



BURDEN AMONG CAREGIVERS OF PERSONS WITH ANEURISM

Neurosurgery

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ABSTRACT

Introduction: Caregivers face multiple problems while caring. In the process of caregiving, burden was reported to be highest. Objectives: To assess the burden among caregivers of persons with aneurism.

Methods: The study adopted descriptive research design. The study participants were recruited with the help of purposive sampling method and pre-determined inclusion and exclusion criteria.

Results: The participant's age was found to be 38.87 ± 14.28 years. The caregivers of aneurism survivors had experienced severe burden in the domains of financial burden (04.97 ± 1.80), disruption of routine family activities (3.75 ± 2.02), disruption of family leisure activities (3.07 ± 1.71), and disruption in family interaction (2.62 ± 1.51).

Conclusion: Addressing psycho social and emotional needs would bring down the burden of care givers during hospitalization and also follow up.

KEYWORDS:

Aneurism, Burden, Caregivers

Introduction

A brain cerebral aneurism is a bulging, weak area in the wall of an artery that supplies blood to the brain. In most of the cases brain aneurism causes no symptoms and goes unnoticed. When a brain aneurism ruptures, the results is called a subarachnoid haemorrhage. Depending on the severity of the haemorrhage brain damage or death may result. In recent years, the fatality rate after Subarachnoid Haemorrhage (SAH) has decreased.(1) Glasgow Outcome Scale (GOS) are reported 50% good recovery, moderate disability 21%, severe disability 14% vegetative state 3% and death 12 %.(2) Persons with aneurisms will undergo paralysis, spasticity, speech and language impairments, dysphagia, sphincter dysfunction, cognitive and functional impairments and participation restrictions.(3) These impairments creates burden on caregivers. The carers of patients who have suffered aneurisms are important in treatment, continuation of treatment and accurate determination of outcome. It is not surprising that this can be at great personal cost to the carer, usually measured in the health care burden and morbidity. Studies focused on burden on caregivers. In the process of caregiving, caregivers also suffer from psychosocial stress.(4) Persistent psychosocial sequel are found such as affecting quality of life of primary caregivers, personal lives, family relationships, financial situation and mood. (5), (6) Post operatively after months family members of aneurisms reported that psychological distress, and moderate to high level of family burden. They also felt it's easier to cope in the initial stage of illness than after discharge. (7), (8) Two to three year follow-up studies also reported that care givers experienced emotional stress, and post-traumatic stress disorder. (9), (10) Over time, there is possibility that disability persist among patients can place an increasing burden on the caregiver. (9) Further, studies reported that need of psychosocial interventions to address the emotional and psychosocial issues of caregivers of persons with aneurisms since they crucial role in the recovery of aneurism patients. (3), (5), (6), (7), (11), (9)

Most of the time studies address the burden of care and psychosocial issues of caregivers confined to western countries. We could not find

any studies that focused exclusively on psychosocial issues of caregivers of aneurisms in India. Thus, the current study aimed to understand the care giver burden of aneurism patients.

Materials and Methods

The study adopted the descriptive research design. The study participants were recruited with help of purposive sampling method and pre-determined inclusion and exclusion criteria. The inclusion and exclusion criteria as follows; All adult primary caregivers who were involved in providing care more than six months for persons with aneurism after surgical interventions, who were able to communicate in Kannada, Tamil and English languages were recruited in the study. In the process, total 55 caregivers were contacted during follow-up at neuro-surgery, out-patient department unit, of which 10 caregivers had language difficulties and 5 caregivers did not give consent to participate in the study, hence excluded from the study. Thus, 40 caregivers were recruited in the study. The socio-demographic details of caregivers such as age, gender, education, domicile, type of family, occupation etc., were collected by using socio-demographic data sheet. Family burden interview scheduled by Pai and Kapur (1981) was used to measure the caregiver burden among caregivers of aneurism patients. The scale measures the subjective burden as experienced by caregivers. It consists 6 domains in terms of financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interaction, effect on physical health of others, effect on mental health of others and overall subjective burden of caregivers. Participants can rate easily on three point scale 2 indicates severe burden, 1 indicates moderate burden and 0 indicate the no burden. Higher the score indicate the higher the burden. The advantage of this instrument is that it was developed in our culture and good reliability and validity was found. The scale was administered by the primary author in a private room after obtaining informed consent from the participant. The data was collected from study participants from August 2014 to May 2015. The data was analysed with the help of R software3.0.1 version. Frequency for nominal and categorical variables and mean and standard deviation for continuous variables

were computed. The written informed consent was obtained from each recruited participant. The ethical clearance was received from National Institute of Mental Health and Neuro-Sciences, Bangalore, Karnataka, India.

