



## RESEARCH ARTICLE

### BURDEN OF STROKE SURVIVORS ON CAREGIVER AND QUALITY OF LIFE

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#### ABSTRACT

**Aim:** To assess level of burden and quality of life of caregivers of stroke survivors.

**Materials and Methods:** A cross-sectional study was conducted among 120 caregivers of stroke survivors. Data were collected by demographic proforma, WHOQOL-BREF to find the quality of life and Zarit Burden Interview (ZBI) questionnaire to assess level of burden of caregivers.

**Results:** The study results revealed that the most of the caregivers were in severe level of burden. The main component of burden was relationship and emotional well-being, which was affected most. In quality of life, all the domain were equally effected, while physical domain had least scores. There was a significant negative correlation between quality of life and burden scores of caregivers.

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#### INTRODUCTION

Globally, stroke is the second most common cause of mortality and produces chronic disabilities among patients. It has been estimated that the life time risk of stroke after the age of 55 years is 1 in 6 for males and 1 in 5 for females (Seshadri et al., 2006; Sharma and Goel, 2017). Studies have reported 55-70% of stroke survivors recovers and becomes almost independent in one year whereas, 7 to 15.7% patients develops complete disabilities (Das et al., 2007). In chronic disorders data regarding incidence, prevalence, and mortality are not sufficient to estimate level of burden. According the world wide statistics from 2004 which included 192 WHO member countries, the stroke related disability-adjusted life year (DALY) loss was from 160 – 2,192 per 100,000 person-years from different countries. Same time, the stroke related DALY loss in India was 597 /100,000 person years (Banerjee et al., 2013). It was estimated that 46% of caregivers were remained under stress for 3 months of post stroke phase, and 43% caregivers were under stress for 6 months after stroke occurrence. These differences in the time duration was based on patients factors like level of disabilities, depression, deprived cognition, and recurrence of stroke (Hung et al., 2012; Almeida et al., 2012). Studies from developed and developing countries have shown that the caregiver of stroke survivors

suffers in different form such as physical, psychological, social, economic and spiritual, especially those with a higher level of disabilities, which produces an undue stress on the caregivers and results into poor quality of life (QOL) (Hung et al., 2012; McCullagh et al., 2005). It is important to identify the interaction between the characteristics of patients, caregivers and support system that determine the burden of care and quality of life (QOL). It will help to develop strategies to help the caregivers and address specific needs of caregivers (Kalra et al., 2004; Berg et al., 2005; Blake and Lincoln, 2000; Choi-Kwon et al., 2005). None of the study have been investigated in Uttarakhand to find the QOL and burden of stroke patient on caregivers. Hence, this study was conducted to determine the level of burden experienced by the caregivers of stroke survivors and, the quality of life of these caregivers, and to find the relationship between the level of burden of care and QOL. This study results may help in planning of educational strategies to maintain caregivers' quality of life and can prevent development of morbidity (Sharma, 2006).

#### MATERIALS AND METHODS

A descriptive cross-sectional study was conducted to assess the quality of life and to determine the level of burden among caregivers of stroke survivors at the Neurology outpatient department of Himalayan Hospital, Dehradun. Himalayan Hospital is a tertiary care teaching hospital located in the centre of three cities Dehradun, Haridwar and Rishikesh. It is a largest

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health care provider in the Uttarakhand state, also serves to the patients from three neighbouring states Uttara Pradesh, Himachal Pradesh and Punjab. Sample size calculation was performed based on previous study (7), assuming  $\alpha=0.05$  and  $\beta=0.10$ . The obtained sample size was 118 for the present study. In present study a purposive sampling technique was used to select participants. The inclusion criteria included healthy caregivers with the age group of 20 to 60 years old caring to stroke survivors from last one month. The caregivers, who were not willing to participate in the study, pregnant woman, suffering from medical and psychiatric condition were excluded. Consecutive 120 caregivers of stroke survivors were recruited after their informed consent. Data collection was done by researcher and the tools used to obtain information were demographic proforma, WHOQOL-BREF to collect quality of life and Zarit Burden Interview Schedule (ZBIS). Zarit Burden Interview questionnaire (Zarit and Zarit, 1990) was developed by Reever Zarit & Peterson Bach. A revised version consist of 22 items with 5 point rating scale. Each question had options range from 0 (Never) to 4 (Nearly Always). The burden score arbitrary categorized as severe burden (61-88), moderate to severe burden (41-60), mild to moderate burden (22-40), and no burden (0-21). Higher score denotes higher level of burden. The WHO QOL- BREF contains a total of 26 items. The WHO QOL-BREF instrument has four domains, physical, psychological, social and environment. Quality of life score was assessed using 26 items, categorized under 4 domains namely physical (7 items), psychological (6 items), social (3 items) and environment (8 items). Getting high score in a particular domain indicates better quality of life. Each participants were interviewed for 45 min. to 1 hour in a counselling room adjacent to Neuro OPD. The data was entered into excel sheet and transformed into SPSS. The data was analysed by using descriptive and inferential statistics. Ethical permission was taken from the Ethical Committee of Swami Rama Himalayan University.

