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):

[1]Dr. Bhawani Rana , Assistant Professor, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India [2]Amar S. Damle, Intern, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India [3]Dr. Kalyani Nagulkar, Professor, Dr. Ulhas Patil college of Physiotherapy, Jalgaon, India [4]Dr. 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 recovers and become almost independent in one year whereas 7%-15.7% patients develops 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]
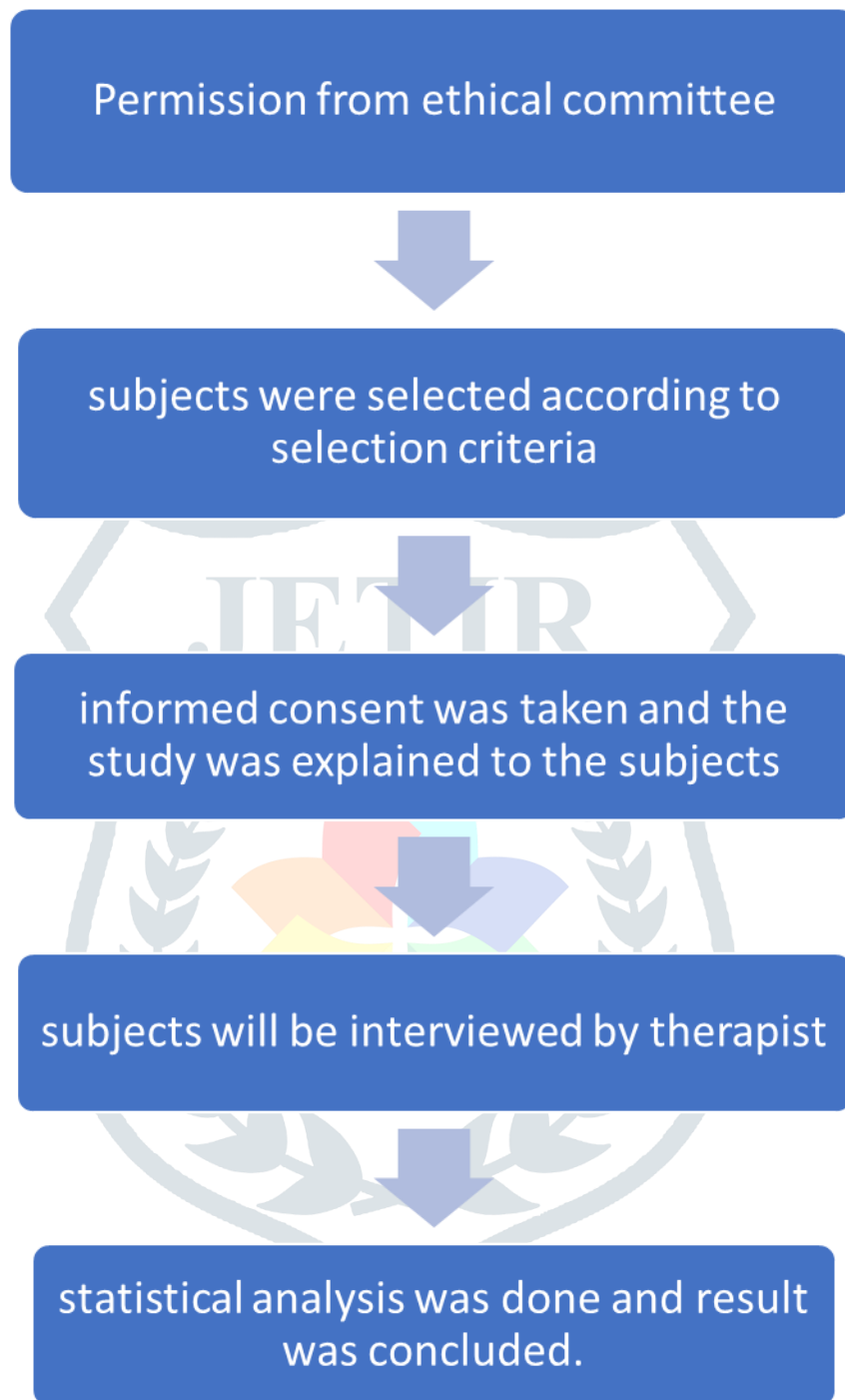
Studies have shown that caring for stroke survivors, especially those with disabling condition, places an undue strain on the quality of life of caregivers .This may also threaten both the sustainability of home care and the recovery of stroke patient. Both patient and caregivers should be advised by 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

