EVALUATION OF QUALITY OF LIFE AND BURDEN ON INFORMAL CAREGIVERS OF STROKE SURVIVORS IN JALGAON DISTRICT.

Authors (to appear on the article; please list only Name, Department, Institution, City, Country, Email):

1Dr. Bhawani Rana, Assistant Professor, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India 2Amar S. Damle, Intern, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India 3Dr. Kalyani Nagulkar, Professor, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India 4Dr. Darshana Chaudhari, Assistant Professor, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India

ABSTRACT

Aim: To assess quality of life and burden of caregivers of stroke survivors.

Background: Disability due to stroke lead to deterioration of quality of life not only patient but also of their caregivers. Identifying the level of burden and quality of life of patient’s caregivers will allow us to improve rehabilitation intervention for patients as well as caregivers.

Method: It is a cross sectional study including 82 caregivers of patients with hemorrhagic and ischemic stroke. Data were collected by demographic proforma, WHOQOL- BREF for assessing quality of life of caregivers, Zarit burden interview (ZBI-12) for burden, Modified Rankin scale for assessing level of disability of patients.

Result: 82 caregivers were evaluated. Caregivers of stroke survivors had mean age 34.92±8.94. The average level of disability of patient is 3.59±0.85. The mean score for quality of life domains were 51.76±11.03, 46.89±12.08 32.08±16.46 46.08±12.81 for physical, psychological, social and environmental domains respectively. The mean score of level of burden on caregivers was 22.84±4.23. Stroke caregivers of stroke survivors were under high level of burden and their quality of life also reduced. There was significant negative correlation found between quality of life and level of burden of caregivers.

Conclusion: Informal caregiver of stroke survivors had high level of burden and low quality of life. Caregiver’s burden and their quality of life should be given adequate attention during interventional therapy.

Keywords: Burden, informal caregivers, quality of life, stroke survivors
INTRODUCTION

Globally, stroke is the second most common cause of mortality and produces chronic disability among patients. Various studies have reported that 55%-70% of stroke survivors recover and become almost independent in one year whereas 7%-15.7% patients develop complete disabilities.

According to worldwide statistics from 2004 which included 192 WHO member countries, the stroke related disability adjusted life year (DALY) loss was from 160-2192/100000 person per year from different countries. Same time DALY loss in India was 597/100000 person per year (Banerjee et al 2013). It was estimated that 43% of caregivers were remained under stress for 3 months of post stroke phase, 43% caregivers were under stress for 6 months after stroke occurance. Studies from lete disability (Das et al, 2007).[1]

Studies from developed and developing countries have shown that caregivers of stroke survivors suffer in different forms such as physical, psychological, social, economic and spiritual which produces undue stress on caregivers and result in their poor quality of life.[1]

For the stroke survivors, consequences of stroke include having to depend on others to perform their activities of daily living and disruption of their social life. This fact has negative impact on the quality of life of patients and also their relatives who usually become their main caregivers taking on the caregiving role is a significant source of stress increasing the caregiver’s risk of developing various physical and mental health problems. [3]

Strong association has been found between mental disorder in caregivers with their burden due to severe disability of patients after stroke; depression, anxiety and the impact of mental stress on caregiver’s physical health has been show high; the increased rates of depression in caregivers, ranging between 34-52% due to reduced social activity of caregivers, patients functional disability and level of dependence. [5]

Quality of life is a complex, multidimensional construct and existing measure of QOL include large domains. It is important indicator to determine the effectiveness of treatment and rehabilitation. [5]

Studies have shown that caring for stroke survivors, especially those with disabling condition, places an undue strain on the quality of life of caregivers. This may also threaten both the sustainability of home care and the recovery of stroke patient. Both patient and caregivers should be advised by the physicians and health care professionals to maximize their wellbeing. [3]

This study’s results may help in planning of educational strategies to maintain caregiver’s quality of life and can prevent development of morbidity.
MATERIALS AND METHODOLOGY

