Abbreviated Key Title: East African Scholars J Med Sci ISSN 2617-4421 (Print) | ISSN 2617-7188 (Online) | Published By East African Scholars Publisher, Kenya

DOI: 10.36349/easms.2019.v02i01.005

Original Research Article

Volume-2 | Issue-1 | January-2019 |

OPEN ACCESS

Stroke: awareness of self-risk and superstitions among persons with sickle cell anemia in Calabar, Nigeria

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Abstract: Identification of gaps in stroke related knowledge among at risk individuals is vital to effective stroke prevention measures. This study aimed to assess the awareness of self risk of stroke and superstitions regarding stroke, among persons with sickle cell anemia in Calabar, Nigeria. We conducted a survey on eighty three members of the sickle cell support club, in Calabar, diagnosed with HbSS hemoglobinopathy. Univariate, bivariate and binary logistic regression were used to analyze data generated with a self-administered questionnaire on awareness of self risk of stroke conferred by inherited HbSS hemoglobin, held superstitions regarding stroke, knowledge of stroke symptoms and their opinion of where stroke is best managed. 34.9% of the respondents were unaware of their increased stroke risk. 27.7% of them believed that stroke is caused by witchcraft or voodoo. Four fifths of those who had up to tertiary level of education did not agree that stroke is caused by voodoo, compared to two thirds of those with less education (p=0.047). 65.1% of the respondents possessed poor awareness of stroke symptoms. High level of education (p=0.04) and recognizing hospital as where stroke is best managed (p= 0.047) were identified predictors of awareness of increased self-risk of stroke. Many of the respondents were unaware of their increased stroke risk, and unable to correctly identify stroke symptoms. Improved population literacy rate and tailored public health education would help to address identified stroke related knowledge gaps and erroneous beliefs. **Keywords:** sickle cell, stroke risk, hemoglobinopathy, superstitions

INTRODUCTION

Stroke is a catastrophic neurological condition contributing significantly to global mortality and morbidity (Grysiewicz RA *et al.*, 2008) It is estimated that about 85% of the global stroke mortality occur in Low and middle income countries (O`Donell MJ, 2010; Song S, 2015). The consequences of stroke place additional burden on available health resources especially in sub-Saharan Africa; a region already grappling with inadequate available resources in the face of rising diverse health demands (Wahab KW, 2008; Chin JH, 2012). Stroke control is linked to measures aimed at identified risk factors.

Sickle cell disease (SCD) is recognized as one of the risk factors for stroke (Powars DR *et al.*, 2005; Strouse JJ *et al.*, 2009; Eke BC *et al.*, 2013). It is an autosomal recessive hemoglobinopathy found in tropical Africa, among populations of African origin, and in some parts of Europe and Asia (Konotey-Ahulu F, 1996). In HbS, valine replaces glutamic acid at the 6^{th} position of the amino acid sequence in the beta chain of hemoglobin (Timothy AW, 2000). The number of persons born with SCD is expected to increase in the coming decades (Piel FB *et al.*, 2013).

Nigeria is ranked among countries with the highest burden of SCD, with a prevalence of up to 2% (Hong GR, 1996; Odame I, 2014). In Nigeria, sickle cell disease is identified as a risk factor for stroke in the young, defined as the occurrence of stroke in a person younger than 50 years, which affects the more productive younger age groups in the society leading to loss of productivity in the local economy (Owolabi LF & Ibrahim A, 2012; Smajlovic D, 2015).