## RESULTS

In present study a total 120 caregivers of stroke survivors included. Table 1 shows description of demographic profile of study participants, the mean age was  $46.8 \pm 12.0$  year. Gender wise ratio of female caregivers was more (60.8%) than male (39.2%). Majority of caregivers were married (88.3%), wife as relation with patient (34.2%), graduate as education (36.7%), housewife as occupation (52.5%) and family income more than Rs.10,000 per month (80.33%). Mode of payment for the treatment was done by self in 74.17% of cases, whereas 74 (61.7%) participants expressed of facing financial problem in the treatment of stroke survivors. In 54 (45%) cases, participants responded that they were providing care from past 3 to 6 months and most of 99 (82.5%) caregivers were caring round the clock to their family member. The quality of life of caregivers was computed domain wise (Table 2). The lowest mean score was in physical health ( $46.10 \pm 11.27$ ), and highest mean score in social health ( $55.66 \pm 13.32$ ) among caregivers of stroke survivors. The mean caregiver burden score was  $42.03 \pm 11.86$ . The domains of Zarit Burden Interview (ZBI) score were arranged in hierarchy wise depicted in Fig. 1. The most burden was expressed by the caregivers was burden in the relationship (49.84%), followed by emotional well-being (44.48%), role strain (42.87%), finance (42.71%), personal strain (42.28%), loss of control over one's life (36.53%). The least burden was reported by participants was social and family life (35.49%). Furthermore, data was categorised into no

burden to sever burden, only four (3.3%) caregiver expressed of no burden (0-21) while majority 68 (56.67%) of participant expressed of severe burdened while providing continuous care to stroke survivors. Pearson correlations showed a significant inverse relationship between caregiver burden and caregiver psychological and environmental domain of QOL ( $p < 0.05$ ). In physical and social domain of QOL and care giver burden scores there was a negative relationship, but the scores were not significant ( $p > 0.05$ ) (Table 3)

**Table 1. Characteristics of caregivers of stroke survivors (n=120)**

Variables	n	%
Age		
< 40 years	51	42.5
≥ 40 years	69	57.5
Gender		
• Male	47	39.2
• Female	73	60.8
Married status		
• Married	106	88.3
• Unmarried	14	11.7
Relationship with patient		
• Wife	41	34.2
• Husband	10	8.3
• Son	38	31.7
• Daughter	31	25.8
Education status		
• No formal education	23	19.2
• Below high school	19	15.8
• Intermediate	34	28.3
• Graduate or above	44	36.7
Occupation		
• Housewife	63	52.5
• Private job	21	17.5
• Government job	10	8.3
• Other	26	21.7
Family Income per month		
• ≤10,000	23	19.67
• >10,001	97	80.33
Mode of payment		
• CGHS/BHEL/ESI	31	25.83
• Self / Other	90	74.17
Financial problem faced by caregiver		
• Yes	74	61.7
• No	46	38.3
Duration of care		
• 1-3 months	25	20.83
• >3-6month	54	45.0
• > 6 months	41	34.17
Care giving time		
• Both day & night Time	99	82.5
• Day Time	6	5.0
• Night Time	15	12.5

**Table 2. WHOQOL-BREF scores of caregivers of stroke survivors (n = 120)**

Domains of Quality of Life	Mean± SD
Physical	46.10± 11.27
Psychological	51.10±13.583
Social	55.66±13.328
Environment	50.11±14.748

**Table 3. Relationship between quality of life and level of burden**

Domains of ZBI	Domains of WHOQOL-BREF			
	Physical	Psychological	Social	Environment
Burden in the relationship	-0.185*	-0.232**	-0.226**	-0.468**
Emotional well-being	-0.122	-0.175*	-0.159*	-0.209*
Social and family life	-0.013	-0.230**	-0.231**	-0.174*
Financial burden	-0.134	-0.254**	-0.212**	-0.317**
Loss of control over one's life	-0.270**	-0.354**	-0.126	-0.431**
Personal strain	-0.178*	-0.205*	-0.159*	-0.221**
Role strain	0.237**	-0.268**	-0.162*	-0.355**

\*\*p<0.01, \*p<0.05.

