

IMPACT OF STROKE ON STATUS OF FAMILY AND CAREGIVERS: A SURVEY

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ABSTRACT

Stroke is a major health condition that causes long-term disability and places a significant emotional, physical, and social burden not only on patients but also on their families and caregivers. This study aimed to evaluate the impact of stroke on family caregivers using the Caregiver Strain Index (CSI) and the Zarit Burden Interview (ZBI) . An observational survey was conducted among 30 caregivers of stroke patients. Data were analyzed using descriptive and inferential statistics with Pearson's correlation. Results indicated that 80% of caregivers experienced high strain levels. The study highlights the need for better caregiver support, training, and counseling as an integral part of post-stroke rehabilitation.

Keywords:

Stroke, Caregiver Burden, Caregiver Strain Index, Zarit Burden Interview, Physiotherapy Rehabilitation

INTRODUCTION

Researchers and clinicians in stroke patients emphasize the vital role of family in the patient's rehabilitation, including physical, cognitive, and vocational recovery. Stroke negatively affects family functioning and satisfaction, with family members often taking on caregiving responsibilities after discharge. The recovery process and changes in the patient's abilities or personality can be particularly stressful for relatives, affecting their ability to manage work and household duties. Thus, family responses to stroke are of significant concern to rehabilitation professionals. However, there is a lack of sufficient empirical research on the family's role, which is crucial for improving rehabilitation practices and understanding family adaptation to stress [13,14,15].

Stroke is one of the main causes of acquired disability in most developed countries and considerably affects the life course of the victims [1]. Depending on the affected brain area, stroke can leave long-term impairments of motor, sensory, and/or cognitive functions, but is also associated with social changes [2]. At the occupational level, an average of two out of five stroke victims working at the time of occurrence were able to return to work; at the personal level, stroke can affect the relationships with children and the partners—including the sexual sphere—as well as deteriorate family dynamics and decrease participation in social activities [3, 4]. Since a majority of the survivors return home, their family caregivers, mainly their partners, also experience these social repercussions of stroke. Expected to provide complex care at home in addition to having new responsibilities (increased home tasks and duties, management of relationships with the professionals, etc.), these dependency workers [5] pose a risk for the healthcare system while their exhaustion increases and their cultural, social, and leisure activities decrease [6, 7]. This workload, in addition to their continual adaptation to the limitations of the patient, may isolate them socially. Thus, when they themselves are affected by the repercussions of the stroke as the caregiver, their capacity to remain healthy becomes a challenge for public health and health policies [8, 9].

Research Through Innovation

NEED OF THE STUDY :-

Stroke is a leading cause of long-term disability worldwide. After a stroke event, the quality of the relationship plays a key role on the respective well-being of the patient and the family caregiver [14]. Stroke caregivers have to deal with not only stroke patients' difficulties in mobility, self-care, and communication, but also their cognitive impairment, depression, and personality changes [16].

Understanding the psychological burden on caregivers is essential to improving patient care and developing appropriate support systems [12]. A strong association exists between the experiences of the patients and their family caregivers thus allowing the patient-caregiver dyads to be considered as entities [14]. This study is important to highlight the emotional, psychological, and social impacts of caregiving after a stroke. It will make much-needed valuable insight available to healthcare providers, policymakers, and families for improved mental health and care strategies for caregivers.

Study Design

A cross-sectional observational survey was conducted to assess the emotional, psychological, and social impact of stroke on family caregivers. The study aimed to determine the level of caregiver strain and burden using standardized assessment tools.

Data were collected from stroke rehabilitation centre, hospitals, and community-based caregiver networks in Pune, Maharashtra, India. Both urban and semi-urban participants were included to ensure representativeness.

Study Duration

The study was carried out over a period of six months (MAY TO OCTOBER 2025).

