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Can trained field community workers identify stroke using a stroke symptom questionnaire as well as neurologists? Adaptation and validation of a community worker administered stroke symptom questionnaire in a peri-urban Pakistani community.

Maria Khan,
Agha Khan University

Ayeesha Kamran Kamal
Agha Khan University, ayeesha.kamal@aku.edu

Muhammad S. Ilyas
Dow University of Health Sciences, Pakistan.

Muhammad Islam
Aga Khan University, muhammad.islam@aku.edu

Iqbal Azam Syed
Aga Khan University, iqbal.azam@aku.edu

See next page for additional authors

Authors
Maria Khan,; Ayeesha Kamran Kamal; Muhammad S. Ilyas; Muhammad Islam; Iqbal Azam Syed; Azam Virk,; Alia Nasir; Hasan Rehman,; Anita Arif,; Muhammad Jan,; Anjum Akhtar,; Minaz Mawani; Junaid Abdul Razzak,; and Omrana Pasha

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Can trained field Community Workers identify stroke using a stroke symptom questionnaire as well as neurologists?:

Adaptation and Validation of a Community worker administered stroke symptom questionnaire in a peri-urban Pakistani community

Maria Khan, MBBS, FCPS Neurology, MSc Epi Bio[1,†], **Ayeesha Kamran Kamal, MBBS, Vascular Neurology**[2,*,†], **Muhammad Islam, MSc Epi Bio**[3], **Iqbal Azam, MSc Epi Bio**[4], **Azam Virk, MBBS**[5], **Alia Nasir, MScN**[6], **Hasan Rehman, MBBS**[7], **Anita Arif, MScnN**[8], **Muhammad Jan, BScn**[8], **Anjum Akhtar, MBBS, FCPS Neurology, Cerebrovascular Clinical Fellow**[9], **Minaz Mawani, MSc Epi Bio**[10], **Junaid Abdul Razzak, MBBS, PhD**[11], and **Omrana Pasha, MBBS, MPH**[12]

[1]Fogarty Cerebrovascular Research Fellow, The International Cerebrovascular Translational Clinical Research Training Program (Fogarty International Center, National Institutes of Health) and Department of Medicine, Aga Khan University, Karachi, Pakistan

[2]Associate Professor Neurology, Stroke Service, The International Cerebrovascular Translational Clinical Research Training Program (Fogarty International Center, National Institutes of Health) and Department of Medicine, Aga Khan University, Karachi, Pakistan

[3]Senior Instructor, Department of Community Health Sciences, Aga Khan University, Karachi, Pakistan

[4]Assistant Professor, Department of Community Health Sciences, Aga Khan University, Karachi, Pakistan

[5]Field Coordinator, AMAN Foundation, Karachi, Pakistan

[6]Field Supervisor, AMAN Foundation, Karachi, Pakistan

[7]Research Associate, Department of Medicine, Aga Khan University, Karachi, Pakistan

[*]Corresponding Author: Ayeesha Kamran Kamal, Associate Professor Neurology, Section of Neurology, Dept. of Medicine, Aga Khan University, Stadium Road – 74800, Karachi, Pakistan, ayeesha.kamal@aku.edu, Phone: 9221 – 34930051-4559, Fax: 9221-34934294/9221-3493-2095.
[†]Joint First Authors

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[8]Research Coordinator and Data Management Stroke Service, Section of Neurology, Department of Medicine, Aga Khan University, Karachi, Pakistan

[9]Post Graduate Medical Education Stroke Fellow, Aga Khan University, Karachi, Pakistan

[10]Senior Instructor-Research, Dept. of Medicine, Aga Khan University, Karachi, Pakistan

[11]Chairman and Associate Professor, Department of Emergency Medicine, Aga Khan University and Chief Executive Officer- AMAN Health, AMAN Foundation Karachi, Pakistan

[12]Associate Professor, Director Masters in Epidemiology and Biostatistics Program, Department of Community Health Sciences, Aga Khan University, Karachi, Pakistan

Abstract

Background—Stroke is a leading cause of morbidity and mortality worldwide. There is a paucity of data from South Asia where stroke is highly prevalent. Validated tools administrable by Community Health Workers (CHWs) are required to identify stroke in the community in a resource strapped region such as this.

Methods—The study was conducted in a transitional slum in Karachi, Pakistan. Questionnaire for Verifying Stroke-Free Status (QVSFS) was adapted and translated into Urdu. Two CHWs, trained by a neurologist, selected 322 community dwelling subjects using purposive sampling. Each CHW collected data independently which was validated by a vascular neurologist who directly examined each participant. To assess the effect of audit and feedback, data from the final 10% of the subjects was collected following a second training session for the CHWs. Sensitivity, specificity and Cohen's kappa was determined for the CHW administered questionnaire against neurovascular assessment.

