Awareness Regarding Stroke among the Caregivers of Stroke Survivors at a Tertiary Level Hospital in Bangladesh

Kaniz Fatema¹, Sifat Parveen Sheikh²*

¹Evercare Hospital, Dhaka, Bangladesh
²Center for Injury Prevention and Research, Bangladesh (CIPRB), Dhaka, Bangladesh
Email: *ssheikh@mail.usf.edu

Abstract

Given the anticipated increase in the burden of stroke in the coming years, and the limited availability of organized stroke care services in Bangladesh, it is important to assess the awareness among caregivers and design stroke prevention strategies based on social-familial factors. Collaborative action with caregiver engagement can minimize the burden of stroke. This study was conducted based on a conceptual framework to assess the knowledge related to stroke among caregivers of stroke patients. A cross-sectional quantitative study was carried out at Shaheed Suhrawardy Medical College and Hospital, Bangladesh, from 25th April to 24th October 2016. Purposive sampling was conducted, and a sample size of 105 was obtained. Sociodemographic data from stroke patients and information related to awareness about stroke among caregivers were collected using validated forms and questionnaires. Data were analyzed using the SPSS Version 24 software. Among the caregivers, 72.5% knew that stroke is a brain disease. All respondents knew that weakness on one side is a clinical manifestation and that hypertension is a primary risk factor for stroke. Around 82% of respondents knew that bed sores are an important complication of stroke. A third of respondents knew that the optimal time for hospitalization of stroke patients is within three hours. Moreover, it was found that 88% of the respondents mentioned drugs as the most important treatment modality for stroke. The present study demonstrates reasonable knowledge among caregivers of stroke. Education provided to caregivers may reduce the risk factors for stroke and complications, which can be a low-cost and effective strategy to minimize the burden of stroke in Bangladesh.

Subject Areas

Neurology

1. Introduction

Globally, stroke is the second most common cause of death and a significant cause of chronic disability [1]. The World Health Organization (WHO) defines stroke as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin" [2]. Stroke is now an important cause of morbidity and mortality in low- and middle-income countries (LMICs) like Bangladesh [3] [4]. In Bangladesh, stroke has been reported as one of the most commonly encountered neurological emergencies at tertiary level hospitals and a rising cause of death and disability in Bangladesh [5]. The growth of the aging population, lack of knowledge on stroke, and increased prevalence of risk factors due to rapid urbanization add to this problem [6] [7] [8]. WHO ranks mortality rate due to stroke in Bangladesh at number 41 in the world [9], while the prevalence of stroke in Bangladesh has been reported as 0.3% [10]. The signs and symptoms of stroke have been extensively studied worldwide, and are the same for the population in Bangladesh [11].

The major clinical manifestations of stroke include vision alterations, headache, numbness, aphasia, dysarthria, dizziness and paralysis [12]. Complications after acute stroke are common and pose a barrier to optimal recovery [13]. Specific complications reported are recurrent stroke, epileptic seizure, urinary tract infections, chest infections, falls with serious injury, pressure/bed sores, thromboembolism, pains, depression, anxiety, and confusion [14] [15]. Such complications can be minimized if the caregiver of the stroke patient is aware and proactive [16]. It is possible to entrust, engage and empower caregivers, if they have a certain level of awareness about the clinical manifestations, risk factors and management of stroke [17]. Studies have shown that caregivers' awareness of clinical manifestations of stroke could potentially allow early therapeutic intervention for the stroke patient and improve their health outcomes [18]. On the contrary, poor knowledge related to stroke among caregivers is a possible cause of poor outcomes for the stroke patient, including prolonged hospitalization [19].

The minimize costs of prolonged hospitalization following a stroke, and there should be a shift towards early hospital discharge [20]. After discharge, the burden of care for the stroke patient falls largely on the family members of the patient, which also affects their mental and physical health [21] [22]. Supportive counselling from the hospital and/or the healthcare provider can address such issues [23]. Studies have demonstrated that education and supportive counselling from the healthcare provider can improve the caregiver's knowledge and problem solving related to stroke [24]. This points towards a window of oppor-

tunity for LMICs like Bangladesh, where patient: provider ratio is disproportionately high [25], and a large proportion of patients cannot afford and/or do not have access to stroke-related medical services [26] [27].

