

# KNOWLEDGE OF FAMILY CAREGIVERS REGARDING POST-DISCHARGE CARE FOR STROKE PATIENTS AT TERTIARY CARE HOSPITAL A DESCRIPTIVE CROSS-SECTIONAL STUDY

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DOI: <http://doi.org/10.5281/zenodo.19083581>

## Keywords

Stroke, Knowledge, Family Caregivers, Discharge

## Article History

Received: 15 January 2026

Accepted: 03 March 2026

Published: 18 March 2026

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## Abstract

**Background:** Stroke is one of the major causes of morbidity and mortality globally. Stroke patient's care is complex and the family caregivers need knowledge. Insufficient knowledge of stroke family caregivers is the major contributing factor that leads to post-stroke complications, frequent hospital readmissions, and use of health care resources.

**Objective:** To assess the level of knowledge of family caregivers regarding post-discharge care for stroke patients at tertiary care hospitals.

**Material & Methods:** A descriptive cross-sectional study was conducted using a consecutive sampling technique. A total of hundred (100) stroke family caregivers were recruited with age  $\geq 18$  years. The self-administered tool was used for data collection. The data was collected from August 2018 to September 2018 from two tertiary care hospitals in Islamabad.

**Results:** Only 7% of family caregivers had high, 50% had average and 43% had low levels of knowledge regarding post-discharge care of stroke patients. The mean knowledge score was 30.86 and the standard deviation (SD  $\pm$  5.29). The participants comprised of male 76% of the sample with a mean age of 35 years.

**Conclusion:** The majority of the stroke family caregivers had a low level of knowledge about stroke risk factors, stroke warning signs, nutrition care, and psycho-social care. There is a need to conduct routine educational sessions and improve the post-discharge teaching strategies for stroke family caregivers at the time of discharge.

## INTRODUCTION

Stroke is a common cerebral vascular disease. It is the second leading cause of death globally and the most common cause of disabilities worldwide (Kamalakannan et al., 2016). Ischemic stroke accounts for almost 87% of all stroke cases, and hemorrhagic stroke accounts for the remaining 13% (AHA, 2017). Stroke is responsible for almost 10% of all deaths worldwide (Johnston, Mendis, & Mathers, 2009).

Pakistan is a developing country with limited resources and a lack of medical care for post-stroke patients, therefore, almost 40% of deaths occurred within 6 months (Khealani, Hameed, & Mapari, 2008). Lack of medical care and limited resources in Pakistan lead to around 40% of stroke-related deaths within six months, which is expected to double by 2020 due to an increase in population aging and rising smoking trends in developing countries. This increase in stroke

cases also contributes to higher healthcare costs for the country.

South Asia accounts for over 40% of stroke-related fatalities globally, with an estimated 250 out of 100,000 people in Pakistan suffering from it annually, resulting in approximately 350,000 new cases each year. The WHO reported 15.3 million stroke cases in a year, and more than a third of these resulted in mortality (WHO., 2015).

The global burden of stroke cases shows that more primary and secondary preventive strategies are required for the reduction of stroke prevalence (Saad, Waqar, Islam, Iqbal & Nomani, 2017). When stroke patients return home with disabling conditions, family support is required to help them to perform activities of daily living (National Alliance for Caregiving, 2009). Family caregivers of stroke survivors face difficulties in providing daily routine care for their patients due to a lack of post-discharge care information (Perry & Middleton, 2011).

Most stroke patients suffer from post-stroke complications such as aspiration pneumonia, contractures, falls, bed sores, urinary tract infections, behavioral changes, and depression. These complications are mostly developed due to inadequate knowledge of family caregivers regarding post-stroke care (Day et al., 2018). About 50% of stroke patients' deaths occur due to post-stroke complications (Nazeer, Kamal, Khan & Tariq, 2009).

Inadequate knowledge of family caregivers regarding post-stroke care of their patients increases the disability of stroke survivors. It also causes frequent hospital admissions and post-stroke complications (Rathore & Waheed, 2014). Therefore, without providing proper post-stroke care-related information to the family members, the home care of stroke patients cannot be predicted to be understood (Day et al., 2018).

Few hospitals conducted studies to evaluate the awareness of stroke warning signs and its risk factors in Pakistani people. The results of these studies revealed that the Pakistani population had poor knowledge about stroke warning signs and its risk factors (Saad et al., 2017; Aly et al., 2009). Knowledge of family caregivers about post-

stroke care of their patients remains a neglected area in the Pakistani context.

