Post-stroke social networks, depressive symptoms, and disability in Tanzania: A prospective study

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Abstract
Background: Evidence suggests that social networks improve functional recovery after stroke, but this work has not been extended to low- and middle-income countries (LMICs). Post-stroke depression interferes with functional outcome but is understudied in LMICs.

Aims: To determine the relationships between social networks, disability, and depressive symptoms in patients surviving 90-days post-stroke in Dar es Salaam, Tanzania.

Methods: Participants ≥ 18 years, admitted ≤ 14 days of stroke onset, were enrolled. Disability was measured using the modified Rankin Scale, social networks by the Berkman-Syme social network index, and depressive symptoms by the Patient Health Questionnaire-9 (PHQ-9) by telephone interview at 90 days. A Kruskal-Wallis test or Spearman’s correlation coefficient was used to assess the associations between social networks, depressive symptoms, and disability.

Results: Of 176 participants, 43% (n = 75) died, with an additional 11% (n = 20) lost to follow-up by 90 days. Among 81 survivors, 94% (n = 76, 57% male, average age 54 years) had complete information on all scales (mean and median follow-up time of 101 and 88 days). Thirty percent (n = 23, 41.9%, 95% confidence interval 20.2) had at least mild depressive symptoms (PHQ-9 ≥ 5 points). Nearly two-thirds (n = 46, 61%) reported ≥ 3 close friends. A higher social network index score was associated with fewer depressive symptoms (p < 0.0001) and showed a trend towards significance with lower disability (p = 0.061). Higher depressive symptom burden was correlated with higher disability (r = 0.52, p < 0.0001).

Conclusion: Post-stroke social isolation is associated with more depressive symptoms in Tanzania. Understanding social networks and the associated mechanisms of recovery in stroke is especially relevant in the context of limited resources.

Keywords
Stroke, depression, disability, social networks, epidemiology, Africa

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Introduction
There is increasing recognition that social networks, characterized by both the quality and quantity of an individual’s personal and community relationships, influence health behaviors and outcomes.¹ Within neurology, epidemiological studies have demonstrated that having small social networks and lack of social support are associated with an increased incidence of stroke,² as well as increased depressive symptoms and poorer functional recovery following a stroke.³⁴ However, while social networks may vary across cultures due to...
differing family sizes, religious beliefs, and relationships within villages or tribes, individuals in low- and middle-income countries (LMICs) like Tanzania are not well represented in the literature. This is despite the reality that social networks and social supports in LMICs may be particularly vital to health outcomes. Social ties often serve as the principal source of tangible and intangible resources, while formal support systems such as a healthcare infrastructure are under-developed and/or under-resourced. The existing social network literature pertaining to LMICs is typically focused on HIV/AIDS. In one systematic review of social networks in LMICs, published in 2015, no included article involved neurologic illness. However, patients with stroke are a population in whom social networks may be especially relevant, given the need for rehabilitation services and family member support to effectively manage post-stroke disabilities as well as sudden loss of livelihoods.

LMICs account for over 75% of the global disability adjusted life-years (DALYs) from stroke, making addressing the burden of stroke in LMICs a public health priority. The burden of disease is estimated to continue to increase unless additional population-wide interventions and risk factor reduction programs are successfully implemented. Sub-Saharan Africa (SSA) is disproportionately affected by this stroke burden. According to the World Health Organization (WHO) Global Burden of Disease estimates, three SSA countries (Angola, Liberia, and Sierra Leone) recorded the highest stroke mortality and DALYs worldwide. The burden of stroke in Tanzania is also increasing.

Aim

Given the need to understand social networks in the recovery of stroke patients in LMICs, we performed a study of social networks and stroke as they relate to disability and depressive symptom burden at 90 days in Tanzania. The urban city referral hospital study site provides a cohort in whom to examine the inter-relationships of social networks, depressive symptoms, and disability in a resource-limited, sub-Saharan African setting.

Methods

Approvals

Ethics board approvals were obtained from the Muhimbili National Hospital (MNH/IRB/I/2016/18), National Institute of Medical Research of Tanzania (NIMR/HQ/R.8a/Vol. IX/2272), and the Institutional Review Board at Partners Healthcare (Massachusetts General Hospital) (2016P000301).