Study Population

The target population included family members who were the primary caregivers of stroke survivors undergoing rehabilitation or home-based care

Inclusion Criteria

1. Family members or relatives who were the primary caregivers of stroke survivors.
2. Both male and female caregivers aged above 18 years.
3. Participants who could understand and respond to the questionnaires in English, Hindi, or Marathi.
4. Caregivers providing continuous care for a minimum duration of six months.
5. Individuals who provided informed consent to participate in the study.

Exclusion Criteria

1. Professional or paid caregivers, such as nurses or attendants.
2. Caregivers with pre-existing major psychiatric disorders or neurological conditions.
3. Participants unwilling or unable to complete the questionnaires.
4. Caregivers with less than six months of caregiving experience.

Sample Size

A total of 30 caregivers meeting the eligibility criteria were selected using convenience sampling. This sample size was determined considering feasibility, study duration, and resource availability.

Study Tools

Two validated scales were used to measure caregiver strain and burden:

1. Caregiver Strain Index (CSI) – A 13-item questionnaire used to assess the level of strain experienced by caregivers. Each “Yes” response scores one point, and a total score of ≥ 7 indicates a high level of stress.
2. Zarit Burden Interview (ZBI) – The 22-item, 12-item, and 4-item versions were used to assess caregiver burden. Higher scores correspond to greater perceived burden.

Both tools have been validated in previous studies ZBI [18] CSI [19,20].

Data Collection Procedure

1. Ethical clearance was obtained from the Institutional Ethics Committee of TMV’s Jayantrao Tilak College of Physiotherapy, Pune.
2. Eligible participants were identified and recruited through rehabilitation centers and caregiver referrals.
3. After obtaining written informed consent, participants were interviewed using structured questionnaires (CSI and ZBI).
4. Demographic data such as age, gender, relationship to patient, employment status, and caregiving duration were recorded.
5. All responses were anonymized to maintain confidentiality.

Statistical Analysis

- Data were entered and analyzed using SPSS version 22.0.
- Descriptive statistics (mean, standard deviation, percentages) were used to summarize demographic and outcome variables.
- Inferential statistics were applied using Pearson’s Correlation Coefficient to determine relationships between the Zarit 22-item, 12-item, and 4-item scales.
- A p-value < 0.05 was considered statistically significant.

Ethical Considerations

- Informed consent was obtained from all participants.
- Confidentiality of all data was strictly maintained.
- Participation was voluntary, and participants were free to withdraw at any point without penalty.

RESULT AND STATISTICAL ANALYSIS

The study involved 30 caregivers aged between 25 and 69 years (mean ± SD: 42.76 ± 13.03). Among them, 50% were males and 50% were females. Spouses formed the largest group of caregivers (43.33%), followed by sons (30%), daughters (16.67%), and brothers (10%). Most caregivers were employed (50%), and 56.67% had been providing care for less than three years.

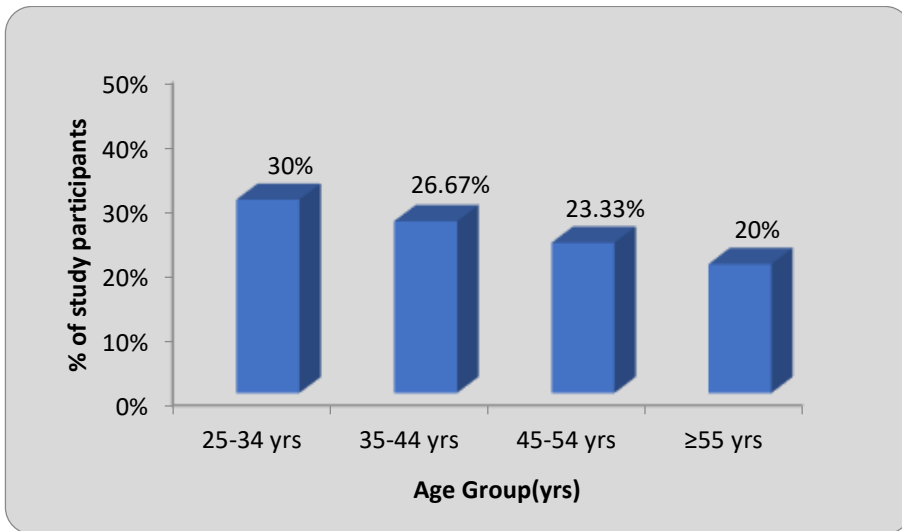
According to the Caregiver Strain Index (CSI), 80% of caregivers experienced high strain, 13.33% showed moderate strain, and 6.67% had mild strain. Correlation between Zarit 22-item, 12-item, and 4-item scales showed a strong positive relationship (p = 0.0001), confirming the consistency of the results.

