Original Article

Association of quality of life of carers with quality of life and functional independence of stroke survivors

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Abstract

Background: Stroke has a great impact not only on patients' but also on their caregivers' lives. Carers may experience high levels of burden that can result in deterioration of their health status, social life, and well-being. Association between quality of life (QOL) of carers and that of stroke survivors in Indian setting is not much researched. **Aims and Settings:** To find out QOL and mental health of caregivers of individuals with stroke visiting Physiotherapy Department of Tertiary Care Center in Western India. **Design and Methodology:** A cross-sectional survey to find QOL and mental health of caregiver of stroke survivors, self-administered screening instrument WHO-QOL BREF, functional independence measurement (FIM) scale, and BRIEF COPE were used for data collection on adult populations. **Statistical Analysis Used:** The statistical analysis was performed by descriptive analysis and correlation. **Result:** Fifty-four stroke patients and their caregivers (all adults) were included in the study. Average FIM score was 83.75 (18.46) while median was 90 (25). FIM score of patients did not much affect QOL of caregivers. **Discussion:** Analysis of QOL data showed that QOL of caregivers was good in all domains, but patient's QOL was good only in social relations. There was no correlation found in QOL of carers and stroke survivors. Nine percent of change in caregivers social relationship scores can be attributed to patients' sphincter scores. **Conclusion:** QOL of carers and stroke survivors may be independent. Stroke patients in the study required a moderate assistance for their functional independence which does not seem to affect the caregivers QOL significantly.

Keywords: Functional independence, hemiplegic, quality of life

Introduction

India like many other developing countries is facing the double burden of communicable and noncommunicable diseases. Among the noncommunicable diseases, we are facing stroke epidemic as there is a huge burden of stroke with significant regional variations documented in India.[1] According to the India stroke fact sheet updated in 2012, the estimated age-adjusted prevalence rate for stroke ranges between 84 and 262 per lac in rural and between 334 and 424 per lac in urban areas, which is a significant number.[2]

Stroke has a great impact not only on the lives of the stroke survivors but also their caregivers. The carers of stroke patients provide informal care ranging from physical help to psychosocial support. As a result, these carers may experience high levels of burden, associated with characteristics of the patients and of the carers themselves.[3-5]

Majority of stroke survivors continue to live with disabilities. The costs of ongoing rehabilitation and long-term care are largely undertaken by other family members, which impoverish the families.[6,7] This burden can thus result in a deterioration of the carers' health status, social life, and well-being, and hence their overall quality of life (QOL) significantly.[3,8]

The multifaceted impact of caring for the stroke survivors on their caregiver has been established in some Western studies. The caregivers were seen to perceive a similar type and level of

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Access this article online

Quick Response Code:

Website: www.jfmpc.com

DOI: 10.4103/2249-4863.184637

How to cite this article: Ganjiwale D, Ganjiwale J, Parikh S. Association of quality of life of carers with quality of life and functional independence of stroke survivors. J Family Med Prim Care 2016;5:129-33.

psychosocial burden and psychological morbidity, independent of the disease.[9]

The social fabric of India is very different from the Western world, and QOL of patients, and the carers also depends on the social support and environment to a great extent.[9,10] Therefore, the current study was taken up to find the association of QOL of carers with the QOL and functional independence of the stroke survivors in an Indian setting.

Methodology

Based on a previous hospital-based study done in India in 2010, where the prevalence of depression and anxiety in stroke survivors is reported to be 37% and 24%, respectively,[11] we assumed the prevalence of poor QOL in carers around 30% and took the acceptable difference at 12%. Thus, the sample size calculated was 57, taking 5% level of significance. All stroke survivors who had suffered a stroke at least 6 months back, visiting a Rural Tertiary Care Centre in Western India during the period between July 2012 and June 2013 for rehabilitation and their carers were approached for participation in the cross-sectional study by convenient sampling. The study was duly approved by the Human Research Ethics Committee of Charutar Arogya Mandal. Written informed consent was taken from the participants.

The basic demographic details were noted for the stroke survivors, and their functional independence was assessed using a functional independence measurement (FIM) scale. WHO-QOL BREF was administered onto the stroke survivors, and their carers for assessing their QOL and Brief COPE scale were administered to the carers to find their coping strategy.

WHO-QOL BREF is a self-administered instrument developed by WHO to document QOL.[12] For administration of it in Gujarati population, it was first translated in Gujarati and then back translated into English by people proficient in both the languages and pilot tested by the investigator.

BRIEF COPE, a 28-item scale is also self-administered scale to measure coping style used, derived from the longer COPE inventory (Carver, Scheier, and Weintraub, 1989). This scale was also translated and back translated and consensually validated was used in the study to note different coping styles adapted by the carers.[13,14]

Data on functional independence measurement scale was completed by a trained physiotherapist and/or occupational therapist after proper assessment of patient's level of the dependency with the FIM scale.[15]

The objectives of the study were to find the relationship between:

- QOL of stroke patients to that of their carers
- Patients' functional independence and QOL of the caregivers and
- Different coping mechanisms employed by the caregivers while caring for the stroke survivors.

