Original Article

Factors Associated with Physical and Psychosocial Problems among Indian Stroke Survivors

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Abstract

Background: Rehabilitative services in India are inadequate in dealing with the physical and psychosocial problems faced by stroke survivors. The present study assessed these problems and the associated sociodemographic factors. **Methods:** Discharged stroke patients were interviewed at home. Logistic regression analysis assessed associations between patient variables and their problems. **Results:** We interviewed 127 stroke patients. Patients with modified Rankin Scale score higher than 3 were more likely to have complaints of pain (odds ratio [OR] = 2.21, 95% confidence interval [CI] = 1.03–4.33), sleeping difficulties (OR = 2.78, 95% CI = 1.34–5.78), and feelings of hopelessness (OR = 2.92, 95% CI = 1.23–6.93). Patients aged 60 years or above were more likely to have feelings of helplessness (OR = 3.64, 95% CI = 1.23–10.75) and hopelessness (OR = 3.28, 95% CI = 1.02–10.54). Male patients were more likely to have feelings of hopelessness (OR = 2.88, 95% CI = 1.06–7.80). Patients residing in rural areas had higher odds of having thoughts of death (OR = 17.18, 95% CI = 1.98–153.93). Married patients were more likely to face difficulty in asking for help (OR = 4.39, 95% CI = 1.19–16.15) and preferred home-based care (OR = 3.95, 95% CI = 1.11–14.05). Patients educated above 2nd grade were more likely to have feelings of hopelessness (OR = 6.31, 95% CI = 2.17–17.29) and anger (OR = 3.35, 95% CI = 1.39–8.07). Employed patients were more likely to have feelings of helplessness (OR = 1.13, 95% CI = 1.03–8.54). **Conclusions:** Sociodemographic variables of stroke patients can predict their physical and psychosocial problems, which can help the health-care professionals optimize rehabilitation strategies. There is an urgent need of expert rehabilitative and palliative services in India.

Keywords: Burden of disease, palliative care, rehabilitation, stroke

Introduction

Stroke is the second most common cause of death and fourth leading cause of disability worldwide.[1] In the last decade, the incidence of stroke and related deaths has declined in high-income countries; however, the incidence has doubled in medium- and low-income countries. According to the World Health Organization estimates, 86% of deaths related to stroke worldwide occurred in developing countries.[2] With increasing life expectancy of the population and high prevalence of lifestyle diseases, low- and middle-income countries are facing great social and financial challenges in coping with disabled stroke survivors.[3] Even with improved diagnostics and therapeutics, the care of stroke patients remains a challenge in India. Eighty-five percent of all strokes are of ischemic type, of which only 11% are thrombolyzed in India.[4] Therefore, stroke remains a disabling and deadly disease for majority of the stroke patients in India, and it is for these reasons that secondary and tertiary prevention including rehabilitative care becomes an important aspect of stroke care.

In India, rehabilitative care infrastructure is virtually nonexistent in the government health-care sector and that available in the private sector is beyond the economic reach of majority of the Indians. A review on long-term impact of stroke on its survivors found that social and emotional consequences represent the single largest problem area among stroke survivors and their caregivers.[5] In addition, the American Stroke Association's scientific statement has deemed palliative care needs of stroke patients to be enormous.[6] However, very scarce literature is available which could elaborate on the nature and the extent of palliative needs of stroke patients in

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India. The present study assessed the physical and psychosocial problems of stroke patients and the factors associated with these problems.

Methods

Study design and sampling

A cross-sectional study of stroke patients was conducted to assess the physical and psychosocial problems they faced in the poststroke period. Eligible stroke patients were identified in the emergency ward or medicine indoor ward of our hospital. Prevalence of stroke has been estimated to range from 44 to 843/100,000 population in India.[7] Approval of the Institutional Ethics Committee (Government Medical College, Amritsar, India) was sought before the commencement of the study. All newly diagnosed stroke patients who were admitted at the department of medicine in our hospital during the study period were included in the study. The diagnosis of stroke was supported in every case by expert clinical opinion and computed tomography scan or magnetic resonance imaging. We excluded the patients who recovered completely at the time of discharge, expired during hospital stay, were unable to communicate, were unwilling to give the consent for participation in the study, or resided outside of the Amritsar district. Eligible patients and their families were approached during the hospital stay and were explained the purpose of the study. Once they agreed to participate in the study, a convenient time of a day 1 month after discharge from the hospital was chosen for an interview at their residences.