Descriptive Statistics:

Table 1: Age wise distribution of study participants

Age Group(yrs)	No of study participants	Percentage
25-34 yrs	9	30
35-44 yrs	8	26.67
45-54 yrs	7	23.33
≥55 yrs	6	20
Total	30	100
Mean±SD	42.76±13.03(25-69 yrs)	

Graph 1: Age wise distribution of study participants



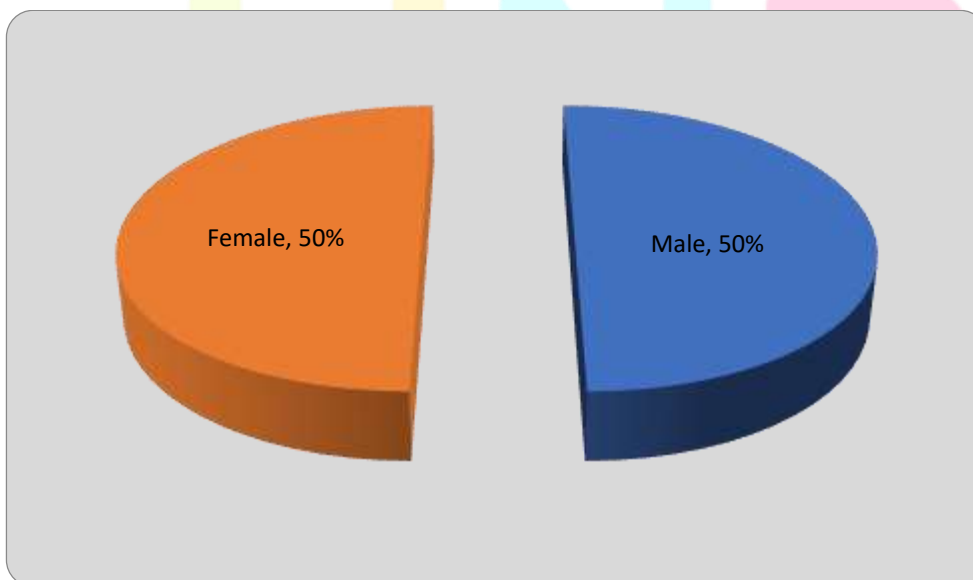
Interpretation:

The majority of caregivers (30%) belonged to the 25–34-year age group, followed by 35–44 years (26.67%), while a smaller proportion were above 55 years (20%). The mean age was 42.76 ± 13.03 years, indicating that caregiving responsibilities were primarily undertaken by young and middle-aged adults who are typically in their active working years. This suggests that caregiving may interfere with employment and family duties, potentially adding to stress and role strain.