Results—Mean age of participants was 56.5 years with 71% of participants being women. The sensitivity and specificity of the questionnaire of detecting stroke was 77.1% (CI: 64.1%–86.9%) and 85.8% (CI: 83.5%–87.5%). The chance corrected agreement using the Cohen's Kappa statistic was 0.51 (CI: 0.38–0.60). Kappa ranged from 0.37 to 0.58 for each of the seven stroke symptoms. Hemianesthesia (72.9%) and hemiplegia (64.6%) were the most sensitive symptoms. The performance and agreement improved from moderate to substantial after audit and feedback.

Conclusion—We found a reasonable sensitivity and specificity and moderate agreement between CHW administered QVSFS and assessment by a vascular neurologist.

Study Registration Number—NCT02073955

Keywords

Stroke; Developing Countries; Epidemiology; Detection; Prevalence

Background

Stroke is a leading cause of morbidity and mortality worldwide [1]. A recent systematic review of population based studies on stroke showed a divergent trend in the incidence of stroke: while high income countries reported a decrease of almost 42%, middle and low income countries reported more than a 100% increase in incidence over the last four decades

[2]. In Pakistan, a community based study reported a life time prevalence of self-reported cerebrovascular events of 21.8% in adults, with an equal distribution among women and men, indicating a need to identify and prevent stroke in this middle and low income country [3].

There is however, a serious lack of epidemiological data from South Asian countries that are most affected by this chronic condition [4]. The WHO recommends three steps for the determination of stroke burden in any community [5]. Step one is a hospital based stroke registry, step two is a community based fatal event register and step three is a community based non-fatal event register. In a country like Pakistan, tertiary care is not accessible to everyone and health care is largely based on fee for service model. This will lead to an underestimation of the field burden of stroke if only step one is used. Similarly, step two will also not provide a reliable measure of stroke burden since recognition and registration of stroke death is inadequate in the community. This is because deaths may be certified at home, might not be documented with rigor due to frequent internal migration or simply due to a lack of stable cohorts reporting to fixed referral centers. Therefore step three, or direct community determination, maybe the best estimate of the true stroke burden in Pakistan. However, one of the biggest challenges in implementing such surveillance programs is the non-availability of locally validated tools for detecting stroke.

Stroke symptom questionnaires (SSQs) have been used extensively to screen individuals for the presence of stroke. One such questionnaire, the Questionnaire to Verify Stroke Free Status (QVSFS) was developed to identify stroke free phenotype for clinical studies on genetics [6, 7]. Its six symptom questions have recently been shown to be effective in screening for stroke or TIA with a high sensitivity and moderate specificity [8]. Hence, these questions have a potential for being used as a public health screening instrument to identify individuals with symptomatic stroke. This idea is supported by community based validation studies in South America [9, 10]. However the challenge to validate and adapt this tool to a high prevalence, low resourced and literacy challenged population such as the one in South Asia still remains.

We hypothesized that properly trained field workers, with minimal education, would be able to use the QVSFS in the community to identify stroke symptoms as well as trained vascular neurologists.

The objective of our study was to translate the QVSFS questions into the local language (Urdu), adapt them in a local context to assist literacy and numeracy challenged populations to report stroke related symptoms, train community health workers in their administration and validate their findings against assessment by vascular neurologists. We also aimed to identify the field feasibility of this process in terms of subject refusals, difficulty in understanding questions and time taken to fill out the questionnaire.

The impact of a successful locally validated community worker led stroke detection instrument could greatly facilitate task shifting and sharing in stroke identification and referral, and approach it as a public health target, by validating a tool that could be used by existing personnel to identify the target disorder with a sensitivity and specificity that would

approximate tertiary care vascular neurologists. This would provide a solution that is much needed in a resource challenged setting with a high disease burden.

Methods

Our study design was a validation study of a stroke symptom questionnaire and its administration by community health workers (CHW). Both CHWs interviewed each patient separately, blinded to the findings of the other CHW. All the participants were evaluated by the neurologist. The gold standard used was assessment by two stroke neurologists (MK and AA) based on history and physical and neurologic examination. In case of a discrepancy in the assessment of the two neurologists, a third stroke neurologist (AKK) evaluated the participant and that assessment was considered final. The inter-CHW reliability was assessed by getting both CHWs to administer the stroke symptom questionnaire to the same subject at different times separate from each other.

The study was carried out at Ibrahim Hyderi, a peri-urban settlement of Karachi, Pakistan which is one of the seven union councils of Bin Qasim Town. Ibrahim Hyderi was chosen as a target site since its population of a 150,000 inhabitants is challenged in resource, numeracy and literacy. It is undergoing rapid urbanization and demographic transition which makes it an ideal setting to test an emerging non-communicable disease threat.