Setting

This prospective cohort study was conducted between July 2016 and March 2017 at the Muhimbili National Hospital (MNH) in Dar es Salaam, Tanzania, an urban center and capital of Tanzania with a population of 4.36 million. Study duration was determined by the amount of funding available. MNH is the largest referral hospital in Tanzania, with a 1500-bed capacity and 1000 to 1200 inpatients admitted weekly, and is a teaching hospital for Muhimbili University of Health and Allied Sciences. There are four neurologists at MNH (Okeng’o, personal communication, October 2017). In Tanzania, the average household size is 5.4 people per household, and there is an East-West regional gradient of 3.7 to 7.1 children per woman. Approximately 70% of Tanzanians live with less than 2 USD per day.

Participants

Inclusion criteria included participants who resided in Tanzania, were ≥ 18 years old, admitted to MNH within 14 days of stroke onset, and meeting the WHO definition of stroke. Hemorrhagic or ischemic stroke patients encountered within the enrollment period who fulfilled the inclusion criteria and gave written consent were included. Proxy consent via a primary relative if a patient was unconscious at admission was allowed. Participants were excluded from analysis if they had a head CT scan that subsequently did not confirm the diagnosis of stroke (Figure 1).

Measurements

Upon study enrollment, a physician performed a neurological examination and determined an NIH Stroke Scale (NIHSS) score. Physicians were trained and certified in the NIHSS using the free online module. Demographic and clinical variables of interest were collected using paper-based interview forms. HIV testing was performed via a rapid antibody test, followed by HIV ELISA and Uni-Gold™ tests on all hospital admissions due to a hospital-wide initiative. Admission and 90-day disability were measured using the modified Rankin Scale (mRS), which provides assessment of motor and functional disability on an ordinal scale from 0 (no disability) to 6 (death). The Berkman-Syme social network index (SNI) and the Patient Health Questionnaire (PHQ-9) were used to measure social networks and post-stroke depressive symptom burden, respectively. Physicians collected interview forms and questionnaires from the participant or his or her designated proxy respondent on admission. All follow-ups were conducted by telephone by African investigators, in the language of the participant. Participants were called at approximately
90 days. The patient herself or himself was asked to answer, but a proxy respondent was accepted. If participants could not be reached at 90 days, there were three subsequent attempts to reach the patient on the phone numbers provided. Participants and family members who could not be reached after a minimum of three attempts to reach them were deemed “lost to follow-up.”

The SNI of social ties includes assessments of marital status, number of contacts with close friends and relatives, and membership and participation in church group and other community groups. It is scaled from 0 to 4, with four categories reflecting type and extent of social contact. Contacts with friends and relatives, marital status, church affiliation and group memberships were weighted equally. A score of 0 represents the most isolated category with increasing scores representing categories of increasing social connectedness.

The PHQ-9 has been validated as a screening tool for depression after stroke, initially in a U.S.-based population and subsequently in other countries including South Africa. A PHQ-9 score ≥ 10 has been found to have a 91% sensitivity and 89% specificity for a diagnosis of major depressive disorder. Notably, a meta-analysis of validation studies of the PHQ-9 revealed no substantial differences in the pooled sensitivity and specificity for a range of cut-off scores from 8 to 11 points when diagnosing major depression. A PHQ-9 score of 5 to 9 suggests mild depression.

**Data analysis**

Participants with scales that could not be scored due to missingness were not included in the final analysis due to the inability to generate a summary score for the outcome variables of interest. Variables were described by their mean and standard deviation if continuous, and proportions and percentages for counts. We considered PHQ-9 and mRS as continuous variables and SNI as a categorical variable when analyzing outcomes. A Spearman’s correlation was used to test the
association between two continuous variables. A Kruskal–Wallis test was used to test the association between a categorical variable and a continuous variable. Thus, the Spearman’s correlation test was used to compare PHQ-9 and mRS and a Kruskal–Wallis test was used to compare SNI with PHQ-9 and with mRS. Analyses were performed using SAS software, version 9.4 (SAS Institute). A p-value of < 0.05 was considered statistically significant.

Results

Enrollment

A total of 176 participants met the WHO clinical criteria for stroke within 14 days of onset prior to hospital admission. One hundred and fifty-three participants had CT scans confirming the diagnosis of stroke (ischemic stroke n = 80; hemorrhagic stroke n = 96). There were no refusals to participate in the study which is not atypical for the region.20 The confirmed 90-day mortality was high at 43% (75/176 patients), although an additional 20 participants (11%) of enrolled participants were lost to follow-up, making the true mortality at 90 days likely even higher. During the follow-up telephone interview by investigators, 81 participants or their proxies responded to the Berkman Syme Social Network Index, PHQ-9, and mRS. There were five respondents who provided incomplete information. Participants with incomplete compared to complete information were similar in age, sex, educational attainment, and employment status. Those with incomplete information were more likely to have experienced an ischemic stroke (p = 0.011), and two were not fully conscious.