Table 2: Gender wise distribution of study participants

Gender	No of study participants	Percentage
Male	15	50
Female	15	50
Total	30	100

Graph 2: Gender wise distribution of study participants



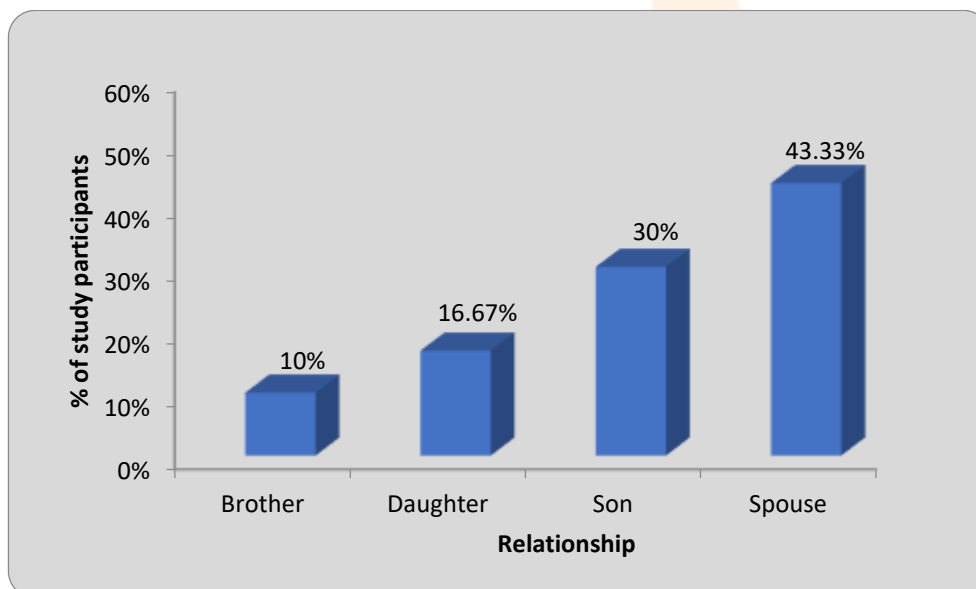
Interpretation:

Both male and female caregivers were equally represented (50% each). This indicates that caregiving responsibilities in stroke rehabilitation are not gender-specific in this population. However, qualitative observations revealed that female caregivers, especially spouses, often engaged more in daily physical assistance, while males were more involved in financial and logistical support.

Table 3: Relationship wise distribution of study participants

Relationship	No of study participants	Percentage
Brother	3	10
Daughter	5	16.67
Son	9	30
Spouse	13	43.33
Total	30	100

Graph 3: Relationship wise distribution of study participants



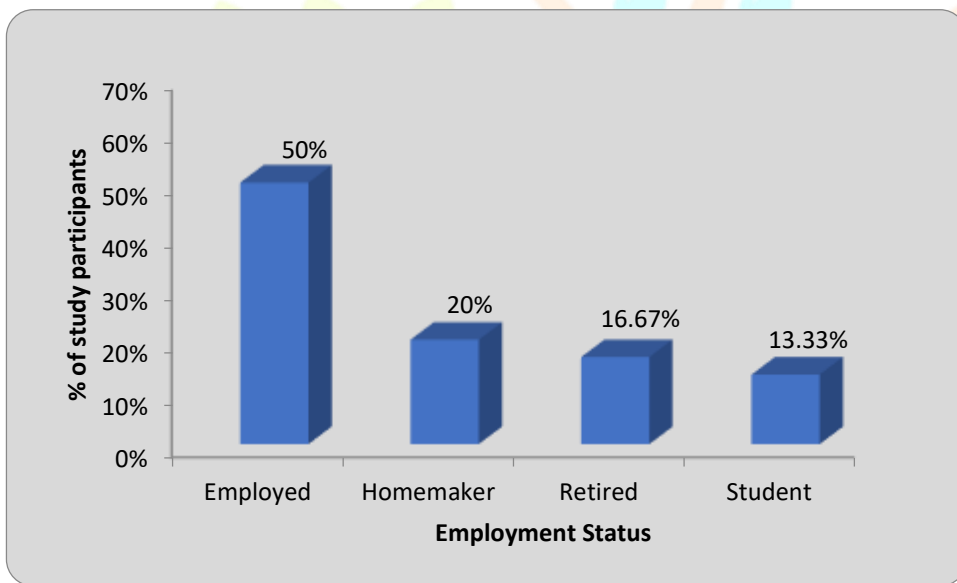
Interpretation:

The highest proportion of caregivers were spouses (43.33%), followed by sons (30%), daughters (16.67%), and brothers (10%). This highlights that stroke caregiving remains a family-centered duty, primarily carried out by immediate family members. The dominance of spousal caregivers also suggests the emotional and social depth of the caregiving role, which often extends beyond physical care to include emotional support.