In Bangladesh, if baseline knowledge related to stroke among caregivers can be established, educational programs can be developed to better equip the caregiver in their role. Studies have shown that effective intervention for stroke requires a holistic approach including, raising awareness about stroke among caregivers and general public, formulating user-friendly guidelines for caregivers, and creating a care continuum across home and hospital by involving caregivers [28] [29] [30]. In the past, only a limited number of studies have tried to assess stroke-related awareness and other factors among caregivers of stroke patients in Bangladesh and other LMICs [5] [31] [32]. There are gaps in evidence related to stroke-related awareness of the caregiver in Bangladesh.

In this study, we have proposed a conceptual framework (adapted from Cho E., 2007) to demonstrate the role of the caregiver in the process and outcome of caregiving for stroke patients and the important factors that influence their quality of care [33] (Figure 1). The framework aims to identify the different *types* of home-based/informal caregivers the *factors affecting quality* of caregiving including knowledge/awareness of stroke among caregivers and how these factors influence the *process* of caregiving and ultimately, the *outcomes* of caregiving for stroke patients (Figure 1). The aim of the current study is to assess the awareness related to stroke (which affects the quality of caregiving) among caregivers of stroke patients admitted to a tertiary care hospital in Bangladesh.
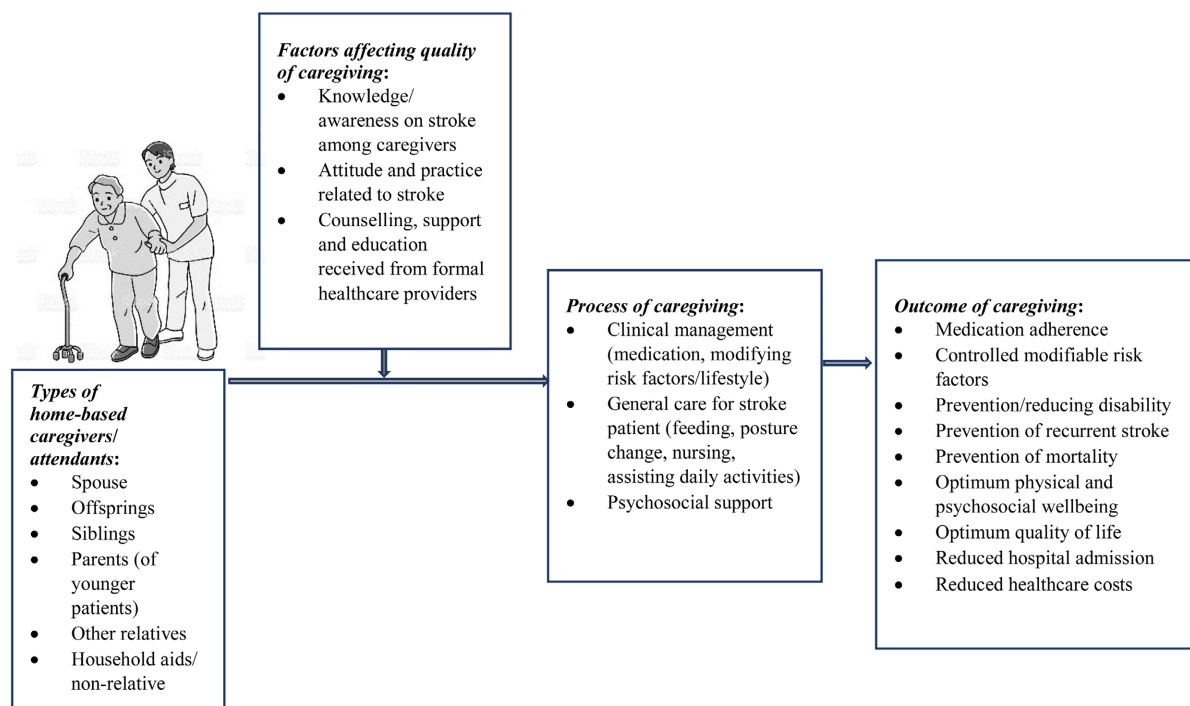

Figure 1. A proposed theoretical framework on the role of caregivers in influencing health-related outcomes of stroke patients (adapted from Cho E. 2007) [33].

