

Lived Experiences of Primary Caregivers of Stroke Patients

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Abstract—The study titled “A Study to Explore the Lived Experiences of Primary Caregivers of Stroke Patients” aimed to investigate the complex emotional, social, and personal dimensions of informal caregiving. Utilizing a qualitative phenomenological research design, 15 primary caregivers were selected via purposive sampling methods until data saturation was achieved. Empirical data were collected through face-to-face semi-structured interviews and subsequently processed using Braun and Clarke’s thematic analysis framework. Eight predominant themes emerged from the structural analysis: transition into the caregiving role; nature of daily caregiving responsibilities; physical and psychological challenges; impact on personal, social, and work life; financial burden and resource constraints; coping strategies and sources of strength; support systems; and gaps in support and unmet needs. The empirical findings reveal that while caregiving is deeply meaningful, it induces profound multi-dimensional strain. The study concludes with a critical emphasis on the immediate implementation of structured educational frameworks, financial packages, and community-level respite resources to mitigate systemic caregiver burden.

Index Terms—Stroke, Primary Caregivers, Lived Experiences, Financial Burden, Coping Strategies, Phenomenology.

I. INTRODUCTION

Stroke is a major global health concern and stands as one of the leading causes of mortality and long-term disability worldwide. The clinical event occurs due to an acute disruption in the blood supply to the cerebral

cortex, resulting in immediate neurological deficits that necessitate prolonged medical treatment, stabilization, and tertiary rehabilitation. Continuous advances in acute clinical care have substantially optimized survival rates post-stroke; however, a large cohort of stroke survivors must live with severe residual impairments that necessitate continuous, long-term assistance.

With the shifting paradigms from hospital-based care to community- and home-based clinical management, the operational responsibility of caring for stroke survivors has transitioned largely to family members, designated as primary caregivers. These informal caregivers assist patients with essential activities of daily living (ADLs), physical mobility, complex medication adherence schedules, and intensive emotional support. The sudden, unannounced onset of a stroke combined with its highly unpredictable recovery trajectory places caregivers in a highly demanding role for which they are baseline unprepared.

Caregiving for stroke patients is highly correlated with severe physical, psychological, social, and financial challenges. Quantitative and qualitative literature indicates that caregivers frequently experience severe stress, clinical anxiety, depressive disorders, and a highly reduced quality of life (QoL) due to the chronic, relentless nature of their caregiving responsibilities. The exact severity of the caregiver burden is heavily modulated by extrinsic and intrinsic factors such as the functional severity of the patient’s disability, the continuous duration of

care, and the baseline availability of formal or informal social support networks.

Conclusively, mapping the lived experiences of primary caregivers is critical to identifying unmet systemic needs, operational challenges, and natural coping mechanisms. These contextual insights are vital to enabling healthcare professionals, community actors, and nursing practitioners to design targeted clinical interventions, counseling frameworks, and institutional support systems to systematically enhance caregiver well-being and secondary patient outcomes.

II. NEED AND SIGNIFICANCE OF THE STUDY

Stroke remains a primary driver of long-term disability and mortality, with a steep trajectory of increasing incidence within India driven by an aging demographic, rapid urbanization, and lifestyle-induced metabolic diseases. Stroke patients frequently experience severe cognitive and motor impairments, rendering them highly dependent on family caregivers. These caregivers, in turn, face extreme emotional, physical, social, and financial burdens. Prior empirical evidence drawn from quantitative, qualitative, and systematic review paradigms establishes that the overall caregiver burden is highly dependent on the degree of patient disability, caregiving duration, and baseline family socioeconomic status, and is robustly associated with severe psychological morbidity.

While select caregivers manage to construct functional coping mechanisms—including spiritual, cognitive, and psychological strategies—the majority report highly critical unmet needs, specifically a lack of institutional support, accessible health information, and formal respite care. Overall, the caregiving ecosystem is demanding and complex, highlighting the urgent requirement for structured, caregiver-focused clinical interventions and public policy support systems to protect the well-being of both caregivers and stroke patients.

III. STATEMENT OF THE PROBLEM

A qualitative phenomenological study to explore the lived experiences of primary caregivers of stroke patients in a selected community setting at Thrissur District, Kerala, India.

IV. OBJECTIVE OF THE STUDY

- To systematically explore the lived experiences of primary caregivers of stroke patients.

V. REVIEW OF LITERATURE

Extensive contemporary literature has evaluated the experiences and systemic burdens borne by caregivers of stroke patients, highlighting multi-dimensional operational challenges. Caregivers universally experience significant physical, emotional, and social strain, which is directly exacerbated by high patient dependency and a lack of formalized institutional support. Research consistently indicates that these individuals report chronic stress, physical fatigue, and low quality-of-life indices.