Table 4: Distribution of study participants according to employment status

Employment Status	No of study participants	Percentage
Employed	15	50
Homemaker	6	20
Retired	5	16.67
Student	4	13.33
Total	30	100

Graph 4: Distribution of study participants according to employment status



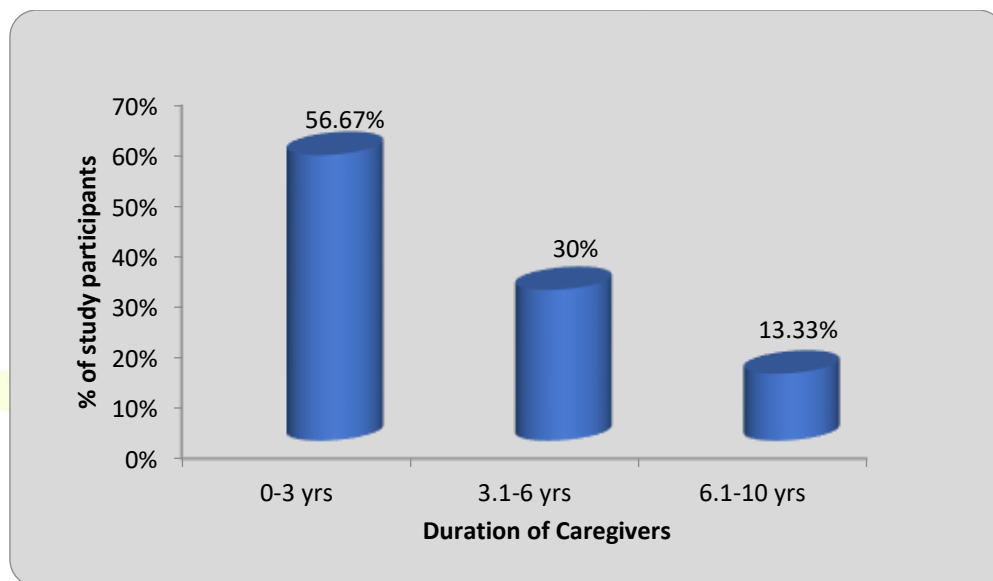
Interpretation:

Half of the caregivers (50%) were employed, while 20% were homemakers, 16.67% retired, and 13.33% students. The high number of employed caregivers indicates that many individuals balance caregiving with professional responsibilities. This dual role likely contributes to increased fatigue, time constraints, and reduced self-care — key factors influencing caregiver strain and burnout.

Table 5: Distribution of study participants according to duration of caregivers

Duration of caregivers	No of study participants	Percentage
0-3 yrs	17	56.67
3.1-6 yrs	9	30
6.1-10 yrs	4	13.33
Total	30	100
Mean±SD	3.63±2.40(6 months-10 yrs)	

Graph 5: Distribution of study participants according to duration of caregivers



Interpretation:

