

A Study on Awareness in Caregivers about Disability and Early Rehabilitation in Stroke at Kempegowda Institute of Medical Sciences Hospital and Research Centre, Bangalore

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Abstract: ***Purpose:** To know the existing knowledge of the stroke patients' caregivers regarding basic stroke care and early rehabilitation in order to design appropriate intervention programs and to enhance stroke care and outcome. **Subjects and Methods:** In this study, 105 caregivers were recruited from KIMSH, Bangalore. The caregivers were asked to answer the question regarding stroke. The answers were recorded to assess the caregivers' knowledge about stroke, stroke care and importance of early rehabilitation. All the collected data were analyzed using SPSS 18.0. **Results:** Respondents were asked the questions and each correct response was given "1" score and wrong answer "0" score. The level of awareness was then classified into 3 categories: high level (more than 75%), average level (50-75%) and low level (<50%). Overall, 74 (70.5%) participants had average level of knowledge regarding disability and early rehabilitation in stroke. **Conclusion:** The caregivers of stroke had average level of awareness about disability and early rehabilitation. Caregivers knowledge on stroke might be of great practicality for early gain of functional abilities in stroke patients.*

Keywords: Stroke; stroke care givers; stroke care awareness; early rehabilitation; disability.

1. Introduction

Stroke is defined 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".^[1]

The global burden of stroke is rapidly increasing. Worldwide, someone is thought to suffer a stroke every other second, with a stroke-related death occurring every six seconds.^[2]

Stroke can cause the loss of control over an arm and a leg, people's abilities to care for themselves in simple ways like walk independently, bathing, getting dressed and daily activities like preparing a meal, cleaning or going to the shops and public transport use are often affected. Even the simplest tasks like brushing teeth, washing face, shaving becomes seemingly unmanageable.^[3]

The term "caregiver" encompasses a wide range of experiences and situations. Caregiving may include caring for a loved one in the caregiver's home, the care recipient's home or in an institutional setting. It may include attending to an individual's emotional well-being and/or physical health. It may involve long-term caregiving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness.^[4]

The role of family members who undertake patient care is unarguably important for stroke rehabilitation.^[5] A competent and knowledgeable caregiver is critical in determining whether a stroke survivor's mental and physical health improves, and whether the survivor or a stroke is institutionalized or can remain at home in his or her community.^[6]

Without proper care and treatment, a stroke may result in many secondary complications, such as pressure sores, joint contracture, shoulder pains, and aspiration pneumonia. To prevent secondary complications and to support the activities of daily living (ADL) in patients, the role of the caregiver is important, particularly if the patients are in an acute stage.^[7]

Many factors contribute to delays in seeking treatment for stroke, but the principal factor is believed to be a lack of public knowledge regarding stroke symptoms and the need for a rapid response.^[8]

The Modified Rankin Score (mRS) is a 6-point disability scale with possible scores ranging from 0 to 5. A separate category of 6 is usually added for patients who expire. The mRS measures the degree of impairment in bodily functions and structures. Although it is inclined towards motor function, it also takes into account patient autonomy and activities of daily living. The Modified Rankin Score (mRS) is the most widely used outcome measure in stroke clinical trials.^{[9]-[10]}

This study was a descriptive study where questionnaire was used for collecting data. The caregivers were asked to answer a set of oral and written question. Questionnaire method are relatively low cost, easy to analyze, simple to administer in a large sample of given population. The format is familiar to many respondents and information is collected in standardized way and are usually straight forward to analyze.^{[11]-[12]}

2. Methods and Procedure

This is a cross-sectional questionnaire-based study with a sample size of 105 subjects. The questions focusing basic stroke care were prepared with the help of literature/article,

physiotherapist and a physician. Questionnaire was divided into 3 parts; Part I: Socio-demographic data (6 questions) and Part II: Stroke disability awareness (20 questions) and Part III: Early rehabilitation awareness (14 questions). All the collected data were analyzed using SPSS 18.0.

Part: I (Socio-demographic characteristics)

- 1) What is your age? What is your sex?
- 2) What is your religion?
 - Hinduism/Islam/Christian/Jainism/Sikhism
- 3) What is your educational status?
 - Literate/Illiterate
 - If literate, what is your level of education?
 - Informal education, Primary level, Secondary level, Higher secondary level and above
- 4) What is your occupation?
 - Farmer, Housewife, Labor, Service, Business, Others (please specify)
- 5) What is your relation with care recipient?
 - Spouse/Offspring/Relatives/Son/Daughter/Others (please specify)
- 6) What is your time duration of providing care to care recipient?

