



Quality of Life in Recent Stroke Patients and Burden on Caregivers in Gujarat state of Western India

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Authors' contributions

This work was carried out in collaboration among all authors. Author PK designed the study, analyzed the data and wrote the first draft of the manuscript, author PN collected data and reviewed literature, author LP reviewed the data and manuscript. All authors read and approved the final manuscript.

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ABSTRACT

Background: Stroke is a global health problem. Patients with stroke may be damaged in many aspects of life, which affects the physical, psychological and social dimensions of quality of life. These factors lead to burden on the caregivers. This burden on the caregivers negatively affects the rehabilitation of the stroke patients.

Objective: To study the quality of life of stroke patients and burden on caregivers.

Methods: Stroke patients fulfilling the inclusion criteria were assessed for the quality of life by the Stroke Specific Quality Of Life Scale and the burden on caregivers was measured using the Zarit Burden Interview on one to one interview basis. The data were analysed using the SPSS software.

Results: The quality of life and burden scores were weakly correlated ($r = -0.558$ and $p = 0.001$). The quality of life and burden scores were also weakly correlated to the MMSE scores.

Conclusion: There is a negative correlation of the burden on caregivers with the quality of life of the stroke patients. There is also a positive correlation of MMSE score with the quality of life. Whereas, there is no correlation of the quality of life and burden scores with the patient's age and sex, type of stroke, duration post stroke and whether any treatment has been taken.

Keywords: *Quality of life; stroke; caregiver burden; stroke specific quality of life scale; zarit burden interview.*

1. INTRODUCTION

Stroke is a global health problem. It is the second commonest cause of death and fourth leading cause of disability worldwide. The WHO clinically defines stroke as ‘the rapid development of clinical signs and symptoms of a focal neurological disturbance lasting more than 24 hours or leading to death with no apparent cause other than vascular origin’ (WHO 2005). The incidence of stroke has also increased in the low and middle-income countries like India. These countries account for 85.5% of total stroke deaths worldwide and the number of disability-adjusted life years in these countries is approximately seven times that in high-income countries [1].

Quality of life is an important aspect of health outcome, along with duration of life, and it is of interest as a determinant of outcome as well. Quality of life (QOL) is increasingly being used as an outcome measure in clinical trials and observational studies designed to evaluate the quality of care for patients with stroke [2]. Stroke rehabilitation is becoming important since the inpatient duration itself as life expectancy of these patients has increased. The purpose of stroke rehabilitation is to equip the stroke patients with the physical, psychological, social, vocational and educational potential to the maximum possible extent [3]. It has a positive impact in the prevention of subsequent acute episodes and supports the individual's ability to live independently through targeted interventions aimed at improving balance, strength, coordination and function. Physiotherapy's focus on restoring physical function offers a positive outcome to stroke patients during the recovery process through low risk activities resulting in high patient satisfaction. Rehabilitation post stroke has a positive impact on disability, physical and social function and quality of life and reduces the risk of poor health outcomes [3,4].

In many high-income countries, stroke management has changed substantially in the past two decades. Organized provision of care in a stroke unit have been found to increase the number of patients who survive, return home, and regain functional independence in their everyday activities. However, implementation of such organized care for stroke is limited and

inadequate in low and middle income countries, especially in a country like India where resources for rehabilitation are scarce and there is a lack of awareness regarding physiotherapy [1]. It is seen that the majority of patients who survive a stroke, after initial hospitalization and stroke rehabilitation are only able to continue their daily activities and return to community by being dependent on their caregivers [3,5,6,7].

Stroke is a life-changing event that affects not only the person who may be disabled, but their family and caregivers. Patients and their families may experience a variety of physical, psychological, social, economic, and spiritual problems. Negative objective and subjective outcomes such as psychological problems, physical health problems, economic and social problems, disturbed family affairs, feelings of not having control of issues arising from all these care services are defined as “care burden” [5,7]. In the rehabilitation period, a training and problem solving process aiming at decreasing the rate of disability of the patient is experienced by focusing on the condition. While the disabled patient is being medically assisted in the focus of the process, the caregivers looking after the patient play a role within the process and are seriously affected by such a process. Moreover, the continuing shift from institutional care to community care makes the impact of stroke care giving more profound than ever [3,7].