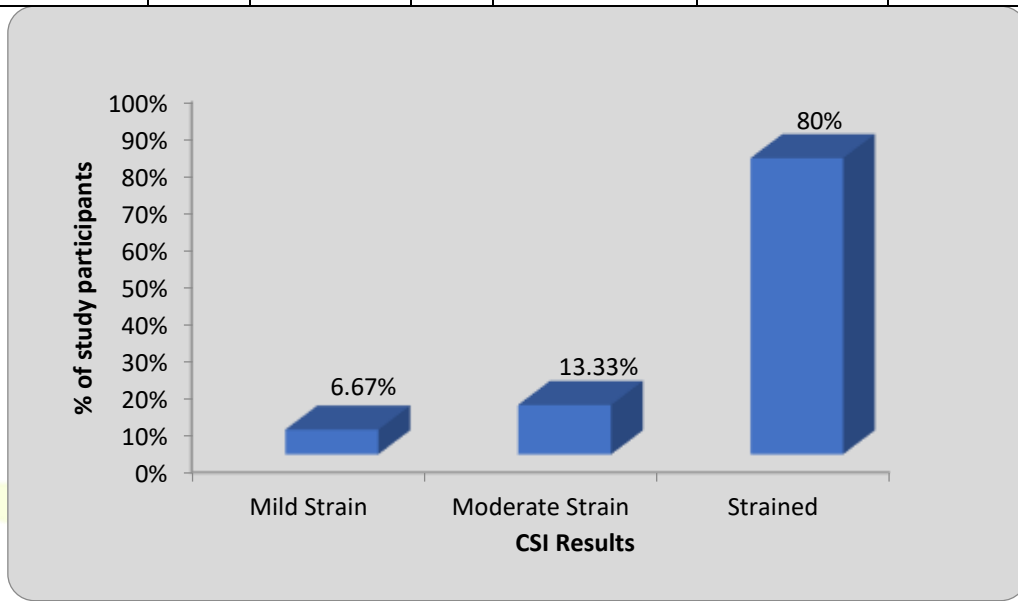
More than half of caregivers (56.67%) had been providing care for up to 3 years, and about one-third (30%) had done so for 3–6 years. Only a few (13.33%) had cared for 6–10 years. The mean caregiving duration was 3.63 ± 2.40 years, demonstrating that caregiving for stroke survivors is often a long-term commitment. Extended caregiving periods can result in cumulative stress, physical exhaustion, and emotional weariness.

Table 6: Distribution of study participants according to CSI results

CSI Results	No of study participants	Percentage
Mild Strain	2	6.67
Moderate Strain	4	13.33
Strained	24	80
Total	30	100

Graph 6: Distribution of study participants according to CSI results

	Mean	Std. Deviation	N	Correlation		
				Zarit 22-item Vs Zarit 12-item	Zarit 22-item Vs Zarit 4-item	Zarit 12-item Vs Zarit 4-item
Zarit 22 –item	50.53	15.56	30	0.986 p=0.0001,S	0.962 p=0.0001,S	0.974 p=0.0001,S
Zarit 12-item	20.16	5.25	30			
Zarit 4-item	10.66	3.29	30			



Interpretation:

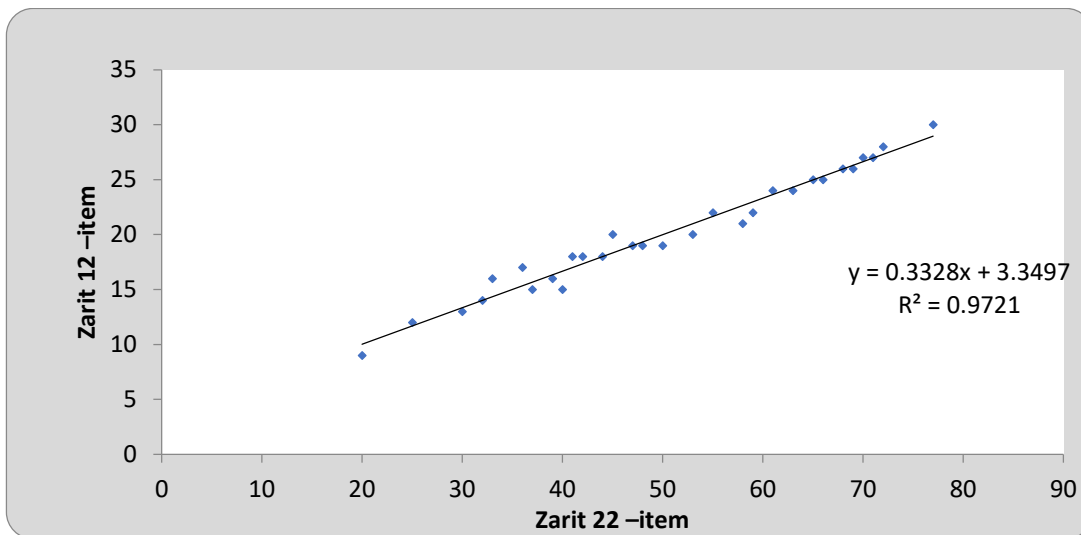
Based on the Caregiver Strain Index (CSI), 80% of caregivers were classified as “Strained”, 13.33% as “Moderately Strained”, and only 6.67% as “Mildly Strained.” This finding clearly indicates that most caregivers experience a high degree of burden due to stroke-related care demands. The elevated CSI scores reflect emotional fatigue, disturbed sleep, and reduced personal and social life. The results align with literature showing that stroke caregiving can significantly affect physical and psychological health.

