



Original Research Article

Pattern of Burden and Quality of Life among Caregivers of Stroke Survivors

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ABSTRACT

Introduction: stroke is a major cause of morbidity and mortality worldwide. Caring for stroke patients leads to caregiver's strain and decrease quality of life. The aim of this study is to assess extent and pattern of burden and health related quality of life among caregivers of stroke survivors.

Methods: in a prospective cross sectional community based survey, 100 caregivers of stroke survivors were identified purposively over a period of 9 months. Zarit Burden Interview Schedule (ZBI) was used to assess burden and World Health Organization Quality of Life scale (WHOQOL-BREF) was used to measure health related quality of life among informal caregivers of stroke.

Results: caregivers reported higher level of burden in the form of disturbed personal relationship (40.96%) and loss of control in life (40.44%). Increased caregiver burden was significantly related to worsening health related quality of life, particularly physical health.

Conclusion: findings indicate that increased burden significantly related to poor health related quality of life. Similar studies with uniform methodologies would help to identify factors responsible for major burden. Integrate rehabilitation services should address burden issues to policy makers to devise and include practical training and counseling services for caregivers of stroke survivors.

Key Words: Burden, Quality of Life, Stroke, Caregiver

INTRODUCTION

Stroke remains one of the major chronic illnesses worldwide that health care organization will need to address for coming decades. ^[1] Stroke is a disease of high incidence and high mortality and morbidity. ^[2] Currently 90% of the survivors of stroke develop some kind of disability, making it a leading cause of chronic disability in adults. ^[3]

Stroke not only affect patient but also their family members that may subsequently affect the recovery of stroke

survivors. Unlike other life style related disease, the onset of stroke is rapid, leaving the family and survivors ill prepared to deal problems at home. After stroke, approximately 35-45 % of patients become totally or partially dependent on family members to meet their basic activity of daily living (ADLs). ^[4] It is been reported that 80% of the patients become dependent to their family members for daily needs. ^[5] Recent years have seen increasing awareness of the role of caregivers in the rehabilitation of stroke patients and realized

that informal caregivers are the backbone of rehabilitative services for stroke patients. [6]

Stroke is a family disease and affects the life of survivors and has an impact on multiple aspects of life of their caregivers. Studies have shown that caring a stroke patient at home, especially those with disabilities, have an undue strain on caregivers, termed as 'burden'. [7] Increase level of burden may threaten sustainability of home care and the recovery of the stroke patients. A longitudinal study shows that 46% & 43% of caregivers were under strain at 3 month and 6 month after the stroke respectively. [4] Stroke is considered the leading cause of disability and reduced quality of life in caregivers.

According to World Health Organization (WHO), the quality of life is defined as, "an individual is perception of their position in life in the cultural context and in the value system in which they live and in relation to their goals, expectation, concerns and desires". [8] Since a long time it is evidenced that increased caregivers burden lead to compromised health related quality of life, particularly among stroke and chronically ill patients caregivers. [9] In a study using the WHOQOL-BREF instrument, it is seen that quality of life of caregivers were significantly reduced in social and environmental domain after discharge of patient from hospital. [10]

Another related study of QoL of caregivers of stroke patients reported that caregivers had the lowest mean scores for quality of life as compared to general public. [11] Similar studies also reported that increase burden is significantly related to worsening quality of life in caregivers of stroke patients. [12,13]

So, it emphasizes the need to assess burden and the quality of life among caregivers of stroke survivors. This study was aimed at determining the level of burden experienced by the informal

caregivers of stroke survivors, and the QoL of these caregivers, and the relationship between the level of burden of care and QoL.

MATERIALS AND METHODS

The study was conducted in the month of April 2014 to January 2015 at conveniently selected community settings of districts Ludhiana and Amritsar, Punjab. The study population comprised of 100 caregivers of survivors of stroke. Inclusion criteria included healthy caregivers aged more than 18 years or more, staying with patient and are involved in the direct care of the patient for at least one month after getting discharge from the hospital. The caregivers, who refused to participate in the study and having chronic psychiatric and medical conditions, were excluded from the study. The caregivers who were coming for follow up along with the patient were interviewed in the hospital. Others were contacted in their home care settings only. Finally, 60 caregivers were interviewed at hospital and remaining 40 caregivers were at their home settings. The tools used for the study were Information Data Sheet, Zarit Burden Interview Schedule (ZBIS), and World Health Organization Quality of Life BREF Scale (WHOQOL-BREF). The permissions for using the tools were sought from each concerned authority.

