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Problems Faced By Caregivers In Primary-Level Palliative Care: A Study In Pandalam Municipality.

Lakshmi N
(Assistant Professor, Department Of Economics, NSS College, Pandalam)

Dr. Pradeep Kumar B
(Principal & Professor, Government Arts & Science College For Women, Malappuram)

Abstract

Family caregivers constitute the cornerstone of community and home-based palliative care delivery. However, managing individuals with life-limiting conditions introduces profound systemic stress, often compromising the caregiver's own health, economic stability, and psychological resilience. This study identifies and evaluates the multidimensional (physical, emotional, financial, and social) challenges experienced by primary-level palliative caregivers. A descriptive cross-sectional study was conducted among randomly selected family caregivers registered under the Family Health Centre in Pandalam Municipality, Kerala. Data were collected via structured personal interviews and evaluated using descriptive statistical analysis. The demographic analysis revealed that 50% of the caregivers were middle-aged (46–60 years) and 55.56% identified as women. Chronic back pain emerged as the most prevalent physical ailment (36.6%), while baseline financial strain was the most prominent economic hurdle (43.33%). Caregiving in primary palliative settings significantly deteriorates the holistic well-being of family members. These findings underscore an immediate need for structured caregiver-centric interventions, targeted social policy reforms, and institutionalized support systems within the regional healthcare framework.

Keywords: *Palliative care, Primary-level care, Family caregiver, Home-based care, Kerala health model.*

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I. Introduction

Palliative care has fundamentally transformed modern healthcare by shifting the clinical focus from purely curative interventions to maximizing the quality of life for patients navigating life-threatening illnesses. According to the World Health Organization, palliative care constitutes an integrated approach designed to mitigate suffering through the early identification, impeccable assessment, and management of pain alongside physical, psychosocial, and spiritual challenges[1]. Palliative care is aimed at improving quality of life by employing what is called “active total care,” treating pain and other symptoms, at the same time offering social, emotional, and spiritual support [2].

Primary-Level Palliative Care in Kerala

Kerala has achieved global recognition as a pioneer in community-based healthcare models. This reputation is rooted in its decentralized, primary-level infrastructure, operationalized through initiatives like the Neighborhood Network in Palliative Care (NNPC) and government-supported primary health units. By embedding palliative services within local public health systems, the state relies heavily on a home-based care model.

However, this structural framework inadvertently shifts the daily operational burden onto unpaid family members. While the decentralized model successfully extends the reach of medical services, it creates an intense dependency on the family unit. Continuous caregiving without systematic institutional relief triggers multidimensional vulnerabilities, exposing caregivers to severe physical and psychological exhaustion[3].

The Strategic Role and Demands of Caregivers

The National Alliance for Caregiving [NAC] and AARP define caregivers as individuals who provide unpaid assistance to adults or children with specialized medical needs [4]. In the landscape of chronic and terminal illnesses, caregiving is traditionally perceived through a cultural lens of familial obligation and moral duty[5].

Sociological literature generally categorizes caregiving roles into four domains: family caregivers, professional/clinical caregivers, volunteer caregivers, and informal community networks. The precise vulnerabilities experienced by a family caregiver are highly variable, dictated by the patient's clinical pathology, the household's socioeconomic standing, existing community safety nets, and the caregiver's baseline physical health[6]. Given the growing reliance on home-based care models, a comprehensive investigation into caregiver precarity is essential for designing sustainable public health interventions and refining state welfare policies.

II. Methodology

This study utilized an exploratory, cross-sectional research design combining primary data with secondary literature. The study locale was restricted to Pandalam Municipality, Pathanamthitta district, Kerala.

- **Sampling Frame:** Family caregivers were randomly selected from the institutional registries of the Family Health Centre (FHC), Pandalam.
- **Data Collection:** Primary data were gathered through face-to-face personal interviews utilizing a validated, structured interview schedule. This instrument captured demographic variables alongside specific physical, emotional, social, and economic indicators.
- **Data Analysis:** The collected data were processed and analyzed using descriptive statistical methods, with findings presented via frequency distributions and percentage tables to highlight core thematic challenges.

