), *Resilience in aging: Concepts, research* (pp. 163–180). Springer.
- Gaugler, J. E. (2010). The longitudinal ramifications of stroke caregiving: A systematic review. *Rehabilitation Psychology*, 55, 108–125.
- Geertz, C. (1973). *The interpretation of cultures: Selected essays*. Basic Books.
- Global Health Observatory (GHO). (2016). <http://apps.who.int/gho/data/node.cco>
- Greenwood, N., Mackenzie, A., Harris, R., Fenton, W., & Cloud, G. (2011). Perceptions of the role of general practice and practical support measures for carers of stroke survivors: A qualitative study. *BMC Family Practice*, 12–57.
- Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*, 112, 39–45.
- Hancock, A. (2007). Intersectionality as a normative and empirical paradigm. *Politics and Gender*, 3(2), 248–253.
- Hankivsky, O. & Cormier, R. (2009). *Intersectionality: Moving women's health research and policy forward*. Vancouver, BC: Women's Health Research Network.
- Hankivsky, O., Reid, C., Cormier, R., Varloe, C., Clark, N., Benoit, C., & Brotman, S. (2010). Exploring the promises of intersectionality for advancing women's health research. *International Journal for Equity in Health*, <http://www.equityhealthj.com/content/9/1/5>
- Imarhiagbe, F. A., Asemota, A. U., Oripelaye, B. A., Akpeke, J. E., Owolabi, A. A., Abidakun, A. O., Akemokwe, F. M., Ogundare, V. O., Azeez, A. L., & Osakue, J. O. (2017). Burden of informal caregivers of stroke survivors: Validation of the Zarit burden interview in an African population. *Annals of African Medicine*, 16, 46–51.
- Isaac, V., Stewart, R., & Krishnamoorthy, E. S. (2011). Caregiver burden and quality of life of older persons with stroke: A community hospital study in South India. *Journal of Applied Gerontology*, 30(5), 643–654.
- Kangethe, S. (2010). Occupational care giving conditions and human rights: A study of elderly caregivers in Botswana. *Indian Journal of Palliative Care*. <https://doi.org/10.4103/0973-1075.68409>