Result

Sixty-two stroke survivors who had suffered a stroke at least 6 months back, visiting a Rural Tertiary Care Centre in Western India during the period between July 2012 and June 2013 for rehabilitation, and their carers were approached for participation, and 54 pairs (17 females and 37 males) agreed to participate. The mean (SD) age of stroke survivors was 59.44 (12.40) and comparable across gender ($P > 0.05$).

The QOL of patients overall in all domains except social support was observed to be compromised, whereas the QOL of carers was seen to be fine in all domains again social support being the highest [Table 1].

Correlation coefficient (r) between QOL of patients and that of carers domain wise was calculated. The correlation coefficient (r) between FIM and different domains of QOL for patients was also calculated and presented as "r" [Table 2], no significant correlation observed. Mean (SD) of FIM score was 83.75 (18.46) and median (interquartile range) 90 (25). The stroke survivor's sphincter score was significantly positively related to all the other domains of FIM ($P < 0.01$) [Table 3].

Majority (70%) of stroke survivors had a poor score in the self-care domain of FIM, but almost all of them had a good score in psychological (93%) and cognitive domain (82%) of FIM scale [Figure 1].

Nine percent of change in the caregivers social relationship scores are attributable to the patients' sphincter scores and also 9% of caregivers' physical health of is attributable to patient's mobility [Table 3].

Table 1: Domain wise distribution of scores of quality of life of stroke survivors and carers

Quality of life domains	Stroke survivors		Caregivers	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Physical health	37.90 (9.50)	38 (13)	64.58 (14.42)	63 (19)
Psychological health	38.16 (10.59)	38 (13)	68.12 (11.26)	69 (12)
Social relationship	64.09 (15.89)	75 (25)	71.26 (26.63)	75 (42.5)
Environmental health	40.77 (10.65)	38 (6.00)	68.78 (15.91)	69 (19)

SD: Standard deviation; IQR: Interquartile range

Table 2: Correlation coefficient between quality of life of patients, carers and the functional independence measurement scores

QOL domains	*r* between QOL of patients and care givers	*r* between QOL of patients with their FIM total
Physical health	−0.002	+0.006
Psychological health	+0.037	+0.042
Social relationship	+0.005	+0.169
Environment	−0.116	−0.104

QOL: Quality of life; FIM: Functional independence measurement

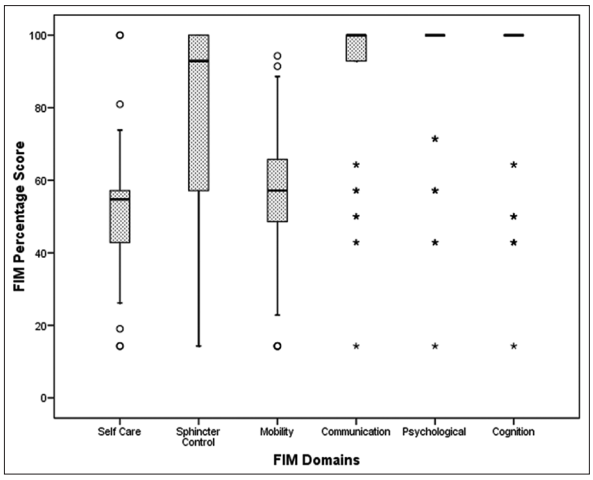

Figure 1: Domain wise functional independence measurement score distribution of stroke survivors

Almost all the patients had maximum scores in the cognitive and psychosocial domains of FIM therefore there was no correlation calculated for the domains as they were constant for all the patients.

Analysis of coping

The BRIEF COPE uses a 4-point Likert scale (I have not been doing this at all to I have been doing this a lot). It includes 14 subscales of two items each grouped into these three coping categories by summing items accordingly (with higher scores indicating a greater intensity of use of the coping strategy). The three coping strategies and their associated subscales were problem-focused coping (active coping, planning, instrumental support, and religion scales); active emotional coping (venting, positive reframing, humor, acceptance, and emotional support scales); and avoidant emotional coping (self-distraction, denial, behavioral disengagement, self-blame, and substance use scales).

Active emotional is the most used coping strategy by the carers of this group, and next most used method is problem focused, and avoidant emotional way were observed to be the least taken way which is a good sign [Table 4].

Multiple linear regression analysis with QOL of caregivers as the dependent variable and QOL, FIM, age of patient, and gender of patient did not show any significance.

Discussion

This study being hospital-based, significant correlation between QOL of patient and carers was expected. However, surprisingly we have not found any significant association of QOL of carers with that of the stroke survivors. The results obtained in the current study suggest that the caregivers' QOL and coping are neither interdependent nor is dependent on the patients' functional independence. There may be possibly more factors and their interaction effects than ones accounted for in the current study that may be influencing the caregiver's QOL.