Information Data Sheet: It consisted of socio-demographic information of the caregivers i.e. age, gender, education, occupation, marital status; relationship with patient, time of care giving, duration of providing care to patient (in months/years), family type, total caregiving time (hours/day), self-reported income, availability of sub/secondary caregivers, self-reported health status, caregiver as the primary earning member of family, helps in activity of daily living of patient, past caregiving experience, family history of

stroke, type of accommodation, availability of financial, social, psychological and other family support and total number of family members.

Zarit Burden Interview Schedule (ZBIS)- It is designed by Steven H Zarit ^[14] (USA), to reflect the stresses experienced by caregivers of disabled patients. It is 5 point Likert rating scale ranging from never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4). 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). Getting high score in a particular domain indicates higher burden. The calculated value of Cronbach alpha was 0.92 for the current study.

The World Health Organization Quality of Life (WHOQoL BREF): WHO has devised this questionnaire to measure health related quality of life (HRQoL). ^[8] The questionnaire consists of 26 items categorized under 4 domains namely Physical (7 items), Psychological (6 items), Social relationship (3 items), and Environment (8 items). Obtaining higher score on domains indicate good quality of life and vice versa. The calculated value of Cronbach alpha was 0.81 for the study.

The permission for data collection was obtained from the competent authorities in the Institutes. After screening the subjects as per the inclusion and exclusion criteria, an informed written consent was obtained from them. After filling the demographic profile sheet, ZBI to assess the extent of burden experienced by them due to patient's illness, and WHOQoL-BREF to determine health related quality of life (HRQOL). In the hospital, the caregivers were interviewed in a separate room in outpatient department at SGRD hospital and at home setting, caregivers were asked to sit at a comfortable

place like rest room that was far away from the patient to avoid any distraction in findings. It took around 1-1.5 hours to conduct one interview. The data was then transferred into SPSS 20.0 Evaluation Version and was analyzed using descriptive and inferential statistics.

Ethical Consideration

The study was approved by the Ethics Committee (EC) of Sri Guru Ram Dass Institute of Medical Sciences and Research Centre (SGRDISMR), Amritsar Punjab India (letter no. 140/Surg/13). Participation in the study was voluntary and each participant was informed that their decision to participate or not, would in no way not affect his/her patient's routine care. Anonymity and confidentiality of the subjects was maintained during the study and they were given full autonomy to withdraw from the study at any time.

RESULTS

The mean age of caregivers was 41.79 years (SD± 14.12, range 21-79). It was observed that 55 % were males, studied up to secondary education (56%), and higher secondary education (27%) and were married (86 %). In term of employment, around 37% of caregivers were housewife followed by 21% working in private sector, and 7% in government sector and earning more than Rs 10,000 per month (71%). Majority of caregivers have their own (98%) accommodation and staying in joint family (56%) with five or more than 5 members (71%) in the family. (Table 1)

In term of caregiving, 30% caregivers were son, followed by 25% wife and 12% were as daughter in law, providing care round the clock (58%) with duration of 2.68±1.89 months. 94% of caregivers reported availability of another caregivers at home to take care of patient and were found healthy (85%).