III. Review Of Literature

The systemic vulnerabilities inherent to caregiving are well-documented across Indian public health literature. Sarkar S et al. (2018) evaluated the challenges of palliative caregivers in urban Pondicherry, observing that the intersections of physical exhaustion, psychological distress, and compounding financial strain necessitated dedicated institutional support mechanisms. Within the specific context of the Kerala health model, Kochuvilayil and Varma (2024) emphasized a critical demographic shift: aging caregivers experience an intensified care burden, signaling an urgent need to integrate geriatric health services with localized palliative care delivery.

Gendered dynamics remain a defining feature of unpaid care work. Jose (2023)[7] analyzed the experiences of female caregivers working within the ambit of the state's *Arogyakeralam Project*, establishing that women disproportionately absorb the emotional and unpaid economic shocks of home care, even when supported by mobile clinical teams. Expanding upon these systemic needs, Murali (2025)[8] conducted a comprehensive community study in rural South India, advocating for a paradigm shift from patient-centric clinical care to a holistic framework that treats the patient-caregiver dyad as a single, co-dependent unit of care.

IV. Results And Analysis

Socio-Demographic Profile

The socio-demographic indicators of the sample population show distinct vulnerabilities regarding age, gender, and economic capacity.

Table 1: Socio-Demographic Characteristics of Caregivers

Demographic Variable	Category	%
Age Distribution	Below 45 years	20.00%
	46–60 years	50.00%
	Above 60 years	30.00%
Educational Attainment	Primary / Upper Primary	53.33%
	Higher Secondary	20.00%
	Graduate and above	26.67%

Demographic Variable	**Category**	**%**
Gender Identity	Male	43.33%
	Female	56.67%
Socioeconomic Status	Above Poverty Line (APL)	46.67%
	Below Poverty Line (BPL)	53.33%

The data show that half of the active caregiving population (50%) falls within the 46–60 age bracket, representing a middle-aged cohort managing their own age-related physical transitions. A significant segment (30%) consists of geriatric individuals (above 60), who are highly vulnerable to physical strain. Corroborating global trends in unpaid care work, women represent the majority of primary caregivers (56.67%). Educational profiles indicate that 53.33% have only completed basic primary or upper primary schooling, which may limit their access to health literacy resources. Furthermore, more than half of the households (53.33%) live below the poverty line (BPL), signaling severe baseline economic vulnerability.

Psychosocial and Emotional Challenges

The psychological toll of managing a relative with a terminal illness is detailed in Table 2.

Table 2: Distribution of Emotional Challenges

Emotional Dimension	**%**
Grief	36.7%
Helplessness	36.7%
Anxiety	13.3%
Depression	13.3%
Total	**100.0%**

Grief and helplessness emerged as the dominant emotional responses, each reported by 36.7% of respondents. These figures illustrate the psychological exhaustion that comes with witnessing the prolonged decline of a family member. Chronic anxiety and clinical depressive symptoms accounted for the remaining 26.6%, indicating a clear need for professional psychological support.

Physical Health Deprivation

The labor-intensive nature of home-based palliative care causes direct physical strain, as quantified in Table 3.

Table 3: Reported Physical Ailments

Physical Condition	**%**
Back Pain	36.6%
Sleep Disturbances	30.0%
Joint Pain	26.7%
Migraine / Chronic Headaches	6.7%
Total	**100.0%**

Musculoskeletal issues were highly prevalent, with back pain affecting 36.6% of the sample, and joint pain reported by 26.7%. These ailments are directly linked to the physical demands of patient transfers, repositioning, and manual handling without assistive devices. Additionally, 30% of caregivers suffered from chronic sleep disturbances, driven by overnight care demands and constant vigilance.

Economic and Financial Strain

The intersection of medical expenses and reduced earning capacity creates substantial economic instability, as shown in Table 4.

