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Research Article

CARING FOR STROKE PATIENTS: CAREGIVERS' KNOWLEDGE AND PRACTICES

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ABSTRACT

Stroke is a major public health problem worldwide. It is estimated that at present, approximately 1.8 million Indians out of a population of 1.2 billion suffer from stroke every year and about one-third of them die annually while another one-third are left with some permanent disability. The disability rate after discharge from the hospital can be effectively reduced by providing appropriate home care provided by caregivers[1]. (Sujata Das *et al,* 2016). The aim of this study was to assess the knowledge and practices of caregivers regarding caring for Cerebrovascular Accident patients.

Methods: A descriptive research approach was used. The study comprised of 100 caregivers of stroke patients form a selected hospital who were willing to participate. Non probability convenience sampling technique was used. Formal permission was obtained from concerned authority for data collection. A structured questionnaire and observation checklist were used for data collection.

Results: The results showed that most of the caregivers (51%) were from 41 – 60 years of age and majority (88%) was females. Maximum caregivers were spouses (52%) and no one had previous knowledge regarding caring for CVA patients. Majority of the Caregivers were having inadequate knowledge and practices regarding caring of CVA patients.. There was no significant association found between the findings with selected demographic variables among caregivers of Cerebrovascular Accident patients.

Conclusion: The study showed that about 60.28% of caregivers did not have adequate knowledge of how to properly care for Cerebrovascular accident patients; in fact, a significant number of caregivers demonstrated insufficient and inappropriate knowledge and practices. It is assumed that provision of regular training will improve the knowledge and practices of the caregivers regarding care of Cerebrovascular Accident patients which would positively affect patient outcomes.

INTRODUCTION

A Cerebrovascular disorder is an umbrella term that refers to any functional abnormality of the central nervous system that occurs when the normal blood supply to the brain is disrupted[2]. (Suzanne CS *et al,* 2004).

The word "stroke" is centuries old. In the 1970s the World Health Organization defined stroke as a "neurological deficit of cerebrovascular cause that persists beyond 24 hours or is interrupted by death within 24 hours." This definition was supposed to reflect the reversibility of tissue damage and was devised for the purpose, with the time frame of 24 hours being chosen arbitrarily[3]. (Wikipedia, 2016).

Cerebrovascular Accident is the primary neurological problem in the world. Stroke is the third ranking cause of death, with an overall mortality rate of 18 % to 37 %. There are approximately two million people surviving strokes that need assistance with activities of daily living[4]. (World Heart Federation, 2016).

Worldwide, stroke is the commonest cause of mortality after coronary artery disease. Also, it is the commonest cause of chronic adult disability. The lifetime risk of stroke after 55 years of age is one in five for women and one in six for men. More than four-fifth of all strokes occur in developing countries. The common risk factors, that is, hypertension, diabetes, smoking, and dyslipidemia are quite prevalent and inadequately controlled; mainly because of poor public awareness and inadequate infrastructure.[5] (Tapas Kumar *et al,* 2016).

Stroke is one of the leading causes of death and disability in India. The estimated adjusted prevalence rate of stroke range, 84-262/100,000 in rural and 334-424/100,000 in urban areas. The incidence rate is 119-145/100,000 based on the recent population based studies. Stroke rehabilitation is not well

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developed in India due to lack of personnel.[6] (Jeyaraj Durai Pandian *et al,* 2013).

"In Pune alone, approximately 10,000 patients suffer from stroke each year. Traditionally, stroke is considered to be a disease of the elderly but now-a-days witnessing stroke cases in the younger population as well. Stroke is the second leading cause of death after cancer in our country," [7] (Umesh Isalkar *et al,* 2015).

Cerebrovascular accident can result in profound disruption of life of the individual. The ability to perform Activities of Daily Living (ADL) may require many adaptive changes as well as assistance from the family members. Home management of the patient may be a challenging situation for the care giver if they are ignorant about the care of the patient. Meeting the educational needs of the family care giver is essential to optimize the quality of life for both the patient and family.[8] (NIHP, 2014).

A longitudinal study conducted on Needs of family caregivers of stroke patients. Study showed that family caregivers expected to obtain assistance and related care information from professionals during the course of the disease. Assessing the needs of family caregivers is important for health care workers in understanding problems from the caregivers' perspectives. Relevant information and counseling should be provided to family caregivers to help them access support when needed.[9] (Pei-Chun Tsai *et al,* 2015).