Table 1. Characteristics of Family Caregivers (n=100)

Variables	Mean ± SD	n (%)
Age (in years)	41.79±14.12, Range = 21-79	
Gender		
Male		55(55.0)
Female		45(45.0)
Education Status		
Up to Secondary		56(56.0)
Higher Secondary		27(27.0)
Graduate and above		17(17.0)
Employment Status		
Govt. Employed		07(07.0)
Private employed		21(21.0)
House wife		37 (37.0)
Student		06(06.0)
Farmer		14(14.0)
Others*		15(15.0)
Marital Status		
Married		86(86.0)
Unmarried		14(14.0)
Family Type		
Nuclear		41(41.0)
Joint		56(56.0)
Extended		03(03.0)
Accommodation type		
Own		98(98.0)
Others**		02(02.0)
Family Income (Rs/month)		
<10,000		29(29.0)
>10,001		71(71.0)

*Others- shopkeeper, self employment, retired, laborer, own business

**Others- PG accommodation and rented accommodation

Table 2. Status of Caregivers' Involvement in care of stroke survivors (n=100)

Variables	n (%)
Relationship with patient	
Wife	25(25.0)
Husband	08 (08.0)
Daughter	06(06.0)
Daughter in-law/son in-law	12(12.0)
Son	30(30.0)
Others*	19 (19.0)
Health Status	
Healthy	85(85.0)
Unhealthy	12(12.0)
Never Checked	03(03.0)
Caregiving Time	
Round the clock	58(58.0)
Day time	28(28.0)
Night times	14(14.0)
Duration of care (Months) Mean ±SD	2.68±1.89
Caregiving total time (Hrs/day)	16.60±6.60
Sub caregiver availability	94(94.0)
Caregiver as primary earning member in family Availability of family support**	37(37.0)
Total	86(86.0)
Partial	10(10.0)
None	04(4.0)
Help in ADLs	94(94.0)
Family history of Stroke	08(8.0)
Past Caregiving Experience	19(19.0)

* Others-grandson, granddaughter, siblings

**Family Support-psychological, social, financial and emotional

Data also reveals that 37% of the caregivers were primary earning member in family and helps (94%) in activity of basic daily living (ADLs). Family history of stroke was reported by 8% of the caregivers and approximately 19% mentioned the experience of caregiving in the past. Majority of caregivers (86%) agreed for availability of family support in the care of their patients. (Table 2)

Pattern of Burden

The mean burden score was 28.36±10.77. The pattern of burden experienced by the caregivers under each domain shows that caregivers felt more 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%). Financial problem was least (11.5%) reported constrained in management of patient by informal caregivers. (Figure 1)

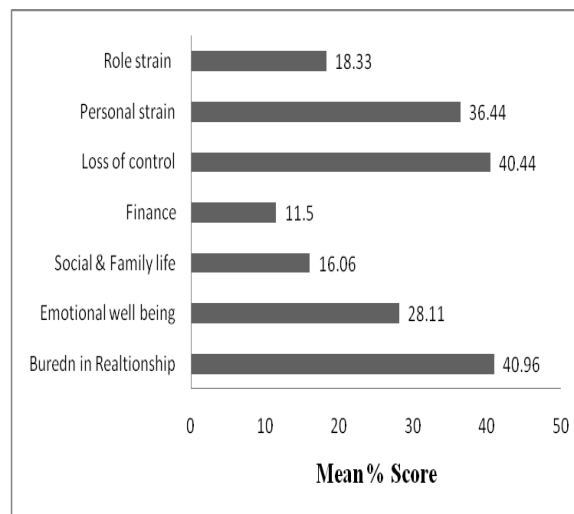


Figure 1. Burden reported by caregivers

Health-related quality of life

Table 3 refers to first two questions of the WHOQOL-BREF, related to overall quality of life. Table 3 also refers to the mean score for each domain of the WHOQOL-BREF and the general quality of

life for caregivers of stroke survivors. Regarding domain wise quality of life, the caregivers with stroke have higher score on social relations domain (69.91±14.87) followed by environment (62.93±12.16), psychological (64.24±12.32) and physical domain (57.64±8.36), suggested a good perception of quality of life.

Table 3. Distribution of mean scores and standard deviations of Question 1 & 2 and domains of WHOQOL-BREF for caregivers (n=100)

Question 1 & 2 and domains	Caregivers (n=100) Mean±SD
1) How would you rate your quality of life?	70.25±20.93
2) How satisfied are you with your health?	70.50±21.72
Physical	57.64±8.36
Psychological	64.24±12.32
Social relations	69.91±14.87
Environment	62.93±12.16

Hierarchical multiple correlation analysis

Correlation was performed to examine relationship between quality of life and level of burden in caregivers of stroke survivors. Results reveal that higher level of burden is negatively associated with physical ($r = -0.062$, $p < 0.01$), psychological ($r = -0.218$, $p < 0.01$), environment ($r = -0.358$, $p < 0.01$) and social relation ($r = -0.371$, $p < 0.01$) domain of quality of life.

