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A descriptive study to determine the level of burden experienced in care giving tasks undertaken by the relatives of stroke patients admitted in government general hospital karaikal

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Abstract

Stroke is a major health problem in both the developed and developing countries. It is the second most leading cause of death above 60 years. The world stroke federation states that every year 15 million people suffer with stroke globally. In that nearly 6 million are left disabled, thus the relatives had been posted with burden to meet the needs of the disability such as meeting the nutritional needs,elimination needs and the other psychological support and also the extended support for the physiological changes that occurs according to the site of the extent in the brain.Life- threatening complications accompanied by other challenges, including the inability to maintain nutrition through normal oral intake and neurologic changes which may vary depending on the site and extent of the lesion as well as on the age at which the stroke occurs. Since the elderly population is most commonly affected by stroke, and may have more difficulty in compensating changes in muscle tone that reduce chewing and decrease tongue pressure.Thus by conclusion the role of care giver has to occupy the major importance in the rehabilitative part of post store recovery for the stroke patients (Johnson, *et al.*, 2014). Descriptive research design was adopted with 70 samples(caregivers) selected by the convenience volunteer sampling technique (Thorne 2008) who were met the inclusion and exclusion criteria.Demographic variables were collected by using the interview method. The data was collected by using the Rivermead Mobility Index (RMI) and Zarit Caregiving Burden Scale (Burden Interview) instruments.19 questions from the instruments dealt with the patient informations and the 30 questions is to reveal the information regarding the caregiver. Difficulties in caregiving for patients were experienced by 72.9% of the caregivers. These problems were related to difficulties in providing care (47.1%), strained family relationships (29.4%), and insufficient support in providing needed care (13.7%). Caregivers' strategies for coping with the problems were sharing their feelings with others (43.2%) and crying (35.3%). The daily lives of the caregivers had been affected by social isolation (55%). Caregivers were unable to get other tasks in their lives completed (23.3%). They were planning their lives according to the patients' schedules and needs (15%), and did not have enough time to take care of their own needs (6.7%). Results also Shown that the longer the care giver caring the patient the mean score in the care giver burden scale is statistically raising ($P<0.05$).Thus the study reveals that the effective counseling and guidance to the care givers will always helps an lot by prior planning for effective implementation of the care to the clients in the post stroke rehabilitative dependent period.

Keywords: stroke, elderly, caregiver burden

1. Introduction

stroke is the third leading cause of death and disability among the various health issues after the cardiac problems and the cancer. The centre of disability analysis reveals a data that the stroke occupies an greater notion in making an great economic burden to the India.Stroke is the second leading cause of death. Stroke causes disability and dependence on others in one of every three patients. After a stroke, patients may become dependent on others to function in daily life to meet their daily needs and some may even need long- term care. In general, the care of patients is undertaken by their families. (Bethoux *et al.*1996) found that nearly 70-80% of stroke patients live in their own home after discharge and they had became completely dependent on the family members which are always increasing the burden of the care givers. (Greveson *et al.*1991) 71% of the post stroke patients continue their life with disability. (Ferri *et al.*2011) found 97.6% of stroke patients in the post rehabilitative phase of stroke need care and 53.7% of them need special care, 72.7% of the stroke patients in India also need additional care which includes the assistance in meeting the financial needs, family role confusion etc. The care provided by the patients' family members is not limited to a single aspect whereas it includes the multi factorial aspects such as health care, administering medication, personal care (bathing, feeding, toilet care, dressing), planning social services, shopping and doing housework, financial management, assistance with finances, and sharing the same house. Although the care provided by the caregiver will gives an sense of belongingness and positive psychological support to the patients for their faster recovery the negative aspect of this is the care giver burden where the caregiver has to play an dual role by meeting both the needs of themselves in addition to meeting the needs of the patients. Most of the studies revelas that there are several factors which implies the level of burden felt by caregivers. The most influential factors are individual personalities and temperaments of caregivers, daily time allocated for care, level of the patients, dependency on the caregiver for daily activities. Long-term care causes physical and mental fatigue of caregivers and an increase in the symptoms of depression. (Morimoto *et al.*2001) found that 50% of caregivers have at least one chronic disease, while some other study revelas that 73% of caregivers had at least one chronic disease, and headache, hypertension, rheumatological diseases and heart disease which may have an direct or indirect relationship with the burden experienced by the care giver. studies have observed that caregivers of stroke patients have the highest levels of anxiety and depression. McCullagh *et al*.conducted an study to determine the level of care burden experienced by the relatives giving care to family members affected by strokes and he found that 62% of the caregivers experienced the social isolation.