Table 4: Economic Impact of Palliative Care

Financial Metric	%
General Financial Strain	43.33%
High Out-of-Pocket Medical Expenditure	33.30%
Resignation from Employment due to Care Duties	16.70%
Severe Poverty due to Loss of Primary Breadwinner	6.67%
Total	**100.0%**

General financial strain was the most prominent concern (43.33%), exacerbated by high out-of-pocket medical expenses (33.30%) for pharmaceuticals, wound care supplies, and specialized nutrition. This economic vulnerability is worsened by a shrinking income base: 16.70% of caregivers had to leave their jobs to provide full-time care, and 6.67% faced severe poverty following the loss of the household's primary income earner.

Social Isolation and Spatial Restrictions

Caregiving responsibilities also shrink the caregiver's social sphere, as detailed in Table 5.

Table 5: Social Dynamics and Restrictions

Social Constraint	**%**
Restrained Mobility / Inability to Travel	40.00%
Severe Time Deficits / Time Management Crises	33.33%
Social Isolation and Alienation	20.00%
Intra-familial Conflicts Regarding Care Allocation	6.67%
Total	**100.0%**

The primary social limitation was a loss of personal mobility, with 40% of respondents unable to leave the home or travel due to constant care duties. Time deficits affected 33.33% of the sample, leaving little room for personal care or rest. This structural isolation caused acute social alienation for 20% of the participants, while 6.67% faced intra-familial conflict over the distribution of caregiving responsibilities.

V. Discussion

The findings of this study demonstrate that while Kerala's decentralized, primary-level palliative model successfully delivers medical care to patients, it relies heavily on the unpaid labor of family members. The demographic data show that this caregiving burden is concentrated among middle-aged and elderly individuals (80% aged 46 or older) and falls disproportionately on women (56.67%). This reflects deeply ingrained gender expectations surrounding domestic labor and clinical care work, cross-validating the findings of specialized gender-centric public health audits in rural areas[7].

The physical health data point to a secondary health crisis among caregivers. The high rates of chronic back pain (36.6%) and joint pain (26.7%) indicate that family members are performing demanding nursing tasks—such as lifting and transferring immobile patients—without proper ergonomic training or mechanical aids. As demonstrated by Lithin et al. (2020)[9], progressive, chronic immobility in patients linearly accelerates the structural musculoskeletal breakdown of their immediate primary caregivers. Combined with widespread sleep deprivation (30%), these physical demands accelerate caregiver burnout and create long-term health liabilities for the caregivers themselves.

Financially, home care often leads to severe economic precarity. Over 53% of the sample lived below the poverty line, meaning the combination of high out-of-pocket medical costs (33.30%) and forced withdrawal from the workforce (16.70%) triggers severe financial distress. This matches the findings of Ranganathan et al. (2023), [10], whose national audit confirmed the devastating scope of "financial toxicity" borne by family members managing terminal conditions in India. This economic strain feeds back into the psychological domain, where widespread feelings of grief (36.7%) and helplessness (36.7%) are intensified by the financial difficulty of securing essential medical supplies. Furthermore, full-time hours spent caregiving without professional relief correlationally match high clinical depression patterns documented in regional primary systems [11].

Socially, the constant demands of caregiving restrict spatial mobility, leaving 40% of respondents unable to leave the home environment. This lack of mobility breaks down community connections, leading to chronic social isolation and a complete loss of personal autonomy.

VI. Conclusion And Policy Recommendations

Family caregivers are essential to the sustainability of primary-level palliative care, yet they bear a heavy physical, psychological, and financial burden. To prevent widespread caregiver burnout and improve the quality of community-based healthcare, the following systemic interventions are recommended:

1. **Institutionalized Respite Care Services:** The state should introduce structured respite care frameworks within local Family Health Centres (FHCs). Providing trained community volunteers or home-health aides to step in temporarily would give primary caregivers essential time for rest, personal care, and social connection.