We selected one male and one female CHW from the community. They had completed ten years of schooling, and had no prior experience of working in healthcare. Neither of the two CHWs had any exposure to stroke in their personal and family lives. They were fluently bilingual and able to speak and read Urdu and Sindhi (the predominant second language in the area). The two neurologists chosen to validate their findings had postgraduate degrees in neurology and had completed additional training in stroke neurology. Each of them had direct experience of acute stroke presentation, thrombolysis, stroke rehabilitation and chronic stroke preventive care. Their competencies included direct assessment of greater than 1200 inpatient strokes, greater than 1500 outpatient vascular assessments and an individual run stroke prevention clinic focused at community outreach and service.

The protocol was approved by the Ethical Review Committee of the Aga Khan University Hospital (protocol approval number 2331- CHS- ERC -12). All progress and questionnaire, field modifications were duly reported to the ERC of the Aga Khan University as per institutional regulations. All study staff that had any direct field contact including research fellows completed Neuroethics, research ethics and informed consent training prior to field work. The course of ethics had internationally standardized content.

Subject Selection

All adults above 40 years of age who were residing permanently in Ibrahim Hyderi were eligible to participate in the study. Those unable to answer for themselves due to any handicap, physical or verbal, were eligible if they had a surrogate who was a primary caregiver and willing to provide necessary information. All participants were required to provide written informed consent. We excluded any individuals who refused to participate in either of the two components of the validation study: CHW assessment or neurologist’s

assessment. Individuals, who were physically handicapped and unable to come to the community center for neurological assessment, were evaluated at home by the two neurologists.

Development of Tool and Training of CHWs

The QVSFS was developed to identify stroke free phenotype for clinical studies on genetics. QVSFS consists of eight questions, six of which are related to stroke symptoms namely hemiplegia, hemi-anesthesia, hemianopia, loss of vision in one eye, inability to speak and inability to understand. The questionnaire was found to be reliable and valid for this kind of screening in subsequent studies.[7, 11]

We translated and adapted the QVSFS as follows: an additional question regarding sudden onset facial weakness was added to it, and a single question on physician diagnosis of stroke was kept. The question regarding Transient Ischemic Attack [12] was excluded as we did not expect understanding of this condition to exist in our community. Culturally relevant pictures were developed to assist understanding of the stroke symptom questions.

The questionnaire was then translated into Urdu by the primary investigator, who is also a practicing neurologist so that the medical terminologies that are pertinent to the local setting can be used. This questionnaire was then back translated to ensure clarity by two bi-lingual individuals, a neurologist and a non-neurologist. They were also asked to give written feedback. No major issues with clarity were found in this process.

The questionnaire underwent field testing with CHW and community feedback was incorporated to ensure clarity. Specifically, communities found the word “stroke” to be too harsh, and associated with a stigma. Hence, they preferred to be questioned regarding the symptoms directly and to be asked about the “vascular disease of the brain” rather than using a local term for stroke.

For training of CHWs, a manual was developed in English and translated into Urdu. CHWs underwent a structured training conducted by vascular neurologists in which they were trained in questionnaire administration using pictures and videos and later by role playing and demonstration in the field. Pilot testing was done and all problems identified were addressed before start of formal data collection.

The subjects were recruited through purposive sampling. Efforts were made to recruit subjects on all days of the week, in order to get male representation which was expected to be low on working days due to their employment commitments.

Each subject recruited in this manner was approached within the next 1–3 weeks by the second CHW and the stroke symptom questionnaire was re-administered. They were given a token containing an identification number and asked to visit the community center between 10 am and 3 pm, Monday through Friday for neurological assessments. On these days, the CHWs actively went to the field and brought subjects to the center for these assessments. Two neurologists blinded to CHWs’ findings did independent assessments of each subject at the community center, and gave appropriate medical advice (Figure 1).

Sample Size Estimation

Using *Power Analysis and Sample Size PASS version 11*, a sample size of 322 was calculated. This sample size was chosen to achieve 80% power to detect a true Kappa value of 0.55 in a test of H_0: Kappa ≤ 0.40 vs. H_a: Kappa > 0.40. Null hypothesis of kappa 0.4 was chosen as we were interested in detecting at least a moderate agreement between CHW's diagnosis and neurologists' diagnosis of stroke. The expected frequency of stroke was taken as 0.21[13] and this power calculation was based on a significance level of 0.05.

Recruitment was planned to be ongoing till required study sample size was met to achieve the required power for Kappa statistics as elaborated above.

Statistical Analysis

The sensitivity, specificity, positive and negative predictive values with 95% confidence interval were calculated by comparing the responses to the questionnaire with the gold standard represented by the assessment by a neurologist. Sensitivity, specificity, and predictive values were calculated for the questionnaire overall and for each item singly. Cohen's kappa coefficient with its 95% CI was used to assess the level of agreement between the questionnaire and neurological assessment. These values were also determined for each CHW separately. Sensitivity analysis was done to assess how the questionnaire behaves in different genders, across different education and socioeconomic strata and across different age categories. Statistical analysis was performed using SPSS version 19 for Windows (SPSS Inc., Chicago, IL, USA).

