

Impacts of Burden on Use of Coping Styles among Stroke Caregivers

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Abstract

Introduction: Stroke is a family disease and prevalent cause of disability cause in developing country including India. After discharge from the hospital, the caregivers will take over the responsibility to look after their patient. Debilitating and chronic nature of stroke often put strain and stress on the caregivers, which threaten the rehabilitation of the stroke patients. The study aimed to find out the impact of burden on coping styles and caregivers' characteristics on burden in caregivers of stroke survivors. **Methods:** A cross sectional descriptive survey was carried out by recruiting 100 caregivers purposively in selected rural community setting Punjab, India. Coping Checklist (CCL) and Zarit Burden Interview (ZBI) schedule was used to determine coping styles and burden in caregivers. Relevant inferential statistics was applied to compute results. **Results:** Findings show that burden and negative coping strategies are dependent on each others. However, positive coping strategies also show a significant positive relationship with burden in relationship aspects. Family history of stroke, education status of caregiver, availability of support in care and duration of care had direct impact on perceived burden in caregivers of stroke patients. **Conclusion:** Use of coping strategies depends on severity and nature of burden in caregivers of stroke survivors. In fact, adoption of coping strategies depends on severity of burden. Study recommend to plan and implement hospital based training program for the caregivers to teach different aspects of home based care in order to decrease caregiving burden and maintain long term quality of life among caregivers.

Keywords: Caregiver, burden, coping, stroke

Introduction

Sudden attack, long term nature and disability in stroke survivors have long lasting impacts on entire family system. Change in health care paradigm from curative to preventive shift the responsibility of caring of a stroke patient from health professionals to the immediate family members and friends who are completely untrained and new to this unavoidable job¹. Family caregivers play an enormous role in taking care of their loved one at home. The sudden and unpredictable onset of stroke gives no time to think, prepare and adjust to the caregivers to their new roles and responsibility to take care their patient. Indeed, short of information, lack of training and guidance to caregivers to look after their patient predispose the caregiver task more complicated and left the caregivers to their own².

Caregiving is an unwelcome job that can encompass 365 days in a year, 24 hours in a day; 7 days in a week, with no holiday, vacation, sick leave, rewards and praise³, which put caregivers at more risk of exposure to strain and burden. This burden could be in the form of physical and psychological problems, financial crisis, disturbed relationship and many other forms⁴. Likewise, hospitalization also exert burden on caregivers in the form of unwanted go away from job, financial crisis, disorganization of family system, and feeling bound to perform certain task. Research on burden in caregivers becomes area of interest in health care system since few years⁵.

Furthermore, long term involvement in care can result in sleep problem, change in eating pattern, indigestion, and impair immune system in the caregivers⁶. Therefore, it is evident that caring task is stressful and burdensome and may result many health problems, such as heart disease, hypertension, peptic ulcer, mood changes, weight loss, problem in concentration at work place and suicidal ideas time to time⁷. Likewise, it is been reported

¹ Simon C, Kumar S, Kendrick T. Chart study of informal cares of first time stroke survivors: Profile of health and social changes in the first year of caregiving. *Social and medicine* 2009;694:404-10

² Das SK, Banarjee TK, Biswa A, Roy T et al. A prospective community based study of stroke in Kolkata, India. *Stroke* 2007;645:645-64

³ Greven C. Prespective: Caring for the caregiver. *OT practice* 2007;12(6):25-6

⁴ Sorensen S, Duberstein P, Gill D, Pinquart M. Dementia care: mental health effect, intervention strategies, and clinical implications. *Lancet Neuro* 2006;5:961-73

⁵ Cardo-Artal, Egado-Navarro JA, Gonzalez-Gutierrez JL, Varela de Seijas E. Perception of long term overload in caregivers of patients who have survived a stroke. *Rev Neurol* 199 1999;28:1130-38

⁶ Barlow DH, Durand VM,. *Abnormal psychology* (2nd Ed.), USA: Rooks/Cole Publishing Company. 1999.