Despite the huge toll exacted by stroke, poor levels of stroke related knowledge have been reported

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	Journal homepage: http://www.easpublisher.com/easjms/ Article History Received: 12.01.2019 Accepted: 22.01.2019 Published: 27.01.2019

among the general public; a trend that is observed even among individuals at increased risk of stroke (Anyanniyi O et al., 2006; Zeng U et al., 2012; Oparah SK et al., 2017). Public health education has been advocated as a preventive strategy in stroke management (Wall HK et al., 2008; Brown DL et al., 2012; Prabhakaran S & Chong JY, 2014). Unfortunately, concerted public health efforts against the stroke menace in many sub-Saharan countries have been largely abysmal (Connor MD et al., 2007; Wahab KW, 2008). Beliefs held by members of the society could affect the effectiveness of public health education (Bandura A, 1977). In many African societies, superstitious beliefs influence the concept of illness (Tenkorang EY, 2011). Indeed, spirituality is a recognized influential factor regarding health related outcomes (Oman D & Thoransen CE, 2002).

Identification of existing gaps in knowledge is necessary to devise appropriately tailored public health interventions, employed as preventive measures, to stem rising stroke incidence and the attendant adverse consequences (Mendis S, 2010).

In this study, we conducted a survey among persons living with sickle cell hemoglobinopathy in Calabar, Nigeria, to determine if they are aware of their increased risk of stroke, their beliefs regarding cause of stroke and stroke related health seeking practices, with the aim of unmasking existing gaps in their level of awareness in addition to generating data to guide the design of effective public health education on stroke; as an arm of the multifaceted approach to mitigate the stroke menace.

METHODS

This study was conducted in Calabar, the capital city of Cross river state, located in south eastern Nigeria. The city is a major tourist destination in the country with the total population put at 371,122 during the last national population census (National Population Commission, 2009). We conducted the study after obtaining approval for the study, and the process was in agreement with the Helsinki declaration of 1975, as revised in 1983.

The respondents were members of the Calabar sickle cell club; a nonprofit organization in the city of Calabar, Nigeria, whose membership includes persons diagnosed with sickle cell disease, health professionals and other stake holders. The club aims to provide needed support and promote optimal health for persons diagnosed with sickle cell disease. Convenience sampling method was employed to conduct this survey during proceedings at a biennial meeting of the club.

Data collection was restricted to consenting members aged 14 years and above who were previously diagnosed with sickle cell anemia (homozygous HbSS), following the determination of their hemoglobin (Hb) genotype, using Hb electrophoresis. Those who declined to give consent were excluded from the study, in addition to those who are healthcare professionals.

Ninety one members of the Sickle cell club, non-healthcare professionals, were available for the survey. Three of the members, aged between 8 to 11 years, were excluded as they were considered too young to complete the survey instrument unaided. Five members of the club, unaffected by sickle cell disease, were excluded.

The survey instrument comprised of a structured self-administered questionnaire with sections on demographic characteristics of participants, including the age, gender and level of education. In the next section, the respondents were asked if their diagnosis of sickle cell hemoglobinopathy confers an increased risk for stroke; if stroke is caused by voodoo or witchcraft; to list five symptoms of stroke and where they consider as the most appropriate place to treat a person who has just suffered a stroke. A respondent who correctly listed two or more symptoms of stroke was considered to be aware of stroke symptoms.

Analysis of the generated data was done with SPSS version 20 statistical package. Simple proportions were used for categorized data whereas means and standard deviation (SD) were used for continuous variables. Student's t test and univariate analyses were used to compare numerical variables and explore association between variables, respectively. Binary logistic regression was used to determine predictors of variables. The level of significance was set at p < 0.05.

RESULTS

Eighty three respondents successfully completed the survey, comprising of 32 (38.6%) males and 51 (61.4%) females. The overall mean age of the respondents was 27.7 years \pm 8.87, with mean ages of 26.1 years \pm 9.51 and 28.7 years \pm 8.40 for the male and female respondents, respectively (p= 0.20). Twenty three (27.7%), 39 (48.2%) and 21 (24.1%) of them had up to secondary, tertiary and postgraduate levels of education, respectively.

