BURDEN, ITS PREDICTORS AND QUALITY OF LIFE IN CAREGIVERS OF STROKE SURVIVORS AT RURAL COMMUNITY, PUNJAB, INDIA

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ABSTRACT

Introduction: Stroke is a common neurological disorder characterized by long term dependency of patient on family members and need rehabilitation at home with consequent disturbances in certain areas of life of caregivers. The aim of the study was to examine specific nature of the burden and to estimate the relative influence of caregivers' characteristics on burden in caregivers.

Methods: A cross sectional descriptive survey was carried out by recruiting 100 caregivers purposively in selected rural community setting Punjab, India. WHOQOL-BREF scale and Zarit burden interview (ZBI) schedule was used to measures quality of life and burden in caregivers. Explanatory factors of burden were studied in term of personal and caregiving characteristics of caregivers. Descriptive statistics was applied to compute level of burden and simple and multiple linear regression analysis was applied to identify true predictors of burden in caregivers.

Results: Caregivers of stroke survivors perceived varied pattern of burden. The most caregiving burden felt in term of feeling disturbance in relationship, loss of control in life and feeling more personal strain. Multiple regression analysis revealed that a higher level of burden could be partially explained by caregivers characteristics in term of female gender (β=0.275, p<0.042), private employment (β=0.233, p<0.049), and significant history of stroke (β=0.388, p<0.000). Findings reported good quality in social relation domain in caregivers.

Conclusions: Caregivers of stroke survivors facing varied level of burden. Sharing responsibility, availability of family support in care and providing financial assistance may be important in the support of caregiving and improvement of quality of life. Study also suggested development of home rehabilitation programme to improve upon quality of life in caregivers of stroke survivors.

Keywords: Stroke, Caregiver, Burden, Quality of life

INTRODUCTION

Stroke is a chronic and debilitating condition in developing countries and India is no exception for that. It is a well-documented and common neurological problem in developing countries in adults and elderly worldwide. The co-morbidities and life style changes associated with stroke can place considerable burden in caregivers, which ultimately can affect their perception and healthy way of life. Health related quality of life encompasses physical, psychological, social and environment dimension of health (WHO)[1].

As a result of rapid demographic and epidemiological transition, stroke has become the third leading cause of death in India. High morbidity, mortality and disability are a grave concern for considerable costs for health care system, for the individual and their family[2]. The estimated economic burden was about 8.7 million dollars because of CHD, diabetes and projected to reach 54.0 billion dollar in 2015 due to these disease[3].

After a transient emergency care at hospital, patient will discharged to home with multiple physical problems, cognitive disabilities[4,5] and behavioral and psychological issues[6] that commonly compromise their autonomy, and make them dependent on family members for long term care and support. The sudden onset of stroke provides no time for preparation of adjustment to change in roles and may not leave family members a choice about becoming caregiver. In most situations, the primary or informal caregiver-take cares the responsibility of care[7].

The strain caregiving impose on physical, psychological, social, financial and spiritual well-being is termed as 'caregiver burden'[8]. It is reported that caregiving task consequent many physical and psychological illness and ultimately reduce health related quality of life[9]. It is research study facts that experience of family member to provide care to their dependent patient is described as burdensome and stressful, which is related to hindrances faced by caregivers[10] in day to day life.

In recent era, the concept of quality of life of family members became topic of interest of several studies[11-13]. Use of WHOQOL-BREF instrument for exploring quality of life in caregivers reported varied results but overall it was very poor and dissatisfied[14]. Therefore, a team of qualified and dedicated community experts is needed to early identify the silent disease host at community level to provide timely treatment and care for them. It also rose as alarm to develop evidenced based intervention to ensure the success of home rehabilitation for stroke patients and their caregivers.

MATERIAL AND METHODS

A community based cross sectional survey was designed in the month of April 2014-January 2015. 100 caregivers were selected purposively from convenient selected community setting at district Amritsar and Ludhiana of Punjab. Caregivers who were healthy and more than 18 years of age and involved for more than 1 month of direct care at home after discharge of patient were included in the study. Pregnant and caregivers who were had history of chronic psychiatric and medical conditions were excluded. A self-developed information and caregiving data sheet was used to collect the information related to personal and caregiving status. Burden and quality of life was assessed by using Zarit Burden Interview Schedule and World Health Quality of Life-BREF Version. Prior permission was ascertained to use, and translate the tools.

ZARIT BURDEN INTERVIEW SCHEDULE (ZBIS)[15]

It is a Likert type 5 point rating scale composed of 22 items. The domains of ZBIS include 'burden in relationship' (6 items), 'emotional well-being' (7 items), 'social and family life' (4 items), 'finances' (1 item), 'loss of control over one's life' (4 items). 'Personal strain' (12 items) and 'role strain' (6 items). Scale was on continuous scale and high score indicate high burden. The tool was translated in to Punjabi language with the help of experts in Punjabi literature and language. The calculated Cronbach alpha value of translated Punjabi version was 0.92 for this study.