⁷ White CL, Lauzon S, Yaffee MJ, & Wood-Dauphinee S. Toward a model of quality of life for family caregivers of stroke survivors. *Rev Lat Am Enfermagem* 2004;12(1):115-21

that caregivers of patients with neurological problems face more burden as compared to other physical diseases¹.

A person's natural reaction to what he or she is exposing is known as 'coping styles'². Coping styles are the ways used by individual to tolerate or bear the disturbances in physical, psychological, emotional and financial areas. Individual caregivers cope to this new situation in their own way and try to use their own either used or invent new coping styles. It has been seen that at early stage of caregiving, caregivers deal positively and try to improve upon the situation by optimistic thoughts that stroke patient will improve, and still have realistic expectations on the patients' level of recovery³. Although, it is obvious for caregivers feel helpless and uncertain initially for new caregiving task.

Coping helps to maintain and regulate emotions, and strain by findings new alternative or by bringing change in the existing ways of problem solving. Coping used to change and depend on the situation time to time. Further, it is also evidenced that emotion coping styles are more used in case of long term stagnant situation such as no improvement in patient condition or deteriorating the symptoms etc⁴. However, the central functions of coping is to prepare an individual to cope with stressful situation. Excessive use of emotion coping strategies indicate poor adaptation to the stress or confront the situation, however, a blend of coping strategies may come across simultaneously to work together and handle the stressful situation more efficiently⁵. Similarly, family members taking care of the patients with neurological problems used different coping styles than dealing with a patient with physical disability⁶.

Therefore, thus we aimed present study to find an impact of burden on coping styles and impact of different caregivers' characteristics on burden among caregivers of stroke survivors.

Material & Methods

100 caregivers of stroke patients were selected purposively from conveniently selected rural community setting, Punjab India. Caregivers who found healthy and more than 18 years of age and involve in direct care for more than one month after discharge of the patient from the hospital, were included in the study. However, pregnant and caregivers with history of severe medical and psychiatric disease were excluded from the study. A self structured information data sheet was used to collect personal and caregiving characteristics of the caregivers.

Zarit Burden Interview Schedule (ZBIS)⁷ It is 22 items 5 point Likert rating scale. These 22 items further categorized in seven sub-areas namely; '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 Coping Checklist (CCL)⁸ It is a comprehensive list of 70 items which are further divided in 3 broad types of coping styles with their sub areas; problem focused (problem solving, 10 items), emotion focused (distraction positive 14 items, distraction negative 9 items, acceptance 11 items, religion/faith 9 items, denial/blame 11 items, and problem and emotion focused (social support, 6 items). Subjects had to answer items in the form of yes or no. Obtaining higher score in a particular area indicates greater use of that individual coping styles. The checklist was translated to Punjabi language in the interest of the rural population with the help of experts in Punjabi language. The validation also sought with the help of experts in the field of nursing and psychiatry. The validity was confirmed from experts in the field of psychiatry, and psychology. The reliability was calculated by application of test-retest method and it came out 0.71 for this study. A prior permission was obtained to use the tool.

¹ Thommessen B, Aarland D, Braekhus A, Oksengaard AR, Engedal K, & Laake K. The psychosocial burden on the spouse of the elderly with stroke, dementia and Parkinson's disease. *Int J Geriatr Psychiatry* 2002;17:78-84

² Skinner EA, Edge K, Altman J & Sherwood H. Searching for the structure of coping: a review and critique of category system for classifying ways of coping. *Psychol Bull* 2000;129(2):216-69

³ Visser -Meily JMA, Post MWM, Riphagen II, & Lindeman E: Measures used to assess burden among caregivers of stroke patients: a review. *Clin Rehabil* 2004;18:601-23

⁴ Folkman S & Lazarus RS. An analysis of coping in a middle-aged community sample. *Journal of health and social behaviour* 1980;21(3):219-39