Twenty nine (34.9%) of the respondents were unaware of the increased risk of stroke, conferred on them by the HbSS hemoglobin variant, and 60 (72.3%) of the respondents correctly identified stroke as an illness that is not caused by witchcraft or voodoo. Two thirds of the respondents who had up to a tertiary level of education knew they have increased risk of stroke whereas, half of those with less than tertiary level of education were unaware of their increased stroke risk (p= 0.04). Four fifths of those who had up to tertiary education affirmed that stroke is not caused by voodoo, compared to two thirds of those with less than tertiary education (p=0.047). Fifty four (65.1%) of the respondents were deficient in the awareness of stroke symptoms. Three fifths of those who possessed up to tertiary education, were deficient in knowledge of stroke symptoms, compared to three quarters of those who had less education (p = 0.30). Two thirds of those who were aware of their increased risk of stroke from sickle cell hemoglobinopathy were deficient in the knowledge of stroke symptoms, compared to about three fifths of those who do not know of their increased risk of stroke (p=0.68).

Sixteen (19.3%) of the respondents do not believe that hospital is the best place for the treatment of someone who has just suffered stroke. Among those who do not approve of hospital as the best place to treat stroke; half believe that stroke is not treatable; a third of them are of the opinion that stroke is best treated spiritually; while the rest believe that stroke is treated at a patent medicine dealer's shop.

Six out of seven, of those with further than secondary education, confirmed the hospital as the best place to manage a person who had just suffered stroke, compared to two thirds of those with less education (p= 0.03).

Possessing further than secondary level of education and correctly identifying the hospital to be where acute stroke is best treated, were identified as predictors of awareness of increased self-risk of stroke from Sickle cell disease and appropriately not believing voodoo to be a cause of stroke, as shown in table1.

Table1. Predictors of awareness of self-risk of stroke and lack of superstitions regarding stroke among
participants

Parameter	<i>p</i> -value ^a	<i>p</i> -value ^b
Gender	0.18	0.28
Age (in years)	0.67	0.24
Greater than secondary level education	0.04	0.047
Correct identification of where stroke is best treated	0.047	0.03
Good knowledge of stroke symptoms	0.68	0.59

a = Predictors of awareness of increased self-risk of stroke due to Sickle cell disease

b = Predictors of not attributing stroke to voodoo

DISCUSSION

Good levels of stroke related knowledge positively impacts on stroke prevention and mitigation of stroke burden (Spilker JA, 1996; Williams LS et al., 1997). Our study reveals that a sizeable proportion of these at risk respondents were unable to identify their condition, of inherited HbSS hemoglobinopathy, as a risk factor for stroke. It is estimated that, barring intervention, 11% and 24% of persons with SCD will suffer from stroke by the time they attain the ages of 20 years and 45 years, respectively. The risk of stroke is highest among those with homozygous HbSS (Ohene-Frempong K et al., 1998). The observed lack of awareness corroborates reports of poor knowledge of stroke risk factors and symptoms in the general public, which is seen even among populations at high risk of stroke (Kothari R et al., 1997; Pancioli AM et al., 1998; Sundseth A et al., 2014; Oparah SK et al., 2017).

In African societies, spirituality plays a remarkable role in cultural practices and diseases are commonly attributed to supernatural phenomena (Tenkorang EY, 2011; Ehiwe E *et al.*, 2013; Simmelink J *et al.*, 2013). This could explain our observation, despite the high level of education among the respondents, an appreciable proportion believe that stroke is caused by witchcraft. This held belief is reminiscent of the report from a similar study, in Ghana, in which up to a quarter of the interviewed

believed stroke to be an illness caused by witchcraft and evil spirits (Donkor ES *et al.*, 2014).

