

HHS Public Access

Author manuscript *J Neurol Sci.* Author manuscript; available in PMC 2018 April 15.

Published in final edited form as:

J Neurol Sci. 2017 April 15; 375: 270–274. doi:10.1016/j.jns.2017.02.018.

Stroke-Related Stigma among West Africans: Patterns and Predictors

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Abstract

Background—Disability-adjusted life-years lost after stroke in Low & Middle-Income Countries (LMICs) is almost seven times those lost in High-income countries. Although individuals living with chronic neurological and mental disorders are prone to stigma, there is a striking paucity of literature on stroke-related stigma particularly from LMICs.

Objective—To assess the prevalence, severity, determinants and psychosocial consequences of stigma among LMIC stroke survivors.

Methods—Between November 2015 and February 2016, we conducted a cross-sectional survey of 200 consecutive stroke survivors attending a neurology clinic in a tertiary medical center in Ghana. The validated 8-Item Stigma Scale for Chronic Illness (SSCI-8) questionnaire was administered to study participants to assess internalized and enacted domains of stigma at the personal dimension with further adaptation to capture family and community stigma experienced by stroke participants. Responses on the SSCI-8 were scored from 1–5 for each item, where 1=never, 2=rarely, 3=sometimes, 4=often and 5=always with a score range of 8–40. Demographic and clinical data on stroke type and severity as well as depression and health-related quality of life indicators were also collected. Predictors of stroke-related stigma were assessed using Linear Models (GLM) via Proc GENMOD in SAS 9.4.

Results—105 (52.5%) subjects recruited were males and the mean \pm SD age of stroke survivors in this survey was 62.0 \pm 14.4 years. Mean SSCI-8 score was highest for personal stigma (13.7 \pm 5.7), which was significantly higher than family stigma (11.9 \pm 4.6; p=0.0005) and social/

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Conflict of Interest: None to declare

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community stigma (11.4 \pm 4.4; p<0.0001). Approximately 80% of the cohort reported experiencing mild-to-moderate degrees of stigma. A graded increase in scores on the Geriatric Depression Scale and Centre for Epidemiological Studies-Depression scale was observed across the three categories. Living in an urban setting was associated with higher SSCI-8 scores. Moreover, stroke subjects with more severe post-stroke residual symptom deficits reported a significantly higher frequency of stigma.

Conclusion—Four out of five stroke survivors in this Ghanaian cohort reported experiencing some form of stigma. Stigmatized individuals were also more likely to be depressed and have lower levels of quality of life. Further studies are required to assess the consequences of stigma from stroke in LMIC.

Keywords

Stigma; quality-of-life; Stroke; West Africa; Rehabilitation; Neglected

INTRODUCTION

Individuals living with neurological disorders experience disabilities that may cause emotional, cognitive, and physical impairments.^{1–6} These impairments may be visible to others, causing stigmatizing social experiences.⁷ Stigma theorists have identified two key domains namely "internalized or felt" stigma and "enacted" stigma⁸ each with multiple dimensions. While "enacted" stigma represents discrimination against the stigmatized person that is imposed by others, "felt" stigma is the fear of "enacted" stigma experienced by the stigmatized person. A plethora of studies assessing stigma associated with neurological disorders have focused on patients with epilepsy and mental disorders^{9–12} with a striking paucity of literature on stigma among stroke subjects. This is particularly relevant in LMICs, including Sub-Saharan Africa (SSA), where the socio-cultural settings could promote stigma to neurological disorders.

The rising global burden of stroke and the paucity of data on stigma represent an important gap in knowledge which needs further documentation and if present, needs effective interventions. Of the people who survive stroke, the majority (75%) do not recover completely, of whom 25% are left with a minor disability and 40% experience moderate-to-severe disabilities. ¹³ Moreover, stroke survivors are at high risk for future vascular events, including recurrent stroke, putting them at a greater risk of death and further disability. A key barrier to optimal post-stroke outcome could be stigma, which has been linked to post-stroke maladaptation¹⁴, a situation that could result in poorer post-stroke outcomes.