⁵ Carver CS & Scheier MF. Situational coping and coping disposition in a stressful Transaction. *Journal of personality and social psychology* 1994;66(1):184-95

⁶ May LR, Thompson A. Supporting family caregivers in stroke care. A review of the evidence for problem solving. (2nd Ed.) Churchill Livingstone: New York 2005;983

⁷ Zarit SH, Zarit JM. The memory and behaviour problem checklist and the burden interview-Penn state Gerontology center, University park;1983

⁸ Rao K, Subbakrishna DK, & Prabhu GG. Development of coping checklist - A preliminary report. *Indian journal of psychiatry* 1989; 31(2):128-33.

Ethical consideration

A brief research proposal was put before the Ethical Committee for ethical approval. The study was approved with wide letter no. 140/Surg/13 after discussing varied ethical principles, including privacy and confidentiality. Investigators also kept in mind other ethical issues during and after data collection. After explaining the study objectives, a written informed consent was also taken from the caregivers. Subjects were given full freedom to withdraw from study at any point of time. However, the reason for non-participation was ascertained.

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 unbiased details. Caregivers were visited at their home during their free time and it took around 20-25 minutes to furnish the asked details.

Results

A small part of study is already published for socio-demographic and caregiving characteristics of the caregivers¹. Table 1 represents the direct relationship of burden on adopted coping strategies by the caregivers of stroke survivors. Findings show that there is no direct relationship between burden and adopted coping strategies in caregivers. However, burden in the form of disturbed relationship subscales shows a statistical positive relationship with use of problem and emotion focused coping strategies. It can be interpreted that caregivers who had more disturbances in relationship maintenance use more emotional and problem focused coping strategies as compared to less disturbance in relationship maintenance.

Table 1. Relationship between burden and coping strategies (n=100)

ZBI sub scales	Coping	Problem focused	Emotion focused	Problem & Emotion focused
Burden	.150	.109	.130	.109
Burden in relationship	.267**	.166	.219**	.285**
Emotional wellbeing	.104	.062	.098	.060
Social & family life	.064	.086	.056	.001
Finance	.104	.109	.087	.053
Loss of control	-.012	-.003	-.009	.019
Personal strain	.173	.081	.155	.159
Role strain	.180	.163	.157	.087

Note= *p<.05; **p value<.001

Data in table 2 represent relationships between various sub-scales of ZBI and CCL. Results show that denial coping strategy had significant relationship burden in all sub scale of ZBI scale. However, social support and acceptance also had significant positive relationship with burden in relationship aspects of ZBI. It can be interpreted that increases in burden simultaneously enable the caregivers to use more denial coping strategy and use of more social support and more acceptable attitude towards problem.

Table 2. Relationship between sub scales of ZBI and CCL (n=100)

ZBI sub scales	1	2	3	4	5	6	7
Burden	.109	-.057	-.020	.011	-.057	.504**	.109
Burden in relationship	.109	.166	.026	.224*	-.091	.351**	.285**
Emotional wellbeing	.062	-.028	-.085	-.064	.040	.395**	.060
Social & family life	.086	-.027	-.070	-.193	.008	.434**	-.001
Finance	.109	.002	-.036	-.094	.023	.335**	.053
Loss of control	-.003	-.164	-.105	-.039	-.089	.410**	-.019
Personal strain	.081	-.036	.002	.127	-.080	.436**	.159
Role strain	.163	.048	.021	-.154	.055	.453**	.087

Note= *p<.05; **p value<.001; ZBI=Zarit Burden Interview; CCL=Coping Checklist;1= Problem solving; 2= Distraction positive;3= Distraction negative;4= Acceptance;5= Religion;6= Denial;7= Social support

Table 3 represents the impact of caregivers' characteristics on burden level. Findings revealed that past family history of stroke, secondary education status of caregiver, availability of family and relatives support in care and providing care for short interval in a day had direct impact on perceived burden in caregivers of stroke patients. It can be interpreted that caregiver with history of stroke experience more burden as compared to those who did not have family history of stroke. Similarly, caregivers who were educated up to secondary education and

