A PILOT STUDY: DEVELOPMENT OF AN EFFECTIVE HOME-BASED PALLIATIVE-CARE TRAINING MODULE FOR RELATIVES OF CANCER PATIENTS IN RURAL INDIA

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ABSTRACT

Background: Family caregivers are central to home-based palliative care in rural India, where access to institutional services remains limited. Training relatives in symptom management, communication, and caregiver self-care can improve patient comfort and reduce caregiver burden. **Objective:** To review existing literature on caregiver training in palliative care and to outline a protocol for the development and pilot evaluation of a pictorial, competency-based training module for relatives of cancer patients in rural India. **Methods:** A narrative review was conducted using PubMed, Scopus, and Google Scholar for studies on caregiver training in palliative care, with emphasis on low- and middle-income country (LMIC) settings. Findings were synthesized to inform module design. A pilot study is proposed using a mixed-methods, pre–post intervention design in two rural districts of India. Fifty caregivers of advanced cancer patients will be recruited. The intervention will include an initial home-based session delivered by community health workers (CHWs), distribution of pictorial job aids, and structured follow-up visits. Primary outcomes will include caregiver knowledge, skills, and burden; secondary outcomes will assess patient symptom scores and unplanned hospital visits. **Expected Results:** It is anticipated that caregivers will demonstrate improved competency and reduced burden, with patients reporting lower symptom distress. Feasibility will be assessed through recruitment, retention, and acceptability. **Conclusion:** A structured, culturally adapted, home-based training module has the potential to strengthen palliative care in rural India by empowering caregivers. Pilot evaluation will provide evidence for scaling the model within community health systems.

KEYWORDS: Palliative care, caregiver training, rural health, cancer, home-based care, India.

INTRODUCTION

Cancer and its associated symptom burden represent a growing health challenge in low- and middle-income countries (LMICs), particularly India, where access to curative and supportive services is unevenly distributed. According to the Global Cancer Observatory (GLOBOCAN 2020), India recorded over 1.3 million new cancer cases and nearly 850,000 deaths annually. The majority of patients (close to 70%) present with advanced or metastatic disease, for which curative treatments are either unavailable or ineffective, thus making palliative care a central component of cancer care. The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through prevention and relief of suffering." This definition explicitly emphasizes the role of families, especially in settings where formal health infrastructure is limited.

Palliative care in rural India: an urgent need

India is home to nearly 65% of its population in rural areas, where access to oncology and specialist palliative care services remains poor. Most tertiary cancer centers are located in urban hubs, forcing rural patients to travel long distances, often at high financial and emotional cost. For advanced cancer patients, repeated hospital visits are not only unsustainable but also diminish the quality of remaining life. Consequently, home-based palliative care emerges as both a necessity and a preferred model in rural settings. However, the effectiveness of such a model is contingent upon the preparedness and capacity of family caregivers.

Role of family caregivers

Family caregivers—often spouses, children, or other close relatives—are the primary providers of physical, psychological, and social support in rural India. They are responsible for administering medications, assisting with feeding and mobility, providing wound and mouth care, monitoring symptoms, and making crucial decisions in collaboration with healthcare providers. Studies have shown that untrained caregivers frequently feel overwhelmed, anxious, and underprepared for these responsibilities, leading to high levels of caregiver burden, poor symptom control in patients, and avoidable hospital admissions.

In LMICs, caregivers may also encounter barriers such as low literacy, cultural stigma surrounding cancer and death, and inadequate access to essential medications like oral morphine. These challenges underline the importance of equipping caregivers with structured, culturally sensitive, and competency-based training tailored to their socio-economic and educational realities.

Evidence from existing models

Several models in India and globally demonstrate the feasibility and effectiveness of involving caregivers in palliative care delivery:

- **Kerala's Neighborhood Network in Palliative Care (NNPC):** This pioneering model mobilizes community volunteers and trains families to deliver essential care at home. It is globally recognized as a cost-effective, community-owned approach. However, it relies heavily on volunteer motivation and community funding, making replication outside Kerala challenging.

- **Tata Memorial Hospital's home-based palliative care program:** This initiative deploys professional teams to provide home care for advanced cancer patients in Mumbai. It demonstrates reductions in hospitalization and improvements in patient satisfaction. Nevertheless, it is resource-intensive and predominantly urban-centric.

- **Community health worker–facilitated models:** Recent feasibility studies in India have explored the use of Accredited Social Health Activists (ASHAs) and other CHWs as mediators of caregiver training and follow-up. These studies suggest that with appropriate training and supervision, CHWs can bridge the gap between professional palliative teams and rural families.