Data collection and data analysis

The patients were interviewed using a pretested, semi-structured questionnaire. While still admitted in the hospital, clinical information was noted. Remaining parts of the questionnaire were filled at patient's residence. Details of the sociodemographic profile such as age, gender, residence, marital status, education, and monthly family incomes of the patients were noted. The patients were asked about the various physical symptoms and social problems they were facing. In addition, the patients were asked about psychological issues such as types of thoughts, difficulty in asking for help, feelings of anger or guilt, and preferred location of care and reasons for it. Modified Rankin Scale (mRS) was used to measure the severity of the global disability in the patients.[8]

The data were numerically coded and analyzed in IBM SPSS Version 23.0. (Armonk, NY: IBM Corp) (64-bit edition) for Macintosh. Frequency distribution tables were created for qualitative variables. Sociodemographic variables associated with patient's physical symptoms and psychosocial problems were analyzed using binomial logistic regression after adjusting for the possible confounders. Predictor confounder variables reaching $P = 0.25$ in the univariate analysis were entered into the model. For analysis, mRS score was dichotomized into ≤3 and >3. This cutoff value for mRS was based on previous literature showing patients with mRS score ≤3 to be associated with favorable clinical outcomes as compared to patients with mRS score >3.[9] Odds ratios were calculated with 95% confidence intervals and $P < 0.05$ was considered as statistically significant.

Results

In the present study, 141 eligible stroke patients were contacted for an interview at their residences. Of these, five patients could not be located even after visiting their homes twice (3.5%), three refused an interview (2%), and six patients expired before the interview could be conducted (4%). As a result, 127 stroke patients were interviewed and included in the final analysis. Age of the patients ranged from 40 to 80 years with the mean age of 65.40 ± 7.88 years, and approximately, three-fourth of the patients belonged to geriatric age group were males, were married, and resided in urban areas [Table 1]. More than 90% of the patients were from lower socioeconomic class and studied till 8th grade. At the time of admission, 42% and 38% of the patients had mRS score of 3 and 4, respectively. All patients except two complained of weakness in some parts of the body, in which the left arm and left leg were reported to be most commonly affected [Table 2]. The second most common complaint was pain, which was reported by 50% of

Table 1: Sociodemographic profile of stroke patients included in the study (*n*=127)

Variables	*n* (%)
Age distribution (years)	
40-50	4 (3)
51-60	26 (21)
61-70	62 (49)
71-80	35 (27)
Gender distribution	
Females	35 (28)
Males	92 (72)
Marital status	
Married	98 (77)
Widower	19 (15)
Widow	10 (8)
Single/divorced/separated	0
Type of residence	
Urban	97 (76)
Rural	30 (24)
Socioeconomic classification (modified Kuppuswamy scale)	
Upper	0
Upper middle	10 (8)
Lower middle	39 (30)
Upper lower	77 (61)
Lower	1 (1)
Education level	
Illiterate	43 (34)
Primary level	43 (34)
Middle level	31 (24)
High level	8 (6)
Intermediate	2 (2)
Graduate/professional	0

the patients. Sensations of tingling and numbness were the third most common complaints and were experienced by 48% of the patients. In addition, 43% of the patients complained of difficulty in sleeping and 15% complained of nausea/vomiting and loss of bowel/bladder control.

On inquiring about the psychosocial problems, 13% of the patients hesitated in revealing about their problems and 75% felt that their families are overconcerned about their diseases [Table 2]. When asked about the type of feelings that patients had in the poststroke period, 41% reported feelings of hopelessness, 39% of helplessness, and 8% had thoughts of death. Numerous reasons were given by the patients for having such thoughts. The most common reason given was feeling of burden on the family, feeling of being dependent on others, worry about the disease prognosis, worry about children, inability to work, feeling of loneliness, possibility of another stroke in the future, and difficulty in asking for help at home. In addition, 13% faced difficulty in asking for help, 53% had feelings of anger, and 17% had feelings of guilt. Home-based care was preferred by majority of the patients (84%).