Results

Approximately 700 individuals were approached by the two Community Health Workers trained to collect data on stroke symptoms. Of these 631(90.1%) agreed to participate in the study but only 322 (46.0%) completed all evaluations including assessment by two neurologists. These made up the final sample for the validation study as per requirements.

Of these 30 (9.4%) subjects were physically disabled and unable to come to the community center for evaluation. These were visited at home by the two neurologists. The rest of the participants underwent assessment at the Community Health Centre.

Mean age of the participants was 56.5 years (SD 11.8 years) and 72% were under 60 years of age. There were 230 (71.4%) women participants and 92 (28.6%) men. The largest ethnic group was Sindhi followed by Balochi (6.5%) and Urdu speaking (3.4%) individuals. Almost two third were part of the fishing industry and most (89.8%) were earning less than PKR 10,000 per month. A mere 11% had received any formal schooling.

Self-reported vascular risk factors were quite prevalent, with 29% reporting hypertension and almost two thirds reporting uses of one or more forms of tobacco. Gutka (chewed tobacco) was the most frequently used form of tobacco being consumed by 106 of the 189 individuals using tobacco. Health seeking behavior was poor as reflected by a mere 1.9% reporting regular visit to any physician.

Criterion Validation

There was consensus on forty eight cases of stroke that were independently identified by the two neurologists. There was only one case in which there was a difference of opinion with regard to the diagnosis, and in this case, a third senior neurologist evaluated the case and her decision was considered final.

Table 1 shows the sensitivity, specificity, negative and positive predictive values along with their 95% CIs for the CHW administered stroke symptom questionnaire validated against Neurological assessment by two neurologists. Of these 322 initial evaluations, half the forms were filled by CHW 1 and the rest by CHW 2. Only the first evaluation at each household was considered for evaluation purposes. The visit by the second CHW was merely done to assess the agreeability between the two CHWs. The CHW administered tool was considered positive for stroke if answer to one or more of the eight questions was in the affirmative. The overall sensitivity of the tool was 77.1% and the specificity was 85.8%. The positive predictive value of the tool was low, but the negative predictive value was over 95%. This chance corrected agreement (kappa) between the CHW's assessment and the neurologist's assessment was 0.51 (95% CI: 0.38–0.60).

Table 2 demonstrates how each of the specific symptom questions behaved in this validation study. All questions had excellent specificity, but sensitivity was low ranging between 27.1 and 72.9%. Chance corrected agreement was fair to moderate for all questions (Range 0.37–0.58). The most sensitive question on the tool was regarding hemianesthesia followed by hemiplegia (72.9 and 64.6% respectively). Least sensitive question to help stroke identification was a history of facial deviation.

Only 18 individuals (37.5%) with stroke according to neurological assessment admitted to having being diagnosed by a physician. The overall tool, therefore helped identify another 19 individuals with the condition.

Individual CHW Performances

Data collected by each community worker was analyzed separately also to assess whether there were differences in performance following a standard training procedure. Interestingly, these differences did exist, with CHW 1 being less sensitive and CHW 2 being less specific in labeling individuals with stroke when compared to assessment by two neurologists. This data is shown in Table 3.

The Inter CHW agreement as measured through kappa was 0.42 (0.31–0.48). The two CHW's although agreed 81% of the time overall, they only agreed on positive interpretation 51% of the time, whereas they agreed on negative interpretations 88% of the time. We noted that a single repeat focused training session improved inter CHW agreement and accuracy. (Table 4)

Sensitivity Analysis

We checked to see how the questionnaire behaved across different genders, age categories, education status and income. The results for this sensitivity analysis are presented in Table 5. Although the difference was not statistically significant, the questionnaire tended to have

better sensitivity in males and in the elderly, and this was irrespective of which CHW was evaluating the subject.

Feasibility of Using CHWs for Stroke Screening

The overall receptiveness in the community to the CHW administered questionnaire was good. Most people (631 out of 700, 90.1%) got the initial questionnaire filled. However, there was reluctance to come to the community centre for a formal neurological evaluation. Qualitative research into this identified several causes for this behavior, namely, work commitments, lack of transport and a lack of trust that any treatment will be provided for the identified condition.

The time taken to fill out the stroke symptom questionnaire was around seven minutes on average (Range 4–20 minutes). 282 (87.6%) individuals did not require two or more explanations to any of the seven stroke symptom questions. Only four (1.3%) required explanations for all seven. Questions posing the greatest difficulty in understanding were about hemiplegia and hemianesthesia but they also required repeat explanation in only 12% subjects.