Our objective for this study was to assess the prevalence, severity, determinants, and psychosocial consequences of stigma among 200 stroke survivors attending a neurology clinic in a tertiary medical center in Kumasi, in the central belt of Ghana.

METHODS

Study design and setting

This cross-sectional study was approved by the Committee on Human Research Publication and Ethics (CHRPE) of the School of Medical Sciences, Kwame Nkrumah University of Science and Technology, and the Komfo Anokye Teaching Hospital, (KATH) Kumasi, Ghana. The study was conducted at the Neurology Clinic of the Komfo Anokye Teaching Hospital, a tertiary medical center in Kumasi, Ghana. Kumasi is the second largest city in Ghana, with an estimated population of 4 million inhabitants. The Neurology Clinic was established in 2011 and runs once a week receiving referrals for adults >16 years with neurologic disorders from 6 out of the 10 administrative regions of Ghana and serves an estimated population of 10 million as previously described.¹⁵

Study Participants

Consecutive stroke survivors attending the Neurology service at KATH were approached for enrollment into the study after obtaining informed consent. Stroke survivors on sedatives, those with profound aphasia without a proxy, and those who could not stand for measurement of weight due to disability were excluded. We felt those on sedatives could not comply with the study protocol because they would be drowsy and may not able to respond appropriately to the survey questions. Similarly, body mass index was a relevant variable in the present study so we thought that study subjects who were not able to stand for weight and height measurements had to be excluded. Recruitment of study participants was performed from November 2015 through to February 2016.

Data Collection—Demographic information including age, gender, educational status, vascular risk factor profile, stroke type, stroke severity (National Institute of Health Stroke Scale [NIHSS]), functional status (Barthel's index and Modified Rankin scale) were collected by two trained research assistants through review of medical charts and interview of stroke survivors and/or their proxy. Current smoking status and alcohol intake status were ascertained from either the patient or a reliable relative. A high alcohol intake was defined as 14 units per week for women, 21 units per week for men.

The following validated instruments were administered to all study subjects:

- The Center for Epidemiologic Studies Depression Scale (CES-D)¹⁶ and Geriatric Depression Scale (GDS)¹⁷ were used to screen for depressive symptoms.
- The Health-Related Quality of Life in Stroke Patients questionnaire (HRQOLISP)¹⁸ was applied to assess the physical, psycho-emotional, cognitive, and socio-economic domains of quality of life. The physical, psycho-emotional, and socio-economic domains of the HRQOLISP has 7 items each with a minimum and maximum scores of 7 and 35 respectively, while the cognitive domain has 5 items with minimum and maximum scores of 5 and 25 respectively. Higher scores on the HRQOLISP indicate a better quality of life and vice versa.

The 8-Item Stigma Scale for Chronic Illness (SSCI-8) questionnaire: The SSCI-8 developed and validated by Molina et al. (2013) is a short, reliable, and valid instrument to assess the impact of stigma in subjects with neurological disorders.¹⁹ The SSCI-8 questionnaire has 8 questions which assesses internalized and enacted domains of stigma at the personal dimension. Responses on the SSCI-8 were scored from 1–5 for each item, where 1=never, 2=rarely, 3=sometimes, 4=often and 5=always with a score range of 8–40. We modified and expanded the tool by adapting each of the original 8 questions to capture family and community stigma identified by the stroke participants.

Statistical Analysis—Means and medians were compared using the Student's t-test or Mann-Whitney's U-test for paired comparisons or ANOVA/Kruskal Wallis tests for more than two group comparisons. Proportions were compared using the Chi-square test or Fisher's exact test for proportions with subgroupings <5. A generalized linear modeling was conducted to assess the independent predictors of stroke related stigma. In all analysis, twotailed p-values <0.05 were considered statistically significant with no adjustments for multiple comparisons. Statistical analysis was performed using SPSS version 19.