Practical care-related knowledge of family caregivers helps in improving patient recovery, preventing disabilities, and saving healthcare resources. It also helps in the early identification of problems and improves the quality of life of stroke patients and their family caregivers (Oupra, Griffiths, Pryor & Mott, 2010).

The study provides evidence about the level of knowledge of stroke family caregivers about post-discharge care. This study also determines the gap between stroke discharge teaching and family caregivers' understanding regarding post-stroke care. Moreover, it helps in the modification of discharge teaching for stroke patients and their family caregivers.

## METHODOLOGY

A descriptive cross-sectional was used to assess the level of knowledge of stroke family caregivers from June 2018 to October 2018 at Shifa International Hospital (SIH), a private tertiary care hospital and the Pakistan Institute of Medical Sciences (PIMS) is a public hospital tertiary care hospital in Islamabad. The Consecutive sampling technique was used for the recruitment of the study participants. The sample size was calculated by using the scientific formula ( $n = (Z)^2 \times p \times q (1-p) / d^2$ ). The calculated sample size of the current study was one hundred and fifty ( $n = 150$ ). However, one hundred samples ( $n = 100$ ) were achieved due to time limitations long duration of hospitalization of stroke patients, and the unwillingness of a few participants to participate in the study. The prevalence (P) value was taken from the previous national study. The self-developed structured questionnaire was used for data collection. They also evaluated the questionnaire items in terms of clarity. The cumulative content validity index (CVI) was 0.83 which is considered an acceptable value. The suggestions of the expert panel were also incorporated into the new version of the questionnaire.

The pilot testing of the tool was conducted on 10% of the total sample size among stroke family caregivers. The data was entered and analyzed by

using the Statistical Package of Social Sciences (SPSS) 20.0 version. The results of the pilot study were not included in the final analysis of the data. The knowledge score was converted to the level of knowledge. The knowledge of family caregivers was measured in three levels by using 60% as the cut-off value. The participants who had scores less than 60% were considered as having a low level of knowledge, 60% to 79% of the total score was considered an average level of knowledge and those who had 80% to 100% of the total score were considered as a high level of knowledge. **RESULTS**

#### Demographic Characteristics of Stroke Patients

Table 1 shows that the total patients were 60% (60) males and 40% (40) females. Of the patients who were married 96% (96) and unmarried 4%

(4). The educational qualifications of 35% (35) patients were illiterate, 25%(25) primary, 21%(21) matric, 10%(10) intermediate, 5% (5) bachelor degree and 7% (7) master degree or above. The occupation of patients was 44% (44) unemployed, 15 % (15) retired, 20% (20) employed and 21% (21) have their own business. The patients who have a family history of stroke disease were 40% (40). Among all stroke patients, only 5% (5) were underwent surgical interventions. Of the patients who were getting fed through feeding tubes 38% (38) and remaining orally 62% (62) at the time of discharge. Patients who had a urinary catheter in place 54% (54) and those passing urine in pampier or using the toilet 46% (46) at the time of discharge.

**Table 1**

Demographic Characteristics of Stroke Patients (n= 100)

| <i>Demographic Characteristics(Categorical Variables)</i> |                          | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------------------------------------|--------------------------|------------------|-------------------|
| Patients Gender                                           | Male                     | 60               | 60%               |
|                                                           | Female                   | 40               | 40%               |
| Patient's Marital status                                  | Married                  | 96               | 96%               |
|                                                           | Unmarried                | 4                | 4%                |
| Education Qualification                                   | Illiterate               | 35               | 35%               |
|                                                           | Primary                  | 25               | 25%               |
|                                                           | Matric                   | 21               | 21%               |
|                                                           | Intermediate             | 10               | 10%               |
|                                                           | Bachelor degree          | 5                | 5%                |
|                                                           | Master's degree or above | 7                | 7%                |

|                                             |            |    |     |
|---------------------------------------------|------------|----|-----|
| Occupation                                  | Unemployed | 44 | 44% |
|                                             | Retired    | 15 | 15% |
|                                             | Employed   | 20 | 20% |
|                                             | Business   | 21 | 21% |
| Patient has a family history of stroke      | Yes        | 40 | 40% |
|                                             | No         | 60 | 60% |
| Surgical intervention after stroke          | Yes        | 5  | 5%  |
|                                             | No         | 95 | 95% |
| Feed through a feeding tube                 | Yes        | 38 | 38% |
|                                             | No         | 62 | 62% |
| The patient has a urinary catheter in place | Yes        | 54 | 54% |
|                                             | No         | 46 | 46% |

Figure 3 illustrates about other co-morbidities that were identified in stroke patients. Among all stroke patients, 78% (78) have high blood pressure, 32% (32) diabetes, 18% (18) heart disease and 10%(10) kidney disease.