Permission from ethical committee

⬇

subjects were selected according to selection criteria

⬇

informed consent was taken and the study was explained to the subjects

⬇

subjects will be interviewed by therapist

⬇

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

Variables	Frequency	%
Age (in years)		
● 16-25	9	10.97%
● 26-35	40	48.78%
● 36-45	20	24.39%
● 46-55	9	10.97%
● 56-60	4	4.87%
Gender		
● Male	37	45%
● Female	45	55%
Relationship with patient		
● Wife	33	40.24%
● Husband	7	8.53%
● Son	37	45.12%
● Daughter	2	2.43%
● Mother	3	3.65%
Education status		
● None	26	31.70%
● Primary	23	28.04%
● Secondary	28	34.14%
● Graduate	5	6.09%
Occupation		
● Housewife	21	26.60%
● Private job	15	18.29%
● Government job	8	9.75%
● Other	38	46.3%
Family income (per month)		
● <10k	52	63.41%
● >10k	30	36.58%
Care given time		
● Both day & night	76	92.68%
● Day time	6	7.31%
● Night time	0	0

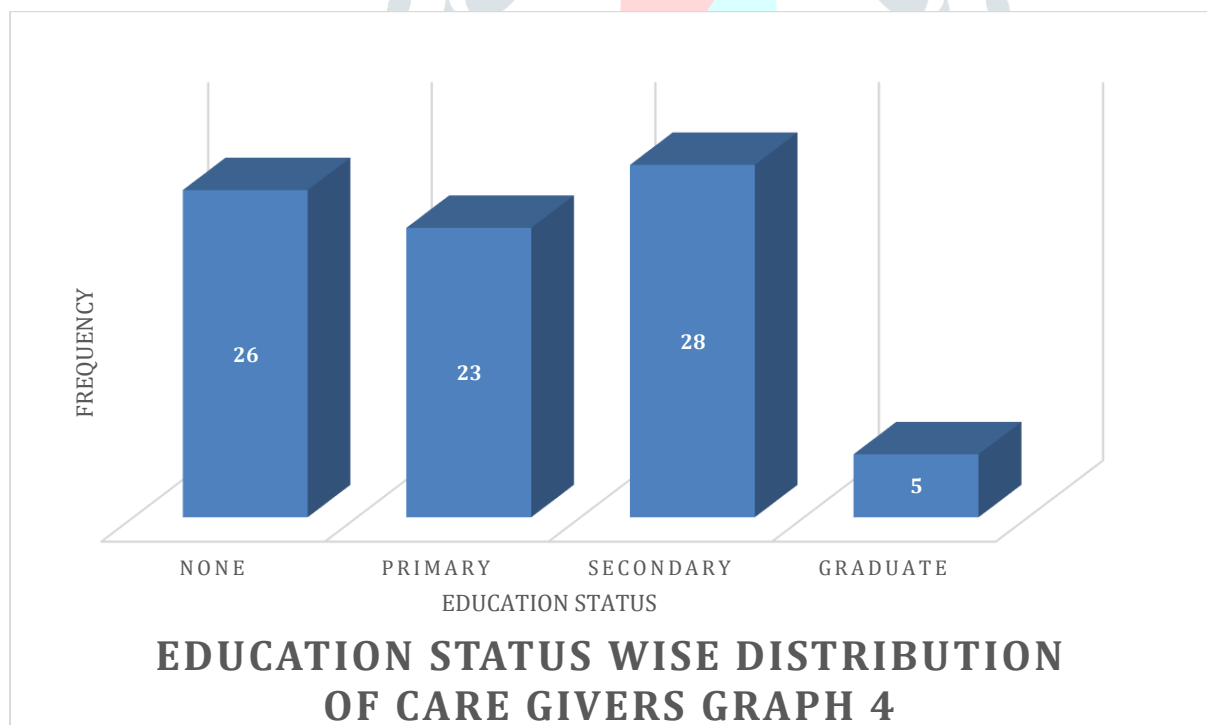Graph no. 1 shows Age wise distribution of caregivers
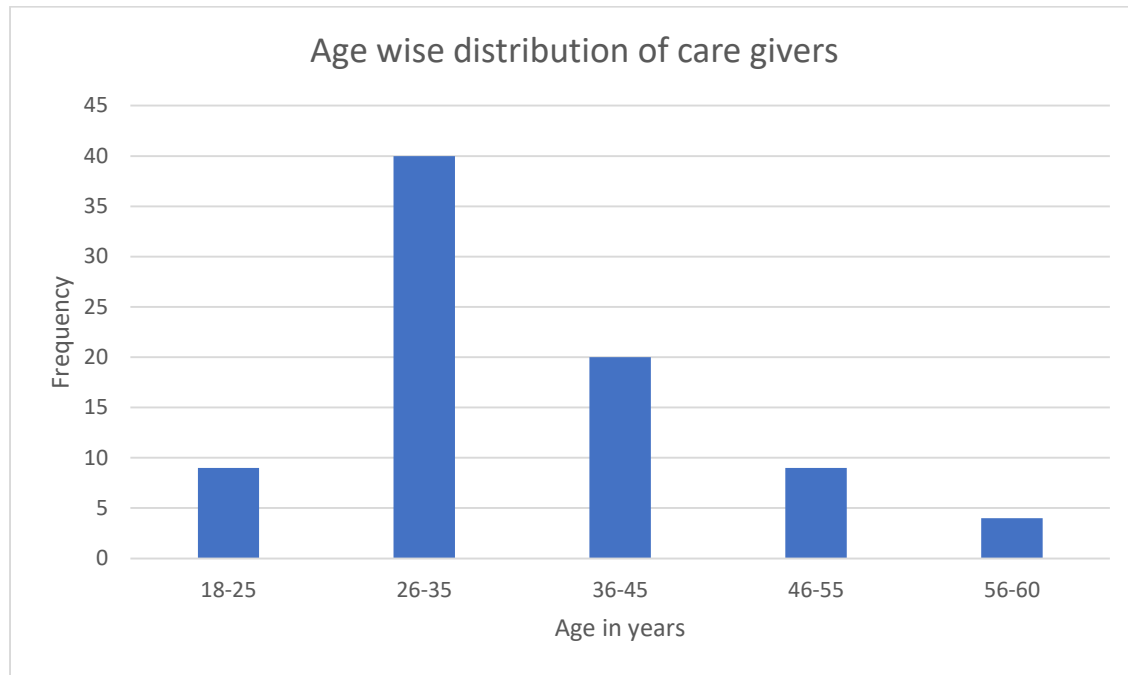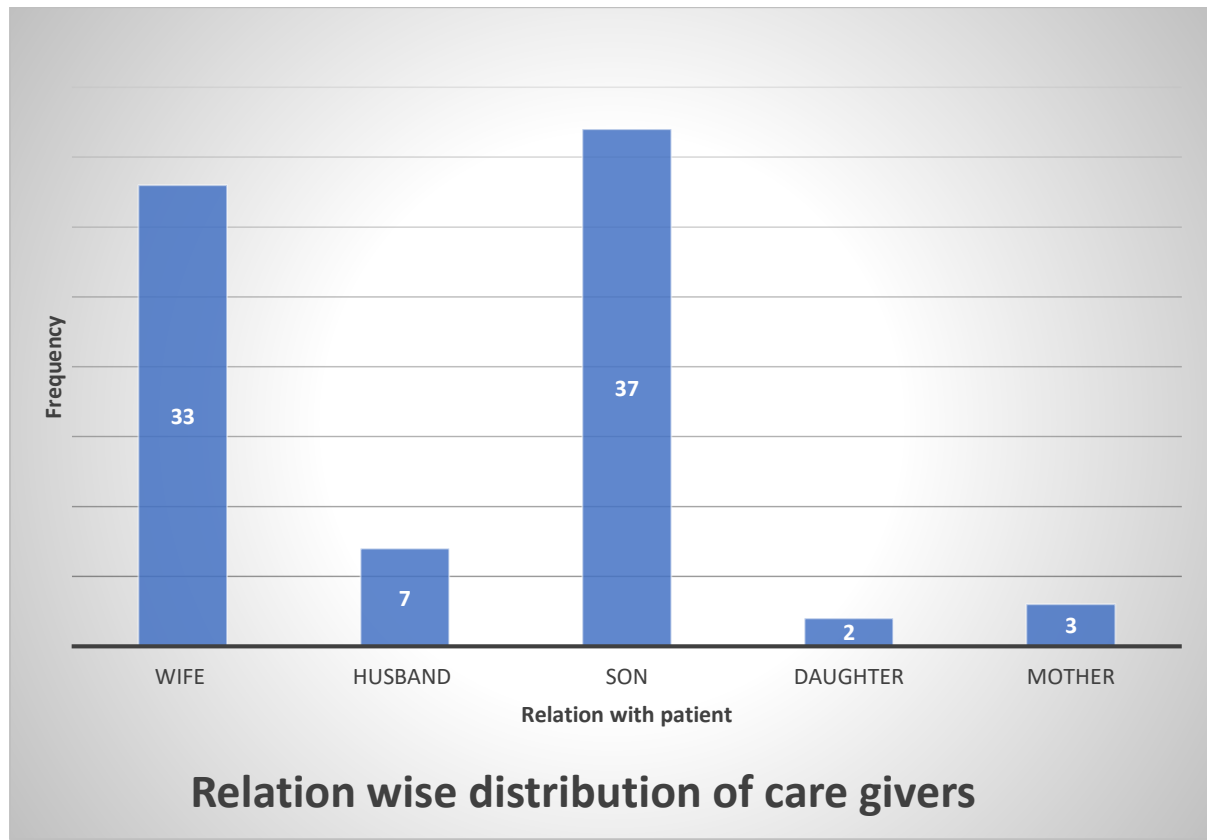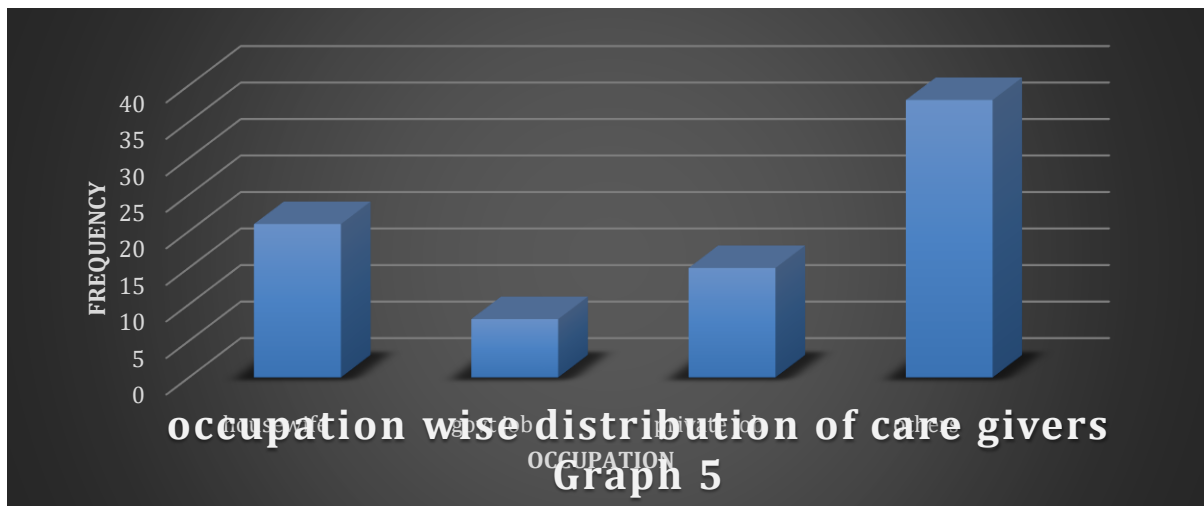