2. Methods

2.1. Study Design, Setting, and Participants

This study employs a cross-sectional survey method to assess the awareness related to stroke among caregivers of stroke survivors. Data were collected from both the inpatient and outpatient departments of Medicine, Shaheed Suhrawardy Medical College and Hospital, Dhaka, Bangladesh from April 25 through October 24, 2016. Attendants/caregivers/family members of patients of stroke who attended in Shaheed Suhrawardy Medical College and Hospital for the management and follow-up of selected stroke patients were enrolled for study. For the purpose of selection and recruitment of stroke patients we used the following operation definition of stroke by the WHO [2]. The diagnosis was confirmed by clinical examination of the patients, evaluation of medical records and laboratory investigations.

Sign symptoms of stroke on physical examination:

- Confusion, with trouble of speaking and understanding;
- Headache, with altered consciousness or vomiting;
- Numbness of the face, arm or leg, particularly on one side of the body;
- Trouble seeing with one or both eyes;
- Trouble with walking, including dizziness and lack of co-ordination [34].

Laboratory investigations:

- Blood test;
- CT scan/MRI;
- Carotid Ultrasound;
- Echocardiogram;
- Cerebral angiogram [34].

The following describes the inclusion and exclusion criteria for both the patients and their caregivers.

Inclusion criteria of patients:

- Patients with diagnosis of ischemic and haemorrhagic stroke and subarachnoid haemorrhage who are confused or unconscious [35];
- Diagnosed stroke patients who are conscious may have disabilities such as hemiplegia, sphincter dysfunction, feeding difficulties, and other symptoms or complications that require assistance from attendants [36].

Exclusion criteria for patients:

- All other patients with stroke like symptoms but non stroke diagnosis [37];
- Patients with history of head injury, Intracranial space occupying lesion and bleeding disorders [37];
- Stroke or TIA (Transient Ischemic Attack) patients who are conscious with or without minor disability and do not require assistance in daily living.

After initial identification of patients matching the inclusion criteria, the study team then recruited attendants and caregivers of the patients using the following criteria:

Inclusion criteria for caregivers/attendants:

- Attendants of patients admitted to Neurology and Medicine Department of Shaheed Suhrawardy Medical College Hospital;
- Attendants who agreed to provide written informed consent;
- Attendants who are oriented, able to speak and hear;
- Attendants who are above 18 years old.

  Exclusion criteria of caregivers/attendants:

- Attendants who are working in the healthcare sector;
- Attendants not giving consent to participate.

2.2. Sample Size and Sampling

The sample size was determined using the following equation:

$$n = \left[\text{DEFF} \times Np(1-p) \right] / \left[d2/Z21 - \alpha/2 \times (N-1) + p \times (1-p) \right] \tag{1}$$

In Equation (1), population size (for finite population correction factor) (N): 1,000,000.

Hypothesized % frequency of outcome factor in the population (p): 50% ± 10.

Confidence limits as % of 100 (absolute ± %) (d): 10%.

Design effect (for cluster surveys-DEFF): 1.

The desired sample size was 97 (for 95% confidence level), considering an 8% non-response rate we approached and included 105 stroke patients.