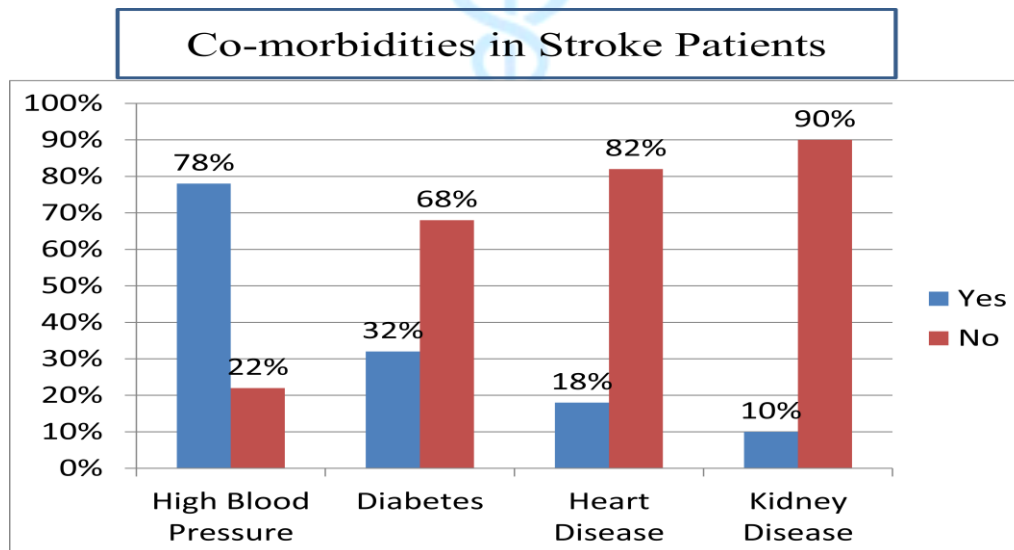


Figure 3 Co-morbidities in Stroke Patients

Figure 6 shows the educational qualification of participants were 15% (15) primary, 29% (29) matric, 18% (18) intermediate, 25% (25)

bachelor degree, 13% (13) master degree or above.

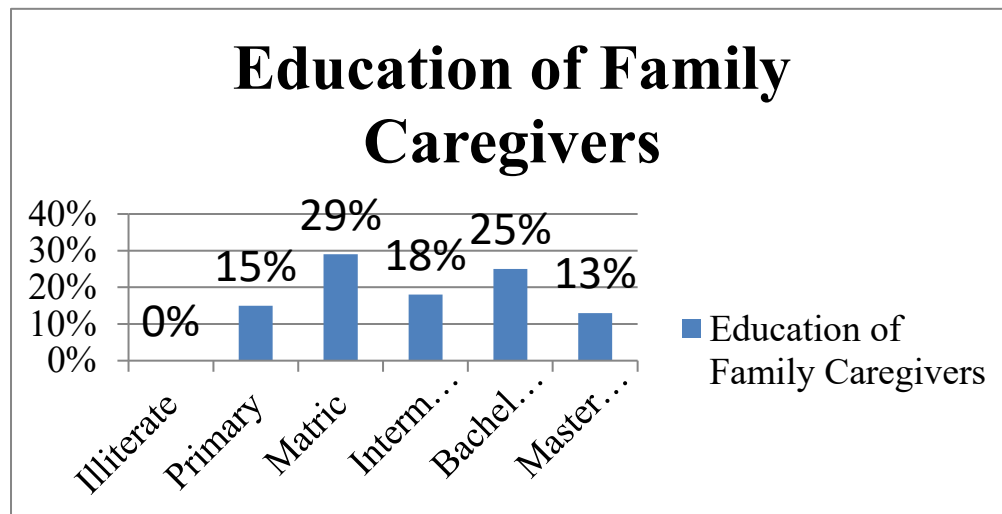


Figure 6 Educational Qualifications of Stroke Family Caregivers

Figure 7 shows the mean of participants was 35.42 and S.D. was  $\pm 11.45$ . The minimum age of participants was 19 years and a maximum of 78 years.