Graph no. 2 shows Gender wise distribution of caregivers
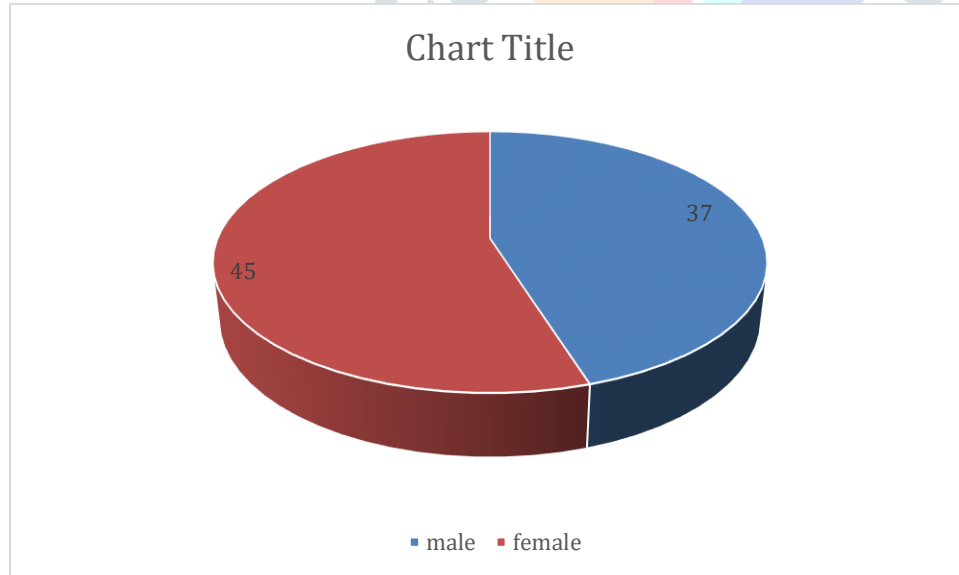
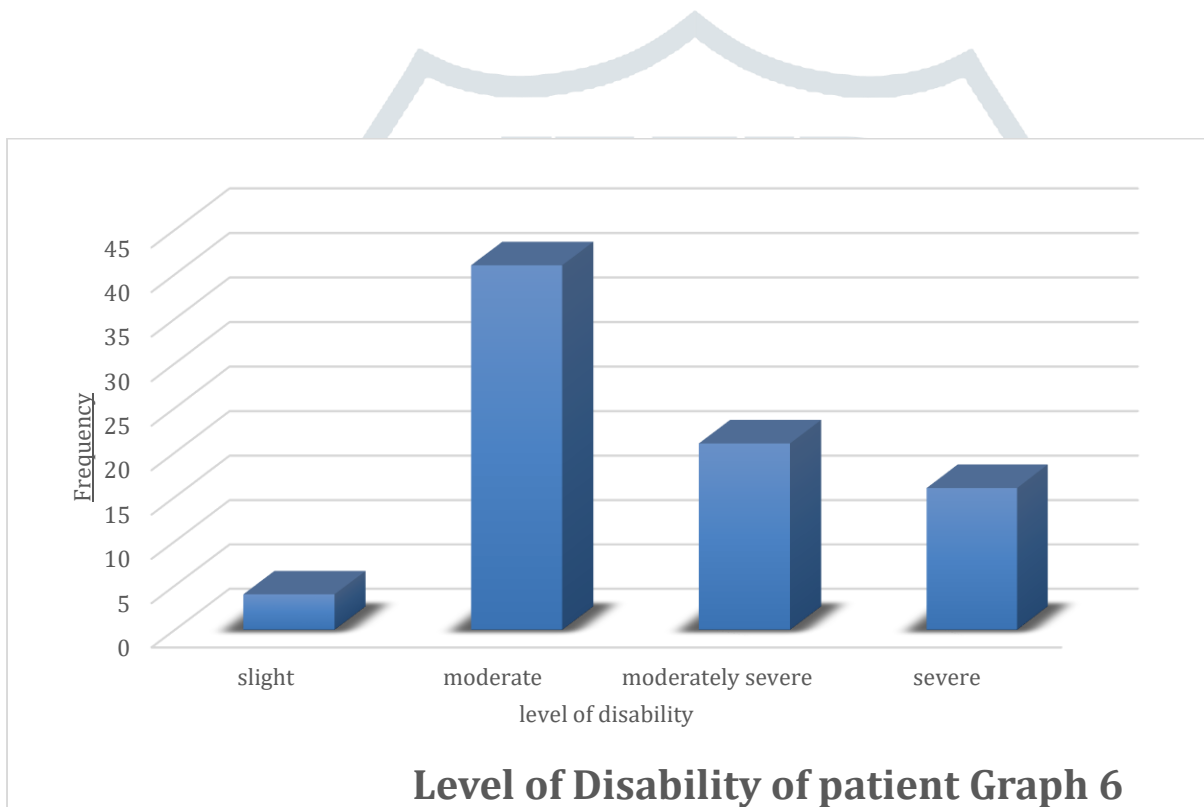Graph no.3 shows Relation wise distribution of caregivers