Table 7: Correlation between Zarit 22-item, Zarit 12-item and Zarit 4-item score(Pearson’s Correlation Coefficient)

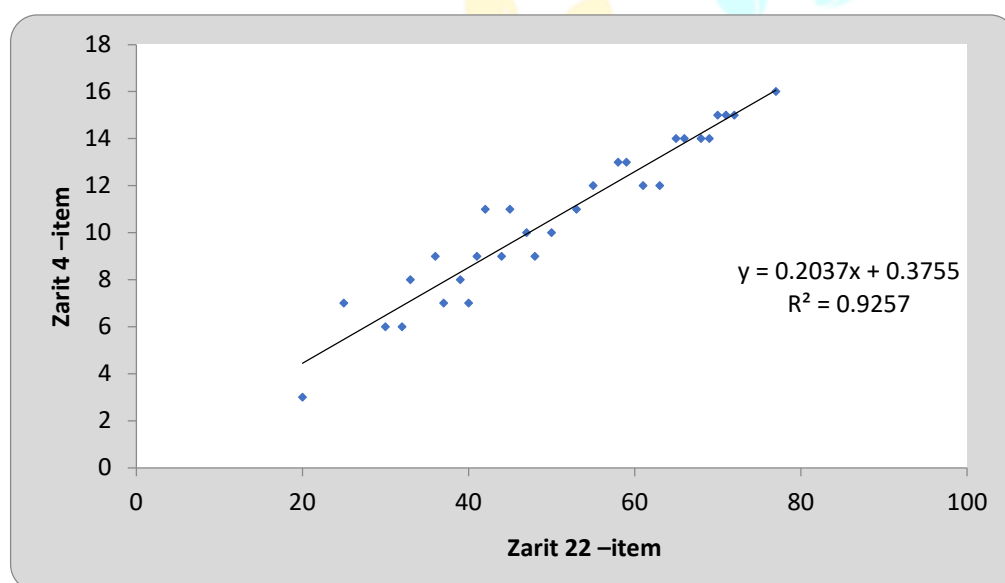
Interpretation:

Mean Zarit 22-item score was 50.53±15.56, mean Zarit 12-item score was 20.16±5.25 and mean Zarit 4-item score was 10.66±3.29. By using Pearson’s Correlation Coefficient statistically positive significant correlation was found between Zarit 22-item and Zarit 12 item score(r=0.986, p=0.0001), between Zarit 22-item Vs Zarit 4-item score(r=0.962, p=0.0001) and between Zarit 12-item Vs Zarit 4-item(r=0.974,p=0.0001).