Table 2: Physical and psychosocial problems of stroke patients (*n*=127)

	n (%)
Physical symptoms	
Weakness in any part of the body	125 (98)
Pain	63 (50)
Sensations of numbness or tingling	61 (48)
Difficulty in sleeping	55 (43)
Others	19 (15)
Psychosocial problems	
Hesitant in revealing about the disease	17 (13)
Feels family is over concerned	95 (75)
Hopelessness	52 (41)
Helplessness	49 (39)
Thoughts of death	10 (8)
Difficulty in asking for help	17 (13)
Feeling of anger	55 (43)
Feeling of guilt	22 (17)
Choice of preferred location of care	
At home	107 (84)
At hospital	20 (16)

Table 3 describes the factors associated with the physical symptoms of the patients. Although the age of the patient was not significantly associated with any of the physical symptoms, patients with mRS score of >3 at the time of admission were twice as more likely to have symptoms of pain and difficulty sleeping. As shown in Table 4, feelings of helplessness were significantly associated with age 60 years or above, female gender, and employed status. Feelings of hopelessness were significantly associated with age 60 years or above, male gender, education higher than primary education, and mRS score higher than 3 at the time of admission. Furthermore, there were significantly higher odds of having thoughts of death and feeling of anger among patients residing in rural areas and those educated higher than 2nd grade, respectively. In addition, the preference of home-based care was significantly associated with being married.

Discussion

In the present study, stroke patients were interviewed to ask about various physical and psychosocial problems that they were facing in the poststroke period. The results of this study show that the burden of these problems is enormous in stroke patients and their palliative needs are huge. The gender ratio in the study population was 2.5:1. This may partly be due to differences in risk factors such as smoking and drinking which are more prevalent among men in India compared with women. Moreover, our sample was derived from hospital admissions, and it has been reported that female stroke patients tend to have lower hospitalization rates as compared to males.[10] In addition, Guru Nanak Dev Hospital, Amritsar, from where the study sample was chosen, is a government-run hospital. Patients from higher socioeconomic class prefer to go to private hospitals, as they believe that more facilities are available in private sectors and this might explain the reason why only 8% of the patient population in the present study were from high socioeconomic class.

Pain in stroke patients has been associated with decreased quality of life. Even when the pain exists before the stroke, its intensity can change in the poststroke period. However, in many patients, it may be difficult to determine whether the pain is clearly stroke related or not. Severe strokes (mRS >3), lower age, and female gender have been reported to be independently associated with the presence of poststroke pain.[11] The pain

Table 3: Factors associated with physical symptoms of stroke patients

Patient variables	OR#			
	Weakness	Pain	Tingling/numbness	Sleeping problems
Age of the patient (years)				
<60	Baseline	Baseline	Baseline	Baseline
≥60	3.11 (0.185-52.5)	0.79 (0.34-1.82)	0.61 (0.26-1.41)	0.75 (0.32-1.76)
mRS score on admission				
≤3	Baseline	Baseline	Baseline	Baseline
>3	>10	2.21* (1.03-4.33)	1.84 (0.90-3.77)	2.78** (1.34-5.78)

#OR (95% CI), *P<0.05, **P<0.01, ***P<0.001. OR: Odds ratio, CIs: Confidence intervals, mRS: modified Rankin Scale

Table 4: Factors associated with psychosocial problems of stroke patients

Patient-related variables	OR						
	Helplessness	Hopelessness	Thoughts of death	Difficulty in asking for help	Feelings of anger	Feelings of guilt	Preferred home care
Age of the patient (years)							
<60	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
≥60	3.64** (1.23-10.75)	3.28* (1.02-10.54)	3.11 (0.12-78.55)	0.27 (0.06-1.28)	0.67 (0.26-1.70)	0.53 (0.17-1.63)	0.13 (0.01-0.84)
Gender of the patient							
Female	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
Male	0.26** (0.18-0.66)	2.88* (1.06-7.80)	2.68 (0.35-20.11)	0.95 (0.27-3.32)	0.79 (0.32-1.92)	1.99 (0.58-6.80)	2.17 (0.63-7.42)
Type of residence							
Urban	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
Rural	1.80 (0.70-4.59)	0.51 (0.19-1.37)	17.18* (1.98-153.93)	1.15 (0.31-4.18)	0.97 (0.40-2.35)	0.97 (0.32-2.88)	0.81 (0.22-2.90)
Marital status of the patient							
Widow/widower	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
Married	1.12 (0.41-3.00)	0.81 (0.28-2.33)	0.62 (0.10-3.79)	4.39* (1.19-16.15)	0.55 (0.21-1.45)	1.22 (0.33-4.56)	3.95* (1.11-14.05)
Education level							
≤Primary	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
>Primary	1.13 (0.45-2.86)	6.31** (2.17-17.29)	0.1 (0.007-1.72)	0.64 (0.14-2.92)	3.35** (1.39-8.07)	1.26 (0.42-3.78)	0.38 (0.11-1.36)
Employment status after the diagnosis							
Unemployed	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
Employed	1.13* (1.03-8.54)	0.45 (0.14-1.37)	0.00 (0.00)	0.61 (0.10-3.70)	0.94 (0.34-2.56)	0.4 (0.10-1.50)	0.27 (0.06-1.23)
mRS score at the time of admission							
≤3	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline	Baseline
>3	1.43 (0.61-3.3)	2.92* (1.23-6.93)	0.00 (0.00)	2.52 (0.75-8.43)	1.6 (0.72-3.58)	0.88 (0.31-2.46)	0.55 (0.18-1.72)