2.3. Study Instrument and Variables

Data for socio-demographic and clinical variables were obtained from all participants by the use of a pre-tested, validated, contextualized and easily understandable questionnaire translated in Bangla. The pre-structured Case Record Form (CRF) was filled up by the study physician, based on the patient's diagnosis, history, and clinical examination and investigation results. The survey questionnaire was adapted from previously used similar instruments [35] [38] and included separate sections for collecting socio-demographic information of both the patients and their caregivers and a set of semi-structured questions to assess the caregivers' knowledge/awareness of stroke. For the socio-demographic information, socioeconomic status of patients and caregivers were determined according to established references [39] [40] [41] [42]. The income group classification used is the following:

- Poor class: A household under the lower poverty line, with a maximum monthly income of approximately BDT 5000 or <5000;
- Non-Poor/middle class: A household at or below the nationally declared minimum taxable income, between BDT 5800 and BDT 19,000;
- Solvent/high-income class: A household with a total monthly income of BDT 19,000 or above.

The set of questions that assessed the caregivers' knowledge/awareness of stroke included different domains such as clinic-pathological aspects of stroke (site, cause, and manifestation), risk factors and complications of stroke, medical management and general care of patients with stroke.

2.4. Data Collection, Analysis and Quality Assurance

Patients initially screened and included for recruitment based on their diagnosis of stroke, was confirmed by evaluation of medical records and investigation results. Patient data such as age, sex, clinical presentation and other relevant information were noted. The survey questionnaire was used for collection of information by interviewing patients' caregivers. After collecting data, it was thoroughly checked, verified for consistency. Data processing consisted of data cleaning, coding, preparation of dummy tables, analysis and matching of data. Descriptive analysis was performed using the software Statistical Package for Social Sciences (SPSS) version 24 and tables were visualized using Microsoft Excel Version 2015. All completed questionnaires were checked for quality by the statistician to identify errors during data collection.

2.5. Ethical Statement

The research protocol was approved by the ethical committee in Shaheed Suhrawardy Medical College and Hospital. Written informed consent was taken from each patient and their caregiver.

3. Results

A total of 105 patients were purposively selected from the out and inpatient departments of Medicine, Shaheed Suhrawardy Medical College and hospital. According to the inclusion criteria, 105 stroke patients were recruited for the study. Table 1 shows the demographic characteristics of the patients.

3.1. Demographic Characteristics of Stroke Patients

The largest proportion (45.7%) of stroke patients was between 46 - 60 years of age followed by 23.8% who were above 60 years of age (Table 1). Mean age of the respondents was found to be 52.08 ± 6.78 years. More than 60% of the patients were male and the male: female ratio was 1.56:1. In terms of education, greater proportion of patients had received primary education (45.7%) and was illiterate (26.7%) (Table 1). Among the female patients, the majority (32.4% among all patients, 83% among females) were housewives. Other occupations reported include businessmen (22.9%), daily wagers (18.1%), unemployed (14.3%) and service holders (12.4%) (Table 1). Based on socioeconomic status (SES), about half of the patients belonged to the lowest income group, followed by middle (31.4%) and high (19.1%) income groups (Table 1).

3.2. Awareness of Clinico-Pathological Aspects, Risk Factors and Complications of Stroke among Caregivers

In terms of clinic-pathological aspects of stroke, two-thirds of the respondents knew that stroke is a disease of the brain, while 21% responded that it was a disease of the heart, while 3.8% mentioned other organs (Table 2). Regarding cause, 60% caregivers knew that stroke was caused by bleeding due to rupture of

a blood vessel within the brain parenchyma. Others mentioned it was caused by blood clots formatting within cerebral artery (23.8%) and narrowing or blocking of arteries to the brain (5.7%), while to 10.4% of respondents the cause was unknown (Table 2). For different manifestations of stroke, the most commonly known manifestation was weakness on one side of the body (100%), followed by altered consciousness (72.3%) and chest pain (18%) (Table 2). Hypertension was a risk factor known to all respondents, followed by diabetes mellitus (61.9%) and smoking (49.5%). The majority (82%) of caregivers knew about pressure sores being a complication of stroke, followed by lung infection (23.8%) and epilepsy (6.6%) (Table 2).