Results Table 1: Socio-Demographic Details of the caregivers of persons with aneurism

Variable	Category	N (%)
Gender	Male	25 (62.5)
	Female	15 (37.5)
Marital status	Married	34 (85)
	Unmarried	6 (15)
Education	Illiterate	7 (17.5)
	Primary	7 (17.5)
	Secondary	6 (15)
Type of family	Graduation	20 (50)
	Nuclear	22 (55)
	Joint family	18 (45)
Domicile	Rural	31 (77.5)
	Urban	9 (22.5)
Occupation	Daily wager	22 (55)
	Private sector	12 (30)
	Government/public sector	06 (15)
Financial constraints	Yes	33 (82.5)
	No	07 (17.5)
Financial support provided by family members	Yes	25 (62.5)
	No	15 (37.5)
Current health status of caregivers	Good	30 (75)
	Poor	10 (25)
Dependant other family members on caregivers	Yes	18 (45)
	No	22 (55)

Table 2. The emotional problems caregivers

Variable	Response	N (%)
Caregiver relationship with patient	Son or Daughter	20 (50%)
	Spouse	16 (40%)
	Father or Mother	4 (10%)
Easily stressed out	Yes	20 (50)
	No	20 (50)
Emotional distress presence in the family	Yes	21 (52.5)
	No	19 (47.5)

Table 3. The descriptive statistics on domains of caregiver burden

Variable	N	Mean	Std. Deviation
Age	40	38.87	14.28
Financial burden	40	4.97	1.80
Disruption of routine family activities	40	3.75	2.02
Disruption of family leisure activities	40	3.07	1.71
Disruption in family interaction	40	2.62	1.51
Effects on physical health of others	40	1.52	0.93
Effect on mental health of others	40	1.45	1.13

The participant's age was found to be 38.87 ± 14.28 years. Male caregivers (62.5%) and female care givers (37.5%), and married care givers were (85%), and caregivers educated up to graduation 50%. The majority of caregivers were from rural background (77.5%), working as daily wager (55%). The table 1 show the socio-demographic details of the caregivers. Son or daughter 50%, spouse 40% and either father or mother of aneurism survivors took the role of caregiving responsibility. The results also showed that in spite the caregiver relationship with aneurism survivor more than 50% caregivers had experienced stress and emotional distress also present in the family. Table to show the caregiver relationship with patient and emotional stress experienced by the caregivers of aneurism survivors. The caregivers of aneurism survivors had experienced severe burden in the domains of financial burden (04.97 ± 1.80), disruption of routine family activities (3.75 ± 2.02), disruption of family leisure activities (3.07 ± 1.71), and disruption in family interaction (2.62 ± 1.51). Moderate burden was found in the domains of effects on physical health of others (1.52 ± 0.93), effects on mental health of others

(1.45 ± 1.13) and other burden on the family (1.80 ± 0.46).

Discussion

Psycho-social issues of caregivers in surgical conditions are overwhelmed especially aneurism survivors. Further, psycho-social concerns of caregivers not measured adequately in families coming from rural background. Thus, current study focused to assess the caregiver burden on pilot basis. It was reported that most the relative importance, possible influence of cost, and the attitude of the different subjects taking in the treatment other than patients like surgeons and patients relatives have not been analysed. (12) In this context, the present study carries significance.

In our study majority of care givers were son, daughter, spouse, father or mother took the caregiving responsibility. Most of the time, these caregivers are unpaid family members in Indian context where closely knitted families exist. This findings goes in accord with pervious study studies the fact is that caregivers are family members. (11) The results showed that caregivers had experienced considerable amount stress and emotional distress in the family. This finding is similar to that aneurism caregivers experience social or emotional stress 53.8%, felt completely overwhelmed 46.4% and carers are closely related. (9)

The finding also showed that caregivers of family members had experienced severe financial burden. They had financial constraints in terms meeting the surgical cost, medicine, travel and accommodation. Only considerable number of caregivers received financial support from their family members, significant close relatives and friends. They had sacrificed their daily wage to look after their loved in during hospitalization as a result they lost source of income which in turn created financial burden on the caregivers. This finding goes in line with previous study reported that one-third of caregivers faced severe financial problems. (8) Adding to that, disruption in routine family activities, family leisure activities, family interaction pattern were also severely disturbed in care giver families. This finding is similar with earlier studies reported that on post discharge, changes in personal lives, family relations, financial situation of care givers of aneurism severely get disturbed. (5), (6) Majority caregivers hailed from nuclear family, reduced social support, other family dependant family members at home especially spouse, and children and travelled long distance for treatment from rural area might have also contributed in disturbances in the family. Further results showed that caregiving showed negative impact on caregiver's physical health, and mental health moderately. This finding is comparable with previous studies reported that considerable number of patients and caregivers have reduced quality of life. Psychosocial scores also correlated with quality of life.(5)

Limitations

The study has certain limitations such as onetime assessment, small sample size, followed non-randomized sample, limited to only one centre, and data analysis restricted to only descriptive statistics. Thus, generalization of current finding are cautioned.

Conclusion

Medical and Psychiatric Social Workers play significant role in providing psychosocial interventions for people undergoing surgical interventions and carers who are providing care during hospitalization and follow-up.(13), (14) Thus, treating team may utilize the existing man power to address the emotional and psychosocial issues of patients and care givers and start referring cases for the same. By addressing emotional and psychosocial needs of the patient and caregivers will bring better quality of life, reduction of burden among caregivers during hospitalization and also follow – up visits.

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