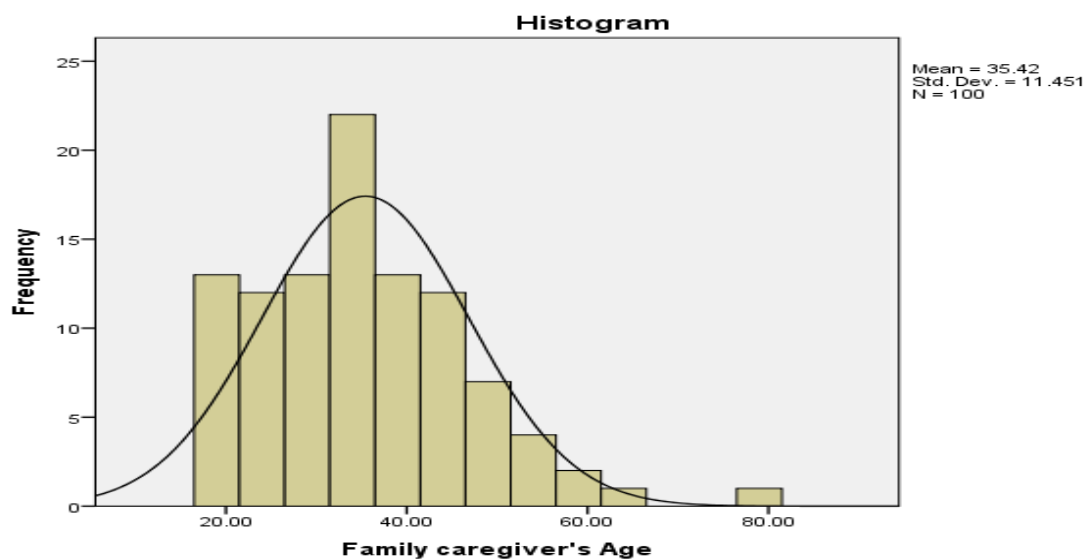


Figure 7 Stroke Family Caregivers Ages

Figure 8 shows that the mean length of stay of stroke family caregivers was 6.86 and S.D.  $\pm 4.383$ . The minimum length of stay of family

caregivers with stroke patients was 2 days and the maximum was 23 days.

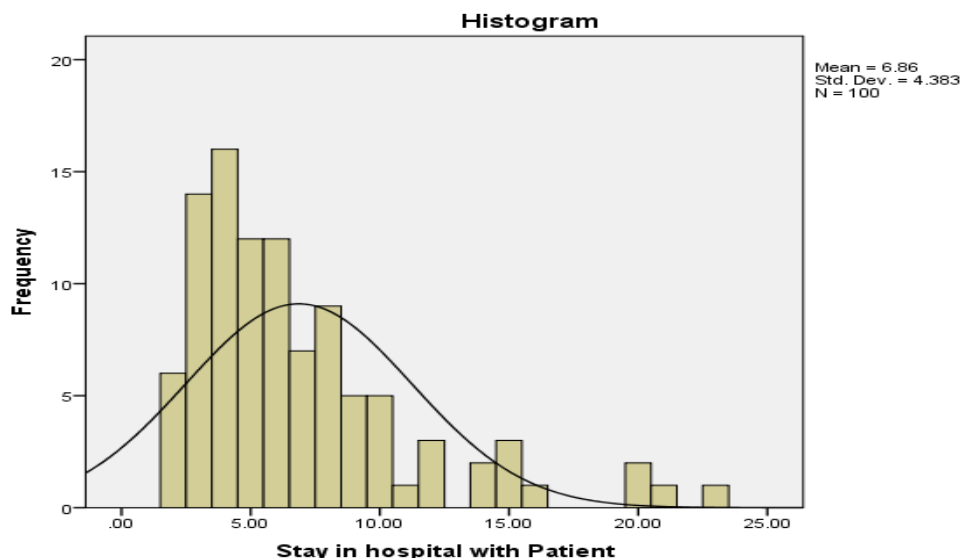


Figure 8 Stroke Family Caregivers Length of stay in Hospital

**Knowledge of Family Caregivers**

Figure 9 shows the knowledge score of family caregivers regarding post-discharge care of their patients. Overall 7% (7) of stroke family

caregivers had high level knowledge and 50% (50) participants had average knowledge. While 43% (43) had low-level knowledge regarding post-discharge care of stroke patients.