Table 1. Demographic characteristics of stroke patients.

Characteristics	N (%)
Age (years)	
18 - 30	9 (8.6%)
31 - 45	23 (21.9%)
46 - 60	48 (45.7%)
>60	25 (23.8%)
Age in yr (Mean ± SD)	52.08 ± 6.78
Sex	
Male	64 (60.9%)
Female	41 (39.1%)
Education	
Primary	48 (45.7%)
Secondary	13 (12.4%)
Higher secondary	10 (9.5%)
Graduate	6 (5.7%)
Illiterate	28 (26.7%)
Occupation	
Service holder	13 (12.4%)
Businessman	24 (22.9%)
Daily wagers	19 (18.1%)
House wife	34 (32.4%)
Unemployed	15 (14.3%)
Socioeconomic groups	
Lowest income group	52 (49.5%)
Middle income group	33 (31.4%)
High income group	20 (19.1%)

Table 2. Awareness regarding clinic-pathological aspects, risk factors and complications of stroke among caregivers of patients with stroke (n = 105).

Knowledge domain	N (%)
Clinico-pathological aspects	
Stroke is disease of	
Brain	79 (75.2%)
Heart	22 (20.9%)
Other organs	4 (3.8%)
Cause of stroke	
Bleeding due to rupture of a blood vessel within the brain parenchyma	63 (60.0%)
Blood clot (thrombus) forms within cerebral artery	25 (23.8%)
Arteries to brain become narrowed or blocked	6 (5.7%)
Unknown	11 (10.4%)
*Manifestation of stroke**	
Weakness of one side of body	105 (100%)
Altered consciousness	76 (72.3%)
Chest pain	19 (18.0%)
Others	10 (9.5%)
Risk factors for stroke*	
Hypertension	105 (100%)
Diabetes Mellitus	65 (61.9%)
Smoking	52 (49.5%)
Lack of physical activity	0 (0%)
Complications of stroke*	
Pressure sore	86 (81.9%)
Lung infection	25 (23.8%)
Epilepsy	7 (6.6%)
Unknown	11 (10.4%)

*Multiple responses.

3.3. Awareness of Medical Management and General Care for Stroke among Caregivers

Thirty-nine percent of respondents stated that the prime time of hospitalization for stroke patients is 3 hours, followed by 6 hours (39.0%) and 12 hours (27.6%) (Table 3). Regarding treatment, the most commonly stated treatment modality were drugs (87.6%) and physiotherapy (81.9%); 12.3% mentioned surgery (Table 3). Forty-two percent respondents mentioned slow reduction of hypertension was ideal for patients with stroke, while a third thought that rapid reduction was ideal. The majority (60%) thought that rest was the most effective preventive

Table 3. Awareness regarding medical management and general care for stroke among caregivers of patients with stroke (n = 105).

Knowledge Domain	N (%)
Medical management of stroke	
Prime time of hospitalization for stroke patients	
3 hours	35 (33.0%)
6 hours	41 (39.0%)
12 hours	29 (27.6%)
24 hours	0 (0%)
*Treatment modality for stroke**	
Drugs	92 (87.6%)
Physiotherapy	86 (81.9%)
Surgery	13 (12.3%)
Safe manner of hypertension control	
Slow reduction	44 (41.9%)
Rapid reduction	34 (32.3%)
Others	27 (25.7%)
Preventive measures for stroke	
Rest	63 (60%)
Control of blood pressure	25 (23.8%)
Control of diabetes	17 (16.1%)
General care for patients with stroke	
Ideal feeding position for stroke patients	
Sitting position	63 (60.0%)
Lying position	42 (40.0%)
Preventive measures for stroke complications	
Skin infection control	46 (43.8%)
Routine posture change	32 (30.4%)
Sitting position always	20 (19.0%)
Others	7 (6.6%)
*Ideal positioning for laying stroke patients**	
Lateral position	77 (73.3%)
Supine position	58 (55.2%)
Recumbent position	19 (18.0%)
*Ideal lifestyle pattern for stroke patients**	
Regular exercise	86 (81.9%)
Restricted fatty food	41 (39.0%)
Restricted table salt	29 (27.6%)
Cessation of smoking	27 (25.7%)

