RESEARCH ARTICLE

Assessment of quality of life of stroke survivors and their caregivers presenting to a tertiary care hospital in Pakistan

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Abstract

Objective: To determine the quality of life of stroke survivors and their caregivers presenting to a tertiary care setup.
Method: The descriptive study was conducted from July to December 2019 at the Neurology Department, Pakistan Institute of Medical Sciences, Islamabad, Pakistan, and comprised patients of either gender with ischaemic or haemorrhagic stroke aged 40-70 years and their caregivers. Data was collected using the stroke-specific quality of life Scale and the caregiver quality of life questionnaire. Data was analysed using SPSS 20.
Results: Of the 80 patients, 50(62.5%) were males and 30(37.5%) were females. The overall mean age was 61.46±11.80 years, and 56(70%) were aged >55 years. Among the patients, speaking power, mobility and mood were more affected with mean levels of 15.51±8.63, 22.63±8.33 and 19.08±7.05, respectively. The domains of social role, self-care and upper extremity function were also affected with mean values of 19.022±7.06, 15.71±8.81 and 18.88±7.02, respectively. Among the caregivers, the levels of physical wellbeing and functional wellbeing were high 15.07±5.65 and 15.35±5.76, respectively. There were differences in terms of age and gender but the difference was not significant (*p*>0.05).
Conclusion: The quality of life of stroke survivors was low, and that of caregivers was also quite compromised.

Keywords: Haemorrhagic stroke, Ischemic stroke, Caregivers, Quality of life, SSQOL, CQLQ, Stroke survivors.
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Introduction

Stroke, also known as cerebrovascular disease, is further divided into haemorrhagic stroke and ischaemic stroke. Haemorrhagic stroke occurs when there is increased blood flow in the cranial cavity outside vessels due to rupture or damage, and ischaemic stroke refers to decreased blood flow in the cerebral vessels, leading to a decrease in oxygen and nutrient supply.[1]

The incidence of stroke, ischaemic and haemorrhagic has increased in the past two decades. However, the incidence is higher in low- and middle-income countries (LMICs) than in high-income countries (HICs). Deaths and morbidity due to stroke have also risen.[2]

Stroke is the leading cause of mortality and morbidity worldwide. However, the prevalence has declined in the West. It is rising in South Asia, including Pakistan, where the risk factors for stroke are enormous, with diabetes being on the top. According to estimates, the annual incidence of stroke in Pakistan is 250/100,000, and one study conducted on a small group of people from Karachi found a prevalence of 4.8%.[3]

Most people recover after a stroke, but some do not, and they require assistance with their daily chores. They cannot avoid unnecessary complications, cannot eat, communicate, ambulate, and perform daily chores. Medical problems, including aspiration pneumonia, deep vein thrombosis (DVT), bedsores and pulmonary embolism, can occur after a stroke.[4]

Stroke affects the quality of life (QOL) of both the patient and the caregiver. With recent advancements in the healthcare system, people suffering from stroke survive, but they still must cope with the functional, psychological and social sequel. Cerebrovascular accidents further deteriorate a patient's life and affect QOL. According to the World Health Organisation (WHO), the QOL is defined as individuals' perception of their position in life in the cultural context and in the value systems in which they live and concerning their goals, expectations, concerns and desires.[5] Thus, the term QOL covers many meanings constituted by a variety of factors, objective and subjective, reflecting knowledge, experience and values of individuals and communities in a cultural, social and historical context.[6]

QOL assessment has been an essential tool for more than 30 years in stroke patients and caregivers.[7] In 2009-10, a study in a Nigerian hospital on QOL among stroke patients demonstrated that decline in functional status and depression were independent risk factors affecting the QOL in post-stroke patients.[8]

The current study was planned to assess the QOL of stroke

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survivors and their caregivers at a tertiary care facility.