Part: II (Stroke Disability Awareness)

- 1) Have you heard about stroke?
 - Yes / No
- 2) Does anybody in your family had stroke?
 - Yes / No
- 3) Do you know which organ is involved in stroke?
 - Yes / No
- 4) What could be the causative factors of stroke?
 - High BP
 - Diabetes
 - Smoking
 - Too much alcohol
 - Too much stress
 - None
- 5) Do you know the consequences/result of the stroke?
 - Yes / No
- 6) Do you know anything about the changes in the physical appearance of the patient following stroke?
 - Yes / No
- 7) Do you think that the patient can function as before and effectively during post stroke stage?
 - Yes / No
- 8) Do you know what happens to the joints/muscle post stroke?
 - Yes / No
- 9) Does their behavior changes after stroke?
 - Yes / No
- 10) Till what extent do you think that the patient might be dependent upon you?
 - Modified Rankin Scale
 - 0- No symptoms at all
 - 1- No significant disability despite symptoms; able to carry out all duties and activities
 - 2- Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance

- 3- Moderate disability, requiring some help, but able to walk without assistance
 - 4- Moderately severe disability; unable to walk and attend to bodily needs without assistance
 - 5- Severe disability; bedridden, incontinent and requiring constant nursing care and attention
 - 6- Dead
- 11) When should the patient be mobilized at first?
 - Mobilize after the condition improve/Must be in complete bed rest/
 - Mobilize as early as possible/Mobilize after a week of stroke
 - 12) Is it necessary to assess the balance of patient before ambulating out of bed?
 - Yes/No (If yes, what should be assessed first?)
 - Balance while sitting /Balance while standing
 - Do you need to use any devices for ambulation?
 - Yes/No (If yes, what is the devices that the patient can use at initial stage?)
 - Crutches/Tripod-Quadripod/Walker/Canes
 - 13) Do you think could they live alone without any help from another person? This means being able to bath, use the toilet, shop, prepare or get meals.
 - Yes / No
 - 14) Do you think can they walk from one room to another without help from another person?
 - Yes / No
 - 15) Can they sit up in bed without any help?
 - Yes / No
 - 16) What is the appropriate position of the patient?
 - Lying on affected side/Upright sitting position/Lying on unaffected side/Supine position
 - 17) What is the required frequency to change the position of patient?
 - 1 hourly/2 hourly/ 3 hourly/ 4 hourly / I don't know
 - 18) Do you think the patient might feel less abled?
 - Yes / No
 - 19) What should be done if the patient has urine incontinence?
 - Keep catheter/Frequently provide bed pan/Use diaper/Let him pass urine on bed
 - 20) What should be done to encourage the patient to communicate effectively?
 - Talk as usual/Ignore the patient/Use gestures, pictures and objects/Provide psychological support

Part III: Early Rehabilitation Awareness

- 1) Does the improper position result joint deformities?
 - Yes / No / I don't know
- 2) What should be done to prevent joint deformities?
 - Position change and exercise/Ambulation/Use of compressive stocking/Proper diet / I don't know
- 3) Do you think early mobilization is important in stroke patients?
 - Yes / No / I don't know
- 4) How many times a day the affected extremities should be exercised passively?
 - 1-2/2-3/3-4/4-5 / I don't know
- 5) Do the pressure sores develop in stroke patients?
 - Yes / No / I don't know
- 6) What should be done to prevent pressure sores?

- Position change/Put on comfortable cloth/Ambulation/Use of stocking/I don't know
- 7) Does the elastic stocking should be used for prevention of deep vein thrombosis?
 - Yes / No / I Don't Know
 - 8) Does the deep breathing and coughing exercise should be done to prevent chest infection?
 - Yes / No / I Don't Know
 - 9) Do you think his balance and posture play an important role for his further management?
 - Yes / No / I don't know
 - 10) How do you think you can improve his endurance/tolerance?
 - Walking briskly
 - Repetitive exercises
 - Diet
 - 11) Is easy fatigability common in stroke?
 - Yes / No
 - 12) Is fall common in stroke?
 - Yes / No
 - 13) How to prevent the patient from falling while walking?
 - Restrict to walk/Hazard assessment in home/Use comfortable shoe/Advice to walk alone slowly/Use of assistive devices
 - 14) How long do you think the patient might take to be independent post stroke?