Objectives

- To determine the level of dependency of the stroke patients in various activities during the phase of post rehabilitative recovery
- To identify the level of burden experienced in various care giving tasks undertaken by the relatives of stroke patients during the phase of post rehabilitative recovery
- To associate the burden experienced by the care givers with their selected demographic and associated variables.

Materials & Methods

Qualitative descriptive research method was adopted for the study.the formal permission was obtained from the Medical head and unit head of the general medicine department of Government General Hospital,Karaikal & the ethical clearance was also obtained from the instution review board & ethical committee which includes the various internal experts from the GH and external experts from the JIPMER branch of Karaikal.The caregivers of 70 stroke patients who were admitted and getting treatment in the Neuro medicine ward of Government General Hospital was selected by using the convenient volunteer sampling technique (Thorne 2008) who had met the inclusion criteria and exclusion criteria. Participant information data sheet was provided to the caregivers and an informed consent was obtained to participate in the study. Demographic datas were collected from the patients case profile and the care givers demographic and associated variables were collected by using the individual interview. Data was collected by using Rivermead Mobility Index (RMI) and Zarit Caregiving Burden Scale (Burden Interview) instrument. The tool consists of 19 questions which reveals informations regarding the patients caharacteristics and the 30 questions establish the infromations regarding the caregivers.The reliability and the validity of the tool were checked by split half method. The RMI’s main aim is to evaluate the effectiveness of rehabilitation efforts as applied to the disabled.It also helpful in determing the mobility issues related to neurological problems and senile changes. Fourteen questions were helpful in gathering informations regarding the mobility of patients. A patient’s own statement is essential in responses to questions. Only the 5th question was assessed by the interviewer.Total score of 15 will be given if for yes response. The Zarit Caregiving Burden Scale was developed by Zarit, Reever and Bach-Peterson in 1980, was used to find out the caregiver burden for stroke patients. The scale consists of 22 questions with a Likert-type evaluation. A minimum of 0 and maximum of 88 points can be scored on the scale.

The SPSS software was used to evaluate the data. In addition to descriptive statistical methods (median, standard deviation), the Chi-square test was used to compare qualitative data. As the data do not have a normal distribution the Mann-Whitney U test were used in pair-group comparisons. The Spearman correlation analysis was used in the relationship between two variables. The results were considered statistically significant ($p<0.05$).

Results

Table 1: Demographic variables of the care Givers (N=70)

Demographic characteristics	Number	Percentage
Age		
20-39 years	10	14.2
40-49 years	16	22.9
50-59 years	19	27.1
60-69 years	16	22.9
70-80 years	9	12.9
Sex		
Male	10	14.3
Female	60	85.7
Education		
Illiterate	27	38.6
Graduated from primary school	26	37.1
Graduated from high school	10	14.3
Graduated from university	7	10
Marital status		
Married	55	78.6
Single	15	21.4
Economic status		
Income and expenses are in balance	17	24.3
Income and expenses are not in balance	53	75.7
Economic status affected by the diseases condition		
Affected	46	65.7
Not affected	24	34.3
History of Health Problems		
Yes	40	57.1
No	30	42.9
Distribution of health problems		
Hypertension	23	48.9
Disc Herniation	18	38.3
Peptic ulcer	13	27.7
Headache	8	17
Hypercholesteremia	8	17
Diabetes	6	12.8
Depresssion	5	10.6
Thyroid problems	5	10.6
Osteoporosis	3	6.4
Asthma	2	4.3
Relationship with the patient		
Husband / wife	30	42.9
His / her daughter	29	41.4
His / her son	6	8.6
Others	5	7.1

Table 1 : reveals the information regarding the demographic variables of the caregivers, most of them 19(27.1%) were falls under the category of 50-59 years,most of the caregivers were females 60(85.7%) regarding the education the highest percentage of 38.6% of them were illiterates and only 10% of them were graduated from university.under the category of marital status 78.6% were married regarding the economical status the higher value of 53(75.7%) of them are not having an balance between their income and expenses

which reveals that economically they were in an distress situation 40(57.1%) of the caregivers were affected with any of the health problems and the distribution of health problems were occupies the distribution of following percentage 23(48.9%) were hypertensive,18(38.3% were affected with the disc herniation,13 (27.7%) were having peptic ulcer,8(17%) were diagnosed with headache and hypercholestremia,6(12.8%) were having the diabetes mellitus,5 (10.6%) were having depression and thyroid problem,3(6.4%) were having osteoporosis and 2(4.3%) were having asthma.

According to the relationship with the patients 30(42.9%) were the husband or wife,29(41.4%) were daughters,6(8.6%) were sons. The longer the period of care giving the more will be burden experienced by the caregivers with the significant median score of P <0.05.The median score of caregivers in the care giving task such as related to meeting the nutritional needs, movement, exctretional needs and following the treatment schedule was significantly high P<0.05.

