

## The Awareness of Stroke in Caregivers of Stroke Patients in Pakistan

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### Abstract

**Aims and Objective:** The aim of this study is to assess the caregiver's knowledge regarding the symptoms of the stroke and their perception. We need to know about their perception before meeting any knowledge gaps.

**Methodology:** This cross-sectional study was done at Fauji Foundation Hospital. The study's duration was one year from March 2016 to February 2017. We enrolled total of 100 caregivers of consecutive stroke patients admitted in Medical Wards. A Stroke Patient was defined as a patient whose presenting complaints one of the predefined symptoms by National Institute of Neurological Disorder were lasting more than 24 hours with no apparent cause other than of vascular origin. The Care giver was defined as the person who was present next to the patient at the time of the event. The second part consists of an open-ended question about caregiver's perception of stroke patient. When the answer to the question was stroke it was defined as correct response, rest of the answers were taken as incorrect response.

**Results:** Out of 100 patients 32 (32%) were illiterate. The literate group was divided into three groups as follows; under matriculation (26), till matriculation (23), graduate and above (09). 11% of caregivers used the term stroke. In logistic regression, education plays a significant role on the correct diagnosis of stroke disease with coefficient of education 1.124 with p value=0.004 which is significant at 5% level of significance.

**Conclusion:** Given the fact that in our region the average age of stroke is 10 years younger we need on emergency basis the required community outreach programs.

**Keywords:** Stroke awareness; Care givers; Stroke patient

### Introduction

Stroke is one of the leading causes of morbidity and mortality world over. Every two seconds, someone across the globe suffers a symptomatic stroke. Stroke rates in middle-aged people are five to ten times higher in Pakistan, India, Russia, China, and Brazil, compared to the UK and USA. 20% of world population resides in South Asia and has one of the highest burdens of cardiovascular disease in the world. Pakistan being the 6<sup>th</sup> most populous countries also 6<sup>th</sup> in order of highest diabetes prevalence and according to one estimate 33% population is suffering from hypertension, both being the leading causes of stroke. Pakistan Society of Neurology estimates the incidence of stroke to be close to 250 per 100,000 population, which means that there are 350,000 new stroke patients every year in this country. According to World Health Organization report of 2002, total mortality due to stroke in Pakistan was 78,512 [1-6].

It was not until last decade of the twentieth century that stroke treatment really changed from passive to aggressive with advent of interventional approach. In Pakistan, the interventional treatment of stroke is still in its infancy with only few centres working across country in major cities. Much effort is still required to come to the level of care provided in the developed countries, that is from the building of infrastructure to the enough skilled manpower. But the foremost thing is the awareness of our people about stroke, its symptoms, risk factors and the treatment. It is estimated that it is estimated that the number of deaths from stroke will increase to 78 million by 2030 with the bulk occurring in the poor countries of the world [5]. Also, economically it is going to be a major burden. To reduce the incidence of stroke and provide the optimum treatment we need a holistic approach, starting from public awareness to the review of our health policy. Assessment of public awareness is of utmost importance for the development of appropriate targeted health promotion campaigns to prevent stroke among high risk populations in our setting. The aim of this study is to assess the caregivers' knowledge of the stroke symptoms and their perception. We need to know first their perception before meeting any knowledge gaps. This study would help the physicians to understand

the caregivers' perspective in order to educate them about stroke for secondary prevention.

### Methodology

This cross-sectional study was done at Fauji Foundation Hospital. The Ethical Committee approval was taken before proceeding with the study. The study's duration was one year from March 2016 to February 2017. This study was an independent project of the department and was not funded by any pharmaceutical organization. The study was reviewed by ethics committee and performed in accordance with the ethical standards laid down in an appropriate version of the 2000 Declaration of Helsinki as well as the Declaration of Istanbul 2008. We enrolled total of 100 caregivers of consecutive stroke patients admitted in Medical Wards. A Stroke Patient was defined as a patient whose presenting complaints were one of the following symptoms lasting more than 24 hours with no apparent cause other than of vascular origin.

1. Sudden numbness or weakness in the face, arm, or leg, especially on one side of the body.
2. Sudden confusion, trouble speaking, or difficulty understanding speech.
3. Sudden trouble seeing in one or both eyes.
4. Sudden trouble walking, dizziness, loss of balance, or lack of coordination.
5. Sudden severe headache with no known cause.