¹ Kumar R, Kaur S, & Reddemma K. Pattern of burden and quality of life among caregivers of stroke survivors. Int J Health Sci Res. 2015;5(4):208-14

informal education found more burdened as compared to primary and higher secondary school educated caregivers. However, caregivers who were providing care for short duration was found more burdensome as compared to caregivers who providing care for long time in a day. Caregivers who were had total support in care were less burdensome as compared to caregivers who did not had support in care.

Table 3. Association of caregivers' characteristics with burden (N=100)

Caregivers' variables	Mean±SD	t /F-value	p-value
History of stroke in family			
Yes	38.00±15.12	2.724 ^a	0.008*
No	27.52±09.18		
Education status			
Informal education	30.14±06.14	2.633 ^b	0.039*
Primary	26.84±08.43		
Secondary	35.00±12.55		
Higher secondary	25.11±09.73		
Graduate & above	27.65±14.04		
Caregiving total time (hrs/day)			
<10	34.17±12.54	2.599 ^a	0.011*
>10	27.09±09.98		
Availability of support			
Total**	26.77±09.06	10.216 ^b	0.000*
Partial	36.40±11.54		
None	47.00±20.85		

*=significant @ $p < 0.05$; a=independent sample -test; b=one way ANOVA;
 Total**-psychological, financial, social & emotional support

Discussion

Stroke is major public health problem and affects both patient and family member who involves in care and support. Long term and sudden unexpected nature of stroke forces family member suddenly in to caregiving process and experience an irresistible sense of strain and burden. Caregivers feel strained while providing care due to uncertainties in care, progress, and outcome in their loved one. Subsequently, disturbed psychological health compel caregivers to use wide variety of coping styles in order to maintain good health to provide round the clock care to their loved one.

Present study findings reported that overall coping and burden are independent to each other and burden do not have direct influence on adoption of coping styles in caregivers of stroke survivors. Still, certain areas of burden had direct influence on selection and use of negative coping styles in caregivers, which is consistent with the findings by Boerboom W et al (2014) that palliative and passive coping styles are more related to higher burden, depression and higher dissatisfaction. Further, findings also found consistent with the findings of the study conducted by Visser-Meily A (2009) which reported that use of passive coping styles is more related to negative outcomes, whereas an active coping styles related to positive outcomes¹.

Similarly, it is been further reported in a study conducted by Ma HP et al (2014) on caregivers of spinal cord injury patients that negative coping styles are more directly related to higher burden in caregivers and vice-versa². Likewise, negative coping styles had positive relationship with role burden in caregivers¹⁵. These findings are in accordance with the findings of a study conducted by Kumar R et al (2012)³, which reported that use of denial is increased as the level of different types of burden increased in caregivers. A close consistent and similar finding reported in a study conducted by Ma HP et al (2014)¹⁵ which reported that increase burden enables caregiver to use more negative coping styles. It can be understood that increase level of burden decrease the reality acceptance in caregivers due to impact on quality of life, especially psychological and cognitive one. Study also emphasized that burden in the form of disturbed relationship compel caregivers to opt out more emotional and problem solving coping strategies as well. It

Further, findings represent that certain caregivers' characteristics had direct impact on the burden level. Similar and consistent result found in previous research which reported that duration of illness of patient,

¹ Visser-Meily A, Post M, van de port I, Mass C, Forstberg-Warleby G, Linderman E. Psychosocial functioning of spouses of patient with stroke from initial inpatient rehabilitation to 3 years post stroke: course and relations with coping strategies. Stroke 2009;40:1399-04

² Ma HP, Hui-Juin Lu, Xiong XY, Yao JY, Yang Z. The investigation of care burden and coping styles in caregivers of spinal cord injury patients. international journal of nursing sciences 2014;1:185-90