Internationally, systematic reviews and integrative analyses highlight the importance of caregiver education programs that are short, practical, pictorial, and role-play based. In high-income countries, caregiver training often involves detailed manuals and professional nurse visits, but these methods are less transferable to rural India where literacy levels are low, and resources are scarce.

Challenges in the Indian context

Despite these models, several barriers hinder the widespread development of caregiver training modules in India:

1. **Lack of standardized modules:** Existing efforts are fragmented, often localized, and not integrated into the national health system.
2. **Low literacy and health literacy:** Many caregivers cannot interpret written instructions or complex drug regimens.
3. **Limited access to essential medicines:** Regulatory restrictions and supply chain issues often limit access to opioids and other symptom control medications in rural areas.
4. **Cultural attitudes:** Discussions about death, dying, and pain management remain taboo in many Indian communities, reducing the willingness to engage with palliative concepts.
5. **Caregiver burden:** With multiple socio-economic responsibilities, caregivers often neglect their own health, leading to burnout and compromised patient care.

Why caregiver training matters

The literature consistently highlights that caregiver training has multiple benefits:

- **Improved patient outcomes:** Adequate symptom control, fewer complications, and reduced emergency hospital visits.
- **Reduced caregiver burden:** Increased confidence, self-efficacy, and psychological resilience.
- **Health system efficiency:** Lower demand on overburdened tertiary care hospitals, more cost-effective use of limited resources.
- **Societal value:** Culturally consonant with Indian traditions of family-centered care, training empowers families without displacing professional services.

A systematic approach to training—emphasizing practical demonstrations, pictorial job aids, and integration with existing community health structures—can help standardize palliative support across rural India.

Identified gaps in literature and practice

A review of the literature reveals that while many Indian studies acknowledge the role of caregivers, few have developed and tested structured, competency-based training interventions tailored to rural, low-literacy populations. Moreover, evidence on the feasibility and acceptability of pictorial and digital reinforcement strategies in rural India remains sparse. This gap underscores the need for piloting an integrated training module that is:

- **Competency-based:** Focused on observable skills rather than abstract knowledge.

- **Culturally adapted:** Reflecting local languages, traditions, and beliefs.
- **Low-literacy friendly:** Using visuals, pictograms, and oral reinforcements.
- **Integrated into PHC/CHW networks:** For sustainability and scalability.
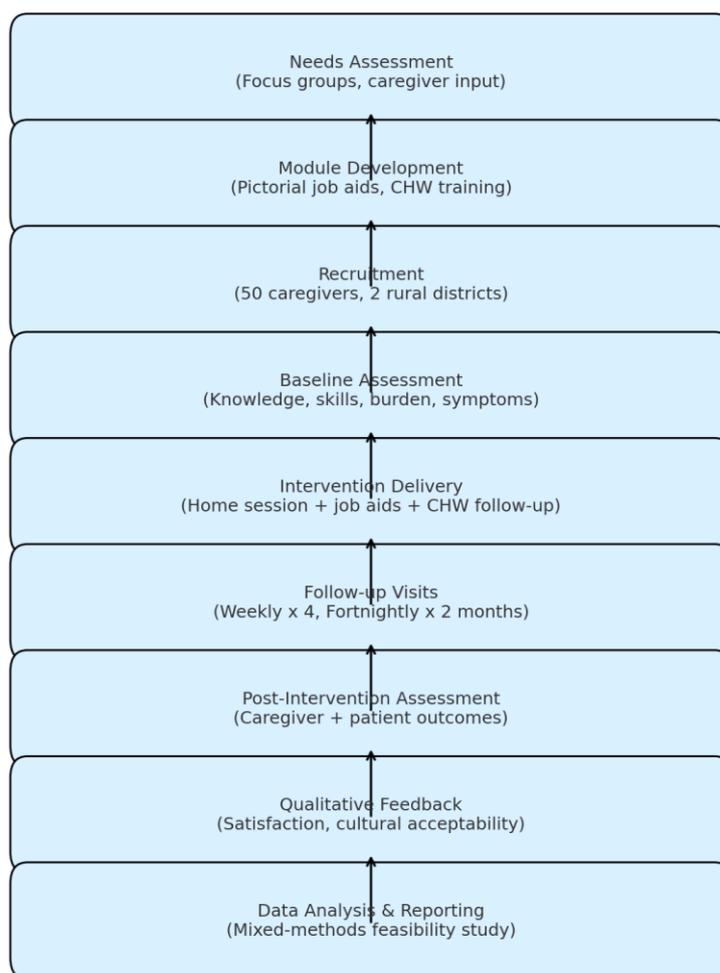
Study rationale

This study aims to address these gaps by developing and piloting a structured home-based training module for family caregivers of cancer patients in rural India. By combining pictorial job aids, CHW support, and mHealth reinforcement, the intervention seeks to enhance caregiver capacity, improve patient outcomes, and reduce avoidable healthcare utilization. The findings will inform future scale-up efforts and integration into national palliative care strategies.