Furthermore, caregivers experience a sudden, unbuffered transition into their demanding role, inducing acute emotional distress, clinical uncertainty, and severe role strain. This sudden shift forces radical lifestyle modifications, profound social isolation, and highly altered family dynamics. Longitudinal evidence shows that caregiver burden increases linearly with the physical severity of the patient's disability and the chronological duration of the caregiving cycle, consistently contributing to anxiety and depressive symptomatology.

Global and regional data confirm that caregivers operate with vast unmet needs regarding information acquisition, emotional support, and practical caregiving skills. Targeted health education and professional counseling have been shown to significantly reduce caregiver burden and optimize adaptive coping. Within the specific Indian socio-cultural context, acute financial strain, rigid cultural expectations, and highly limited formal institutional support networks serve to intensify the caregiver burden. While caregivers often adopt personal coping strategies—such as drawing on family support systems, religious spirituality, and psychological acceptance—their core psychological, financial, and informational needs remain largely unmet by formal healthcare frameworks.

VI. RESEARCH METHODOLOGY

6.1 Research Approach and Design

This study implemented a rigorous qualitative research approach using an empirical phenomenological research design to uncover and systematically map the lived experiences of primary caregivers of stroke patients.

6.2 Setting and Population

The investigative field research was conducted within a designated community setting located in the Thrissur district of Kerala, India. The target population comprised active primary caregivers managing stroke survivors within home environments.

6.3 Sample and Sampling Technique

A sample size of N=15 primary caregivers was selected using a non-probability purposive sampling technique. The final sample size was determined strictly based on data saturation, where additional interviews yielded no novel conceptual themes. The inclusion criteria required a minimum continuous caregiving duration of three months.

6.4 Tool and Data Collection

The primary research tool consisted of a semi-structured interview schedule containing nine open-ended, expert-validated questions designed to elicit deep narrative descriptions. Data collection was executed via face-to-face, in-depth personal interviews. Formal written informed consent was obtained from each participant prior to initiating the audio-recorded interview sessions.

6.5 Data Analysis

The qualitative text corpora obtained from the interviews were transcribed verbatim and analyzed using the established thematic framework outlined by Braun and Clarke. This involved initial data familiarization, systematic generation of initial codes, searching for broader themes, reviewing and refining themes, and final naming and definition of explicit themes.

VII. RESULTS AND DISCUSSION

7.1 Demographic Characteristics of Primary Caregivers

The demographic profile of the participants was evaluated across multiple parameters, including age, sex, marital status, educational background, occupational status, relationship to the patient, duration of care, daily caregiving hours, monthly family income, presence of other dependents, and the baseline dependency level of the stroke patient.

Sl. No.	Demographic Variable	Category	Frequency (f)	Percentage (%)
1	Age (Years)	26–35	1	6.67
		36–45	2	13.33
		46–55	3	20.00
		56–65	5	33.33
		66–75	1	6.67
		76–85	3	20.00
2	Sex	Male	3	20.00
		Female	12	80.00
3	Marital Status	Married	15	100.00
		Unmarried	0	0.00
4	Educational Status	Illiterate / Primary	0	0.00
		Secondary Education	8	53.34
		Higher Secondary	2	13.33
		Intermediate	2	13.33
		Graduate	1	6.67
		Postgraduate	2	13.33

5	Occupational Status	Employed	2	13.33
		Not Employed	13	86.67
6	Relationship with Client	Spouse	13	86.67
		Child	2	13.33
7	Duration of Care (Years)	0–5	7	46.67
		6–10	6	40.00
		11–15	1	6.67
		16–20	1	6.67
8	Daily Caregiving Hours	0–6	2	13.33
		7–12	7	46.67
		13–18	1	6.67
		19–24	5	33.33
9	Family Income / Month	₹0–10,000	6	40.00
		₹10,001–20,000	5	33.33
		₹20,001–30,000	2	13.33
		₹30,001–40,000	1	6.67
		₹40,001–50,000	1	6.67
10	Other Dependents	Yes	6	40.00
		No	9	60.00
11	Patient Dependency Level	Independent / Partial	4	26.67

		Completely Dependent	11	73.33
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Data analysis from Table 1 illustrates that the standard majority of caregivers fall within the age range of 56–65 years (33.33%), are predominantly female (80%), are married (100%), and function as the direct spouse of the stroke survivor (86.67%). Educationally, 53.34% possess secondary school qualifications, while 86.67% are unemployed, having left or abstained from formal work to provide full-time care. Chronologically, 46.67% have provided care for 0–5 years, with another 40% managing 6–10 years. In terms of daily operational intensity, 46.67% dedicate 7–12 hours per day to caregiving, and 33.33% provide around-the-clock (19–24 hours) management. Financially, 40% survive within a low monthly bracket of ₹0–10,000. Strikingly, 73.33% of these caregivers manage stroke patients who are clinically categorized as completely dependent.