Discussion

To the best of our knowledge, this is one of the first community based validation studies of a stroke symptom questionnaire from South Asia, a region that harbors 20% of the world's stroke population [14]. The tool we tested consisted of an adapted questionnaire and structured training of CHWs. We found reasonable sensitivity and good specificity of the tool. Our overall sensitivity of 77.1% and specificity of 85.8% is similar to findings from the only other validation study utilizing community workers [9]. These results suggest the feasibility of a community based approach to stroke identification and prevention.

Although the QVSFS has been designed for ascertaining stroke free status, its six symptoms questions have recently been shown to be an effective tool for screening for stroke or TIA with a high sensitivity and moderate specificity [8]. Validation of most stroke symptom questionnaires have been carried out in hospitals or other clinical set ups using trained research assistants.[6–8, 11, 15] However, when translated in local languages using relevant terminology, a similar set of questions were shown to have an excellent sensitivity in a community based validation study in Mexico.[16] The sensitivity was in the range of 70% when administered by Community Health Workers (CHWs) in another recent study from Brazil [9]. Table 6 describes the various validation studies carried out on stroke screening tools along with their performances and limitations.

Although the results of our study suggest that CHWs are promising task sharing options for stroke surveillance in communities of middle and low income countries, the inter-CHW differences we found suggest operator dependency. This variability may be eliminated with audit and feedback when CHWs are utilized for this purpose. This observation is supported by the improvement we saw following the second training session and highlights the importance of rigorous and targeted audited training in improving performance. Refresher trainings and feedback for CHWs are an expected part of robust CHW led programs.[17]

Our findings also highlight the value of developing such community worker administered tools in terms of their feasibility. Even in a low literacy setting like ours, where only 11% subjects had received any formal schooling, a majority of the participants found no difficulty in understanding the stroke symptom questions. We added pictures to the tool and this might have contributed towards this clarity. The feasibility is also reflected in the wide acceptance of the community worker administered questionnaire as opposed to people's reluctance to visit the neurologist at the community centre.

Table 6 presents a comparison of various validation studies for similar stroke symptom questionnaires. We feel these studies have limited comparability to our settings since most of these studies have been carried out in developed countries, where it is expected that the awareness of stroke symptoms would be better and access to medical care for stroke sufferers is also good.

Important differences exist between our study and previous validation studies that need special mention. Firstly, some of the screening tools that have been validated previously differ somewhat from ours. Some have utilized a single question regarding history of stroke or diagnosis by a physician to screen for the presence of stroke[18, 19]. Others have tested a combination of questions related to stroke symptoms [6, 10, 20]. A combination of these two has been shown to be the better approach[21] avoiding underestimation of strokes in the community when used for prevalence determination. We used this latter approach for our study, where we tested the combination of symptom questions along with single question regarding physician diagnosis of stroke.

Secondly, differences also exist in the method of administration of these questionnaires and the settings in which the studies have been carried out. There is reason to believe that differences would exist in the performance of the tool depending on the person administering it. This difference is highlighted in our study where we have shown that following a standard training procedure, important differences exist in the performances of the two CHWs and the tool therefore is operator dependent.

Furthermore, the gold standard utilized for validation has also differed from study to study. While most have used assessments by neurologists, some have also relied on medical records for event verification [6, 19, 20]. The studies that have relied on physician assessments however, are not true validations as evaluations of individuals who test negative on the tool were not done. We not only had neurological evaluations for all subjects, we only considered the diagnosis when two neurologists agreed on it, adding more objectivity to our gold standard.

We also evaluated the performance of individual symptom questions in identifying stroke patients. Only hemi-anesthesia (72.9%) and hemiplegia (64.6%) achieved reasonable sensitivities. The specificities however, were above 90% for all symptom questions. These findings are similar to what was observed in the previously mentioned validation studies [7, 9], although our results are better than what were observed in these two studies.

The main difference was observed in the question regarding physician diagnosis of stroke. This was the most sensitive question (79%) in the original validation study of QVSFS [7],

but in our setting it had very poor sensitivity (39.6%) showing that six out of ten stroke patients possibly never visit a physician for their symptoms, or even if they do, their diagnosis is missed. This is an important finding and reflects the sub-optimal access to quality health care in these communities.

Limitations

This validation study of a stroke symptom assessment tool has the following limitations. Firstly its criterion validity is limited to peri-urban transitional communities, rural areas may have different stroke patterns, risk behaviors, prevalence and access to physicians and this may impact the sensitivity of the questionnaire. Secondly, our preliminary observations suggest that performance of the tool may differ across the two genders, likely due to different stroke presentation profiles of symptoms between women and men, this needs further study focused on gender based tool development. Thirdly, we used expert vascular neurologists to verify presentations and review medical data; a brain MRI for all patients to document stroke burden biologically would have been supportive information on the presence of asymptomatic strokes and tissue verification of symptomatic cases, however MRI wasn't a feasible option in a field based protocol to perform on normal individuals. Furthermore, we intentionally did not use a "biologic" standard since that would seriously limit the external validity and use of our questionnaire in a pragmatic way, since few would be able to afford MRI in actual clinical practice to verify every single stroke. Finally, we would like to reiterate the operator dependency and inter observer variability of this questionnaire when used by a lay worker, which may be greatly reduced by targeted feedback. Recognizing these limitations, we feel we have provided useful information on a viable option for stroke screening and task sharing in resource challenged settings which may facilitate broader community based interventions for prevention, identification and early targeted referral.