The World Health Organization Quality of Life (WHOQoL-BREF version):[1] questionnaire consists of 26 items categorized under 4 domains; physical (7 items), psychological (6 items), social relationship (3 items), and environment (8 items). Item 1 and 2 focused on overall quality of life and excluded from all domains. Obtaining higher score on a particular domain indicate good quality of life and vice versa. The tool was translated in to Punjabi language with the help of experts in Punjabi literature and language. The calculated Cronbach alpha value of translated Punjabi version was 0.81 for this study.

DATA COLLECTION

A written permission was obtained from concerned authority of hospital to collect the records of the patients to trace their home setting. Caregivers were telephonically contacted after taking their home address for their availability and went on their address to conduct interview. While interview, it was assured that caregivers were free from all types of distractions to furnish the necessary details. After explaining the study objectives, a written informed consent was also sought from the caregivers. Caregivers were visited at their home during their free time and it took around 20-25 minutes to furnish the asked details.

ETHICAL CONSIDERATION

A proposal was put before the Ethical Committee of Sri Guru Ram Das Institute of Medical Sciences and Research, Amritsar Punjab for ethical approval. The study approved with wide letter no. 140/Surg/13 after discussing varied ethical principles. Investigators also kept in mind other ethical issues during and after data collection. Subjects were given full freedom to withdraw from study at any point of time. However, the reason for non-participation was ascertained.

RESULTS
Nature of burden

The pattern of burden experienced by the caregivers under each sub-domain shows that caregivers felt frustrated in making relationship with other family and friends (40.96%) followed by feeling of loss of control in life (40.44%), personally strained (36.44%), and disturbed in emotional well-being (32.14%). However, financial problem was least (11.5%) reported constrained in management of patient by caregivers (Figure 1).

Predicators of burden

To identify the predictors of burden in caregivers, simple linear regression analysis applied. In linear regression analysis, the direct effect of caregiver's characteristics on the nature of burden was studied. When caregivers characteristics regressed on ZBI burden, gender (female), private employment status and total support in care found significantly associated with burden level. Family support in care was strongest predictor with 39% of the variance (Table 1).

To see the rigorous effect of personal and caregiving characteristics of caregivers on sub scales of ZBI, multiple regression analysis was computed. Socio-demographic and caregiving characteristics were entered into different sub scales of ZBI burden scale. Table 2 represents that female gender and family
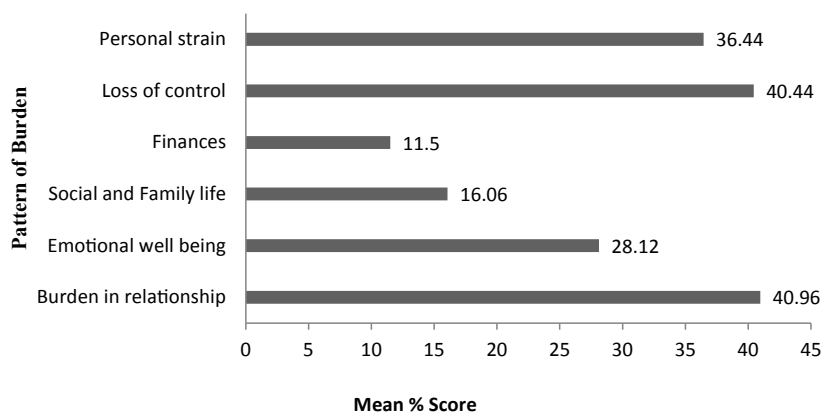
Figure 1: Mean percentage of pattern of burden in caregivers.

support in care together have highest contribution for role strain burden and social family life disturbances with a unique variation of 40.9% and 38.9% respectively. Equally, family support was also reported true predictor for personal strain types of burden with a variation of 29.6% in burden. So, we can conclude that availability of support in care is a true predictor for all domain of burden (except financial burden) in caregivers of stroke survivors.

However, to find a long term effects of predictors on burden, hierarchal regression model was built in step manner. Hierarchal regression models were built by taking in to account the problem of confounding factors and co-linearity. The best predictors with standardized coefficient and corresponding are shown in Table 3.

The contribution of availability of support in care at step 1 shows 17.1% variation in burden. Addition of caregiver as a primary earning member at step 2 explained an additional variation of 3.4% in burden and this change in R^2 was significant (F=12.524, p<0.05). Family history of stroke attachment to previous two variables explained an additional 3.9% variation in the burden and this change in R2 was also significant (F=10.317, p>0.05). This concludes that the most important predictor for burden was availability of support in care explained 17.1% variation in burden. Together all three independent variables accounted for 24.4% variations in burden (Table 3).

Quality of Life in Caregivers

Score on WHOQOL-BREF reveal that the highest quality of life score was in the social (69.91 ± 14.87) sub-scale followed by psychological (64.24 ± 12.32), environment (62.93 ± 12.16) and lowest in the physical (57.64 ± 8.36) sub-scale of quality of life (Table 4).