3. Results

The questionnaire-based study was done among 105 participants who were caregivers of patients with stroke. In the study, there were 56 females (53.3%) and 49 males (46.7%), who were between age group < 20 to 70 years. Most of the participants had studied until secondary level of education, who were mostly housewives or involved in services or businesses. Age distributions of the participants studied were between age group < 20 to 70 years. Most of the caregivers were 31-50 years of age. Fifty-six (53.3%) participants were female and forty-nine (46.7%) were male

as a respondent. 51 participants (48.6) had done secondary level of education. Spouse and children were involved in providing care with the number 77(73.4%).

Seventy-Seven (73.3%) participants had known the term 'stroke' and 48 (45.7%) knew about the organ involved in stroke. 70 participants (66.7%) could answer about the causative factor of stroke being high BP.

34 participants (32.4%) mentioned that tripod/quadripod can be used for the stroke patients at initial stage. 74 participants (70.5%) considered supine position to be ideal for the stroke patients. 28 participants (26.7%) said that it was better to change the position every 2 hourly.

60 participants (57.1%) were aware of catheter, whoever had urine incontinence. 92 participants (87.6%) mentioned that they should talk as usual to the patient in order to encourage the patient to communicate effectively.

82 participants (78.1%) knew about the importance of position change and exercise in order to prevent joint deformities and 85 participants (81%) had awareness regarding early mobilization and its importance in stroke.

44 participants (41.9%) were aware of development of pressure sores and only 15 participants (14.3%) were aware of the use of elastic stocking for prevention of deep venous thrombosis.

Importance of balance and posture were appreciated by majority of the participants (76.2%) and 85 participants (81%) were aware of fall in stroke patients.

Overall, 74 (70.5%) participants had average level of knowledge regarding disability and early rehabilitation in stroke.