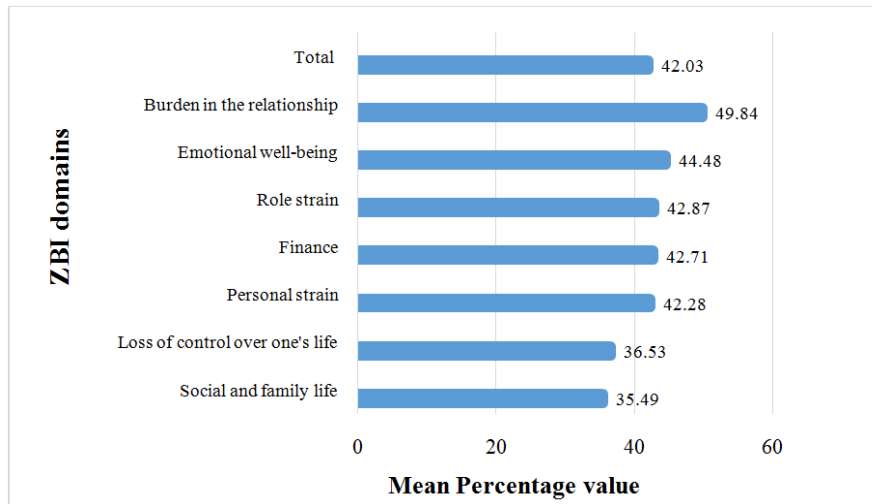


Figure 1. Level of burden experienced by caregivers of stroke survivors

## DISCUSSION

This study was aimed to assess the level of burden and quality of life of caregivers of stroke survivors and to identify the relationship between caregivers burden and caregivers QOL of stroke survivors. It is clear from the results that the caring a stroke survivors disrupts the integrity of the families and produces ill effect on the quality of life of caregivers. Developing country like India, where changes in lifestyle, aging population and urbanisation and industrialisation have contributed in more number of communicable diseases, including stroke (Dalal *et al.*, 2007). Almost one third of stroke survivors live with the family and take most of the medical care at home, which creates a lot burden on the caregivers. In India the culture of joint family exist with insufficient per capita space and many members such as grandparents, parents, spouse, and children stay together sharing infrastructural facilities. Furthermore, due to economic constrains many of patients cannot afford long term health care facilities and unwillingly has to stay at home which creates lots of burden on caregivers at home which deteriorates quality of life too. In present study use of ZBI was to find the personal and role strain aspects that referred to direct stress while caring to stroke survivors and limitations in social roles of caregivers. The finding of current study shows that the caregivers were in sever burden as the mean score of ZBI was  $42.03 \pm 11.86$ , this score is very high then the other studies (Evcı *et al.*, 2012; Rigby *et al.*, 2009; Carod-Artal *et al.*, 2009; González-Pisano *et al.*, 2009). Study from Spain (González-Pisano *et al.*, 2009), Netherlands (op Reimer *et al.*, 1998) and China (Ken *et al.*, 2010), a high level of burden was reported in 67.4%, 47.1% and 70.8% respectively. Studies have shown with multiple factors such as financial worries, emotional stress, and long care giving time duration were the key factors for burden and increasing strain among caregivers (Bhattacharjee *et al.*, 2012; Das *et al.*, 2010). The quality of life is a multiple dimension which mainly consist of physical, psychological, social and environmental health of an individual. In present study, the quality of life of caregivers were classified in each domain wise. Among all the four domain, physical health was most affected and social health was least affected. Studies results were corresponding with other studies from India (Raju *et al.*, 2012; Arathy *et al.*, 2015) and other countries (Lima *et al.*, 2014; Fatoye *et al.*, 2006). This is because of the caregivers have multiple responsibilities to deliver within the limited time, which leads to deterioration in their physical health. Most of the stroke

survivors becomes partially or completely dependent on caregiver for their hygiene need, feeding, etc. and all these activities are performed by the caregivers and gradually they neglect their own health. Physical health is synchronised with psychological health, declining in any one of them may affect other one. The same phenomenon was observed in present study. The difference in mean score of physical and psychological domain of caregivers were close. The higher mean score in social health domain corroborates a study among elderly stroke patient caregivers (67.57) (Santos *et al.*, 2012). Taking care of stroke survivors is not easy job, every caregiver has their own life, feelings and adding new responsibility disturbs their life schedule. In this condition, social help gives a great support and protection for the caregiver and makes better social health. The caregivers not only provide care but also they compromise in their own physical space for better care of stroke survivors, which affect the environmental health of caregivers. In present study all the components of ZBI had a significant negative relationship with psychological, social, environmental and physical (except with role strain) domain of quality of life of caregivers. These results were consisted with other studies (Morimoto *et al.*, 2003; White *et al.*, 2004), where high level of burden resulted in deteriorated quality of life of caregivers specially in psychological and social health domains (McCullagh *et al.*, 2005; Nelson *et al.*, 2008).

## Conclusion

In conclusion, stroke survivors as they becomes disabled partially or completely, creates a high level of burden among caregivers. This burden gradually produces a negative effects on the quality of life of caregivers. Hence, it is necessary for the health care professionals, along with stroke survivors, caregivers must be taken care in terms of training about home care management of stroke survivors.

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