Conclusion

This CHW administered stroke symptom questionnaire has reasonable validity for picking up stroke symptoms in a peri-urban Pakistani community when CHWs receive appropriate feedback and training.

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References

1. Di Carlo A. Human and economic burden of stroke. Age and ageing. 2009; 38:4–5. [PubMed: 19141505]

2. Feigin VL, Lawes CMM, Bennett DA, et al. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. The Lancet Neurology. 2009; 8:355–69. [PubMed: 19233729]
3. Kamal A, Itrat A, Murtaza M, et al. The burden of stroke and transient ischemic attack in Pakistan: a community-based prevalence study. BMC neurology. 2009; 9:58. [PubMed: 19948076]
4. Kulshreshtha A, Anderson LM, Goyal A, et al. Stroke in South Asia: a systematic review of epidemiologic literature from 1980 to 2010. Neuroepidemiology. 2012; 38:123–9. [PubMed: 22433930]
5. Truelsen T, Heuschmann PU, Bonita R, et al. Standard method for developing stroke registers in low-income and middle-income countries: experiences from a feasibility study of a stepwise approach to stroke surveillance (STEPS Stroke). Lancet Neurol. 2007; 6:134–9. [PubMed: 17239800]
6. Meschia JF, Brott TG, Chukwudelunzu FE, et al. Verifying the stroke-free phenotype by structured telephone interview. Stroke. 2000; 31:1076–80. [PubMed: 10797168]
7. Jones WJ, Williams LS, Meschia JF. Validating the Questionnaire for Verifying Stroke-Free Status (QVSFS) by neurological history and examination. Stroke. 2001; 32:2232–6. [PubMed: 11588306]
8. Sung VW, Johnson N, Granstaff US, et al. Sensitivity and specificity of stroke symptom questions to detect stroke or transient ischemic attack. Neuroepidemiology. 2011; 36:100–4. [PubMed: 21311197]
9. Abe IM, Goulart AC, Santos WR Junior, et al. Validation of a stroke symptom questionnaire for epidemiological surveys. Sao Paulo Med J. 2010; 128:225–31. [PubMed: 21120435]
10. Cantu-Brito C, Majersik JJ, Sanchez BN, et al. Door-to-door capture of incident and prevalent stroke cases in Durango, Mexico: the Brain Attack Surveillance in Durango Study. Stroke. 2011; 42:601–6. [PubMed: 21212398]
11. Meschia JF, Lojacono MA, Miller MJ. Reliability of the questionnaire for verifying stroke-free status. Cerebrovascular Diseases. 2004:17. [PubMed: 14730254]
12. Pop-Eleches C, Thirumurthy H, Habyarimana J, et al. Mobile Phone Technologies Improve Adherence to Antiretroviral Treatment in Resource-Limited Settings: A Randomized Controlled Trial of Text Message Reminders. Aids. 2011; 25:825–34. [PubMed: 21252632]
13. Kamal AK, Itrat A, Murtaza M, et al. The burden of stroke and transient ischemic attack in Pakistan: a community-based prevalence study. BMC Neurol. 2009; 9:58. [PubMed: 19948076]
14. Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. Lancet Neurol. 2007; 6:182–7. [PubMed: 17239805]
15. Karanjia PN, Nelson JJ, Lefkowitz DS, et al. Validation of the ACAS TIA/stroke algorithm. Neurology. 1997; 48:346–51. [PubMed: 9040719]
16. Del Brutto OH, Idrovo L, Mosquera A, et al. Validation of a screening questionnaire for stroke detection in Spanish-speaking communities. Rev Neurol. 2004; 39:301–4. [PubMed: 15340885]
17. Bhutta, ZA.; Lassi, ZS.; Pariyo, G., et al. Global experience of community health workers for delivery of health related Millennium Development Goals: a systematic review, country case studies, and recommendations for integration into national health systems. Geneva, Switzerland: Global Health Workforce Alliance; 2010.
18. O'Mahony PG, Dobson R, Rodgers H, et al. Validation of a population screening questionnaire to assess prevalence of stroke. Stroke. 1995; 26:1334–7. [PubMed: 7631332]
19. Berger K, Hense HW, Rothdach A, et al. A single question about prior stroke versus a stroke questionnaire to assess stroke prevalence in populations. Neuroepidemiology. 2000; 19:245–57. [PubMed: 10965237]
20. Orlandi G, Gelli A, Fanucchi S, et al. Prevalence of stroke and transient ischaemic attack in the elderly population of an Italian rural community. European journal of epidemiology. 2003; 18:879–82. [PubMed: 14561047]
21. Jungehulsing GJ, Muller-Nordhorn J, Nolte CH, et al. Prevalence of stroke and stroke symptoms: a population-based survey of 28,090 participants. Neuroepidemiology. 2008; 30:51–7. [PubMed: 18259083]