*Multiple responses.

measure for stroke, while others reported control of blood pressure (23.8%) and diabetes mellitus (16.1%) (Table 3). The majority (60%) knew that the ideal feeding position for the stroke patient was sitting, while others (40%) knew it was lying position (Table 3). For prevention of complications of stroke, caregivers mentioned control of skin infection (43.8%), and routine posture change (30.4%) (Table 3). For ideal laying position of stroke patients, the most common response was lateral position/sleeping on their side (73.3%). Caregivers most commonly reported exercising regularly (81.9%), restricted consumption of fatty food (39.0%), restricted intake of table salt (27.6%) and cessation of smoking (25.7%) as important lifestyle modifications for stroke patients (Table 3).

4. Discussion

In this study we assessed awareness regarding stroke among caregivers of 105 stroke patients at a tertiary level hospital in urban Bangladesh. The largest proportion (45.7%) of stroke patients were between 46 - 60 years of age and mean age was 52.08 ± 6.78 years, 49% were from a poor SES and the majority of patients were from urban areas (64.0%). In terms of knowledge related to stroke, the majority of caregivers could state that stroke is a disease of the brain (75.2%). All respondents reported weakness of one (any) side as a clinical manifestation of stroke and knew about hypertension being a prime risk factor for stroke. About 82% of respondents had knowledge regarding pressure sore as an important complication of stroke, while 10.4% respondents had no knowledge regarding complications of stroke. One-third of the respondents knew that the prime time for hospitalization for stroke patients is within three hours. More than 80% respondents mentioned drugs (87.6%) and physiotherapy (81.9%) as the most important treatment modality for stroke.

In this study, the mean age for stroke patients was found to be 52.08 ± 6.78 years which is consistent with previous studies in Bangladesh, that found the mean age for stroke patients to be 49 years [43] and the largest proportion of patients belonged to the age group 51 - 60 years [44] [45]. Although increasing age is a known risk factor for stroke, in recent years stroke has been found to be more prevalent among a relatively younger age group. This is important in the context of an LMIC such as Bangladesh: it is alarming that the age of onset of stroke is advancing and younger age group being affected by stroke translates to loss of income for families and a higher financial burden [46]. However, early intervention and rehabilitation measures for younger stroke patients imply better clinical outcomes and higher chances of recovery [47] [48]. Therefore, screening for risk factors of stroke must start at a younger age and greater emphasis should be placed on primary prevention measures [49]. In terms of sex, the male: female ratio in the current study is almost equal (1.56:1), whereas previous studies found much higher prevalence of stroke among men compared to women [43] [50]. A large proportion of patients in this study belonged to low SES and resided in urban areas, which are consistent with findings from pre-

vious studies [44] [45] [50]. The study setting being a tertiary level government hospital located in urban Dhaka is more likely to attract urban residents from lower income groups. Care-seeking for stroke by female patients and the poor, as reflected in our study findings, has positive implications from an equity perspective. However, a national level tertiary health facility catering mostly to an urban patient population points towards the need to improve access to stroke-related services for rural population.

In terms of awareness related to stroke among the caregivers, the majority (75.2%) could recognize brain as the primary organ affected by stroke. This finding is consistent with a study conducted at a university hospital in Turkey, where 76.8% caregivers mentioned brain as the target organ for stroke [51]. On the contrary, a study in Uganda assessing caregiver knowledge reported only 24% correct response to a similar question [52]. In terms of clinical manifestations or warning signs for stroke, all respondents could mention weakness of one (any) side in our study, which is comparable to the study conducted in Turkey where 94.6% caregivers responded similarly [51]. In Bangladesh, a previous study reported a relatively lower (76.1%) [5] and in Uganda, an even lower proportion of respondents (12%) knowing about weakness of the body as a clinical manifestation of stroke [52]. In our study, all respondents knew about hypertension being a prime risk factor for stroke, while in previous studies conducted in Turkey, Bangladesh and Uganda revealed that 87.7%, 66.7% and only 28.9% caregivers respectively mentioned hypertension as the major risk factor for stroke [5] [51] [52].