Since a caregiver is a critical element of home care, if the burden on a caregiver becomes too great, the home care support may be seriously jeopardized. Increased caregiver burden increases the use of formal, paid helpers. Higher levels of burden can lead to an earlier institutionalization of the patient in a nursing home. Caregivers can experience deterioration in their physical and psychological health due to their new role. Care giving stress has the potential to hamper rehabilitation of the patients and is of vital importance both as a research topic and the focus of clinical care. So it is essential to study the quality of life in the stroke patients and its effect on the caregivers.

2. METHODOLOGY

2.1 Study Design

Cross sectional study.

2.2 Method

Stroke patients from Medicine ward of Dhiraj Hospital and other private hospitals of Vadodara, Gujarat were approached and details of the patients and contact numbers of the patients were obtained from there. The patients were contacted on the phone and explained in detail about the study procedure. They were visited on their convenient time and were screened for inclusion and exclusion criteria. Those patients having first episode of stroke were included in the study. Caregivers of such stroke patients i.e. next of kin, or the persons who physically assisted majority of the activities of the included stroke patients were included in the study. The stroke patients were excluded if they had a recurrent episode of stroke, whose MMSE score was ≤ 24 and who had any other neuro musculo skeletal conditions that could affect the quality of life. A total of 82 patients were screened of which 30 were recruited for the study and the rest were excluded.

The quality of life was assessed using the Stroke Specific Quality of Life Scale (SSQOL). It contains 49 items. Items are assessed on 5-point Guttman-type scales. Each item is answered using 1 of 3 different response sets. It provides both summary and domain specific scores. The scores range from 49-245. Higher scores indicate better functioning. The twelve domains include: Mobility, Energy, Upper Extremity Function, Work and Productivity, Mood, Self-care, Social Roles, Family Roles, Vision, Language, Thinking, Personality. It takes 10-15 minutes to administer the scale.

The burden on the caregivers was assessed using the Zarit Burden Interview (ZBI). It assesses caregiver perceptions of burden that may inadvertently affect their health, personal, social or financial wellbeing. It contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). Total score is obtained by summing all items endorsed. It takes 30 minutes to administer. Interpretation of Score: 0 – 21 little or no burden, 21 – 40 mild to moderate burden, 41 – 60 moderate to severe burden, 61 – 88 severe burden.

The questionnaires were administered on one to one interview basis. All the data obtained was then documented in the data collection form and

later entered in MS Excel sheet and was used for data analysis.

3. RESULTS AND DISCUSSION

3.1 Participant Demographics

A total of 30 stroke patients along with their caregivers were recruited in the study. The study population comprised of 16 female (51%) and 14 male (49%) patients. The mean age of the patients was 58.16 ± 11.84 years. The mean post stroke duration was 2.84 ± 1.76 months and the mean MMSE score was 27.66 ± 1.84 . (Table 1) The mean age of the caregivers was 45.27 ± 14.91 years. (Table 1).

Table 1. Descriptive statistics (mean and S.D)

Stroke patients Age, years	58.16 (11.84)
Stroke Duration, months	2.84 (1.76)
Stroke patients MMSE score	27.66 (1.84)
QOL total	163.4 (42.42)
Care giver Age, years	45.27 (14.91)

Out of the 30 caregivers, 24 were females and 6 were males which mean almost 80% of them were females. Male and female stroke patients were nearly 50% each in the study however the care takers were mostly women. Previous studies in India and elsewhere have also reported a similar pattern of female care givers [8,9]. "Filial piety" is an important virtue in Indian culture and that could explain why more women are involved as care takers.

3.2 Quality of Life

In present study, the SSQOL was used to measure the quality of life in the stroke patients. Williams et al. developed a scale that measures the stroke specific quality of life which also included the domains like language, cognitive, psychological and social functioning which were missed in the other outcomes that measured the quality of life [10]. The quality of life as studied in the present study in the sub-acute period post stroke was average, ranging from bad to good (163.4 ± 42.4). A similar QOL score has also been reported from Pakistan, a neighboring country that shares border with Gujarat [11]. These scores are better than the other Low and Middle income countries like Brazil (139.7 ± 38.4) [12] and South East Nigeria (156.71 ± 41.64) [13]. The Pakistan study cites joint family system with good social support, similar to India, could be the reason for the better SSQOL score [11].