Patients and Methods

The descriptive study was conducted from July to December 2019 at the Neurology Department, Pakistan Institute of Medical Sciences (PIMS), Islamabad, Pakistan. After approval from the institutional ethics review committee, the sample size was calculated with confidence level 95%, alpha error 5%, and the anticipated proportion with the stroke 4.8%.[3] The final sample size was adjusted to accommodate a non-response rate of 15%. The sample was raised using consecutive sampling technique. Those included were patients of either gender aged 40-70 years who presented with ischaemic or haemorrhagic stroke. The critically ill patients in intensive care unit (ICU) settings were excluded.

Data was collected after taking written informed consent from all the subjects. The participants were interviewed by a single researcher to maintain data continuity and quality. A direct interview was preferred for the QOL instruments because of doubts regarding the potential difficulty of reading and literacy among the participants.

The QOL of the patients was evaluated using the stroke-specific quality of life Scale (SS-QOL)[9] tool, whereas the caregiver quality of life questionnaire (CQLQ)[10] was used to assess the caregivers' QOL. The SSQOL questionnaire consists of 49 items divided into 12 subdomains; energy, family role, language, mobility, mood, personality, social role, self-care, thinking, upper extremity function, vision, and work productivity. The CQLQ consists of 19 items divided into 5 domains; health history, physical, social/family, emotional, and functional wellbeing.

Data was analysed using SPSS 20. Continuous numerical variables were expressed as mean, standard deviation, and standard error of the mean (SEM). Independent sample t-test was used for comparing mean indices of QOL of stroke survivors and caregivers according to gender and age. The level of significance was set at $p<0.05$.

Table-1: Quality of life (QOL) of stroke survivors (n=80).

	Mean±SD	SEM
Energy	11.36±4.23	0.47
Family role	8.47±5.10	0.57
Language	15.51±8.63	0.96
Mobility	22.63±8.33	0.93
Mood	19.08±7.05	0.78
Personality	11.42±4.28	0.47
Social role	19.02±7.06	0.78
Self-care	15.71±8.81	0.98
Thinking	11.41±4.26	0.47
Upper extremity function	18.88±7.02	0.78
Vision	11.43±4.33	0.48
Work productivity	13.25±2.00	0.22

SD: Standard deviation, SEM: Standard error of mean

Results

Of the 80 patients, 50(62.5%) were males and 30(37.5%) were females. The overall mean age was 61.46±11.80 years, and 56(70%) were aged >55 years.

Table-2: Quality of life (QOL) of caregivers (n=80).

	Mean±SD	SEM
Health history	8.91±0.99	0.11
Physical Wellbeing	15.07±5.65	0.63
Social/family wellbeing	11.62±7.05	0.78
Emotional wellbeing	11.11±8.36	0.93
Functional wellbeing	15.35±5.76	0.64

SD: Standard deviation, SEM: Standard error of mean

Table-3: Quality of life (QOL) of stroke patients and caregivers according to gender.