In addition, the relationship between quality of life and burden by spearman's correlation showed that caregivers' quality of life was dependent on level of burden. (Table 4)

Table 4. Relationship between burden and quality of life (n=100)

ZBI Domains	WHOQOL-BREF			
	Physical	Psychological	Social relation	Environment
Burden in relation	-.039	-.023	-.197*	-.091
Emotional well being	-.091	-.206*	-.304**	-.250*
Social & family life	-.115	-.303**	-.422**	-.371**
Finances	-.052	-.334**	-.233*	-.264**
Loss of control	-.041	-.227*	-.307**	-.391**
Personal strain	-.049	-.106	-.232*	-.223*
Role strain	-.117	-.257**	-.375**	-.320**
ZBI Total	-.062	-.218*	-.371**	-.358**

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

DISCUSSION

The aim of this study is to gain a better understanding of extent and pattern of burden among informal caregivers and as well as relationship between burden and health related quality of life of informal caregivers of stroke patients. The burden suffered by informal caregivers in the course of taking care of stroke patients evidenced high burden in the form of disturbed relationship and loss of control in life. Findings from the caregiver burden replicate previous findings in the literature which reported that certain types of caregiving tasks exacerbate burden, specifically, caregivers who assist care recipients with activities of daily living and/or care for person with behavioral problems. [15,16]

Consistent with the previous research, a higher burden was reported in different aspects of burden on caregivers involved in stroke patient care.

The quality of life according to WHOQOL-BREF, the physical domain (57.64) was most affected domain in the quality of life of informal caregivers followed by environment (62.93), psychological (64.24), and social domain (69.91). Poor physical quality of life in the caregivers of stroke survivors point out that with the occurrence of stroke, the caregivers start to have limitations and/or on all its functionality and performance of activities. The individual who has suffered a stroke and start to necessitate a caregiver presents a decrease of its autonomy.

Previous research on neurological patients shows consistent findings which reported a lower mean score in the physical domain (38.83) followed by psychological (50.76), social (49.13) and environment domain (48.53). [10,17,18]

In our study, increased burden found significantly related to worsening health related quality of life. Many studies [9,19-25] reported consistent findings as evident in the study for negative relationship between burden and health related quality of life, suggested that increased burden of daily care may have a harmful impact on the quality of life of informal caregivers.

CONCLUSION

In general, it was found that the caregivers had higher level of caregiving burden and poor health related quality of life. Attention to the treatment of depression, and rehabilitation for disability among the patient has the potential to improve caregiver health related quality of life. The findings support the call for a specific targeted intervention (i.e. telestroke, home based rehabilitation, telephone service) and specific psychosocial programme for caregivers to enhancing their quality of life and caregiving role. This study finding may be useful for policy makers in relation to family and medical-social issues of stroke home based rehabilitation.

Limitations

The data in the present study may be subject to selection bias as the respondents were purposively selected. In order to make findings generalizable, a large geographical area based study based on random sampling technique will be recommended to assess pattern of burden and quality of life. Finally, we acknowledge the limitation of our study sample and of cross sectional analysis with respect to temporal relationship and imputation of causality of study findings.