Relation wise distribution of care givers

EDUCATION STATUS WISE DISTRIBUTION OF CARE GIVERS GRAPH 4

Graph no.4 shows education status wise distribution of caregivers

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

Domains of quality of life	Mean $\pm SD$
Physical	51.76±11.03
Psychological	46.89±12.08
Social	32.08±16.46
Environmental	46.08±12.81

	Domains of WHOQOL BREF			
	Physical	Psychological	Social	Environmental
ZBI Score	-0.2715	-0.039	-0.018	0.0038

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), where as positive relation between environmental domain of life and level of burden (0<r>+1).

r = pearson's coefficient of correlation.

Table no.4 Relationship between Quality of life of caregiver and level of disability of patient

	Domains of WHOQOL BREF			
	Physical	Psychological	Social	Environmental
ZBI Score	-0.2715	-0.039	-0.018	0.0038

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

Variables	Level of burden of caregivers
Level of Disability of patient	r = 0.0975

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.

<u>REFERENCES</u>

1. Mamata Rawat and Rakesh Sharma (2017) burden of stroke survivor and caregiver and quality of life, International Journal of Current Research Vol.9 Issue 11, November,2017.

2. Michael O. Ogunlana (2013) Quality of life and burden of informal caregiver of stroke survivor. Hong Kong Physiotherapy Journal (2014) 32,6-12.

3. Pinedo S. And San Martin V. (2017) Quality of life of stroke patient and their caregivers. International journal of physical medicine and rehabilitation 2017.

4. Hashmi M, Khan M, Wasay M (2013) Growing burden of stroke in Pakistan: A review of progress and limitations. M Int J Stroke 8: 575-581.

5.   Parpa Efi and Katri Fani (2017) Quality of life and Psychological distress of caregivers of stroke people. Acta neurol taiwanica volume 26 number 4 December 2017.

6. Alkosile et al (2011)Quality of life and its correlatates in caregivers of stroke surviours fro m Nigerian population .Qual life Res 2011;20:1379-84

7. Farooq MU, Majid A, Reeves MJ, Birbeck GL (2009) The epidemiology of stroke in Pakistan: Past, present, and future. Int J Stroke 4: 381 -389.

8. Aly Z, Abbas K, Kazim SF, Taj F, Aziz F, et al. (2009) Awareness of stroke risk factors, signs and treatment in a Pakistani population. J Pak Med Ass 59: 495-499.

9. Kamal A, Itrat A, Murtaza M (2009) The burden of stroke and transient ischemic attack in Pakistan: A community-based prevalence study. BMC Neurology 9:58.

10. Das S, Paul N, Hazra A, Ghosal M, Ray BK, et al. (2012) Cognitive dysfunction in stroke survivors: A community-based prospective study from Kolkata, India. J Stroke Cerebrovasc Dis 22: 1233-1242.