DISCUSSION

Caregivers have an important role in chronic and life styles related disease and stroke is one of them. Most caregivers feel burdened when caring a relative with stroke, as it has unpredictable recovery and long lasting nature. Rather than focusing on hospital confined care it is also mandatory to explore the caregiving experiences of caregivers at community level. Exploring the concept of caregiving would help in better home rehabilitation of stroke patients.

This study found varied level of burden and multiple predictors for burden in caregivers of stroke survivors. Similar steady findings evidenced in a many previous studies for higher burden in caregivers[16-18].

Table 1
Direct effects of caregiving characteristics on burden-simple linear regression.

Variables	B	Sr²	t-value	R	R^2	R²-change
Gender	5.195	0.275	2.062*			
Employment status	1.343	0.233	1.994*	0.603	0.363	0.363
Family support	8.706	0.388	3.656*			
*Note: N=100; *p<0.05, Total R=0.363 (36.3%)*						

Table 2
Summary of hierarchal regression analysis predicting burden.

Predictors	β	t	Sr²	R	R^2	R²-change
Step 1						
Support in care	8.706	3.656*	0.388	0.414	0.171	0.171
Step 2						
Caregiver as earning member	4.253	1.613*	0.192	0.453	0.205	0.034
Step 3						
Family h/o of stroke	-8.208	-1.748*	-0.208	0.494	0.244	0.039

Table 3
Predictors of burden. Multiple regression analysis.

ZBI sub scales	Predictors	B	β	t-value	R	R^2	R^2 change
Burden in relationship	Age (yrs)	0.060	-0.262	1.399*	0.551	0.303	0.303
	Employment status	0.464	-0.270	2.207*			
	H/o Stroke in family	-4.354	0.370	2.971*			
	FS	1.567	0.234	2.108*			
Emotional well being	Gender	2.103	0.291	2.189*	0.605	0.386	0.366
	Caregiver only earning member	2.101	0.282	2.380*			
	FS	2.424	0.322	3.039*			
Social and family life	Gender	1.671	0.301	2.308*	0.624	0.389	0.389
	FS	1.935	0.335	3.224*			
Finances	Caregiver only earning member	0.555	0.310	2.394*	0.495	0.245	0.245
Loss of control	FS	1.826	0.312	2.886*	0.580	0.337	0.337
Personal strain	FS	3.241	0.277	2.480*	0.544	0.296	0.296
Role strain	Gender	2.766	0.333	2.598*	0.640	0.409	0.409
	FS	2.913	0.337	3.296*			

*Note: n=100, FS-family support (total), *p<0.05, all sub scale shows variance range of 25%-40%*

Table 4
Mean and SD score on WHOQoL-BREF (n=100).

WHOQOL-BREF sub-scales	Mean ± SD
Physical	57.64 ± 08.36
Psychological	64.24 ± 12.32
Social relations	69.91 ± 14.87
Environment	62.93 ± 12.16

Present study reported that caregiver factors related to high burden score were younger age, family support, being female, employment status, and caregiver as only earning member.

It is evident that younger caregivers face more disturbances in their daily life and it is difficult for them to maintain a balance between different spheres of life[19]. Literature reported that family support in care will help to overcome exaggeration of burden[20-22]. Present study revealed that female caregivers were more burdensome as compared to male. Similarly, other previous research justify same findings that being a female caregiver, it is very difficult to maintain balance between care of patient and house hold chores[23-25]. With regards to occupation, it is reported that unemployed caregivers felt more burdensome due to insufficient earning and extra expenditure on survivor's care[24,26,27].

Not surprisingly, stroke has a wide ranging impact on caregivers, with many factors having been shown to be significantly related to caregiver quality of life. Feeling burdensome and disturbances in different spheres of life is most direct consequence of the caregiving. Quality of life is directly related to burden and more wider and indirect consequence of caregiving. Caregivers' quality of life was affected in practically all domains with mean score ranging between 57.64 ± 08.36 to 69.91 ± 14.87. Worst score for caregivers were however observed in the physical quality of life due to exaggerated caregiving burden. This findings is consistent with previous reports associated with caregivers' burden with worsening health and health related quality of life[16,19,25-32].

CONCLUSIONS

The study did not investigate a casual relationship and findings were only extrapolated based on observed association. Other limitations to the main study are small sample size and one time cross sectional

investigation had been previously noted. More importantly, attention should be placed on the physical and psychological needs of these caregivers. Appropriate handling techniques and adequate emotional support will help to improve caregivers' effectiveness in their often new caregiving roles. It is also important for all health care professionals to involve adequate teaching skills for caregivers in their educational plan to anticipate unbeaten rehabilitation of stroke patients placed on the physical and psychological needs of these caregivers. Appropriate handling techniques and adequate emotional support will help to improve caregivers' effectiveness in their often new caregiving roles. It is also important for all health care professionals to involve adequate teaching skills for caregivers in their educational plan to anticipate unbeaten rehabilitation of stroke patients.

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