There were 76 participants with complete data for the final analyses with a mean and median follow-up time of 101 and 88 days. The 76 respondents were compared to the 100 participants who did not respond, or did not respond in full, at 90 days (Table 1). Non-participation was most often due to participant fatality (n = 75), but an additional 20 participants were loss to follow-up likely due to fatality (n = 20), and 5 others provided incomplete survey data, making analysis of their responses impossible. Consistent with this situation, the most important difference between the 76 respondents and 100 non-respondents was the baseline NIHSS scores: respondents had a mean of nine points lower NIHSSs than non-respondents, indicating less severe stroke events among survivors. There were 63 proxy respondents and 13 self-reporting participants: 57% were male (n = 43) with an average age of 54.1 years (standard deviation 14.1 years). Five percent (n = 4) were HIV infected. The histograms of mRS, PHQ-9, and SNI scores at follow-up are depicted graphically in Figure 2.

Social isolation versus integration post-stroke

Of the 76 patients, 32% (n = 24) had a 90-day mRS of 4–5 (moderately severe to severe disability). At 90 days post-stroke, 61% (n = 46) reported having ≥3 close friends. Similarly, the majority of participants reported at least one group affiliation (66%, n = 50). Fifty-four (71%) were married. The majority (65%, n = 49) had SNI scores of 3 or 4 representing a high degree of social connectedness, whereas only 13% (n = 10) had SNI scores of 0 or 1. There was more social isolation reported by women than men in a univariate analysis (p < 0.05).

Post-stroke depressive symptoms

Thirty percent (95% confidence interval 20.2, 41.9%) of stroke survivors (n = 23) had PHQ-9 scores of 5 or
more, while 39% (n = 30) had PHQ-9 scores of zero. There was no significant difference by sex in PHQ-9 scores in univariate analysis (p = 0.99). In univariate analyses, done to determine predictors of post-stroke depressive symptoms at 90 days, baseline age, employment status, education, and history of alcohol or drug use were not statistically significant (p-values all > 0.10), in contrast to NIH Stroke Scale Score which was significant (p-value < 0.05, data not shown).

**Correlations between variables at 90 days**

A higher number of depressive symptoms was moderately correlated with a lower social network index (r = −0.51, p < 0.0001) and higher disability on mRS (r = 0.52, p < 0.0001) (Figure 3). A higher social network index showed a trend towards statistical significance with lower motor disability but did not meet our pre-defined cut-off value for statistical significance of 0.05 (p = 0.061).

Figure 3. Correlation between outcome variables at 90 days.
Discussion

A lower post-stroke social network index was associated with more depressive symptoms in a prospective cohort study of stroke survivors in Dar es Salaam, Tanzania. Although a causal mechanism is not established in our data, since our depressive symptom and social network index scales were collected at the same timepoints as the disability questionnaire, our findings add to the limited data on social networks in stroke survivors in sub-Saharan Africa. Post-stroke depressive symptoms were also significantly associated with higher disability burden.

The relationship between social networks, depressive symptoms, and recovery following stroke is complex. The benefit of social networks can be emotional (e.g. encouragement, expression of empathy), instrumental (e.g. assistance with tangible needs such as cooking), and/or informational (e.g. health education and advice). This may be particularly applicable to the post-stroke setting, as post-stroke disability contributes to loss of employment and carries a limited likelihood of return to work. In LMICs, the reliance on economic practices such as money sharing and lending may be even greater within social networks, enhancing this moderating effect of social networks in times of financial strain. Since most participants in our study were of working age (average study participant age of early 50s), this may be especially true in SSA where younger onset stroke is well recognized. Members of social networks may also provide concrete assistance in which care is shared among members of the network, or have access to better medical care or more forms of transit to the health center.