Quality of life was studied by several authors at different periods post stroke. Hopman et al., in their study on quality of life during and after inpatient stroke rehabilitation reported that the quality of life was bad during the inpatient rehabilitation but it improved at 6 months post discharge. However, it still did not reach the original quality of life [14]. Few authors also used different scales measuring the quality of life. Dayapoglu et al in their study used the SF-36 scale and stated that the quality of life is lower in patients post stroke [15].

Poor SF-36 score in all domains with specifically lowest scores in the domains of “role limitations due to physical problems and “physical function” was also reported for stroke patients living in Kerala state of Southern India [16].

Carod-Artal et al. evaluated the quality of life in the stroke survivors after 1 year after stroke and found that the functional status and depression of the patients were the predictors of their quality of lives. Patients who were independent in their activities of daily living suffered from a deterioration of the psychosocial dimension of the SIP [17]. The results of this study were similar to those obtained in the present study.

In the present study, 28 patients had ischemic stroke and out of them, 17 patients had average to good quality of life and the rest 11 showed worse to bad quality of life. Gurcay et al. studied the health related quality of life in first ever stroke patients in which majority of them had ischemic stroke. They found that in stroke patients the quality of life was not restored to the pre- stroke level and that the functional status of the patient was a determinant for the low HRQoL [18]. Similarly, Naess et al compared the HRQoL of the young patients with ischemic stroke to those of the controls. They concluded that low level of HRQoL among young adults with ischemic stroke was most pronounced in regard to physical functioning [19]. Nichols-Larsen et al in their study of factors influencing stroke survivors’ quality of life during sub acute recovery also reported a poor result in the patients with ischemic stroke and those having their dominant side affected [20].

In a study that examined QOL, anxiety, depression, and functional independence among Indian stroke survivors had reported negative correlation between Age and the functional independence of stroke patients [21]. Another Indian study had reported Functional

dependence as valid predictor of QOL in stroke patients [22].

Regarding the quality of life, the energy, mobility, social rules and mood, were the main domains that were affected. The language, vision, thinking and personality were the domains that were not much affected. This can be because the stroke patients with no or minimal cognitive impairments were included for the study. The upper extremity function and the work productivity were preserved in those patients who had the affection of the non-dominant side. This also made them independent in their ADLs which is seen in the self-care domain as it also showed less affection. The family roles domain also showed a less affection, which suggests that the patients were not felt as a burden to their family.

This is a cross sectional study and the mean duration of stroke was 2.84 months. A prospective cohort study with follow up of 16 months post stroke had reported improvement in QOL in stroke patients as the duration increases. Despite deterioration in patients’ self-perceived physical function QOL showed improvements over the period of time. This improvement took place in social, emotional and mental domains and suggests that patients started to adapt to new life situations [23].

3.3 Burden on Caregivers

Here, in this study, the ZBI was used to measure the burden on the caregivers of the stroke patients. The care giver burden in the present study was found to be 19.73 ± 7.58 (Table 2), which indicated a very less burden in the caregivers of the stroke population.

Table 2. Burden on caregivers (ZBI)

Caregiver	Mean	Standard deviation
ZBI- Total	19.73	7.58
Spouse	17.64	5.44
Children	20.25	8.84
Siblings	22.50	13.44
Daughter-in-law	22.78	9.16
Caretaker	14.00	0.00