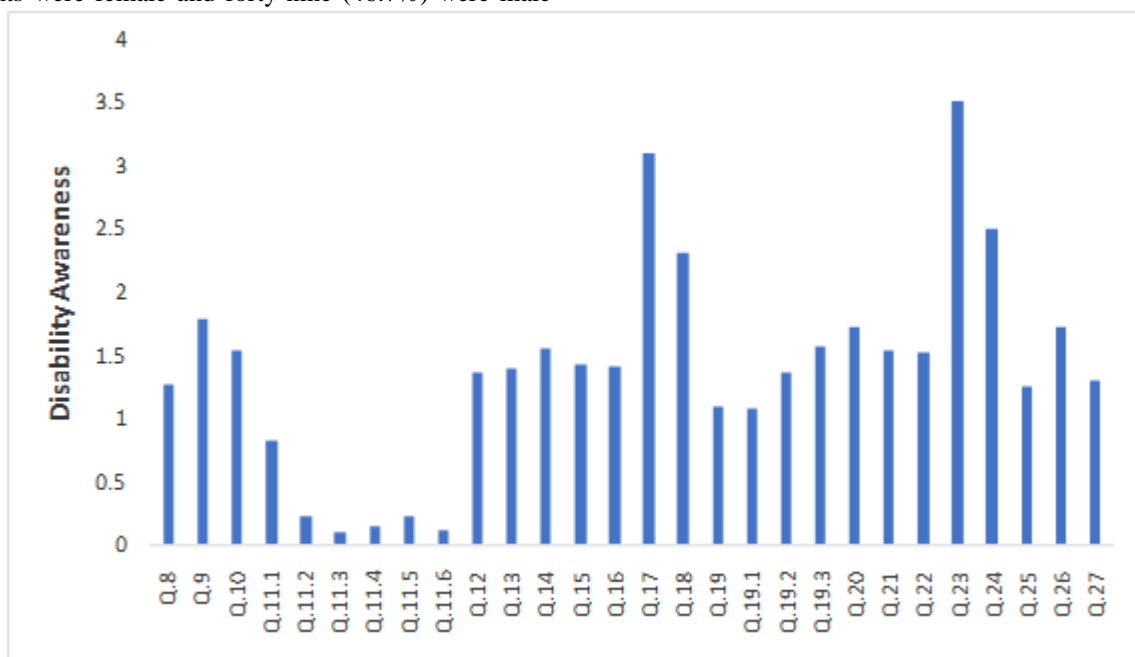


Figure 1: Graphical Representation of Mean ±SD of Stroke disability awareness

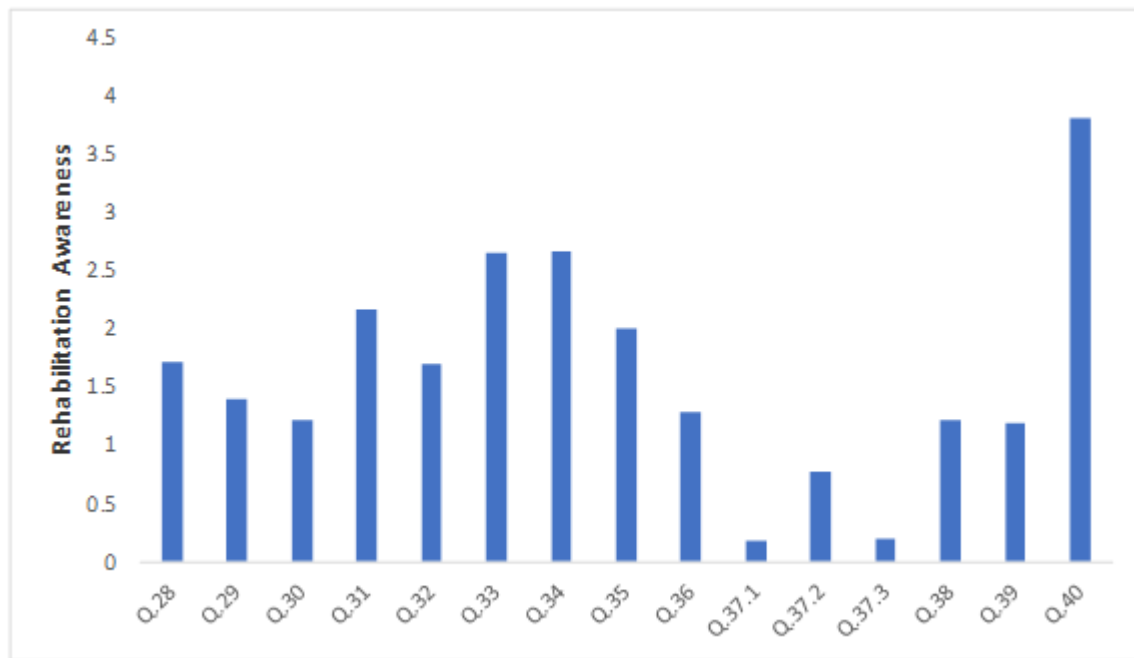


Figure 2: Graphical Representation of Mean \pm SD of Rehabilitation awareness

4. Discussion

A stroke or Cerebrovascular accident (CVA) is defined as an abrupt onset of a neurologic deficit that is attributed to a focal vascular cause.^[1]

The purpose of the study was to know the knowledge of the stroke patients' caregivers regarding basic stroke care and early rehabilitation in order to design appropriate intervention programs and to enhance stroke care and outcome.

Usually, either spouse or children were seen to be involved in stroke care for the stroke survivors. Nayeri et al also suggested the similar observation in which 61.5% caregivers were offspring and 38.5% were spouse^[13]. Likewise, in our study 22 participants (21%) were spouses and 21 (37.5%) were daughters and 34 (69.4%) were sons.

Most of the participants used to take care of the patient for more than 12 hours a day i.e. 42 participants (40%). A cross-sectional questionnaire-based study conducted in Mangalore hospital by Rajegowda et al revealed that 70% of caregivers had known about the term 'stroke'.^[14] In our study 73.3% of caregivers had heard about the term 'stroke'. In a same study conducted by Rajegowda et al, 94% of caregivers mentioned that the 'brain' is the affected organ in stroke, wherein, in this study 45.7% of caregivers had an idea, 'brain' as an involved organ in Stroke.

A cross-sectional study conducted by Osahon et al suggested that the most commonly recognized risk factors of stroke were Hypertension (89.9%), aging (80%), previous stroke (56.6%) and excessive alcohol consumption (44.1%). Loss of ability to speak (62%), loss of ability to walk (52.6%) and one-sided paralysis (50%) were the most recognized consequences of stroke.^[15] In this study 66.7% of caregivers were aware of High BP as one of the causative factors of

stroke, as against 78% and 27% in studies from Mangalore hospital^[14] and Pakistan hospital^[16] respectively.