A study conducted on Knowledge, attitude and practice of stroke among community people in India versus other developed and developing countries. The study showed that rising stroke and higher mortality among Indian population needs focused attention for prevention and early management of stroke. In India, very few studies have been carried out to determine the causes of deficiencies in knowledge, attitude and practice (KAP) of stroke among Indians. Study on KAP is essential to improve the awareness about stroke, early diagnosis and institution of appropriate management.[10] (Sujata Das *et al,* 2013).

A study was conducted to measure stroke knowledge and pre stroke personal health behaviors of stroke patients undergoing in-patient rehabilitation. Their caregivers were also included. A total of 130 stroke patients and 85 caregivers interviewed after an ischemic stroke. The study showed large deficiencies in patient and caregiver stroke knowledge: fifty-two percent of patients could not name any stroke risk factors, 52% were unable to name a stroke warning sign, and 35% were unable to identify appropriate actions to take in a stroke emergency. Stroke patients participating in in-patient rehabilitation and their caregivers have large gaps in stroke knowledge and have suboptimal personal health behaviors, thereby putting patients at high risk for recurrent stroke. There is a need to develop stroke education programs for rehabilitating patients that are effective in closing these gaps in knowledge.[11] (Koenig KL *et al,* 2007).

A descriptive study was conducted to assess the knowledge and practice of caregivers of immobilized patients regarding prevention of complications related to immobilization. A purposive sampling has been used with thirty caregivers. Study result showed that caregivers had unsatisfactory knowledge and inadequate performance. Therefore training and educational program to enhance knowledge and practice of caregivers are needed.[12] (Fathia A. Mersal *et al,* 2014).

A survey was conducted on Caregivers' Knowledge about Caring for Stroke Patients. Formal caregivers (n=217), who worked for stroke patients at 8 hospitals, participated in this study. About 33.8% of caregivers did not have adequate knowledge of how to properly care for stroke patients; in fact, a significant number of caregivers demonstrated inappropriate and insufficient knowledge in several areas. [13] (Lee KW *et al,* 2015).

A quantitative descriptive study was conducted in Utrecht to investigate the feasibility and practicability of a nurse lead training program for stroke survivors and their caregivers within a stroke rehabilitation ward. The study concluded that providing knowledge and involving caregivers in training activities of stroke patients may be seen as an important way of improving activity and rehabilitation.[14] (Annette Kleijburg 2011).

A study was conducted on patients with acute stroke (n=250) and their carers who were randomly allocated to an intervention group and a control group. Control group received standard care and intervention group received services from a Family Support Organizer. .Assessments was administered at 4 months and 9 months post-randomization. Patients and carers were assessed for knowledge of stroke. Results revealed significant differences in intervention group.[15] (Lincoln, N.B *et al,* 2005).

A study was conducted on 'Public perception of stroke warning signs and knowledge of potential risk factors'. Interviews were completed by 1880 respondents. The results revealed that education is needed to increase the public's awareness of the warning signs and risk factors for stroke. Respondents with self-reported risk factors for stroke were largely unaware of their increased risk. The population was the least knowledgeable about 'stroke warning signs and risk factors'.[16] (Pancioli AM *et al*).

A randomized controlled trial was undertaken to determine the effectiveness of a multidisciplinary Stroke Education Program (SEP) for patients and their informal carers Two hundred four patients admitted with acute stroke and their 176 informal carers were randomized to receive an invitation to the SEP or to receive conventional stroke unit care. The SEP improved patient and informal carers knowledge about stroke and patient satisfaction with some components of stroke services.[17] (Rodgers H *et al,* 1999).

MATERIAL AND METHODS

A Quantitative research design with descriptive research study approach was used. The study comprised of 100 caregivers of Cerebrovascular accident patients admitted in a selected Hospital fulfilling the inclusion criteria, recruited by non-probability convenience sampling technique. A Structured questionnaire and observation checklist were used for data collection. The reliability of the research tool was s 0.85 and 0.90 respectively.

RESULTS

Analysis and interpretation is based on the objectives of the study. The analysis was done with the help of descriptive and inferential statistics.