	Age categories	Mean±SD	*p*-value
QOL of stroke survivors			
Energy	< 55 yrs. (n=24)	11.20±4.38	0.83
	> 55 yrs. (n=56)	11.42±4.20	
Family role	< 55 yrs. (n=24)	9.16±5.36	0.43
	> 55 yrs. (n=56)	8.17±5.01	
Language	< 55 yrs. (n=24)	14.50±8.97	0.49
	> 55 yrs. (n=56)	15.94±8.52	
Mobility	< 55 yrs. (n=24)	22.58±8.75	0.97
	> 55 yrs. (n=56)	22.66±8.23	
Mood	< 55 yrs. (n=24)	18.54±7.17	0.65
	> 55 yrs. (n=56)	19.32±7.05	
Personality	< 55 yrs. (n=24)	11.29±4.40	0.85
	> 55 yrs. (n=56)	11.48±4.26	
Self-care	< 55 yrs. (n=24)	15.62±9.21	0.94
	> 55 yrs. (n=56)	15.78±8.72	
Social role	< 55 yrs. (n=24)	18.75±7.15	0.82
	> 55 yrs. (n=56)	19.14±7.07	
Thinking	< 55 yrs. (n=24)	11.50±4.54	0.90
	> 55 yrs. (n=56)	11.37±4.18	
Upper extremity function	< 55 yrs. (n=24)	19.08±7.43	0.87
	> 55 yrs. (n=56)	18.80±6.91	
Vision	< 55 yrs. (n=24)	11.54±4.57	0.88
	> 55 yrs. (n=56)	11.39±4.26	
Work productivity	< 55 yrs. (n=24)	12.70±2.51	0.11
	> 55 yrs. (n=56)	13.40±1.71	
QOL of caregivers			
Health history	< 55 yrs. (n=24)	9.12±0.85	0.21
	> 55 yrs. (n=56)	8.82±1.04	
Physical wellbeing	< 55 yrs. (n=24)	14.83±5.77	0.80
	> 55 yrs. (n=56)	15.17±5.64	
Social function wellbeing	< 55 yrs. (n=24)	11.79±7.18	0.89
	> 55 yrs. (n=56)	11.55±7.06	
Emotional wellbeing	< 55 yrs. (n=24)	10.91±8.31	0.89
	> 55 yrs. (n=56)	11.19±8.46	
Family wellbeing	< 55 yrs. (n=24)	15.37±6.01	0.98
	> 55 yrs. (n=56)	15.33±5.71	

SD: Standard deviation, M: Male, F: Female.

Table-3: Quality of life (QOL) of stroke patients and caregivers according to gender.

	Gender	Mean±SD	*p*-value
QOL of stroke patients			
Energy	M (n=50)	11.40±4.27	0.91
	F (n=30)	11.30±4.22	
Family	M (n=50)	8.98±5.15	0.25
	F (n=30)	7.63±5.00	
Language	M (n=50)	14.80±8.813	0.34
	F (n=30)	16.70±8.33	
Mobility	M (n=50)	22.52±8.33	0.87
	F (n=30)	22.83±8.47	
Mood	M (n=50)	19.02±7.01	0.91
	F (n=30)	19.20±7.23	
Personality	M (n=50)	11.38±4.31	0.90
	F (n=30)	11.50±4.30	
Self-care	M (n=50)	14.68±9.06	0.16
	F (n=30)	17.50±8.23	
Social role	M (n=50)	18.92±7.05	0.86
	F (n=30)	19.20±7.19	
Thinking	M (n=50)	11.38±4.25	0.93
	F (n=30)	11.46±4.36	
Upper extremity function	M (n=50)	19.02±7.08	0.82
	F (n=30)	18.66±7.04	
Vision	M (n=50)	11.42±4.34	0.96
	F (n=30)	11.46±4.37	
Work productivity	M (n=50)	13.28±2.03	0.86
	F (n=30)	13.20±1.98	
QOL of caregivers			
Health history	M (n=50)	8.94±1.07	0.75
	F (n=30)	8.86±0.86	
Physical wellbeing	M (n=50)	14.90±5.63	0.72
	F (n=30)	15.36±5.76	
Social function wellbeing	M (n=50)	11.64±7.04	0.98
	F (n=30)	11.60±7.18	
Emotional wellbeing	M (n=50)	10.16±8.07	0.19
	F (n=30)	12.70±8.72	
Family wellbeing	M (n=50)	15.36±5.78	0.98
	F (n=30)	15.33±5.83	

SD: Standard deviation, M: Male, F: Female.

Among the patients, speaking power, mobility and mood were more affected with mean levels of 15.51±8.63, 22.63±8.33 and 19.08±7.05, respectively. The domains of social role, self-care and upper extremity function were also affected with mean values of 19.022±7.06, 15.71±8.81 and 18.88±7.02, respectively (Table 1).