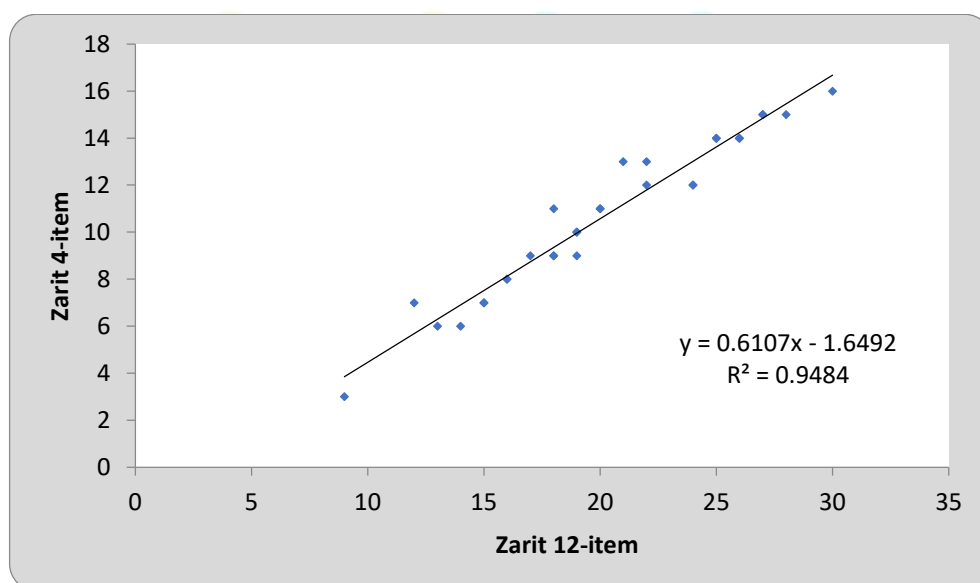
Graph 7.1: Correlation between Zarit 22-item, Zarit 12-item Score



Graph 7.2: Correlation between Zarit 22-item, Zarit 4-item Score



Graph 7.3: Correlation between Zarit 12-item, Zarit 4-item Score



Interpretation:

The mean scores were 50.53 ± 15.56 (Zarit-22), 20.16 ± 5.25 (Zarit-12), and 10.66 ± 3.29 (Zarit-4). A **high positive correlation** was observed among all three versions:

Zarit 22 vs. Zarit 12: $r = 0.986$, $p = 0.0001$

Zarit 22 vs. Zarit 4: $r = 0.962$, $p = 0.0001$

Zarit 12 vs. Zarit 4: $r = 0.974$, $p = 0.0001$

Statistical analysis was done by using descriptive and inferential statistics using Pearson's Correlation Coefficient and software used in the analysis was SPSS 22.0 version and $p < 0.05$ is considered as level of significance.

HYPOTHESIS TESTING

Null Hypothesis (H_0):

Stroke caregiving does not have a significant impact on the status of family caregivers.

Alternative Hypothesis (H_1):

Stroke caregiving has a significant negative impact on the status of family caregivers, leading to increased stress, anxiety, depression, and reduced quality of life.

Test Applied:

Pearson's Correlation Coefficient (r) was used to determine the relationship between different forms of the Zarit Burden Interview (22-item, 12-item, and 4-item), validating the consistency of caregiver burden measurement. Descriptive and inferential statistics were performed using SPSS version 22.0, and a p -value < 0.05 was considered statistically significant.

Comparison	Correlation Coefficient (r)	p-value	Significance
Zarit 22-item vs Zarit 12-item	0.986	0.0001	Significant
Zarit 22-item vs Zarit 4-item	0.962	0.0001	Significant
Zarit 12-item vs Zarit 4-item	0.974	0.0001	Significant

Interpretation:

All three versions of the Zarit Burden Interview showed a high positive correlation with each other ($r > 0.96$, $p < 0.05$). This indicates that caregiver burden was consistently identified across all scales, confirming the reliability of the findings.

Additionally, 80% of caregivers reported "high strain" according to the Caregiver Strain Index (CSI). This shows a strong convergence between CSI and ZBI results, supporting the hypothesis that stroke caregiving causes a substantial negative impact on caregivers' mental and emotional health.

Since the p -values (0.0001) are less than 0.05, the null hypothesis (H_0) is rejected and the alternative hypothesis (H_1) is accepted.

There is a statistically significant relationship between caregiving for stroke patients and the increased level of caregiver burden as measured by the CSI and ZBI scales. The findings confirm that stroke caregiving has a negative psychosocial impact on family caregivers, affecting their emotional well-being, social relationships, and daily functioning.

These results align with prior research showing that long-term stroke caregiving contributes to psychological stress, social isolation, and reduced quality of life, emphasizing the urgent need for caregiver support interventions within physiotherapy and rehabilitation programs.

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