95.7% of the patients were diagnosed with any of the additional diseases 80.6% were hypertensive,40.3% of them were having hyperchlostremia and 40.3% were diagnosed with coronary artery diseases,60% of patients were diagnosed with paresis and 40% of them had plegia,45.3% of them had right hand and right leg plegia and 31.2% were affected in the left side.The patients were experiencing the following problems because of the stroke.79.4% of them were having loss of balance,66.2% of them were having gait problems,57.4% of them were having urinary incontinence,51.5% were having nutritional issues,39.7% were having difficulties in communication,26.5% were having vision problems,20.6% were having insomnia,11.8% were having fecal incontinence.

Table 2: Characteristics of the Patients

Characters	Number	Percentage
Required time for care		
3-5 months	17	24.3
6-11months	11	15.7
12-23months	9	12.9
24 months or more	33	47
Required time for daily routine of care		
1-4 hours	14	20
5-9 hours	6	8.6
10-14 hours	24	34.3
14 hours and more	26	37.1
Care giving task		
Meeting personal hygiene	62	88.6
Meeting the Nutritional Needs	58	82.9
Medication administration	54	77.1
Helping for performing activities	49	70
Financial assistances	48	68.6
Helping for meeting the Elimination Needs	40	57
Requirement of another assistance for care giving		
Yes	50	71.4
No	20	28.6
Number of Helpers assistance in patient care		
1	27	54
2	18	36
3 and more	5	10

Table 2: depicts the information regarding the characteristics of the patients in care giving.24.3% of the patients require the care for the period of 3-5 months and 47% of them requires the care for 24 months and 37.1% of them requires 14 hours in an day for providing the daily routine of care.71.4% of them requires 2 assistants for care giving,10% of them requires more than 3 persons for providing the required care.

The caregivers were experiencing 72.9% of difficulties in delivering the essential care to the stroke patients.there were many problems such as 29.4% of them were having strained family relationships,13.7% of them were having insufficient support in providing the needed care,43.2% of them were having problems in sharing their feelings with others,55% of the care givers had been affected with the social isolation,23.3% of them were unable to meet their own daily task, 15 % of them were having difficulties in planning their schedules and needs.6.7% of them were not having enough time to meet their own needs.

Discussion

In the current study most of the care givers were women and wives for the affected individuals since the women plays an very important role in compassionate care with the stronger relationship and also the study founds that for major of care givers there was an imbalance between the income and expenditure. Joseland & Montgomery etal shows that most of times the additional expenditures involved in the treating facilities were not covered by insurance and so many of the caregivers were forced to an situation to quit their regular employment to get the retirement money to meet the care giving routines to the patients. The current study also founds that half of the caregivers were affected with anyone of the health problems such as hypertension, stomach ulcer, headache and hyper cholestremia.

Morimoto *et al* determined that 50% of the caregivers are having anyone of the chronic diseases.Thus present study concludes that the health problems of the caregivers were also having the direct influence in increasing the level of burden.

Draber *et al* shows that in most of the stroke patients the recovery will occur at a very slow steady phase and in sometimes the recovery period can’t be predicted so again the longer period of care delivery will reduce the thought of patients improvement there by the psychological aspect of the caregiver strength will be reduced to an greater extent.

Subgranon etal supported that when the patients had discharged from the hospital the distance between the health care providers and the patients will be increased and again this will reduce the coping ability of caregivers and also the patients,in the current study 66.8% of the caregivers were experiencing problems in coping ability because of the inadequate information’s from the health care providers after discharge.

Magrliano *et al* founds that neurological deficiency of the patients are also increasing the burden of care givers.In the current study 42.5% of the patients were having neurological deficit.Thus in the part of conclusion even though the burden of care delivery is not found to be very high various factors such as physical, social, psychological determinants of the caregivers are having an direct influence on the perception of burden in care delivery aspect of stroke patients.since the care givers were finding an less time for their personal life they were experiencing negative emotions such as feeling alone and burdened,helpless in various situation.when the coping abilities were examined they restored various behaviors such as crying and expressing their frustrations by talking with other persons. If any of the above mentioned coping abilities are not attempted they were put into more physical and mental distress.

Conclusion

The current study reveals that there were various factors which may increase care givers burden for each individuals which may vary the role of education and counseling programmers' with the aim of providing the information's regarding the patient management system along with the economical management which always finds an specialized pathway in improving the coping ability of both patients and the caregivers. The advanced directives such as discharge information's and training plays an greater role for the caregivers in reducing their feeling of care giving burden. Lastly the nurses and other health care providers has to be imparted with specialized skills related to counseling for the patients and care givers.Thus an directed relationships of proper education to the care givers will always reduces the burden felt by them.

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