Among the caregivers, the levels physical wellbeing and functional wellbeing were high 15.07±5.65 and 15.35±5.76, respectively (Table 2).

There were differences in terms of gender (Table 3) and age (Table 4), but the difference was not significant ($p>0.05$).

Discussion

The current study found that the QOL of stroke patients was relatively low and compromised. Many other investigators have also found similar findings.[7,11-14]

The current study also observed that the QOL of the caregivers was affected, as the levels of physical and functional wellbeing were significantly low. Earlier studies have also reported a similar trend[15] and the QOL decreased as the burden increased.[16] Evidence suggests that stroke caregivers often report more somatic and depressive symptoms, sleep disorders and social isolation. Their QOL is poorer than the general population.[17] Another study found that the low functional status of stroke survivors was found significantly related to lower QOL and higher caregiver strain index of the caregivers.[18] Another longitudinal study found that caregivers had significantly lower averages in most domains of QOL.[19]

In the present study, the QOL was stratified according to gender and age, but no significant differences were observed. It was noted that the self-care of female stroke survivors was more affected than their male counterparts, and the work productivity of patients aged >55 was also more affected. With respect to caregivers' QOL, females had emotional wellbeing issues. Other studies have reported similar findings.[15,20,21]

The findings regarding compromised QOL of stroke survivors and their caregivers have significant implications and demand urgent and focussed interventions to minimise their sufferings. One of the options could be health education and proper counselling of patients and their caregivers by nursing staff and medical doctors.[13] Another solution could be the availability of special health units and departments with appropriate facilities and services for the management and sustenance of stroke survivors.

The current study has its strengths being among the first attempts in the local context to evaluate the QOL of stroke survivors and their caregivers. Besides, it had a large sample size, and compared the QOL with gender and age.

In terms of limitations, the sample size was based on the prevalence of stroke and not on the primary outcome measure, which was the QOL of stroke patients and their caregivers.

Conclusion

The QOL of stroke survivors was found to be low. Moreover, the QOL of caregivers was also quite compromised.