RESULTS

Demographic & clinical characteristics

Two hundred and thirty-four (234) subjects were approached but 34 were excluded due to profound aphasia with no proxy (n=13), declined participation in the study (n=15), or could not stand for anthropometric measurements (n=6), leaving 200 subjects eligible for the present analysis. Of the 200 stroke survivors, 105 (52.5%) subjects were males and the mean \pm SD age of stroke survivors in this survey was 62.0 \pm 14.4 years. Nearly 50% had no or primary level education and 70% were urban residents. The predominant vascular risk factors identified include hypertension (93%), overweight and obesity (65.5%), dyslipidemia (42.5%), and diabetes mellitus (31.0%). The median (IQR) duration of stroke diagnosis was 2 (range=1–4) years and stroke was ischemic type in 70%, hemorrhagic in 18%, and the type undetermined in 12% of subjects. The median (IQR) NIHSS score and modified Rankin score were 8 (2–12) and 2 (1–4) respectively.

Frequency and severity of stroke-related stigma

The frequencies of responses to each of the modified 8-Item Stigma Scale for Chronic Illness (SSCI-8) questionnaire assessing personal, family and community stigma are shown in Table 1. The mean \pm SD scores for personal, family, and social/community stigma were 13.7 ± 5.7 , 11.9 ± 4.6 and 11.4 ± 4.4 respectively, p<0.0001 as shown in Figure 1. Dividing the scores overall into quintiles, 21%, 37%, and 38% respectively had a score of 8/40 and felt no stigma at either personal, family, or community levels whereas only 1% each reported feeling stigma always at each of these three levels with scores ranging between 33 and 40. The greater majority of respondents rarely, sometimes, or often felt stigma. Notably at the personal level, 14.5% 'always' thought it was their fault that they had a stroke (enacted stigma), 13% 'always' felt embarrassed because their physical limitations (internalized stigma).

Determinants and Psychosocial associations of stroke-related stigma

The relationships between an array of demographic, clinical, psychological, and healthrelated quality-of-life indicators and stroke-related personal stigma are shown in Table 2. When SSCI-8 scores were arbitrarily divided into 8, 8–19, and >20, location of residence, the Geriatric depression score, CES-D scores were significantly different across the three groups. Specifically, those with scores >20 were more likely to reside in urban settings, had significantly higher GDS and CES-D scores.

There were significant differences between those with score of 8 (n=42) compared with a score >8 (n=158) as shown in Table 2. Briefly, stroke survivors with score of 8 had a mean \pm SD NIHSS score of 6.0 \pm 5.7 versus 8.8 \pm 7.7, p=0.03. Furthermore, mean score on the psycho-emotional domain of 24.0 \pm 4.7 among those with score of 8 was higher than 22.2 \pm 4.6, p=0.03 among those with score >8. Similarly, on the eco-social domain of the Health-Related Quality of Life in Stroke Patients questionnaire stroke survivors without perceived personal stigma had a higher mean \pm SD score of 27.5 \pm 4.3 vs 25.7 \pm 4.8, p=0.03 among those with a score >8. (Table 2)

Predictors of Stroke-related Stigma

The only predictor of stroke-related stigma identified using the Generalized linear model was absence of family history of stroke (Table 3).

DISCUSSION

To our knowledge, this is the first study to assess the determinants and frequencies of stigma specifically among stroke survivors. In fact, stroke related stigma is under-reported and neglected worldwide. A PubMed search on November 15, 2016 using the simplest terms "stroke" and "stigma" revealed just 38 hits, most of which do not directly address the relationship between these entities. There is a wide gap in the literature regarding comprehensive community-based data for post-stroke stigma, perhaps because often stigmatized stroke patients do not use biomedical health services or are lost to follow-up preferring to be treated with complementary and alternative medical therapies.

We found in this study that the overwhelming majority of stroke patients had mild-tomoderate severity of stigma, with the mean scores in response to personal level stigma questions generally higher than those experienced from family and community members. A report among a group of U.S. individuals with diverse neurological disorders namely stroke, epilepsy, multiple sclerosis, Parkinson's disease, and amyotrophic lateral sclerosis where stigma scores were assessed using the SSCI-8 showed relatively low levels of stigma for these neurological populations¹⁹. Among the socio-demographic indicators explored, we observed that urban dwellers significantly experienced more stigma compared with rural or semi-urban dwellers. Furthermore, individuals who felt stigmatized significantly had more residual neurological deficits evidenced by higher NIHSS scores than those who felt no stigma although type and duration of stroke were not associated with stigma. This would support a notion that stroke subjects with enduring physical deficits in large urban populations are more likely to experience stigma.