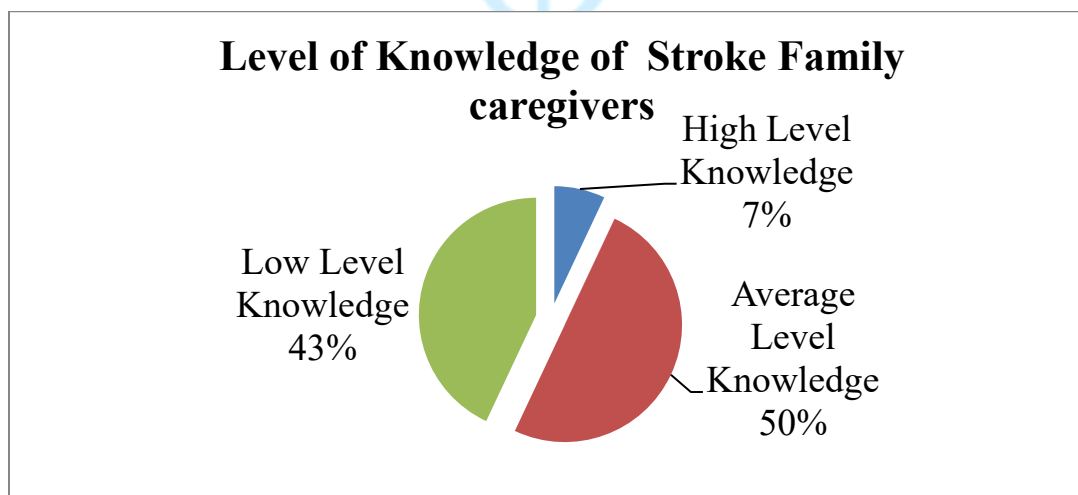


Figure 9 Level of Knowledge of Stroke Family Caregivers

Figure 10 shows that the mean knowledge score was 30.86 and the standard deviation (S.D  $\pm$

5.29). The participant's minimum score was 18 and maximum 45.

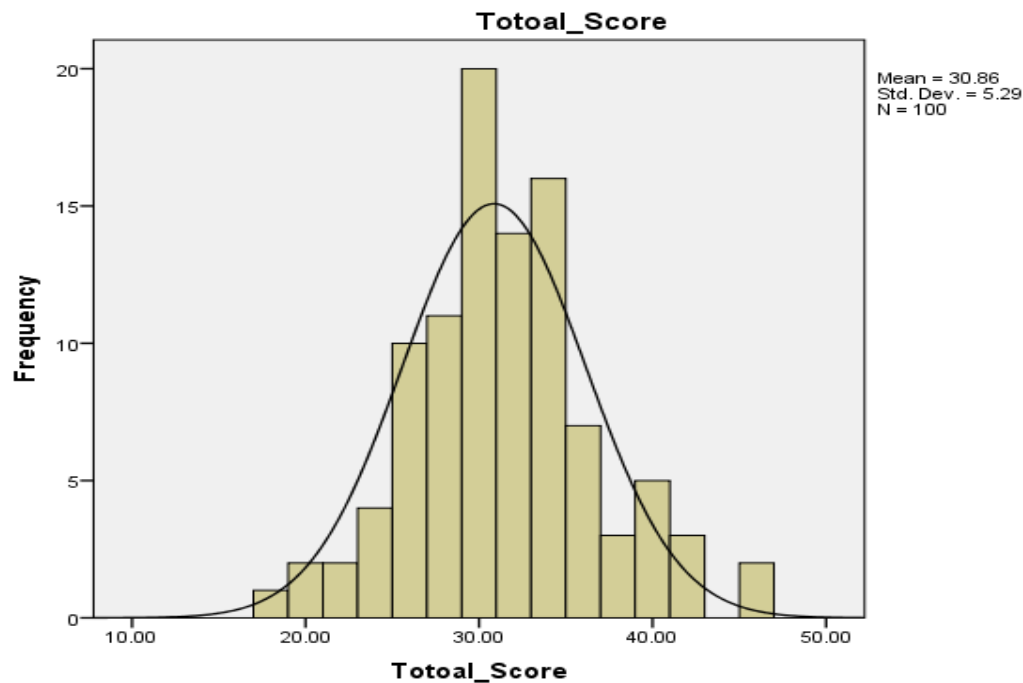


Figure 10 Total Knowledge Score of Stroke Family Care

#### Comparison of The Knowledge Between Public and Private Hospitals

The total number of participants from Shifa International Hospital (SIH) was 49 and from the

Pakistan Institute of Medical Sciences (PIMS) was 51.