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References

1. Unnithan AKA, Das JM, Mehta P. Hemorrhagic Stroke. Treasure Island, Florida: StatPearls Publishing; 2021.
2. Avan A, Digaleh H, Di Napoli M, Stranges S, Behrouz R, Shojaeianbabaei G, et al. Socioeconomic status and stroke incidence, prevalence, mortality, and worldwide burden: an ecological analysis from the Global Burden of Disease Study 2017. BMC Med 2019;17:191. doi: 10.1186/s12916-019-1397-3.
3. Nomani AZ, Nabi S, Badshah M, Ahmed S. Review of acute ischaemic stroke in Pakistan: progress in management and future perspectives. Stroke Vasc Neurol 2017;2:e30-9. doi: 10.1136/svn-2016-000041.
4. Patient education: Hemorrhagic stroke treatment (Beyond the Basics). Caplan LR. [Online] 2021 [Cited 2021 March 27]. Available from URL: https://www.uptodate.com/contents/hemorrhagic-stroke-treatment-beyond-the-basics/print.
5. Mahesh PKB, Gunathunga MW, Jayasinghe S, Arnold SM, Haniffa R, De Silva AP. Pre-event quality of life and its influence on the post-event quality of life among patients with ST elevation and non-ST elevation myocardial infarctions of a premier province of Sri Lanka. Health Qual Life Outcomes 2017;15:154. doi: 10.1186/s12955-017-0730-9.
6. Palovicova Z. Understanding the Concept of Life Quality within the Framework of Social Service Provision: Theoretical Analysis and a Case Study. In: Boas AAV, eds. Quality of life and Quality of Working Life, 1st ed. Rijeka, Croatia: InTech; 2017.
7. Khalid W, Rozi S, Ali TS, Azam I, Mullen MT, Illyas S, et al. Quality of life after stroke in Pakistan. BMC Neurol 2016;16:250. doi: 10.1186/s12883-016-0774-1.
8. Chen Q, Cao C, Gong L, Zhang Y. Health related quality of life in stroke patients and risk factors associated with patients for return to work. Medicine (Baltimore) 2019;98:e15130. doi: 10.1097/MD.0000000000015130.
9. Riphah International University. Translation of Stroke Specific Quality of Life Questionnaire Into Local Languages of Pakistan. [Online] 2022 [Cited 2022 April 16]. Available at URL: https://clinicaltrials.gov/ct2/show/NCT04843254.
10. Bates GE, Hashimi AK, Bressler T, Zajac J, Hesdorffer M, Taub RN. Caregiver Quality Of Life Questionnaire (Physical & Emotional) (CQLQ). [Online] 2022 [Cited 2022 April 16]. Available at URL: https://eprovide.mapi-trust.org/instruments/caregiver-quality-of-life-questionnaire-physical-emotional.
11. Ramos-Lima MJM, Brasileiro IC, Lima TL, Braga-Neto P. Quality of life after stroke: impact of clinical and sociodemographic factors. Clinics (Sao Paulo) 2018;73:e418. doi: 10.6061/clinics/2017/e418.
12. Gao Y, Jiang B, Sun H, Ru X, Sun D, Wang L, et al. The burden of stroke in China: Results from a nationwide population-based epidemiological survey. PLoS One 2018;13:e0208398. doi: 10.1371/journal.pone.0208398.
13. Centers of Disease Control and Prevention. Stroke Facts. [Online] 2021 [Cited 2021 March 20]. Available at URL: http://www.cdc.gov/stroke/facts.htm.
14. Karakurt P, Unsal A, Tanriverdi D. Evaluation of Care Burden and Quality of Life of Caregivers of Patients with Stroke. Int J Caring Sci 2018; 11:529-42.
15. Pinedo S, SanMartin V, Zaldibar B, Miranda M, Tejada P, Erazo P, et al. Quality of Life of Stroke Patients and their Caregivers. Int J Phys Med Rehabil 2017;5:386. doi: 10.4172/2329-9096.1000387
16. Ugur HG, Erci B. The Effect of Home Care for Stroke Patients and Education of Caregivers on the Caregiver Burden and Quality of Life. Acta Clin Croat 2019;58:321-32. doi: 10.20471/acc.2019.58.02.16.
17. Tsai YH, Lou MF, Feng TH, Chu TL, Chen YJ, Liu HE. Mediating effects of burden on quality of life for caregivers of first-time stroke patients discharged from the hospital within one year. BMC Neurol 2018;18:50. doi: 10.1186/s12883-018-1057-9.
18. Badaru UM, Ogwumike OO, Adeniyi AF, Nelson EE. Determinants of caregiving burden and quality of life of informal caregivers of African stroke survivors: literature review. Int J Disabil Hum Dev 2017;16:249-58. doi: 10.1515/ijdhd-2016-0041
19. Farahani MA, Bahloli S, JamshidiOrak R, Ghaffari F. Investigating the needs of family caregivers of older stroke patients: a longitudinal study in Iran. BMC Geriatr 2020;20:313. doi: 10.1186/s12877-020-01670-0.
20. Persson J, Holmegaard L, Karlberg I, Redfors P, Jood K, Jern C, et al. Spouses of Stroke Survivors Report Reduced Health-Related Quality of Life Even in Long-Term Follow-Up: Results From Sahlgrenska Academy Study on Ischaemic Stroke. Stroke 2015;46:2584-90. doi: 10.1161/STROKEAHA.115.009791.
21. Menon B, Salini P, Habeeba K, Conjeevaram J, Munisusmitha K. Female Caregivers and Stroke Severity Determines Caregiver Stress in Stroke Patients. Ann Indian Acad Neurol 2017;20:418-24. doi: 10.4103/aian.AIAN_203_17.