All numbers are OR (95% CIs). *P<0.05, **P<0.01. OR: Odds ratio, CIs: Confidence intervals, mRS: modified Rankin Scale

may also result in disturbed sleep in stroke patients,[12] and many have been reported to suffer from insomnia.[13] Sleep disturbance can be caused by multiple factors including psychological, personal, and social, and the subjective nature of symptoms makes it difficult to assess its severity. Wallace *et al*. hypothesized that sleep disturbance may include daytime activities and concentration, resulting in disturbed rehabilitation and delayed functional recovery, which may further increase the risk for stroke recurrence.[14]

Feelings of hopelessness, helplessness, and anxiety can considerably prolong the rehabilitation and delay recovery time in stroke patients.[15] Astrom *et al*. reported that hopelessness is probably the most common psychological outcome observed in stroke patients. In addition, accumulating evidence suggests that stroke patients face an increased risk of suicide.[16] Suicide-related ideation affects 7%–15% of stroke patients, which is similar to the finding of the present study.[17] Furthermore, patients' age, gender, disease duration, and stroke type have been shown to be significantly associated with psychological problems such as anger, helplessness, and emotional instability.[18] Lewis *et al*. explained that psychological distress such as emotional irritability and helplessness might reduce motivation to engage in activities of daily living, adversely affecting the functional recovery and overall survival of stroke patients.[19] Similar to the results of the present study, stroke patients living in rural China had higher odds of having suicidal ideation.[20] In the rural regions of India, poorer socioeconomic conditions force stroke patients to bear heavier financial burdens and greater psychological pressures. Although not measured in the present study, prestroke depression has also been identified as an important risk factor influencing suicidal ideation in stroke patients.[21]

Stroke is a disease with long-term sequelae for the patient. As a result, the patients sometimes view their disability as a burden on the family, and therefore, hesitate in asking for help. Nonavailability of family members to care is also commonly seen, as families with lower socioeconomic status are busy with their paid employments. In addition, stroke patients may show aggressive behaviors including hitting others, kicking, biting, pushing, throwing objects, cursing, and screaming.[22] A recently published systematic review of observational studies by Crayton *et al*. identified anger as a psychological determinant that was significantly associated with poor medication adherence in stroke survivors.[23] In our study, anger among the stroke patients was mostly associated with the feeling of "why me?" It was observed that most patients had some form of responsibility toward their families, whether financial or social-like marriage of their children. Suffering from stroke was a big setback for them and they were, therefore, angry. In our patient population, only 16% of the patients preferred to be cared at an institutional facility rather than their homes. In an Israeli study of 191 stroke patients, 52% preferred to be cared at an institution.[24] The authors concluded that patients with comorbidities and those with difficult ambulation were more likely to choose institutional care. In the Indian culture, the joint family system ensures that every member of the family contributes in caregiving.[25] In contrast, some patients may prefer to stay at a nearby health-care facility; however, this may not always be possible on account of economic constraints and deficient infrastructure facilities.

There are a few limitations of this study. First, our sample was derived from hospital admissions, which might result in selection bias of patients. Mild strokes, which might not reach hospital and get admitted, might have been underrepresented in this study. Second, the subjectivity of the responses obtained the patients may introduce information and observer's bias. Third, longer follow-up of the stroke patients is required to understand the dynamic nature of stroke disability and associated social factors. Albeit these limitations, this study is among the very few from Northern India which investigated the association of sociodemographic variables of stroke patients with their physical and psychosocial problems. Our observations can help the doctors and nurses caring for stroke patients in developing a rehabilitation plan at the time of discharge. More importantly, this study highlights the need of expert rehabilitative and palliative services in India and urges the policy-makers to ensure the availability of these services.

Conclusions

Physical and psychosocial burden among stroke patients is enormous. Clinicians should make an effort to identify such issues through a targeted needs assessment of stroke patients. Rigorous, multisite evidence-based research is needed to determine the best methods for patient communication, identifying patient needs, and treatment preferences. But most importantly, especially in India where research and practice of palliative care are in its infancy, sensitization, and advocacy about palliation in stroke patients at individual, community, and institutional level should be pursued.

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Conflicts of interest

There are no conflicts of interest.

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