Social support is postulated either to enhance health—irrespective of the level of stress—or to buffer and moderate the effects of stress. In one survey-based study in >80,000 adults in Sweden, social support was particularly helpful at high levels of financial stress, supporting the buffer hypothesis. Conversely, social isolation may contribute to decreased medication adherence, decreased participation in physical activities, fewer returns to the hospital or health center for medical follow-up, and/or depression. Social isolation was found in 30% of 818 stroke survivors in rural China, often exacerbated by a lack of environmental necessities, including handrails near toilets, access to light switches, and appropriate seating for those with physical weakness.

Post-stroke depression affects one-third of stroke patients, although these studies have typically been conducted in high-income countries. In one systematic review on the frequency of depression after stroke, data from only two LMICs were included and none were from Africa. This absence of data in the SSA region has important implications, since post-stroke depression is associated with decreased quality of life, worse rehabilitation outcomes, and increased disability and mortality. Extant studies reveal a broad range of post-stroke depression burden in SSA. For example, Uganda, Democratic Republic of Congo, and Central African Republic reported post-stroke depression prevalences at 32%, 54%, and 89%, respectively. In a systematic review of post-stroke depression in the Middle East and North Africa, the prevalence ranged from 17% to 73%, highlighting the importance of developing this line of investigation among LMICs.

Table 1. Clinical and demographic characteristics of cohort on admission (n = 176) and at 90-days (n = 76).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n = 100</th>
<th>n = 76</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD), years</td>
<td>58.2 ± 18.8</td>
<td>54.4 ± 14.1</td>
</tr>
<tr>
<td>&lt;50 years</td>
<td>29 (29.0)</td>
<td>31 (40.7)</td>
</tr>
<tr>
<td>Female (%)</td>
<td>47 (47.0)</td>
<td>33 (43.4)</td>
</tr>
<tr>
<td>HIV infection (%)</td>
<td>9 (9.4)</td>
<td>4 (5.4)</td>
</tr>
<tr>
<td>Ischemic (%)</td>
<td>51 (51.0)</td>
<td>29 (38.2)</td>
</tr>
<tr>
<td>Hemorrhagic (%)</td>
<td>49 (61.8)</td>
<td>47 (61.8)</td>
</tr>
<tr>
<td>NIH Stroke Scale Score (SD) at admission</td>
<td>22.4 ± 9.8</td>
<td>13.1 ± 8.0</td>
</tr>
<tr>
<td>Highest educational attainment a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>35 (35.0)</td>
<td>18 (23.1)</td>
</tr>
<tr>
<td>Primary school</td>
<td>45 (45.0)</td>
<td>42 (53.8)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>11 (11.0)</td>
<td>9 (11.5)</td>
</tr>
<tr>
<td>Post-secondary school</td>
<td>8 (8.0)</td>
<td>5 (6.4)</td>
</tr>
<tr>
<td>Employment status (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>33 (33.0)</td>
<td>40 (51.3)</td>
</tr>
<tr>
<td>Peasant</td>
<td>11 (11.0)</td>
<td>7 (9.0)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>35 (35.0)</td>
<td>18 (23.1)</td>
</tr>
<tr>
<td>Retired</td>
<td>8 (8.0)</td>
<td>3 (3.8)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>13 (13.0)</td>
<td>8 (10.3)</td>
</tr>
<tr>
<td>History of self-reported alcohol or drug abuse</td>
<td>16 (16.0)</td>
<td>7 (9.2)</td>
</tr>
</tbody>
</table>

aRapid HIV results missing for two participants.
bEducational level listed as “other” for two participants and was excluded here.
depression in these settings has not been well studied, but one proposed mechanism is the potential for social networks and social supports to buffer the effects of stigma associated with post-stroke disability. In one cross-sectional study of 200 stroke survivors in Ghana, four out of five reported experiencing some form of disability-associated stigma. Stroke survivors with more severe post-stroke deficits reported a significantly higher frequency of stigma. Stigmatized individuals were also more likely to be depressed and have lower levels of quality of life.

On the other hand, depression and disability can themselves serve as an impediment to performance of social roles within social networks. In a cross-sectional study of 71 community-dwelling survivors in Nigeria, disability was cited as a primary reason for the difficulty in community re-integration post-stroke. Community re-integration was also influenced by age, post-stroke employment, and type of assistive mobility device. Analyses of pre- and post-stroke social networks reveal a vulnerability of a person’s social network, with a shift from a diverse social network into a family-based one after stroke. Future research can help to clarify the mechanisms by which social networks and post-stroke depression affect stroke recovery and disability. This area likely requires mixed methods research including qualitative and quantitative approaches given the paucity of data on this topic.