11. Das S, Hazra A, Ray BK, Ghosal M, Banerjee TK, et al. (2010) Burden among stroke caregivers: Results of a community-based study from Kolkata, India. Stroke. 41: 2965-2968.

12. Gupta A, Pansari K, Shetty H (2002) Post-stroke depression. Int J ClinPract. 56: 531-537.

13. Lenzi GL, Altieri M, Maestrini I (2008) Post-stroke depression. Rev Neurol (Paris) 164: 837-840.

14. Seana LP, Jonathan WS, Helen MD, Geoffrey AD, Richard AL, et al. (2005) Long-term outcome in the North-East Melbourne stroke incidence study predictors of quality of life at 5 years after stroke. Thrift Stroke 36: 2082-2086.

15. Sulena S, Kumawat BL, Sharma AK (2016) Awareness of stroke among stroke patients in a tertiary-care level hospital in northwest India. Int J Med Sci Public Health 5: 1-5.

16. Reeves MJ, Rafferty AP, Aranha AAR, Theisen V (2002) Changes in knowledge of stroke risk factors and warning signs among Michigan adults. Neurology 59: 1547-1552.

17. Haghighi AB, Karimi AA, Amiri A, Ghaffarpasand F (1999) Knowledge and attitude towards stroke risk factors, warning symptoms and treatment in an Iranian population. Cerebrovasc Dis 9: 119-123.

18. Cheung RT, Li LS, Mak W, Tsang KL, Lauder IJ, et al. (1999) Cerebrovascular diseases knowledge of stroke in Hong Kong and Chinese. Cerebrovasc Dis 9: 119-123.

19. Sundseth A, Faiz KW, Ronning MO, Thommessen B (2014) Factors related to knowledge of stroke symptoms and risk factors in a Norwegian stroke population. J Stroke Cerebrovasc Dis 23: 18491855.

20. Barro RJ, Lee JW (1993) International comparisons of educational attainment. J Monet Econ.

21. Greenlund KJ, Neff LJ, Zheng ZJ, Keenan NL, Giles WH, et al. (2003) Low public recognition of major stroke symptoms. Am J Prev Med 25: 315-319.

22. Stern EB, Berman M, Thomas JJ, Klassen AC (1993) Community education for stroke awareness: An efficacy study. Stroke 30: 720-723.

23. Alberts MJ, Perry A, Dawson DV, Bertels C (1992) Effects of public and professional education on reducing the delay in presentation and referral of stroke patients. Stroke 23: 352-356.

24. Moser DK, Kimble LP, Alberts MJ, Alonzo A, Croft JB, et al. (2006) Reducing delay in seeking treatment by patients with acute coronary syndrome and stroke: A scientific statement from the American heart association council on cardiovascular nursing and stroke council. Circulation 114: 168-182.

25. Zivin JA (2009) Acute stroke therapy with tissue plasminogen activator (tPA) since it was approved by the US Food and Drug Administration (FDA). Ann Neurol 66: 6-10.

26. Schneider AT, Pancioli AM (2003) Trends in community knowledge of the warning signs and risk factors for stroke. JAMA 289: 343-346.

27. Kleindorfer D, Khoury J, Broderick JP, Rademacher E, Woo D, et al. (2009) Temporal in public awareness of stroke warning signs, risk factors, and treatment. Stroke 40: 2502-2506.

28. Jarou Z, Harris N, Gill L, Azizi M, Gabasha S, et al. (2013) Public stroke knowledge: Those most at risk, least able to identify symptoms. MSRJ 3.

29. Ciccone MM, Aquilino A, Cortese F (2010) Feasibility and effectiveness of a disease and care management model in the primary health care system for patients with heart failure and diabetes (Project Leonardo). Vasc Health Risk Manag 6: 297305.

30. Das S, Das SK (2013) Knowledge, attitude and practice of stroke in India versus other developed and developing countries. Ann Indian Acad Neurol 16: 488-493.

31. Wellwood I, Dennis MS, Warlow CP (1994) Perceptions and knowledge of stroke among surviving patients with stroke and their carers. Age Ageing 23: 293-298.