Conflict of Interest- Nil

REFERENCES

1. Patel MD, McKewitt C, Lawrence E, Rudd AG, Wolfe CDA. Clinical determinants of long term quality of life after stroke. *Age and aging* 2007; 36:316-22.
2. Chagas NR, Monieiro ARM. Educacao em saude e familia: o cuidado ao paciente, vitima de acidente vascular cerebral. *Acta Sci Health Sci* 2004; 26(1):193-204
3. Makiyama TY, Battistella LR, Litvoc J, Martins LC. Estudo sobre a qualidade de vida de pacientes hemiplegicos por acidente vascular cerebral e de seus cuidadores. *Acta Fisiatr* 2004; 11:106-9
4. Chiu L, Shyu WC & Chen TRA. Cost effectiveness analysis of home care and community based nursing homes for stroke patients and their families. *Journal of Advanced Nursing* 1997;26(5): 872-8
5. Han B, Haley WE. Family caregiving for patient with stroke: Review and analysis. *Stroke* 1999;30:1478-85
6. Anderson CS, Linto J, Stewart-Wynne EG. A population based assessment of the impact and burden of caregiving for long term stroke survivors. *Stroke* 1995;26:843-9
7. Hung JW, Huang YC, Chen JH, Liao LN, Lin CJ, Chuo CY, et al. Factors associated with strain in informal caregivers of stroke patients. *Chang Gung Med J* 2012; 35:392-01
8. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. *Soc Sci Med* 1995;41(10):1403-09
9. Morimoto T, Schreiner AS, Asano H. Caregiver burden and health related quality of life among Japanese stroke Caregivers. *Age and Aging* 2003;32(2):218-3
10. Adams C. Quality of life for caregivers and stroke survivors in the immediate discharge period. *Appl Nurse Res* 2003;16(2):126-30

11. Lima MLD, Santos JLF, Sawada NO, Lia LAPD. Quality of life of individual with stroke and their caregivers in a city of Triangulo Mineiro. *Bras Epidemiol* 2014;453-64
12. Hughes SL, Giobbie –Hurder A, Weaver FM, Kubal JD, Henderson W. Relationship between caregiver burden and health related quality of life. *Gerontologist* 1999;39:534-45
13. George LK, % Gwyther LP. Caregiver well being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist* 1986;26:253-259
14. Zari SH, Zarit JM. The memory and behaviour problems checklist and the burden interview- University Park, PA: Penn State Gerontology Centre, 1990
15. Gottlieb BH, Kelloway EK & Fraboni M. Aspects of elder care that place employees at risk. *The Gerontologist* 1994; 34:815-21
16. Rankin D. Haut MW, Keefover RW, & Franzen MD. The establishment of clinical cutoffs in measuring caregiver burden in dementia. *The Gerontologist* 1994;34:828-32
17. Carod –Artal FJ, Egido –Navarro JA, Gonzalez-Gutierrez JL, Varela de Seijas E. Perception of long term overload in caregivers of patient who have survived a stroke. *Rev Neurol* 199;28:1130-8
18. Bugge C, Alexander H, Hagan S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* 1999;30:1517-23
19. Gupta A, Deepika S, Taly AB, Srivastava A, Surender V, Thyloth M. Quality of life and psychological problems in patients undergoing neurological rehabilitation. *Ann Indian Acad Neurol* 2008;11(4):225-30
20. Pan JH, Song XY, Lee SY, Kwok T. Longitudinal analysis of quality of life for stroke survivors using latent curve models. *Stroke* 2008;39(10):2795-802
21. Bolsche F, Hasenbein U, Ressler H, Schlote A, Wallesch CW. Result of inpatient post-stroke rehabilitation over 6 months. *Fortschr Neurol Psychiatr* 2003;71(9):458-68
22. Akosile Co, Okoye EC, Nwankwo MJ, Akosile Co, Mbada CE. Quality of life and its correlates in caregivers of stroke survivors from a Nigerian population. *Qual Life Res* 2011;20:1379e84
23. Susan L. Hughes, Anita GH, Frances M. Weaver, Joseph D. Kubal, and William Henderson. Relationship Between Caregiver Burden and Health-Related Quality of Life *The Gerontologist* 1999;39(5):534-45
24. Asmahan FA, Jude UO, Abdel WA and Asser AM. Family caregiver quality of life in multiple sclerosis among Kuwaitis: a controlled study. *BMC Health Services Research* 2008;8:206
25. Yu Y, Hu J, Efird JT, & McCoy TP. Social support, coping strategies and health related quality of life among primary caregivers of survivors in China. *Journal of Clinical Nursing* 2013;22(15-16):2160-71.

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