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The Care giver was defined as the person who was present next to the patient at the time of the event. Since we were unable to find a standard questionnaire about the stroke perception, the survey tool was self-devised. In the first part, the care givers social demographics were noted in the form of Age, Residence, Gender, City/Town the relation to the patient and Education level. The second part consists of an open-ended question about caregivers' perception of stroke patient. When the answer was stroke it was defined as correct response, rest of the answers were taken as incorrect response. There were two interviewers who were postgraduate trainees and the questionnaire was discussed among them and qualified Neurologist. 100 consecutive stroke patients care givers were enrolled. The data was analyzed through SPSS version 16 and the results were calculated.

## Results

Out of 100 patients care givers 94 (94%) were females and 6 (6%) were males. The minimum age of care givers was 36 years and maximum was 57 years with mean being 35.7 with SD ± 9.126. The City /Townthey belonged to was divided into big and small city according to the 1998 Census of Pakistan. The population of more than 0.3 million was defined as Big city while those with number less than 0.3 million was defined as small city. Out of 100 patients 32 (32%) were illiterate. The literate group was further divided into three groups with number of CG in each group as follows. Under matriculation (26), till matriculation (23), graduate and above (09) (Figure 1).

The presenting symptom with the highest frequency of 54% was Hemiplegia/Hemi anaesthesia. Speech Deficit followed it 30% (30), while rest of the patients presented with other enlisted symptoms in the following frequency order; visual loss 1%, loss of balance 8% (8), and severe headache 9% (9). The caregivers' perception of symptomatology of stroke revealed the highest response of high Blood Pressure. The total frequency was 27% (27). The word unconsciousness followed this 17% (17). Only 11% (11) caregivers used the term stroke. The term headache, loss of speech and falls were used by 7% (7) each. The next most frequent response was high blood glucose and vomiting 5% (5). 4% (4) recorded the statement of weakness of limbs. 2% took it as heart problem and facial deviation each (Figure 2).

The responses of CGs were further analyzed with patient's symptomatology. The highest symptom which was correctly identified was hemiplegia/hemianesthesia 14.8%, followed by speech deficit 10.3%. The rest of the symptoms could not be picked up by CG as symptoms of stroke (Table 1).

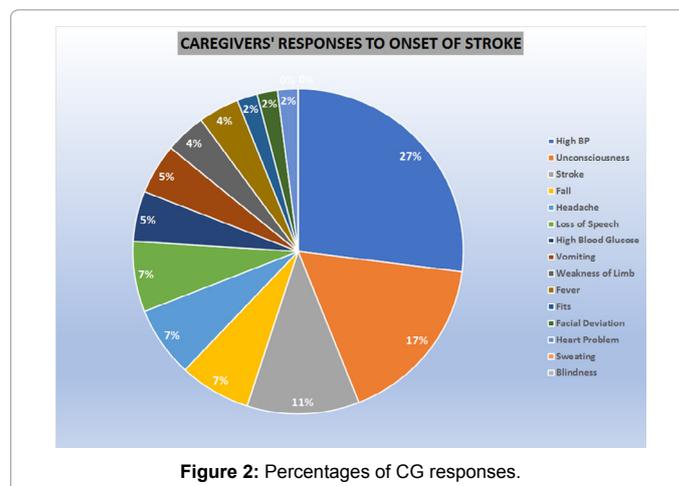


Figure 2: Percentages of CG responses.

Neurological deficits					
Response	Hemiplegia/ Hemianesthesia	Speech Deficit	Loss of Balance/ Coordination	Severe Headache	Total
No (not detect stroke)	46	26	8	9	89
Yes (detect stroke)	8	3	0	0	11
Total	54	29	8	9	100

Table 1: Correct responses vs. neurological deficits.

The correct response city wise was 7 out of 38 (big cities) CG and 4 out of 51 (small cities) with p-value 0.188. Next, we calculated different responses with respect to the literacy level. Out of 32CG who were illiterate only 3.1% (1) gave the correct response, while 96.9% (31) gave incorrect response. None of the CG could identify the stroke in under matric group 100%, while out of the matric group 79.3% (23) gave incorrect response and only 20.7% could correctly identify stroke. Similarly, in our last category of graduation and above 69.2 (9) caregivers did not identify correctly while only 30.8% (4) correctly identified stroke. The education and correct response is highly associated with P value=0.004 (Table 2).