Bed sore was the most commonly reported complication of stroke (82%) among our respondents, while only 6.9% of caregivers mentioned bed sore in the previous study conducted in Bangladesh [5]. A noteworthy finding of our study is that 10.4% respondents had no knowledge regarding the complications of stroke. This implies that such caregivers may not know what to expect after their patients have suffered from stroke and points towards the need for caregiver education by the healthcare provider before hospital discharge. In this study, only 33% of caregivers knew that 3 hours was the prime time for hospitalization for stroke patients. Bhat *et al.* found similar results in Bangladesh: only 26.4% participants knew about the importance of seeking treatment within 4.5 hours after stroke onset of stroke symptoms. The cut-off points for "golden hour" of seeking thrombolytic treatment for stroke varies across studies [53] but for our study we have used a cut-off point for 3 hours based on previous studies in the region [54]. Sixty percent of the respondents in our study mentioned bed rest as the mainstay for prevention of stroke, while respondents from other studies have emphasized on the control of blood pressure and diabetes and reduced smoking [5] [51]. In this study, drugs (87.6%) and physiotherapy (81.9%) were mentioned as most important therapeutic measures for stroke, while similar findings were revealed from the previous study conducted in Bangladesh [55].

The findings of this study provide important insights related to stroke patients and their caregivers in Bangladesh. The majority of intervention studies targeted

towards improving the knowledge level of stroke caregivers in other countries have initially conducted an assessment of their baseline knowledge level [17] [18] [56] [57]. There is a scarcity of literature related to stroke-related knowledge among caregivers of stroke patients in Bangladesh. To our knowledge, this is the first study conducted in Bangladesh that uses a conceptual framework to understand different factors, including caregivers' knowledge, that influence the outcomes for stroke patients. We believe this study will help form a basis for future studies that explore knowledge, attitude and practice among caregivers of stroke and formulate behaviour change communication strategies to improve their knowledge.

5. Conclusion

This study found that the majority of caregivers for stroke patients had basic knowledge regarding the clinic-pathological aspects, risk factors, and complications of stroke. However, there were gaps in their knowledge regarding the medical management of stroke and general care for patients with stroke. Less than a third of the caregivers could accurately state the optimal time for hospitalization of stroke patients. This is very alarming and can have dire consequences. It is important to address such knowledge gaps regarding stroke among caregivers and the general population. Since stroke poses significant long-term social, health-related, and economic impacts on individuals, families, and countries, there should be greater emphasis on enabling caregivers to prevent stroke occurrence and recurrence. Recognizing warning signs and clinical manifestations of stroke within the golden hour for intervention can reduce mortality, while skillful nursing care at home can delay the onset of complications and improve patients' quality of life.

6. Limitations of the Study

There were some limitations in this study. Firstly, the study population consisted of stroke patients visiting tertiary level hospital, which mainly caters to people from very low socioeconomic status. The study conducted in a tertiary care hospital may not represent primary or secondary health facilities. Thus, it cannot be considered representative of all Bangladeshi population. The sample size was small: only patients of ShSMCH were taken for the study. Thus, this will not reflect the overall picture of the country. The purposive sampling technique may have introduced biases. A large-scale study employing a purposive sampling technique, across different tiers of health facilities needs to be conducted in the future.

Consent for Publication

Consent was given by all the authors.

Authors' Contributions

Kaniz Fatema conceptualized the study and contributed to data acquisition. Sifat

Parveen Sheikh contributed to the data analysis and drafting of the paper. All the authors read and approved the final manuscript.

Conflicts of Interest

The authors declare that they have no competing interests.

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