Table 3: Correlation of quality of life of carers with different domains of functional independence measurement of patients

	Self-care	Sphincters	Mobility	Communication
QOL physical health	−0.028	0.260	0.291*	0.142
QOL psychological health	−0.001	+0.084	0.109	+0.169
QOL social relationship	−0.131	0.279*	0.124	−0.130
QOL environment	−0.141	0.036	−0.047	−0.003

*P<0.05. QOL: Quality of life

Table 4: Distribution of average scores for different coping indices

COPE (maximum score)	Mean (SD)	Median (IQR)
Problem focused (32)	23.85 (3.76)	24 (4)
Active emotional (40)	27.81 (3.60)	28 (4)
Avoidant emotional (40)	24.62 (5.15)	24 (7)

SD: Standard deviation; IQR: Interquartile range

The analysis of QOL data showed that the QOL of caregivers was good in all the domains, but the patient's QOL was good only in social relations [Table 1 and Figure 2]. The QOL scores of stroke survivors in this study are low in rest of the domains, and similar findings are reported by another Indian study.[16] There are studies emphasizing the importance of social support in having good QOL. The qualitative study done by Lynch *et al.* said that they found social support to be the first theme talked about by the patients. There have been reports of many stroke patients being deserted by their significant relatives which affect their QOL adversely.[17]

A study done by Bergström *et al.* reported that caregiver's perceived burden increases if the patients' satisfaction with life is low, while in our study, we found that both the caregivers and the takers had good QOL with respect to social support.[18] Overall, we believe that the possible reason for our study finding being different from the other Western studies could be the strong social support that is readily available.

In a study done in the UK, emotional status of both patient and caregiver, age and gender of caregiver, and their participation in caregiver training were found to be predicting caregivers' burden and QOL independently.[19] We found the relation of carers QOL with neither the gender of patients nor carers. In addition, unfortunately, we have no structured training program for the carers of stroke patients to help them get oriented to the task. Because there was no correlation found between the QOL of carers and patients, no special referral for rehabilitation was suggested for the carers.

The study by Berg *et al.* suggested that the stroke severity and patient's functional independence are associated and positively correlated to the prevalence of depression among the carers.[5] In the current study, all the patients had good cognitive and psychological scores suggestive of mild to moderate severity

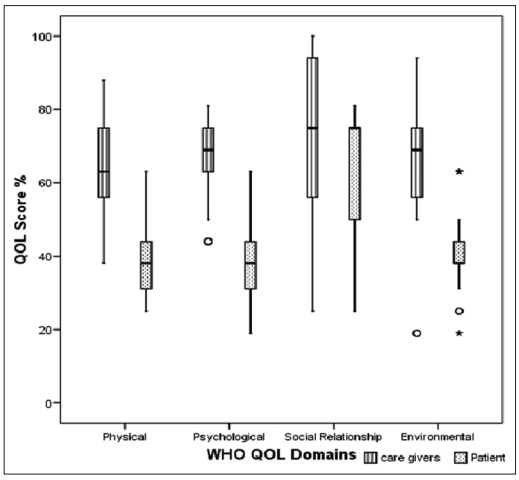

Figure 2: Distribution of quality of life domain wise for stroke survivors and the care givers

of stroke at the time of the study. Furthermore, none of the caregivers were found to be disturbed psychologically. Although we also got a positive correlation between social relations of caregiver and independence of patients in sphincter use, but other than that the FIM score of patients did not seem to influence the carers' QOL. In many studies, FIM of patients is found to be correlated with the QOL of carers at different time points.[20]

The domain wise mean scores of QOL of carers found in this study are comparable to a study conducted in Nigeria except for the environmental domain.[8] The mean environmental score is better in our study ($P < 0.01$). In the Nigerian study, it is also reported that anxiety and depression in caregivers did not have much significant correlation with the QOL domain scores.

Another study from South India has reported that the functional disability of stroke patients contributed to employment loss and decline in their social function too. Yet, similar to our findings, this did not significantly affect the caregivers' QOL.[21]

The caregivers' burden as found by the population-based study done in 2012 in Mumbai is inconvenience, demands on time, and financial stress.[22] Unfortunately, the current study does not have data on these parameters, making this a limitation of the study.

Understanding the need and importance of rehabilitation and lack of facilities in low-resource countries including India, there are web base modules developed which is smartphone-enabled educational intervention for management of physical disabilities following stroke called "care for stroke."[23] This module can also positively influence the caregiving burden of the carers in times to come.

Conclusion

QOL of stroke survivors is low in all domains except social relationship. Average QOL of carers is not correlating well with that of stroke survivors but this could be because of other confounding factors not accounted for in the study. The stroke patients required moderate assistance for their functional independence which does not seem to affect the caregivers QOL significantly except for the patient's sphincter use. As the patients' sphincter scores improved, the carers' QOL in social relationship domain improved.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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