With P value=0.0415, to test the proportion of true diagnosis in population we use one sample t test with the hypothesis that the proportion of true diagnosis is greater or equal to 0.165 against the alternative that this is less. Here P value is less than 0.05 so that we reject our null hypothesis against the alternative that the proportion of true diagnosis of stroke is less than 16.5% in our population with 5% level of significance. In the logistic regression analysis, it is shown that the education plays a significant role on the correct diagnosis of stroke disease with coefficient of education 1.124 with p value=0.004 which is significant at 5% level of significance. It is also shown that it is some other hidden variables which can disturb the correct response. Those other variable's facts also include in this logistic regression by constant having coefficient -5.098 which is also significant with P value=0.000 at 5% level of significance. In multivariate analysis, we include intercept (omitted variables which are not included in our data), education, sex, and area. It is noted that intercept and education is playing significant role to predict correct responses. The coefficient of intercept and education are 5.485 and -1.088 respectively with their p values 0.003 and 0.007. The significance of intercept coefficient shows that we miss some necessary variable maybe they are different socio-economic characteristics which are related to correct response. The power of the test of our study with our sample size is 88.3%.

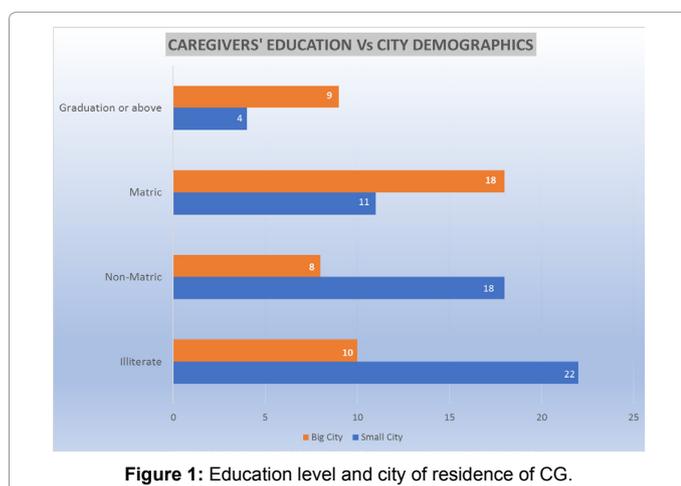


Figure 1: Education level and city of residence of CG.

Variables		Education				Total	
		Illiterate	Literate	Matric	Graduation or above		
Correct response	No (not detect stroke)	Count	31	26	23	9	89
		% within Education	96.9%	100.0%	79.3%	69.2%	89.0%
	Yes (detect stroke)	Count	1	0	6	4	11
		% within Education	3.1%	0.0%	20.7%	30.8%	11.0%
Total		Count	32	26	29	13	100
		% within Education	100.0%	100.0%	100.0%	100.0%	100.0%

Table 2: Correct response × Education cross-tabulation.

## Discussion

Pakistan is a developing country. Like many other fields the Medical community of Pakistan is doing its best to turn around the state of health sector with the help of the state run and private sector hospitals. Pakistan born peers in Neurology from US and Canada are trying to bring in the expertise to our local training programs. There is genuine effort to bring out the best for the community at large. We are in the era of interventional treatment of stroke. The practice of thrombolysis and thrombus retrieval in acute stroke requires the state of the art facility and involves high cost budget. In Pakistan, this facility is in its infancy stage. But before we can embark on this journey we need the public awareness and their education. Patients who suffer from stroke in countries such as Pakistan are almost a decade younger than their western counterparts and thus, the disability in stroke survivors and resulting economic losses may be greater, [7]. The disability incurred is just not physical its psychosocial effects are far more worse not only at individual level but also national level [8-15].