A study conducted by Rajegowda et al suggested some of the physical changes encountered in stroke patients, such as: sudden onset weakness of arm, sudden onset weakness of the leg and speech disturbances were the most identified features of stroke. Other correctly identified symptoms were sudden onset fainting, loss of vision, headache and dizziness.^[14] In this study, most of the participants knew about the physical changes that occurs post stroke.

The caregivers also had an idea about the importance of assessing balance and posture, ambulation of the patient out of the bed, as well as, the advantages of using assistive devices for safe ambulation. They also knew the proper way of handling the patients, regarding positioning and care of bladder, as well as, modes of improving their communication skills and providing psychological support. A study conducted by N. Sharma et al revealed that majority (62%) of caregivers were aware regarding daily catheter care.^[17] However, in this study, we observed 57.1% participants aware of daily catheter care.

A study conducted by Bruno et al. suggested that the modified Rankin Scale appears to be useful in clinical stroke and it has excellent reliability.^[18] In this study 5 participants (4.8%) scored 1 for the stroke victims, 20 participants (19%) scored 2 to the stroke survivors, 44 participants (41.9%) scored the stroke survivors 3, 30 participants (28.6%) scored the stroke survivors 4 and 6 participants (5.7%) scored the stroke victim with 5 in the Modified Rankin Scale.

A descriptive research study conducted by Pandit et al suggested that the total mean practice score in positioning was 27.77 and in back care it was 5.45. It indicates that the caregivers were having poor practices about caring of CVA patients.^[19] In this study 82 participants (78.1%) mentioned that position change and exercise must be done to prevent joint deformities.

A study conducted by N. Sharma revealed that 31 (62%) respondents were aware of pneumonia in stroke patients and 50% knew the importance of deep breathing and coughing exercises which helps in preventing infection.^[17] In this study 40 participants (38.1%) mentioned that deep breathing and coughing exercise should be done to prevent chest infection and 25 participants (23.8%) mentioned that deep breathing and coughing exercise had nothing to do with preventing chest infection.

In this study 19 participants (18.1%) mentioned that we can improve the patient's endurance/tolerance by walking. 81 participants (77.1%) mentioned that the patient's endurance can be improved by repetitive exercise. 21 participants (20%) mentioned that diet can be induced to improve the endurance of the stroke patients. 82 participants (78.1%) mentioned that easy fatigability is common in stroke. Whereas, 23 participants (21.9%) don't think that easy fatigability is common in stroke.

In this study 6 participants (5.7%) didn't have any idea how long the patient might take to be independent post stroke. 74 participants (70.5%) said that it might take < 6 months for the patient to be independent post stroke. 20 participants (19%) mentioned that it might take 6-12 months to be independent post stroke. 5 participants (4.8%) mentioned that it might take >12 months for the patient to be independent post stroke.

5. Limitations

- Multiple-choice questions were given to the respondents in which only limited options are available to study participants and he/she can guess the answer, unlike open-ended questions.
- Follow up was not taken to know the awareness level of the caregivers.
- The days of hospital stay has to be considered, since caregivers might learn via observation.

6. Recommendations

- Follow up of the caregivers can be taken in order to assess the awareness of the caregivers.
- Further large-scale study with in-depth analysis of individual care-item may reveal better understanding of caregiver's knowledge and help institute appropriately targeted intervention for better stroke patients' care and outcome.

7. Conclusion

Majority of stroke patients complain of activity limitations and participation restrictions. It is reported that approximately 50% of subjects after stroke remain dependent on others for some activities, 54% show limitations in carrying out activities of daily living, and 65% report restrictions in reintegration into community activities.

Caregivers play a very important role in supporting stroke survivors but research consistently reports adverse impacts

on caregivers. These include negative effects on mental health, burden and stress thus making it important they are supported both for themselves and those they care for.

The purpose of this study was to investigate the knowledge of the stroke patient's caregivers regarding basic stroke care and early rehabilitation in order to design appropriate intervention programs and to enhance stroke care and outcome.

Our study has demonstrated an average level of awareness amongst majority of caregivers interviewed in different areas of basic care and early rehabilitation awareness of stroke patients.

Average level of knowledge is extracted via the following procedure. Respondents were asked the questions and each correct response was given "1" score and wrong answer "0" score. The level of awareness was then classified into 3 categories: high level (more than 75%), average level (50-75%) and low level (<50%). All the collected data were analyzed using SPSS 18.0.

Educational and awareness programs at the community level involving campaigns, informal education, mass media, schools, universities and governmental agencies are needed in order to improve stroke awareness among the population.

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