- Khedr, E. M., Fawi, G., Abdela, M., Mohammed, T., Mohamed, A., El-Fetoh, N. A., & Zaki, A. (2014). Prevalence of ischemic and hemorrhagic strokes in Qena Governorate, Egypt: Community-based study. *Journal of Stroke and Cerebrovascular Diseases*, 23, 1843–1848.
- Koenig, H. G. (2002). *Spirituality in patient care: Why, how, when, and what*. Templeton Foundation Press.
- Kpassagou, B. L., & Soedje, K. M. A. (2017). Health practitioners' emotional reactions to caring for hospitalized children in Lomé, Togo: A qualitative study. *BMC Health Services Research*, 17, 700.
- L'Institut National d'Assurance Maladie. (2016). Le système d'assurance maladie pratiqué par l'INAM conté aux professionnels des medias. <http://news.alome.com/h/82074.html>. Accessed February 14, 2018.
- Lyons, J. G., Cauley, J. A., & Fredman, L. (2015). The effect of transitions in caregiving status and intensity on perceived stress among 992 female caregivers and noncaregivers. *The Journal of Gerontology: Biological Sciences*, 70(8), 1018–1023.
- McGurk, R., & Kneebone, I. I. (2013). The problems faced by informal carers to people with aphasia after stroke: A literature review. *Aphasiology*, 27, 765–783.
- Miles, M., & Huberman, M. (1994). *Qualitative data analysis: An expanded sourcebook*. Sage.
- Morrow, M., Hankivsky, O., & Varcoe, C. (2007). *Women's Health in Canada: Critical theory, policy and practice Toronto*. University of Toronto Press.
- Olai, L. (2010). Life after a stroke event. With special reference to prognosis, health and municipality care utilization and life satisfaction among patients and their informal caregivers. [Dissertation, Uppsala University].
- Pandian, J. D., Gandhi, D. B., Lindley, R. I., & Bettger, J. P. (2016). Informal caregiving: A growing need for inclusion in stroke rehabilitation. *Stroke*, 47(12), 3057–3062.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Sage.
- Pearce, M. (2005). A critical review of the forms and value of religious coping among informal caregivers. *Journal of Religion and Health*, 44(1), 81–115.
- Pearce, M. J., Medoff, D., Lawrence, R. E., & Dixon, L. (2016). Religious coping among adults caring for family members with serious mental illness. *Community Mental Health Journal*, 52(2), 194–202.
- Pickle, L. M., Mungiole, M., & Gillum, R. F. (1997). Geographic variation in stroke mortality in Blacks and Whites in the United States. *Stroke*, 28, 1639–1647.
- Reed, P. G. (1987). Spirituality and well-being in terminally ill hospital adults. *Research in Nursing & Health*, 10(5), 334–335.
- Rombough, R. E., Howse, E. L., Bagg, S. D., & Bartfay, W. J. (2007). A comparison of studies on the quality of life of primary caregivers of stroke survivors: A systematic review of the literature. *Top Stroke Rehabilitation*, 14, 69–79.
- Sacco, R. L., Boden-Albala, B., Gan, R., Chen, X., Kargman, D. E., Shea, S., Paik, M. C., & Hauser, W. A. (1998). Stroke incidence among White, Black, and Hispanic residents of an urban community: The Northern Manhattan Stroke Study. *American Journal of Epidemiology*, 147(3), 259–268.
- Salter, K., Zettler, L., Foley, N., & Teasell, R. (2010). Impact of caring for individuals with stroke on perceived physical health of informal caregivers. *Disability and Rehabilitation*, 32, 273–281.
- Simien, E. (2007). Doing intersectionality research: From conceptual issues to practical examples. *Politics & Gender*, 3(2), 264–271.
- Stroke Association. (2013). Feeling overwhelmed. The emotional impact of stroke. *Stroke Association*.
- Taylor, Y. (2009). Complexities and complications: Intersections of class and sexuality. *Journal of Lesbian Studies*, 13, 189–203.
- Van de Vijver, S., Akinyi, A., Oti, S., Olajide, A., Agyemang, C., Aboderlin, I., & Kyobutungi, C. (2013). Status report on hypertension in Africa- Consultative review for the 6<sup>th</sup> session of the African Union Conference of Ministers of Health on NCD's. *The Pan African Medical Journal*, 61, 38.
- Versey, S. H. (2017). Caregiving and women's health: Toward an intersectional approach. *Women's Health Issues*, 27(2), 117–120.
- Walker, R., Whiting, D., Unwin, N., Mugusi, F., Swai, M., Aris, E., Jusabani, A., Kabadi, G., Gray, W. K., Lewanga, M., & Alberti, G. (2010). Stroke incidence in rural and urban Tanzania: A prospective, community-based study. *The Lancet Neurology*, 9(8), 786–792.
- Walker, R. W., Jusabani, A., & Aris, E. (2011). Post-stroke case fatality within an incident population in rural Tanzania. *Journal of Neurology, Neurosurgery, and Psychiatry*, 82, 1001–1005.
- Weber, L. (2005). Whose questions, what evidence, which practice? Feminist intersectional challenges to traditional biomedical approaches to health disparities in Philadelphia: Invited Presentation, Annual Meeting of the American Public Health Association 2005.

- Weldon, L. (2008). Intersectionality. In G. Geerty & A. Mazur (Eds.), *Politics, Gender, and Concepts* (pp. 193–215). Cambridge University Press.
- White, C. L., Lauzon, S., Yaffe, M. J., & Wood-Dauphinee, S. (2004). Toward a model of quality of life for family caregivers of stroke survivors. *Quality of Life Research, 13*, 625–638.
- World Bank (2018). Togo – Overview. <http://www.worldbank.org/en/country/togo/overview>
- World Health Organization. (May, 2014). *Togo: Country Cooperation Strategy*. Switzerland.
- Zerai, A. (2000). Agents of knowledge and action. *Cultural Dynamics, 12*(2), 182–222.

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