High-income countries’ literature lends important insights into the importance of social support in post-stroke depressive symptoms and stroke recovery. Treatment of depressive symptoms was the only variable found to improve the social role functioning at four months post stroke in a study of 371 new stroke patients in Indianapolis, U.S.A. Similarly, in 96 German ischemic stroke patients, high levels of perceived social support, no history of pre-stroke depression, and high self-efficacy were the strongest protective factors against depressive symptoms. In the Netherlands, a longer study of 249 stroke patients followed for three years post-stroke found that survivors experience a decline in function in social support over time. Whereas support in problem situations was associated with more depressive symptoms, everyday and esteem support were associated with less depressive symptoms. In a 2013 systematic review, attempting to synthesize findings on social support and stroke survivors’ health-related quality of life post-stroke, the authors concluded that the number of studies was too small and the heterogeneity of methods that assessed the types of social support too broad to draw a clear statement. Taken together, the relationship between depressive symptoms and social networks as well as between social networks and disability are not unidirectional and co-evolve in stroke recovery. Improvement of each of these outcome variables almost certainly improves the situation of the other outcomes.

Regardless, the need to develop both individual and population-level strategies that address psychosocial and community factors in addition to clinical factors is supported by our initial findings. Understanding how social networks influence health outcomes is a particularly cost-effective strategy to amplify effects of existing interventions in LMICs and also presents an opportunity to improve effectiveness of future public health interventions that are more biological such as treating blood pressure or cholesterol.

Limitations of this study include the low sample size of stroke survivors at 90-days, with a high mortality rate of enrolled participants. For example, the correlation between motor disability and social networks may have been significant in a larger sample. Further, many people suffering stroke in Tanzania may not seek or receive hospital-based care. There are also limitations to construct validity, with PHQ-9 potentially not serving as an adequate screening tool of depression in Tanzania in the absence of validation studies. However, the PHQ-9 has been validated elsewhere in SSA. Further, alternative depression scales could have been used for aphasic patients such as the Aphasic Depression Rating Scale, an important consideration for stroke patients. We made no additional provisions for aphasic patients; removal of aphasic patients would have potentially altered our results since language and mood symptoms both have hemispheric dominance. Proxy respondents had a large role in our study due to convenience for respondents and severity of the strokes; we are uncertain how proxy respondents and the participants may have differed in the responses. Previous studies have been inconclusive with regard to proxy reliability in reporting stroke patients’ social health, with some studies demonstrating high agreement in responses between people with aphasia and proxy responses, and others demonstrating no relationship between proxies’ and patients’ ratings of social health and quality of life indicators. Pre-stroke depression was not reported and pre-stroke antidepressants were inquired but were absent; therefore, given the low recognition of depression in this setting, we are unable to provide a pre-stroke prevalence of depression in this cohort. In some cases, missing data were due to inability to comprehend a particular question, and there was at least one participant who could not participate in the follow-up surveys due to reduced consciousness. We study social networks but do not study social supports which would be an important complementary area to examine. Further work on refinement of these scales for the modern African context is an area of high future need. Similarly, different cultural conceptualizations of social networks may exist in Tanzania that may not be fully captured in the Berkman Syme social
networks questionnaire, making our scales overlook important nuances in the social networks of Tanzanian patients.

Moving forwards, education of local healthcare workers regarding the psychosocial implications of stroke is important in the management of this growing burden of disease. Simple screening of patients for depressive symptoms at a community level could take place so that support can be targeted for patients at high risk of post-stroke depression. Similarly, improving mobility to enhance a stroke survivor’s ability to engage outside of the home through such basic infrastructure as sidewalks, accessible seating, and toilets could be lifechanging. Given the importance of social networks and negative health effects of social isolation, interventions that improve or develop new social network connections and utilize community health workers may be especially effective in addressing stroke recovery. Re-integration into religious groups would also be a method of intervention given the high number of faith-based organizations targeted towards health in SSA.42 Post-stroke depression and social supports in patients with both HIV/AIDS and stroke are areas that require further research, given the dual burden of stigma associated with HIV and post-stroke disability. These social interventions may be both effective and inexpensive, a welcome opportunity especially for SSA populations where strong social structures have shown to be protective and even lifesaving. Ultimately, understanding the relationship between social networks, depression, and post-stroke recovery in resource-limited settings will help inform cost-effective interventions for rehabilitation of stroke survivors.

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