Furthermore, the poor knowledge of stroke symptoms seen in an even greater proportion of the respondents suggests that many of these at risk individuals would be unable to promptly recognize when they have suffered a stroke. Even the highly educated ones among the respondents were not spared of deficiency in the knowledge of stroke symptoms. Monitoring for chronic complications such as stroke, kidney disease and pulmonary hypertension, is an important component of comprehensive care for persons living with sickle cell disease (McGann PT et al., 2013). Failure to recognize stroke symptoms could pose a barrier to the adoption of recommended health seeking behavior in stroke, which emphasizes on the prompt presentation to an appropriate health facility (Williams LS et al., 1997). Adoption of the recommended practice of a prompt transfer to a hospital following onset of stroke is further hindered by the expressed belief, by some of the respondents, that stroke is not treatable. A proportion of those who agreed that stroke is treatable are of the opinion that the hospital is not the best place for stroke treatment, and would rather opt for spiritual or healing centers. Spirituality and traditional health practices largely dictate health beliefs and influence health seeking behavior in Nigerians (Chukwuneke FN et al., 2012).

Thus, prayers and spiritual interventions are commonly employed in managing illnesses (Vaughan LM & Holloway M, 2010).

Exploiting the opportunities presented by identification of barriers to treatment is of importance in designing the strategic measures to control the stroke menace (Brainin M *et al.*, 2007). Community stroke education, for example, is of immense benefits as a strategy to reduce delayed presentations and referrals of stroke patients (Spilker JA, 1996; Williams LS *et al.*, 1997; Pancioli AM *et al.*, 1998).

It is noteworthy that the participants in our study, who showed an appreciable ignorance of their increased stroke risk and beliefs regarding stroke, have a high literacy rate; as none of them possessed less than a secondary level of formal education, with over twothirds of them possessing a graduate or post-graduate level of education. However, the positive impact of education on their performance was not lacking as the more highly educated participants, who had up to tertiary education, were better aware of the increased risk of stroke conferred by their HbSS status; were less likely to believe stroke to be a result of voodoo or witchcraft attacks in addition to being better informed on the appropriate place for stroke management. Indeed, some studies have identified high level of education as a predictor of good knowledge of stroke symptoms and risk factors (Zeng U et al., 2012; Shravani K et al., 2015; Vincent-Onabanjo G & Moses T, 2016). Notwithstanding, there are reports of inadequate stroke related knowledge even among populations in tertiary educational institutions (Obembe AO et al., 2014).

The youthful ages of the respondents in our survey could be a reflection of the shortened lifespan of persons living with sickle cell disease. In the region, childhood mortality from sickle cell related causes is remarkably high that less than half of affected children survive up to the age of 5 years. This mortality trend continues throughout the periods of childhood and adolescence such that by the time they become adults, the prevalence of HbSS is ten times lower than the birth incidence rate (Grosse SD *et al.*, 2011).

CONCLUSION

We conclude that an appreciable proportion of the respondents, with sickle cell hemoglobinopathy, were unaware of their increased stroke risk and an even greater proportion failed to correctly identify stroke symptoms. Some believed that stroke is caused by voodoo and that the hospital is not the most appropriate place to treat stroke. Such deficiencies in awareness and erroneous beliefs about stroke hinder adoption of appropriate health seeking behavior, pivotal to stroke prevention and management. There is need for appropriately tailored public health education to correct identified knowledge gaps and erroneous beliefs; as part of the preventive measures aimed at tackling the stroke menace. Furthermore, improvements in the quality and level of literacy in the general population would positively rub off on public stroke awareness.

Acknowledgement

The authors would like to acknowledge the useful contributions and cooperation they received from the members of the Calabar Sickle cell club.

Authors` contributions

SKO was involved in the conception, design, data collection, supervised development of the work, data analysis and interpretation, initial manuscript draft, approval of final version, and acted as the corresponding author. He agreed to be accountable for all aspects of the work regarding accuracy and integrity. **SOO** contributed to data analysis, interpretation, critical review of article and approval of the final version. He agreed to be accountable for all aspects of the work regarding aspects of the work regarding accuracy and integrity.

KOA contributed to data collection, supervised development of the work, critical review of the article and approval of final version. He agreed to be accountable for all aspects of the work regarding accuracy and integrity.

Conflict of interests

The authors have no conflict of interests to declare. The study was wholly funded by the authors.

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