³ Kumar & Saini R. Extent of burden and coping strategies among caregivers of mentally ill patients. Nursing and midwifery research journal 2018;8(4):274-84

caregiving total time, occupation status, relationship with patient (Da Costa TF et al 2015; Chakrabarti S et al,1995)^{1,2}are significantly associated with the amount of burden perceived by caregivers. Similarly, it is also reported in many studies (Chow KS et al 2009; Dalwandi A et al 2010) conducted on caregivers of stroke survivors that amount of social support^{3,4} and total time of caregiving (Watanabe A et al 2015; Vincent C 2009)^{5,6} found a statistically significant relationship with extent of burden. Similarly, congruent findings reported that total caregiving time, and use of necessary support services had significant relationship with extent of burden^{20,7} (Watanabe A et al 2015; Begum S 2014).

Conclusion

Stroke can have disabling effects not only on stroke survivors but also on family members and country as whole. Coping is an important personality traits enable a human to outweigh the health hazards in order to maintain good health and prosperity. Caregivers go for negative coping styles as the burden level increased in order to maintain harmony in different sphere of the life and better quality of life. However, a tolerable level of burden enables the caregivers to adopt positive and healthy coping styles and vice-versa.

Recommendations

It is noted that developing country like India have inadequate provision and uses of support services for caregivers are contributory factors to increased caregiver burden. This level of burden is further multiplied by the sudden nature of stroke and lack of preparedness of the caregiver to look after their loved one. Therefore, it is very important for the health professionals to take an initiative to train caregiver before discharge and ensure preparedness for a successful home rehabilitation. Adequate training and instruction to caregivers will have a great influence on stroke patient's rehabilitation outcomes.

Limitations

The present study was a modest attempt to determine the relationships between coping styles and burden and study the impact of caregiving characteristics on burden in caregivers. Still, the study should be seen under certain limitations like small sample size, one time cross sectional survey and use of purposive sampling may infuse bias in the findings, which could impede generalization of the findings on larger population. However, the study findings should be considered preliminary in this area.

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Conflict of Interest- NIL

Source of Funding- Self

Ethical Permission- Yes

¹ Da Costa TF, Macedo Costa, Fernandes M, Martin PK, Silmery da SB. Quality of life of caregivers for patient of cerebrovascular accidents: association of (socio-demographic) characteristics and burden. *Rev Esc Enferm USP* 2015;49(2):243-50

² Chakrabarti S, Kulhara P, Avasthi A & Verma S. Comparison of the extent and pattern of family burden among affective disorder and schizophrenia. *Indian journal of psychiatry* 1999;37(3):105-12

³ Chow Kwon S, Mithcell PM, Veith R, Teri L, Buzaitis , & Cain KE et al. Comparing perceived burden for Korea and American informal caregivers of stroke patients. *PMC* 2009;34(4):141

⁴ Dalwandi A, Heikkila K, Maddah SSB, Khankeh HR & Ekman SL. Life experiences after stroke Iranian stroke patients. *International nursing review* 2010;57:247-53

⁵ Vincent C, Desrosiers J, Landreville, Demers L & The BRAD group. Burden of caregivers of people with stroke-Evaluation and predictions. *Cerebrovascular disease* 2009;27:456-61

⁶ Watanabe A, Fukuda M, Suzuki M, Kawaguchi T, Habata T, & Akutsu T & Kanda T. Factors decreasing caregiver burden to allow patients with cerebrovascular disease to continue in long-term home care. *journal of stroke and cerebrovascular diseases* 2015;24(2):424-30

⁷ Begum S. Level of caregiver burden: a study on caregivers of stroke patients at CRP in Bangladesh. Unpublished Thesis for the subject RESEARCH 2 & 3 and partial fulfillment of the requirement for degree: Bachelor of Science in Occupational Therapy Bangladesh Health Professional Institute (BHPI) Faculty of Medicine, University of Dhaka 2014