Table 1 Percentage wise distribution of caregivers of CVA patients according to their demographic characteristics

n=100

Demographic Variables		
Age in years	**Frequency**	**Percentage**
21-30 yrs	15	15
31-40 yrs	34	34
41-50 yrs	26	26
51-60 yrs	25	25
Gender		
Male	12	12
Female	88	88
Educational Status		
Illiterate	26	26
Primary	18	18
Secondary	26	26
Higher Secondary	13	13
Graduates	17	17
Occupational Status		
Housewife	79	79
Student	07	07
Laborer	01	01
Service	13	13
Relationship with the patients		
Son	09	09
Daughter	23	23
Daughter-in-law	10	10
Wife	52	52
Mother	02	02
Brother / Sister	04	04
Previous knowledge		
Yes	00	00
No	100	100

The above Table 1 shows that distribution of caregivers according to age, gender, educational status, occupational status, relationship with the patients and previous knowledge. Thirty four percentages of the caregivers were in the age of 31-40 years, and 25% of the caregivers were in the age of 51-60 years. Majority 88% were females. Educational status revealed that 26% were illiterates, 18% were educated up to primary and 43% were educated up to secondary and above. 100% had no previous knowledge regarding care of stroke patients.

Table 2 Assessment of knowledge of caregivers about caring of CVA patients

n=100

Category	Minimum score	Maximum score	Mean	Standard deviation	Mean percentage
Knowledge	05	14	9.93	2.01	39.72

The above table 2 indicates that most of the caregivers were having only average knowledge about caring of Cerebrovascular accident patients.

Table 3 Assessment of practices of caregivers about caring of CVA patients

n=100

Category	Minimum score	Maximum score	Mean	Standard deviation	Mean percentage
Practices	11	19	15.53	2.01	19.42

The above table 3 depicts that the mean practice score among caregivers of CVA patients about caring of CVA patients was 15.53. The mean percentage score was 19.42. This indicates that most of the caregivers were having poor practices about caring of CVA patients.

Table 4 Assessment of area wise practices of caregivers about caring of CVA patients n=100

Category	Mean	Standard deviation	Mean percentage
Mouth Care	2.43	0.92	17.35
Bathing	4.64	1.93	29.00
Toileting	4.12	1.40	17.91
Feeding	1.64	0.59	18.22
Positioning	2.5	1.02	27.77
Back Care	0.6	0.66	5.45

The above table 4 depicts that the item wise practices of caregivers regarding care of CVA patients. In mouth care the mean practice score was 17.35, in bathing it was 29.00, in toileting it was 17.91, in feeding 18.22, in positioning 27.77 and in back care it was 5.45. It indicates that the caregivers was having poor practices about caring of CVA patients and needs information regarding care of CVA patients.

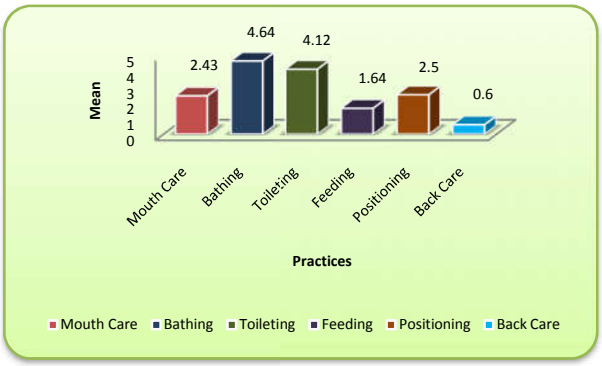

Figure 1 Assessment of area wise practices of caregivers about caring of CVA patients

DISCUSSION

Cerebrovascular Accident patients with neurological deficit require long term hospitalization or home care. Knowledge of stroke risk factors and symptoms are necessary prerequisite for prevention. Stroke-related knowledge was particularly poor in the population. Novel approaches will be needed to improve awareness and prevention in this high-risk group[18]. (Goldstein LB *et al,* 2009). In the present study also the caregivers mean knowledge and practice score were only 9.93 and 15.93 respectively regarding care of CVA patients.

A telephone survey was conducted in Israeli population (n=300) to investigate the scope of knowledge on stroke among men and women. The study demonstrated lack of knowledge on stroke. Knowledge was particularly poor regarding the possibility of stroke prevention through risk factor management, and with respect to recognition of symptoms of acute stroke.[19] (Tanne D *et al,* 2004).

CONCLUSION

The study aimed to assess the knowledge and practices of caregivers regarding care of CVA patients. The results showed that caregivers were having average knowledge and poor practices regarding caring of CVA patients emphasizing the need for educating the patients as well as their caregivers on care of Cerebrovascular accident patients.

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