1. **Type of study:** Cross sectional study
2. **Sample size:** 82
3. **Study Design:** Observational study
4. **Method of sampling:** Convenient sampling technique.
5. **SELECTION CRITERIA:**
   a) **Inclusion criteria:**
   i. Healthy caregivers with age group of 20-60 year old.
   ii. Caregivers who stay with patient for minimum 2 weeks.
   b) **Exclusion Criteria:**
   i. Caregivers who were not willing to participate in study.
   ii. Caregivers suffering from medical and psychiatric condition.
   iii. Hospital staff and nurses.
   iv. Caregivers with age less than 18 years and more than 60 years.
6. **Study place:** Jalgaon District
7. **Study duration:** 6 months
8. **Materials required:** Pen, Paper,
9. **Outcome measures:** Demographic proforma, WHOQOL-BREF, Zarit burden interview questionnaire, Modified Rankin Scale.
PROCEDURE

1. Permission from ethical committee
2. Subjects were selected according to selection criteria
3. Informed consent was taken and the study was explained to the subjects
4. Subjects will be interviewed by therapist
5. Statistical analysis was done and result was concluded.
METHOD

Materials and methods: The study was conducted in Dr. Ulhas Patil Medical College and Hospital, Jalgaon between December 2020 and June 2021.

Participants: Participants were selected after meeting inclusion criteria. There was 82 informal caregivers of stroke survivors and data was collected by using WHOQOL-BREF for quality of life of caregivers, ZBI-12 for level of burden, Modified Rankin scale for level of disability of patient. Inclusion criteria consists of Healthy caregivers with age group of 20-60 year old, Caregivers who were present at the time of stroke, Caregivers who stay longer with patient. Exclusion criteria were Caregivers who were not willing to participate in study, Caregivers suffering from medical and psychiatric condition, Hospital staff and nurses, Caregivers with age less than 18 years and more than 60 years.

Instruments: 1 trained researcher or physiotherapist obtained the necessary data from a caregiver of stroke survivor using the following instruments. For assessment of quality of life of caregiver WHOQOL-BREF was used. It is valid and reliable. It consisted of 26 items categorized under 4 domains namely- Physical (7 items), Psychological (6 items), Social (3 items), and Environmental (8 items). Getting high score in particular domain indicates better quality of life. The level of burden of caregivers was assessed by using Zarit burden interview-12. The ZBI-12 questionnaire was developed by Reever zarit and Peterson bach. A revised version consisted of 12 items with 5 points rating scale. Each question had option range from 0 (Never) to 4 (Nearly always). The burden score categorized as 0-10: no to mild burden, 10-20: mild to moderate burden, >20: high burden. For assessment of level of disability modified Rankin scale was used. The demographic data was collected by using demographic proforma. Each participants were interviewed for 4-5 minutes to 1 hour.

Statistical analysis: The data was entered into excel sheet and transformed into SPSS. The data was analyzed by using descriptive and interferential statistics. Data was expressed as mean ± SD for continuous variables and as percentages for categorical. A Pearson’s correlation coefficient is used to determine relationship between two variables.

RESULTS

A total 82 informal caregivers of stroke survivor participated in this study. Descriptive statistics of frequency distribution, mean and percentage were used to summarize the demographic information.

Socio-economic variables for caregiver have been presented in table 1. Most of the caregivers were female (55%) and male (45%). From the participants 42.24% were wives, 8.53% were husbands, 45.12% were son, 2.43% were daughters and 3.63% were mothers of patients. The mean age of caregivers was 34.9±8.94 years.
The education status of the caregivers of stroke survivors was as follows: 31.70% uneducated, 28.04% primarily educated, 34.14% secondarily educated and 6.09% were graduated. 26.60% were housewives, 9.75% were government employees, 18.29% were private sector employees and 46.3% were in other occupations.

63.41% caregivers were having monthly income less than 10k, and 36.58% caregivers were earning above 10k monthly.

The quality of life of caregivers according to domains is given in table 2.

The lowest mean score was in social health (32.08±16.46) and highest mean score was found in physical health (51.76±11.03). The mean score for psychological domain was 46.89±12.08 and for environmental domain was 46.08±12.8.

The mean caregiver’s burden was 22.84±4.23. The average level of disability of patient were moderately severe. Among all patients, 4.87% were slightly disabled, 50% were moderately disabled, 25.65% were moderately severely disabled and 19.51% were severely disabled.