22. Meneghini F, Rocca WA, Anderson DW, et al. Validating screening instruments for neuroepidemiologic surveys: experience in Sicily. Journal of clinical epidemiology. 1992; 45:319–31. [PubMed: 1314889]

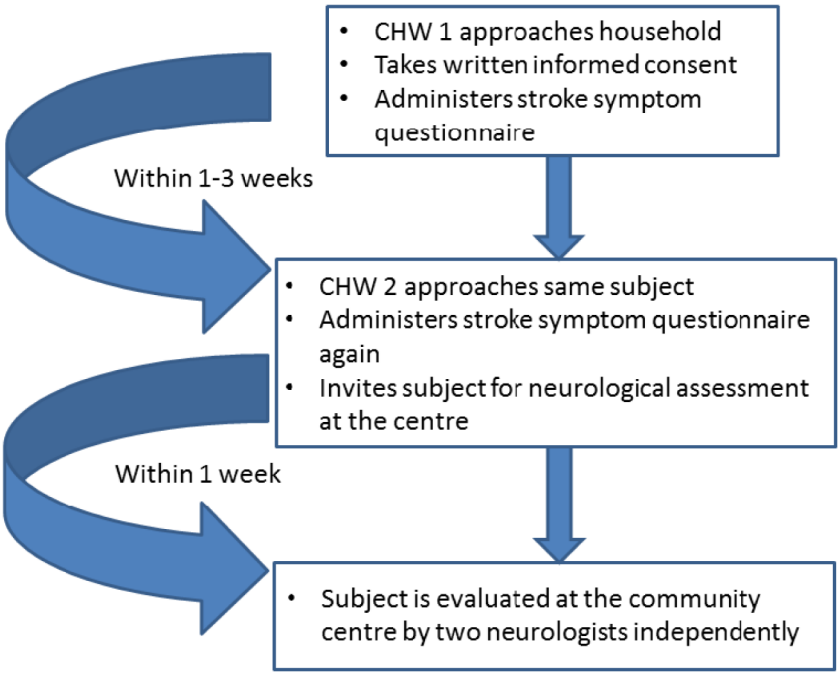

Figure 1.
Recruitment, Field Strategy and Study Flow

Table 1

Overall Performance of the CHW administered tool against Neurologists' Assessment n=322

Total	Stroke (Neurologists' Evaluation)		
	Yes	No	
Stroke (CHW Assessment)			
Yes	37	39	76
No	11	235	246
Total	48	274	322
Overall tool n=322			
Sensitivity % (95%CI)		77.1 (64.1–86.9)	
Specificity % (95%CI)		85.8 (83.5–87.5)	
PPV % (95%CI)		48.7 (40.5–54.9)	
NPV % (95%CI)		95.5 (93.0–97.4)	
Kappa		0.51 (0.38–0.60)	

* CHW=Community Health Worker

Table 2

Performance of individual symptom questions against Neurologists' Diagnosis of Stroke n=322

Symptom	Sensitivity % (95% CI)	Specificity % (95% CI)	Kappa (95% CI)
Hemiplegia	64.6 (52.0–75.3)	92.3 (90.1–94.2)	0.55 (0.41–0.67)
Hemianesthesia	72.9 (60.2–83.1)	90.9 (88.7–92.7)	0.58 (0.44–0.69)
Monocular Blindness	47.9 (35.4–59.8)	90.9 (88.7–93.0)	0.39 (0.24–0.53)
Hemianopia	39.6 (28.5–49.3)	95.6 (93.7–97.3)	0.41 (0.26–0.55)
Receptive Aphasia	47.9 (35.6–59.5)	92.0 (89.8–94.0)	0.41 (0.26–0.55)
Expressive Aphasia	45.8 (33.9–56.7)	93.8 (91.7–95.7)	0.43 (0.28–0.57)
Facial Weakness	27.1 (18.7–30.5)	99.3 (97.8–99.9)	0.37 (0.23–0.42)
Physician Diagnosis	39.6 (30.1–44.2)	98.9 (97.2–99.7)	0.50 (0.35–0.57)

Table 3

Individual Performance of CHWs following first training session (n=322)

	CHW 1	CHW 2
Sensitivity % (95% CI)	62.5 (51.3–70.5)	89.6 (77.8–96.0)
Specificity % (95% CI)	97.1 (95.1–98.5)	83.9 (81.9–85.1)
Kappa (95% CI)	0.65 (0.51–0.71)	0.55 (0.45–0.61)
Accuracy %	91.9	84.8