Amidst the high frequencies of mild-to-moderate severity of stigma observed in the present cohort, we identified a graded increase in risk of depression using both the Geriatric Depression Scale and the Center for Epidemiologic Studies Depression scale and strokerelated stigma. Additionally, individuals with stigma had significantly lower scores in the psychosocial and eco-social domains of the health-related quality of life questionnaire than those without stigma. The observed associations between stigma and psycho-social impairments identified using the HRQOLISP is thus supported by correlations found between stigma and the CES-D and GDS depression scales. This may be because the items under the psycho-social domain of the HRQOLISP assesses the psychological well being of individuals with greater emphasis on depressive symptoms¹⁸. We however did not observe significant associations between stigma and the physical and cognitive domains of the quality of life questionnaire. It is also noteworthy that although stroke survivors who experienced stigma had significantly higher NIHSS scores and thus more severe neurological deficits than those without stigma, this difference was not noticeable on comparison of the mean scores on the physical domain between those with stigma and those without. Taken together these findings suggest that stroke-associated stigma may qualitatively and quantitatively affect domains of the multidimensional quality of life indicators in a differential manner.

In a review by Mukherjee et al. (2006), stroke related-stigma was identified as a major potential contributor to social isolation, depression, and post-stroke recovery¹⁴. 58% of stroke patients without stigma displayed good motivation during rehabilitation programs, but this percentage dropped to 33% among the highly stigmatized patients highlighting the importance of stigma on post-stroke recovery.^{13,14,20} Thus, there appears to be a toxic link between residual physical limitations, stigma, and psycho-social distress among stroke sufferers which could impact significantly on re habilitation and re-integration of stroke subjects. In this regard, qualitative studies among stroke subjects to explore their experiences could be revealing in helping us understand the societal determinants and unmeasured factors that promotes stigma related to stroke. This would be particularly relevant in elucidating some of the unexplained observations in the present study such as the reasons for the significant association between family history of stroke and stroke-related stigma.

Our study has limitations. First, while we surveyed consecutively encountered patients over a defined period of time, these findings are based on a convenience sample, not a systematic community-based study. As such, it is conceivable that patients with severe stigma, may not have been captured in our study, but also suggests that our data may under-estimate the frequency of stroke-related stigma in the region. Second, since this study was conducted at a single hospital in SSA, its results may not necessarily be generalizable to other countries, cultures, and systems beyond the region. However, the socio-demographic-clinical characteristics of the cohort are consistent with those seen in published studies of stroke survivors in other African countries. Furthermore, due to its cross-sectional design, causal inferences cannot be drawn from associations observed.

In conclusion, our study suggests that up to four out of five stroke survivors may experience some form of stigma. Furthermore, stroke survivors who experience mild-to-moderate levels of stigma are more likely to be depressed or have lower levels of quality of life. The full

impact of and implication from stroke-related stigma requires further study, particularly within the broader community as stroke survivors with severe stigma may be living in isolation in their homes.

Acknowledgments

Source of funding: National Institute of Health-National Institute of Neurological Disorders & Stroke; R21 NS094033 and NHGRI, NIH-NINDS; U54 HG007479.

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Highlights

• There is limited data on stigma among stroke survivors globally

- 80% of Ghanaian stroke survivors experienced some form of stigma
- Stigma was associated with depression and lower quality of life
- Further studies are needed to explore the consequences of stroke-related stigma



Figure 1. Stigma among Ghanaian Stroke survivors

Stigma-Scale for Chronic Illnesses-Short Form-8 (SSCI-8) adapted to assess stigma at Personal, Family and Social/Community levels. Each block represents a mean and error bars are for standard deviation about the mean for 200 subjects.