Table 16 Level of knowledge of private and public hospitals

|       | Low-level knowledge | Average level knowledge | High-level knowledge |
|-------|---------------------|-------------------------|----------------------|
| SIH   | 46.9%               | 46.9%                   | 6.1%                 |
| PIMS  | 39.2%               | 52.9%                   | 7.8%                 |
| Total | 43.0%               | 50.0%                   | 7.0%                 |

Table 17 shows that the private and public hospitals' family caregiver knowledge was compared by using the Fisher exact test. There is

an insignificant difference ( $P$  value  $> 0.05$ ) between the knowledge level of stroke family caregivers from private and public hospitals.

**Table 17****Comparison of knowledge between private and public hospital**

|                     | Value | P value |
|---------------------|-------|---------|
| Fisher's Exact Test | 0.692 | 0.738   |

**Comparison of knowledge score with the level of education**

Table 18 shows that there is a borderline significant relationship (P value =0.058) between

knowledge score and level of education of stroke family caregivers.

**Table 18****Comparison between knowledge score and level of education of family caregivers**

|                    | Value | P Value |
|--------------------|-------|---------|
| Pearson Chi-Square | 14.85 | 0.058   |

**DISCUSSION**

The mean age of stroke patients was 61.62 years in our study, this finding is affirmed with the previous studies by Tsai et al., (2015); Pitthayapong et al., (2017). In contrast, a Western study showed the mean age of stroke patients is about 70 years, these findings revealed that the mean age of stroke patients in our study is about one decade younger than the Western countries as explained by Carlo et al., (2003). This difference may be because of a lack of public education about stroke risk factors and the high prevalence of smoking, hypertension, and diabetes in our country as studied by Aly et al., (2009); and Kamal et al., (2009).

Patients who were admitted with stroke were more males as compared to females in our study. This finding is consistent with the previous studies done by Tsai et al., (2015); Barker-Collo et al., (2015) that have shown increased incidence of stroke occur in males. A history of hypertension was found in most of our stroke patients. It is congruent with the previous studies conducted by Manabe et al., (2009). It is alarming that nearly one-third of patients (30%) were admitted with the diagnosis of recurrent stroke in the present study. In contrast, a previous study in Thailand shown the incidence of recurrence of stroke is about 12%. Stroke patients and their family caregivers' lack of awareness about stroke risk factors and their unhealthy lifestyle leads to recurrent stroke as found by Saengsuwan, Suangpho & Tiamkao., (2017).

The data was collected from the hundred (100) stroke family caregivers at the time of their patient's discharge from the hospital. About 76% of the sample was comprised of male participants in the present study and most (48%) were the sons of stroke patients. These findings are consistent with the finding of a study by Ain et al., (2014) who also found that most caregivers were male and the majority of them were sons. Whereas, the study conducted by Sharma et al., (2013) in Nepal reported an equal male and female ratio. The reason for this difference in findings from the Nepal study is that in the current study, most stroke patients were males and in our culture, it is preferred that male family caregivers usually stay with male patients in hospital.

Most family caregivers were adults (mean age=35.42 years) in our sample. A similar mean age of stroke family caregivers is found in a previous study conducted by Saad et al., (2017). The majority of participants were Matric or above in terms of educational qualification. Therefore, they were able to read and understand the study questionnaire well. It was found in our study that the levels of education have a significant relationship with the level of knowledge about post-discharge care. This finding from the current study is congruent with the findings of previous studies finding conducted by Saad et al., (2017); Nakibuuka et al., (2014).

About half (57%) of the participants had high and average knowledge about post-discharge care of stroke patients. While nearly half (43%) of the participants have a low level of knowledge about post-discharge care of stroke patients, this finding is affirmed by the previous study finding conducted by Sharma et al., (2013) shown that about half (52%) of family caregivers had low level of knowledge about stroke care. A similar finding was reported from the study conducted in the Netherlands that stroke patients and their family caregivers receive little information about stroke care during hospitalization (van Veenendaal, Grinspun & Adriaanse, 1996).

## CONCLUSION

The results of this study concluded that half of the family caregivers had an average level of knowledge and about half of the family caregivers had a low level of knowledge regarding post-discharge care of stroke patients. This study has highlighted the aspects of stroke care in which the majority of stroke family caregivers had a low level of knowledge such as stroke risk factors, warning signs, nutrition, and psycho-social care. Lack of discharge care teaching policies and protocols were the reasons for these findings in our context.

There is a need to conduct routine educational sessions and improve the discharge teaching strategies for stroke patients and their family caregivers during the hospital stay and also at the time of discharge. These study findings will help to develop better-written discharge teaching for stroke family caregivers.

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