The majority of the caregivers did not feel that their relative asked for more help than they needed. Some felt that the patients frequently asked for more help. Almost 70% of the caregivers felt that because of the time they

spent with the patient, they did not have enough time for themselves. 50% caregivers were stressed between caring for their relative and trying to meet other responsibilities for family or work. Caro et al reported reduction in social activities in the care givers possibly due to lack of time. The reported increased burden in the caregivers is due to decreased free time and social isolation⁹. The incidence of embarrassment and discomfort in the caregivers because of their relatives was hardly 7- 10 %. However, presence of the relative also made a few of the caregivers angry. Caring for the relative did not affect any other relationships with other family members or friends in a negative way. Fear related to future was present in 50% of the caregivers. Financial and social burden was found to be less in the caregivers included in the present study. A few caregivers sometimes felt that their health had suffered because of their involvement with their relative. Almost all caregivers did not wish to leave the care of their relative to someone else. They felt that they should be doing more and could do a better job in caring for their relative. When being asked about the overall burden felt in caring for their relative, it was found that 60% caregivers were not burdened at all and the rest sometimes felt burdened. However it is important note that mean stroke duration of the present study was 2.84 months. Many studies have reported that burden on care givers of Stroke patients is long lasting and caregivers experience increase in the burden as the chronicity of the stroke increases [24].

Das S. et al studied burden among caregivers of stroke survivors in Kolkata. Their study included the patient caregiver pairs, in which majority were women. In the present study also the majority of the caregivers are women. In their study, the caregivers experienced financial, physical, and mental stress and the influence on familial and social relationships was seen among them. However, women caregivers received a greater appreciation as compared to the males [25].

Looking at the burden of care giving on the spouses of the stroke survivors, the burden was found to be less as compared to the other groups of caregivers. One such study in Canada, by Coombs UE et al suggested that the caregivers were committed to their task of care giving and felt it as a responsibility to care for their affected partners. However, changes in their relationship after stroke were a major consequence of the study. The spouses found it

difficult to cope up with the condition of the patient [26]. This result contradicts the findings of the present study. It may be because of the cultural differences present in the societies; as in India, caring for their partner is not perceived as a burden to the spouse. They also felt that they could do a better job in caring for their relative and that they should be doing more for their relative.

The maximum burden of care giving was seen in the daughters in law of the patients. The children and siblings of the stroke patients also experienced burden but, it was less as compared to that of the daughter in law group. It was more as compared to that of the spouses of the patients. These results were similar to those of one study by Reed et al, in which they studied the differential associations in adult-child and spousal caregivers of patients with Alzheimer's disease. It suggested that the burden on the adult child caregiver was more as compared to the spousal care givers [27]. The caretaker of the patient also perceived less burden compared to the rest of the groups as she considered caring for her patient as her duty and was being paid for taking care of the patient. (Table 2)

An earlier Indian study reported a high prevalence of caregiver burden associated with stroke. The study cited culture, care taker continue to work for full time to meet expenses, family conflicts arising out of receiving assistance while continue to work and out of the pocket expenses for caring the patients might had resulted in increase in the experiences of burde [8].

3.4 Correlation of Burden and Quality of life

The present study shows a positive correlation between the quality of life of the patients and the burden on caregivers, that is, the burden among the caregivers reduced with the improvement in the quality of life of the patients. The patients having higher scores on the SSQOL scale were functionally independent in majority of their activities of daily living and this reduced the burden on the caregivers. (Table 3).

There was no correlation of the QOL and burden scores with the patient gender. The males and females did not show a significant difference in the QOL and burden scores. Similarly, the type of stroke also did not influence the QOL and Burden scores of the patients and caregivers.

Table 3. Correlation of burden and quality of life

		QOL				Total
		Worst	Bad	Medium	Good	
Burden	Little or no burden	0	3	9	6	18
	Mild to moderate burden	2	7	1	1	11
	Moderate to severe burden	0	0	1	0	1
Total		2	10	11	7	30
Fischer's exact test		Value 14.495			Exact p-value 0.005	

Table 4. Correlations

		Duration Post Stroke (month)	MMSE score	QOL– Total	Burden score
Patient Age	Pearson correlation	0.244	-0.168	-0.069	-0.117
	P- value	0.194	0.375	0.715	0.539
Duration post stroke (month)	Pearson correlation		0.474	0.536	-0.292
	P-value		0.008	0.002	0.118
MMSE score	Pearson correlation			0.702	-0.515
	P-value			0.000	0.004
QOL – Total	Pearson correlation				-0.558
	P-value				0.001

- There is a weak negative correlation between MMSE score and burden score.
- There is a weak negative correlation between QOL and burden score.
- There is a strong positive correlation between MMSE score and QOL total score.