* CHW=Community Health Worker

Table 4

Individual Performance of CHWs following repeat focused training session (n = 322)

	CHW 1 before	CHW 1 after	CHW 2 before	CHW 2 after
Sensitivity % (95% CI)	61.5 (38.0–74.0)	76.9 (53.9–84.2)	85.7 (45.9–99.2)	71.4 (35.6–84.9)
Specificity % (95% CI)	90.5 (75.9–98.2)	95.5 (81.8–99.8)	74.1 (63.8–77.6)	96.3 (87.0–99.8)
Kappa (95% CI)	0.54 (0.15–0.76)	0.75 (0.37–0.87)	0.45 (0.07–0.58)	0.72 (0.36–0.85)
Accuracy %	79.4	88.6	76.4	91.2

* CHW=Community Health Worker

Table 5

Questionnaire validity in different subgroups of subjects by CHW
n=322

Subject Subgroup	Sensitivity CHW1	Sensitivity CHW2	Specificity CHW1	Specificity CHW2
Gender				
Male (n=92)	77.3 (61.4–81.6)	95.5 (78.0–99.8)	98.6 (93.6–99.9)	81.4 (75.9–82.8)
Female (n=230)	50.0 (33.5–63.2)	80.8 (61.9–92.5)	96.6 (94.5–98.2)	84.8 (82.4–86.3)
Education				
No formal education (n=286)	61.9 (49.6–70.9)	88.1 (75.0–95.4)	96.7 (94.6–98.3)	83.6 (81.4–84.9)
Formal education (n=36)	66.7 (28.1–82.4)	83.3 (40.3–99.1)	96.7 (88.9–99.8)	86.7 (78.1–89.8)
Age				
≤60 years (n=231)	60.5 (48.8–66.3)	85.7 (70.9–94.4)	98.5 (96.2–99.6)	85.2 (82.6–86.8)
>60 years (n=91)	76.9 (50.4–93.0)	92.9 (67.0–99.6)	93.6 (89.2–96.3)	80.5 (75.8–81.8)
Income				
≤10,000 PKR (n=272)	61.0 (49.5–67.4)	87.8 (74.6–95.3)	98.3 (96.2–99.4)	85.3 (82.9–86.6)
>10,000 PKR (n=31)	75.0 (24.3–98.6)	80.0 (32.2–98.9)	92.6 (85.1–96.1)	74.1 (65.2–77.6)

* CHW=Community Health Worker

Table 6

Validation Studies of Stroke Screening Questionnaires

Author/Year/Country	Sample Size	Tool/Administered by	Gold Standard used	Results	Limitations
Meneghini F.[22] **1992 Sicily**	43	Symptom questions **self- administered,** physical tasks assessed by research assistants	Neurological exam by neurologists	Sensitivity 81.8% for symptom questions	Subjects recruited from hospital, specificity for stroke alone, not reported
O'Mahony [18] **1995 UK**	1663	Single question "Have you ever had a stroke" sent via **mail**	Home visit by physician, and medical records from various sources for all subjects	Sensitivity 95% Specificity 96%	Only those testing positive were examined by physician
Berger K [19] **2000 Germany**	384	Single question about prior stroke vs SSQ-**self administered**	Neurological exam and event validation by medical record	SSQ had a high false positive rate	
Meschia J. F[6] **2000 USA**	70	SSQ administered by **Research coordinator** on telephone	Medical record review for all subjects	Sensitivity 100% Specificity 86%	Subjects selected from medical outpatient department
Jones W. J. [7] **2001 USA**	155	QVSFS administered by **Research Assistant** in stroke and general medicine clinics	Interview and examination by neurologist	Sensitivity 97.4% Specificity 60%	Area of patient selection might have biased findings
Orlandi G.[20] **2003 Italy**		SSQ administered by **investigator** trained in diagnosis of cerebrovascular disease	Medical records plus neurologist evaluated those testing positive on SSQ	Validation study results not published	Only those testing positive were examined by physician
Abe I. M.[9] **2010 Brazil**	36	SSQ administered by **CHW** trained by physician	Assessment by one neurologist	Sensitivity 72.2% Specificity 94.4%	Small sample size, no evaluation of individual performances of CHWs
Cantu-Brito C. [10] **2011 Mexico**	2437	**5 field workers** trained in use of survey questionnaire	Interview and examination by Neurologist only for those testing positive	30 screened positive, 10 did not have a stroke as per neurologist	Only those testing positive were examined by physician
Sung V. W.[8] **2011 USA**		QVSFS administered by **Research Assistant** in stroke and general medicine clinics	Neurologists interviewed and examined all subjects	Sensitivity 82% Specificity 62%	Area of patient selection might have biased findings