There were significant inverse relationship between level of burden and quality of life of caregivers of stroke survivors. As correlation coefficient between level of burden & domains of quality of life were found to be -0.27,-0.039,-0.018 for physical psychological & social domain respectively.

There were inverse relationship found between quality of life of caregiver & level of disability of patient.

There were significant positive correlation found between level of burden of caregiver & level of disability of patient as correlation coefficient is 0.0975.
Table no.1 Socio-demographic characteristics of caregivers

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (in years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● 16-25</td>
<td>9</td>
<td>10.97%</td>
</tr>
<tr>
<td>● 26-35</td>
<td>40</td>
<td>48.78%</td>
</tr>
<tr>
<td>● 36-45</td>
<td>20</td>
<td>24.39%</td>
</tr>
<tr>
<td>● 46-55</td>
<td>9</td>
<td>10.97%</td>
</tr>
<tr>
<td>● 56-60</td>
<td>4</td>
<td>4.87%</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Male</td>
<td>37</td>
<td>45%</td>
</tr>
<tr>
<td>● Female</td>
<td>45</td>
<td>55%</td>
</tr>
<tr>
<td><strong>Relationship with patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Wife</td>
<td>33</td>
<td>40.24%</td>
</tr>
<tr>
<td>● Husband</td>
<td>7</td>
<td>8.53%</td>
</tr>
<tr>
<td>● Son</td>
<td>37</td>
<td>45.12%</td>
</tr>
<tr>
<td>● Daughter</td>
<td>2</td>
<td>2.43%</td>
</tr>
<tr>
<td>● Mother</td>
<td>3</td>
<td>3.65%</td>
</tr>
<tr>
<td><strong>Education status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● None</td>
<td>26</td>
<td>31.70%</td>
</tr>
<tr>
<td>● Primary</td>
<td>23</td>
<td>28.04%</td>
</tr>
<tr>
<td>● Secondary</td>
<td>28</td>
<td>34.14%</td>
</tr>
<tr>
<td>● Graduate</td>
<td>5</td>
<td>6.09%</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Housewife</td>
<td>21</td>
<td>26.60%</td>
</tr>
<tr>
<td>● Private job</td>
<td>15</td>
<td>18.29%</td>
</tr>
<tr>
<td>● Government job</td>
<td>8</td>
<td>9.75%</td>
</tr>
<tr>
<td>● Other</td>
<td>38</td>
<td>46.3%</td>
</tr>
<tr>
<td><strong>Family income (per month)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● &lt;10k</td>
<td>52</td>
<td>63.41%</td>
</tr>
<tr>
<td>● &gt;10k</td>
<td>30</td>
<td>36.58%</td>
</tr>
<tr>
<td><strong>Care given time</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Both day &amp; night</td>
<td>76</td>
<td>92.68%</td>
</tr>
<tr>
<td>● Day time</td>
<td>6</td>
<td>7.31%</td>
</tr>
<tr>
<td>● Night time</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Graph no. 1 shows Age wise distribution of caregivers

![Bar Chart: Age wise distribution of caregivers](chart1.png)

Graph no. 2 shows Gender wise distribution of caregivers

![Pie Chart: Gender wise distribution of caregivers](chart2.png)
Graph no.3 shows Relation wise distribution of caregivers

![Graph showing relation wise distribution of caregivers]

Relation wise distribution of care givers

Graph no.4 shows education status wise distribution of caregivers

![Graph showing education status wise distribution of caregivers]

Education status wise distribution of care givers graph 4
Graph no. 5 shows Occupation wise distribution of caregivers.

Graph no. 6 shows Disability wise distribution of caregivers.
Table no.2 Shows WHOQOL-BREF mean score of caregivers of stroke survivors

<table>
<thead>
<tr>
<th>Domains of quality of life</th>
<th>Mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>51.76±11.03</td>
</tr>
<tr>
<td>Psychological</td>
<td>46.89±12.08</td>
</tr>
<tr>
<td>Social</td>
<td>32.08±16.46</td>
</tr>
<tr>
<td>Environmental</td>
<td>46.08±12.81</td>
</tr>
</tbody>
</table>

Table no.3 Relationship between Quality of life and level of burden

Above table shows the inverse relation between physical, psychological and social domains of quality of life and level of burden (-1<r<0), whereas positive relation between environmental domain of life and level of burden (0<r<1).