2. **Ergonomic and Clinical Training Programs:** Local health networks should provide mandatory training modules on patient handling, ergonomics, and home-safety mechanics. Equipping caregivers with proper lifting techniques can directly reduce the high prevalence of musculoskeletal injuries like back and joint pain.
3. **Gender-Aware Support Frameworks:** Given that women provide the majority of unpaid home care, public health initiatives must offer targeted emotional support, mental health counseling, and peer support groups to address the specific vulnerabilities faced by female caregivers.
4. **Targeted Financial Assistance and Welfare Policies:** State palliative programs should integrate financial safety nets, such as direct cash transfers, subsidized pharmaceutical pipelines, and supply distributions (e.g., mobility aids, diapers, and nutritional supplements) for low-income and BPL households to ease out-of-pocket healthcare costs.
5. **Universal Psychosocial Counseling:** Routine psychological assessments and professional counseling sessions should be integrated into home-based clinical visits. Addressing caregiver grief, anxiety, and helplessness must be prioritized alongside treating the patient's clinical symptoms.

By adopting a caregiver-centric approach, public health policies can better support the well-being of family members, ensuring the long-term sustainability and effectiveness of community palliative care.

References:

[1]. Who, W. (2020). Palliative Care: Key Facts. World Health Organization. Https://Www.Who.Int/News-Room/Fact-Sheets/Detail/Palliative-Care

[2]. Government Of Kerala. (2008). Pain And Palliative Care Policy Of Kerala. Department Of Health And Family Welfare. Https://Palliumindia.Org/Wp-Content/Uploads/2022/09/Palliative-Care-Policy-Kerala-109-2008-Hfwd-Dated-15.4.08.Pdf

[3]. Kochuvilayil, A., & Varma, R. P. (2024). Understanding Caregiver Burden And Quality Of Life In Kerala’s Primary Palliative Care Program: A Mixed Methods Study From Caregivers And Providers’ Perspectives. International Journal For Equity In Health, 23(1), 92.

[4]. National Alliance For Caregiving. (2009). Caregiving In The Us: Executive Summary.

[5]. Jacob, S. L., Nayak, M. G., George, L. S., Macaden, L., & Braggs, P. L. (2025). Experiences And Perspectives By Family Caregivers On A Palliative Care Journey: A Case Report From India. Palliative Care And Social Practice, 19, 26323524251355286.

[6]. Sarkar, S., & Kar, S. S. (2018). Needs Of People Requiring Palliative Care In An Urban Area Of Pondicherry, South India: An Exploratory Study. National Journal Of Community Medicine, 9(05), 372-379.

[7]. Jose, F. (2023). Women Caregivers Of Palliative Care Patients: The Arogyakeralam Project In Kerala, India. Journal Of International Women's Studies, 25(3), 7.

[8]. Murali, A. J., Vasudevan, B., Varghese, R. G., Joseph, J., Areekal, B., Bhaskar, A., & Madhavikutty, G. D. (2026). Palliative Care Needs Of Patients And Caregivers In A Rural Low-And Middle-Income Country Setting. Palliative Medicine In Practice, 20.

[9]. Lithin, Z., Thomas, P. T., Warrier, G. M., Bhaskar, A., Nashi, S., Vengalil, S., ... & Pal, P. K. (2020). Palliative Care Needs And Caregiver Burden In Neurodegenerative Diseases: A Cross-Sectional Study. Annals Of Indian Academy Of Neurology, 23(3), 313-317.

[10]. Ranganathan, S., Tomar, V., Chino, F., Jain, B., Patel, T. A., Dee, E. C., & Mathew, A. (2023). A Burden Shared: The Financial, Psychological, And Health-Related Consequences Borne By Family Members And Caregivers Of People With Cancer In India. Supportive Care In Cancer, 31(7), 420.

[11]. Suresh, A., Ts, G., & Jaya, S. (2025). Factors Influencing Caregiver Burden And Its Prevalence Level Amongst Family Caregivers Of Patients With Palliative Care Needs And Serious Illnesses. Bmc Palliative Care, 24(1), 289.