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Perceived Personal, Family, Social/Community Stigma among Ghanaian Stroke Survivors

Questions on Perceived Personal Stigma	Stigma Domain	Never (%)	Rarely (%)	Sometimes (%)	Often (%)	Always (%)
Because of my illness (stroke), I felt uncomfortable with some family and friends.	Enacted	59.5	13	11	8	8.5
Because of my illness (stroke), I avoided some family and friends.	Enacted	64.5	17	6.5	5.5	6.5
Because of my illness (stroke), I felt left out of things.	Enacted/Internalized	63	19	6	6.5	5.5
Because of my illness (stroke), I w as unkind to some family and friends.	Enacted	78	18.5	2	1	0.5
Because of my illness (stress), I avoided looking at me (in mirror).	Enacted	73.5	17.5	4.5	1	3.5
I felt embarrassed about my illness (stroke).	Internalized	64	16	4.5	5.5	10
I felt embarrassed because of my physical limitations.	Internalized	61	19	2.5	4.5	13
I thought it w as my fault I have this illness (stroke).	Enacted	64.5	15.5	1	4.5	14.5
Total Score Quintiles	SSCI-8 SCORE	8	9-16	17–24	25-32	33-40
Percent of Respondents with Score	N (%)	42 (21)	109 (54.5)	38 (19)	9 (4.5)	2 (1)
Questions on Perceived Family Stigma	Stigma Domain	Never (%)	Rarely (%)	Sometimes (%)	Often (%)	Always (%)
Because of my illness (stroke), some of my family seemed uncomfortable with me.		58.5	19.5	10	9	9
Because of my illness (stroke), some of my family avoided me.		70.5	16.5	5.5	5.5	2
Because of my illness (stroke), some of my family left me out of things.		65.5	16	7	4.5	7
Because of my illness (stroke), some family members w ere unkind to me.		77.5	19	1.5	1	1
Because of my illness (stroke), some family members avoided looking at me.		74	19	3.5	1	2.5
Some of my family felt embarrassed about my illness (stroke).		77.5	17.5	2.5	1	1.5
Some of my family felt embarrassed because of my physical limitations.		LL	17	1.5	0.5	4
Some family members acted as though it w as my fault I have this illness (stroke).		77	14.5	1.5	0	7
Total Score Quintiles	SSCI-8 SCORE	8	9–16	17–24	25-32	33-40
Percent of Respondents with Score	%	74 (37)	102 (51)	16 (8)	6 (3)	2 (1)
Questions on Perceived Social/Community Stigma	Stigma Domain	Never (%)	Rarely (%)	Sometimes (%)	Often (%)	Always (%)
Because of my illness (stroke), some other people seemed uncomfortable with me. Because of my illness (stroke), some other people avoided me.		67 76	17 13.5	10 6.5	3.5 2	2.5 2

Questions on Perceived Personal Stigma	Stigma Domain	Never (%)	Rarely (%)	Sometimes (%)	Often (%)
Because of my illness (stroke), some of my friends left me out of things.		68	18	9	4
Because of my illness (stroke), people w ere unkind to me.		74	19	2.5	1.5
Because of my illness (stroke), some people avoided looking at me		79	15	2.5	1.5
Some of my friends felt embarrassed about my illness (stroke).		82	12.5	ю	1.5
Some of my friends felt embarrassed because of my physical limitations.		79.5	16	1.5	0.5
Some people acted as though it w as my fault I have this illness (stroke).		75	13.5	1.5	4
Total Score Quintiles	SSCI-8 SCORE	œ	9-16	17–24	25-32

2(1)

16(8)

104 (52)

76 (38)

%

Percent of Respondents with Score

Always (%)

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Table 2

Demographic and Clinical Characteristics of Stroke Survivors according to three categories based on SSCI-8 Score on Stigma.