In present study, 24 patients took physiotherapy treatment following stroke. But the quality of life of these patients was no different from those who did not take physiotherapy treatment. This may be because the patients were recruited from the different centers and they took physiotherapy treatment at different places for different durations. The physiotherapy was not standardized for the included group of patients. However another study conducted in India reported a better physical domain of QOL and attributed Physiotherapy treatment as the reason for it [28]. A study which studied whether rehabilitation reduced the burden of the next-of-kin of stroke victims. They divided the population into two groups, one group receiving rehabilitation in a day clinic and other in a home setting and concluded that the next-of-kin of the victims of the day clinic experienced more burden than those victims who were in a home setting. According to them counseling of the

family and friends of the victims in the home setting had a strong effect in reducing the burden [5].

A strong positive correlation was also seen between the MMSE score and the QOL total score along with a weak negative correlation between the MMSE score and ZBI score. The patients with a higher MMSE score showed a better quality of life and in turn, a reduced burden on the caregivers (Table 4).

No correlation of the QOL and burden score was found with that of the patient's age. The quality of life of one young patient was similar to the elderly patients included in the study. The functional dependency was the major reason for the reduced quality of life of the young patient where as in the elderly patients age itself could be a factor leading to a reduced quality of life (Table 5). These results contradict the results of a study done by Tokunaga M et al to see the effects of age on FIM score gain in stroke patients. They reported that the score gain in the FIM scores was lower in elderly patients as compared to those of the younger ones suggesting a poor QOL in the elderly patients [29].

Awareness of sex differences in functional status and QOL after a stroke may eventually enable better targeting of prevention, intervention, and

Table 5. Comparison between quality of life of males and females

		Mean	Standard Deviation	p value
Energy	Male	6.92	4.23	0.418
	Female	8.18	4.15	
Family roles	Male	10.85	4.22	0.384
	Female	9.62	3.40	
Language	Male	18.28	6.14	0.112
	Female	21.5	4.56	
Mobility	Male	19.64	9.45	0.413
	Female	16.5	11.02	
Mood	Male	14.71	5.79	0.803
	Female	15.25	5.84	
Personality	Male	8.07	4.32	0.049
	Female	11.56	4.89	
Self care	Male	19.57	7.45	0.228
	Female	16.18	7.52	
Social roles	Male	13.28	5.62	0.743
	Female	12.62	5.30	
Thinking	Male	11.5	3.56	0.804
	Female	11.81	3.25	
Upper extremity function	Male	18.14	7.71	0.324
	Female	15.43	7.03	
Vision	Male	14.35	1.59	0.951
	Female	14.31	2.24	
Work productivity	Male	10.42	5.10	0.171
	Female	7.93	4.59	
QOL- Total	Male	1.6579	43.89	0.760
	Female	1.6094	42.07	

rehabilitation services to relevant populations. Gargano JW et al. in their study has reported that women are more likely to have physical impairments and limitations in activities of daily living (ADL), or basic components of self-care, on follow up. Women experience more mental impairment, depression, and fatigue and lower overall QOL than men after stroke [30]. However, the results of the present study show no significant difference in the quality of life of the men and women (Table 5).

4. CONCLUSION

The present study suggests that there is a negative correlation between the burden of care giving on caregivers and quality of life of the stroke patients. The correlation between ZBI and QOL scores is statistically significant ($r = -0.558$ and $p = 0.001$). Both, QOL and ZBI scores were co-related to the MMSE scores. There is a positive correlation of the MMSE score with the quality of life of the stroke patients and hence a negative correlation with the burden of care giving on the caregivers. Variables like patient's age, patient's sex, duration post stroke, type of

stroke, treatment taken, and their effects on quality of life has no correlation with the burden of care giving.

DISCLAIMER

Herewith all the authors declare that no competing interests exist.

CONSENT

All authors declare that 'written informed consent was obtained from the patient (or other approved parties) for publication of this case report and accompanying images. A copy of the written consent is available for review by the Editorial office/Chief Editor/Editorial Board members of this journal.

ETHICAL APPROVAL

All authors hereby declare that all experiments have been examined and approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical

standards laid down in the 1964 Declaration of Helsinki.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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