The primary objective of this study was to establish the perception of stroke symptoms in general population. Our aim was not to develop a study tool to measure the knowledge of stroke or its perception therefore we did not vigorously test our questionnaire for validity or reliability. Our study showed that the correct identification of stroke was with symptoms hemiparesis (14.8%) followed by speech deficit (10.3%), while none of the other symptomatology could be correctly identified by CG. Sulena et al. has shown in the study the most correctly identified stroke symptom was of motor weakness by 68.4% respondents followed by sensory involvement in 61.2%, aphasia in 21.9%, and headache in 8% and seizures in 4.6% patients [13]. The most frequently mentioned warning signs were sudden weakness or numbness (46%) and sudden slurred speech, disorientation, or difficulty understanding (30%) was reported by Matthew from Michigan United States [14]. Borhani Haghighi et al. from Iran in similar study have shown abdominal pain 96.1% and chest pain 88.7% as the warning sign of stroke [15]. Cheung RT1 from Hong Kong has discussed a correct description of stroke, those with a positive household history of stroke and those with a better knowledge of potential risk factors [16].

This study has also shown overall very poor knowledge and understanding about stroke in general population given the fact that only 11% in our sample correctly identified. Literacy played a very significant role as p value was 0.004. There was not much difference between big and small cities as the p value turned out to be 0.188. These results are stating very important point here: education plays a key role in understanding of Stroke. It is obvious that increasing the literacy rate overall would help in achieving our goal of spreading knowledge about stroke. Aly et al. showed in their study from Karachi Pakistan that overall, only 23.1% believed that they have sufficient knowledge about stroke. The belief of having sufficient knowledge about stroke was more common among intermediate-and-above level of education (72.8%) and professionals/skilled population (64%). Almost half of the individuals interviewed (50.8%) identified “brain” as the organ involved

in stroke [6]. Norway has literacy rate of 99%. Sundseth et al. has shown in his study that 71% knew at least 1 symptom of stroke [17,18]. Low education level has been shown with low level of awareness about stroke knowledge [19].

Extrapolating our results showed only 16.5% population with 95% confidence interval is aware of stroke symptoms. This is a huge gap as according to Pakistan Society of Neurology the incidence rate of stroke is 250/100000. This is an alarming situation. We need to be proactively working on strategy to spread the knowledge of stroke. We need to have short term and long-term planning. For short term, stroke specific programs at community level can be carried out. The use of electronic media as well as print media has been shown to increase the knowledge of stroke in public which has resulted in earlier presentation of stroke patients to hospital thus preventing the mortality ratio among stroke patients [20-22]. In United states tissue plasminogen activator (TPA), the first Food and Drug Administration–approved treatment for acute ischemic stroke, became available for use in 1996 by Schneider et al. [23] discussed how the knowledge of stroke improved in five-year time period from 1998 to 2003 after advent of TPA and how mass media helped in spreading the knowledge of stroke [24]. However, Kleindorfer et al. in 2009 published the data about low knowledge of TPA in Kentucky [25]. Jarou showed positive correlation between education level and identifying stroke symptoms. In his study only 20% people identified the primary physician as source of knowledge, and overwhelming majority described mass communication as a basic source of knowledge [26]. Ciccone et al. in Project Leonardo introduced the role of care manager to improvise the health care system for patients with chronic diseases. The introduction of the care manager helped bridge the communication gap among the patients, family physician and the specialist. Physicians, care managers, and patients all unanimously agreed regarding the positive impact on patient health and self-management, and attributed the outcomes to the strong “partnership” between the care manager and the patient and the collaboration between the physician and the care manager [27].

The study’s limitation was a considerable small size. There was a gender bias, most of the CGs were females. Also, this study should have included the socioeconomic status along with the education. Socioeconomic factor plays pivotal role in health outcomes. This factor cannot be ignored when perception of stroke is being discussed. Income level and level of education have previously been shown to be predictive of stroke knowledge [26,28,29]. The assessment of knowledge of risk factors in the same interview would have helped to make this study a better tool for future planning.

## Conclusion

In our setup for effective intervention and prevention of stroke we require much needed mass awareness campaigns about stroke. This study however would prove to be very useful in assessing the perception of stroke in common people. Studies like this and others would help us make the road map. This would prove very beneficial for our economic

growth as saving one person from stroke is equal to the saving of years of productivity. Evidently scientific study about the effectiveness of stroke educational efforts at individual and aggregate levels is warranted.

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