Variables	SSCI-8 score 8 'No stigma' n = 42	SSCI-8 score 9 to 19 'Some stigma' n = 130	SSCI-8 score 20 'More stigma' n =28	P-value ANOVA	P-value SSCI-8 score of 8 versus score >8
Male gender, n (%)	26 (61.2)	65 (50.0)	12 (42.9)	0.25	0.13
Age, mean \pm SD	63.9 ± 15.6	62.0 ± 14.8	59.2 ± 9.9	0.41	0.34
Type of domicile				0.01	0.76
Urban	30 (71.4)	83 (63.8)	26 (92.9)		
Semi-urban/rural	12 (28.6)	47 (36.2)	2 (7.1)		
Marital Status				0.68	0.40
Married	25 (59.5)	87 (66.9)	18 (64.3)		
Not married *	17 (40.5)	43 (33.1)	10 (35.7)		
Formal Education				0.13	0.06
None/Primary	14 (33.3)	66 (50.8)	12 (42.9)		
> Secondary	28 (66.7)	64 (49.2)	16 (57.1)		
Primary occupation				0.32	0.15
Skilled workers	27 (64.3)	61 (46.9)	16 (57.1)		
Manual workers	8 (19.0)	29 (22.3)	5 (17.9)		
Unemployed	7 (16.7)	40 (30.8)	7 (25.0)		
Stroke type				0.83	0.54
Ischemic	27 (64.3)	94 (72.3)	19 (67.9)		
Hemorrhagic	10 (23.8)	21 (16.2)	5 (17.9)		
Untyped	5 (11.9)	15 (11.5)	4 (14.2)		
Duration of stroke (years), mean \pm SD	2.8 ± 2.4	2.9 ± 3.3	2.9 ± 2.4	0.99	0.91
Cigarette smoking, n (%)	1 (2.4)	9 (6.9)	3 (10.7)	0.36	0.31
Alcohol intake (yes), n (%)	6 (14.3)	31 (23.8)	11 (39.3)	0.06	0.10
Positive Family history of stroke, n (%)	19 (45.2)	54 (41.5)	19 (32.1)	0.54	0.53
MRS mean \pm SD	2.4 ± 1.4	2.5 ± 1.4	2.5 ± 1.4	0.20	0.72
NIHSS, mean \pm SD	6.0 ± 5.7	9.0 ± 7.9	8.0 ± 6.6	0.07	0.03
Barthel's index, mean \pm SD	79.2 ± 30.3	73.0 ± 30.9	77.1 ± 28.0	0.47	0.30
Geriatric Depression Score, mean \pm SD	4.9 ± 2.5	5.2 ± 2.5	6.8 ± 3.4	0.01	0.24
CES-D, mean \pm SD	19.3 ± 5.4	19.9 ± 6.4	22.9 ± 5.9	0.03	0.28

Variables	SSCI-8 score 8 'No stigma' n = 42	SSCI-8 score 9 to 19 'Some stigma' n = 130	SSCI-8 score 20 'More stigma' n =28	P-value ANOVA	P-value SSCI-8 score of 8 versus score >8
HRQOLISP**					
Physical domain, mean \pm SD	23.2 ± 7.7	21.5 ± 6.5	21.5 ± 6.9	0.36	0.15
Psycho-emotional domain, mean \pm SD	24.0 ± 4.7	22.3 ± 4.7	22.0 ± 4.3	0.10	0.03
Cognitive domain, mean \pm SD	18.4 ± 5.9	17.7 ± 5.2	17.3 ± 5.1	0.68	0.43
Eco-social domain, mean \pm SD	27.5 ± 4.3	25.8 ± 4.7	25.3 ± 5.1	0.08	0.03
* Includes single, divorced, widowed or se	separated individuals.				

** HRQOLISP= Health-Related Quality of Life in Stroke Patients questionnaire

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Table 3

Predictors of Stigma using a Generalized Linear Model.

Variable	Estimate ± Standard error	P-value
Female vs male gender	1.54 ± 0.92	0.09
Rural vs urban domicile	-0.96 ± 0.74	0.20
Married vs single	1.14 ± 0.83	0.17
No family History of stroke	1.58 ± 0.76	0.03
Highly skilled employed/employed vs unemployed	-1.55 ± 0.88	0.07
Stroke severity on NIHSS for each point higher	-0.12 ± 0.09	0.18
HQLSR		
Physical domain, each point higher	0.02 ± 0.08	0.83
Psychological domain, each point higher	-0.04 ± 0.13	0.76
Cognitive domain, each point higher	-0.20 ± 0.11	0.07
Eco-social domain, each point higher	-0.08 ± 0.11	0.46

J Neurol Sci. Author manuscript; available in PMC 2018 April 15.