\( r = \text{pearson’s coefficient of correlation.} \)
Table no.4 Relationship between Quality of life of caregiver and level of disability of patient

<table>
<thead>
<tr>
<th>Domains of WHOQOL BREF</th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZBI Score</td>
<td>-0.2715</td>
<td>-0.039</td>
<td>-0.018</td>
<td>0.0038</td>
</tr>
</tbody>
</table>

Above table shows the inverse relation between all domains of quality of life of caregivers and level of disability of patients (-1<r>0)

r = pearson’s coefficient of correlation.

Table no.5 Relationship between level of burden of caregiver and level of disability of patient

<table>
<thead>
<tr>
<th>Variables</th>
<th>Level of burden of caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Disability of patient</td>
<td>r = 0.0975</td>
</tr>
</tbody>
</table>

Above table shows positive correlation between level of disability of patient and level of burden of caregivers, as (0<r>+1)

r = pearson’s coefficient of correlation.

DISCUSSION

The main objective of rehabilitation in stroke patient is to maximize their functional capacity and quality of life and relatives have essential role in this process. Around half of the people who have had a stroke have some difficulties in performing activities such as walking, dressing, bathing, and other activities of daily living. [3]

The stroke is the most common chronic neurological disease and is one of the main cause of disability, morbidity and mortality worldwide. Rigby et al. have found that in caregivers
of stroke patient’s age, gender, poor mental health, functional disability were significant correlate with level of burden on caregivers. [5]

The majority of participants were female because in many societies women involve full in their family members with chronic disease care. The role of caregiver in the management of stroke patient is important and their quality of life should be emphasized which is influenced by their satisfaction with physical psychological, social and environmental wellbeing as well as the burden experienced by them.

It is clear from the result that the caring a stroke survivor negatively affect quality of life of caregivers. Developing countries like India where changes in lifestyle, ageing population and urbanization and industrialization have contributed in more numbers of communicable disease, including stroke (Dalal et al, 2007).

Almost all the four domains were equally affected. Studies result were corresponding with other study from India (Arathy et al., 2015). This is due caregivers have multiple responsibilities to deliver within the short time which leads to degradation of physical health. Most of the stroke patients fully or partially depend on caregivers for their activities of daily living.

The study show that caregivers were under high level of burden while caring a stroke survivors as the mean score of ZBI-12 was 22.84± 4.23. The results were compared with other studies (Carod-Artal et al.,2009)

Relationship between level of burden and quality of life of informal caregivers:

The burden suffered by informal caregivers in the course of taking care of stroke survivors was evident as the ZBI-12 score indicated that they had high level of burden. Akosile et al [6], reported similar findings as evident in this study that an inverse relationship existed between ZBI-12 score and quality of life domains physical (r= -0.2715), psychological (-0.039), social (-0.018) suggesting that an increase in burden of caregivers of stroke survivors may have negative impact on quality of life of these caregivers. (Table 3)

Relationship between level of disability of patients and quality of life of caregivers:

There is inverse relationship found between level of disability of patient and quality of life of caregiver. The more the level of disability of patient reduces the all the domains of quality of life of caregivers. (Table 4)

Relationship between level of disability of patient and level of burden of caregiver:

These study reveal positive correlation between level of disability of patient and level of burden of caregiver as r =0.097 ( Table 5)
CONCLUSION

- Informal caregiver of stroke survivor had high level of burden and low quality of life. Caregiver’s burden and their quality of life should be given adequate attention during interventional therapy.

LIMITATIONS OF THIS STUDY

Sample size was small. Further studies should be carried out by taking large sample size.

FUTURE SCOPE OF STUDY

- Further studies should be carried out for developing strategies for caregivers to reduce their burden and improve quality of life.
- Intervention of training about home care management of stroke survivor needs further research.

REFERENCES