7.2 Qualitative Themes and Discussion

The thematic extraction process derived eight primary themes that explain the phenomenon of informal stroke caregiving:

- **Theme 1: Transition into the Caregiving Role:** Respondents reported an abrupt, unbuffered shift into caregiving immediately post-stroke, accompanied by acute emotional distress and profound psychological difficulty adjusting to the sudden operational responsibilities.
- **Theme 2: Nature of Daily Caregiving Responsibilities:** Daily tasks required direct management of basic ADLs, physical transfers, complex medication timing, and frequent clinical visits, which participants described as physically exhausting and highly demanding.
- **Theme 3: Physical and Psychological Challenges:** Caregivers presented with chronic physical fatigue, musculoskeletal issues, persistent emotional distress, and severe role overload stemming from unrelenting care demands.
- **Theme 4: Impact on Personal, Social, and Work Life:** Findings indicated a near-complete reduction in personal leisure and social activities,

severe loss of workforce participation, and altered internal family dynamics, which created an intense reliance on immediate family support.

- Theme 5: Financial Burden and Resource Constraints: The data revealed severe financial stress driven by high out-of-pocket medical costs and rehabilitation equipment expenses, compounded by limited access to state-sponsored transport or financial aid.
- Theme 6: Coping Strategies and Sources of Strength: Caregivers achieved psychological stability by relying on extended family support, internal philosophical acceptance, deep spiritual beliefs, and a strong sense of marital/filial duty and love.
- Theme 7: Support Systems in Caregiving: Participants described highly fragmented support, receiving mixed assistance from family and healthcare staff, while noting a severe lack of structured community nursing or social services.
- Theme 8: Gaps in Support and Unmet Needs: Critical systemic gaps were identified, specifically a lack of professional healthcare information, formal skills training, structured emotional counseling, and accessible regional rehabilitation care.

VIII. CONCLUSION AND RECOMMENDATIONS

8.1 Conclusion

This study highlights the irreplaceable role that primary family caregivers fulfill in the long-term management and rehabilitation of stroke survivors. The research shows that these caregivers carry a heavy burden across emotional, physical, social, and financial dimensions, often without any formal preparation, skills training, or institutional relief. Developing robust, formal support frameworks—specifically targeted caregiver education, mental health counseling, practical skills training, financial safety nets, and community-based home health services—is essential to protect caregiver health and improve clinical outcomes for stroke survivors.

8.2 Recommendations

- Design Structured Caregiver Programs: Formulate and launch hospital-led caregiver training programs that provide essential practical skills, anatomical safety guidance, and basic clinical training before patient discharge.
- Implement Supportive Public Policy: Propose state-level policy frameworks that provide direct financial allowances, subsidized medical supplies, and institutional respite services for home-bound caregivers.
- Expand Academic Research: Conduct large-scale, multi-center longitudinal studies to map the changing needs and health status of caregivers over extended caregiving timelines.
- Optimize Professional Training: Train hospital nursing staff and community health workers to proactively assess, document, and manage caregiver stress and health needs during clinical interactions.
- Establish Family-Centered Rehabilitation: Systematically integrate primary caregivers into formal stroke rehabilitation planning and multidisciplinary clinical decision-making processes.

8.3 Implications for Nursing Practice

- Clinical Education: Clinical nurses must design and deliver structured pre-discharge training modules focusing on patient transfer techniques, feeding practices, and medication management.
- Mental Health Systems: Institutionalize accessible psychological counseling and support groups for informal caregivers within tertiary care centers.
- Community Nursing: Transition from purely hospital-focused care to family-centered community nursing models that actively utilize home visits.
- Resource Linking: Nursing case managers must actively connect vulnerable, low-income caregiving families with available state aids and non-governmental community rehabilitation resources.

8.4 Limitations of the Study

- The small qualitative sample size (N=15) limits the direct statistical generalizability of these findings to larger national populations.
- The geographical scope was limited to a single district, potentially missing varying experiences from different socio-cultural landscapes.
- The study focused exclusively on primary caregivers, omitting secondary or paid care delivery perspectives.
- The reliance on self-reported narrative accounts introduces potential recall or social desirability biases.

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