METHODS

Study Design

This study is designed as a **mixed-methods, pre–post intervention feasibility trial**. A mixed-methods approach was chosen to provide both quantitative measures of caregiver knowledge, skills, and patient outcomes, as well as qualitative insights into the acceptability and cultural appropriateness of the training module. The pre–post design enables evaluation of changes attributable to the intervention, while feasibility testing will inform the refinement of the module before larger-scale trials.

Figure 1. Pilot Study Protocol Flow

Needs Assessment
(Focus groups, caregiver input)

Module Development
(Pictorial job aids, CHW training)

Recruitment
(50 caregivers, 2 rural districts)

Baseline Assessment
(Knowledge, skills, burden, symptoms)

Intervention Delivery
(Home session + job aids + CHW follow-up)

Follow-up Visits
(Weekly x 4, Fortnightly x 2 months)

Post-Intervention Assessment
(Caregiver + patient outcomes)

Qualitative Feedback
(Satisfaction, cultural acceptability)

Data Analysis & Reporting
(Mixed-methods feasibility study)

Study Setting

The pilot was conducted in two rural districts of India, each with a functioning network of **Primary Health Centres (PHCs)** and **community health workers (CHWs)** such as Accredited Social Health Activists (ASHAs) and Auxiliary Nurse Midwives (ANMs). Districts will be selected purposively based on:

1. Availability of cancer patients receiving palliative care at home.
2. Willingness of local health authorities to collaborate.
3. Connectivity for CHWs and minimal Health infrastructure to support reinforcement messages.

Study Population

Inclusion criteria

- Primary caregivers of adult cancer patients with advanced or metastatic disease requiring palliative care.
- Aged ≥18 years.
- Living within a 30 km catchment area of the PHC.
- Providing unpaid, daily care at home.
- Willing to provide informed consent.

Exclusion criteria

- Paid or professional caregivers.
- Patients expected to survive less than 2 weeks (to avoid ethical concerns and minimize attrition).
- Caregivers with severe cognitive impairment or inability to communicate.

Sample size justification

As this is a pilot feasibility study, a sample size of **50 caregivers** was proposed. This number is sufficient to test recruitment and retention rates, assess outcome variability, and generate effect size estimates for future powered trials. Feasibility will be considered achieved if recruitment ≥70% and retention ≥80%.

Recruitment Strategy

- Patient lists were obtained from district hospitals, oncology clinics, and PHCs.
- Eligible caregivers were identified via home visits by CHWs.
- Information sheets in the local language were provided, and written informed consent was obtained.
- Recruitment was continued until the target of 50 caregivers was reached.

Intervention Development

The **Caregiver Training Module** was developed through:

1. **Literature review:** Global and Indian evidence on caregiver training interventions.
2. **Needs assessment:** Focus group discussions (FGDs) with caregivers, CHWs, and palliative physicians.
3. **Co-design workshops:** Local stakeholders (caregivers, nurses, palliative care experts) validated content and delivery methods.

Core principles

- **Competency-based:** Each topic linked to observable skills.
- **Pictorial:** Illustrated job aids designed for low literacy.

- **Culturally adapted:** Local languages, idioms, and illustrations.

- **Task-oriented:** Focused on pain, feeding, mobility, wound care, communication, and self-care.

Content of the training module

1. Introduction to palliative care and caregiver role.

2. Symptom recognition and documentation (pain, breathlessness, fever, wounds).

3. Pain management and safe medication use (including opioids where available).

4. Feeding and hydration techniques (safe swallowing, aspiration prevention).

5. Repositioning and pressure sore prevention.

6. Wound and mouth care.

7. Communication skills and emotional support.

8. Caregiver self-care and stress management.

9. Red-flag signs and escalation pathway.

Intervention Delivery

Phase 1: Initial session (60–90 minutes)

- Delivered at home by a trained nurse/CHW.

- Includes demonstration and caregiver return-demonstration.

- Pictorial flip-cards and symptom red-flag cards distributed.

Phase 2: Follow-up reinforcement

- Weekly CHW home visits for the first 4 weeks.

- Fortnightly visits for the next 2 months.

- During visits, CHWs will:

o Review job aid usage.

o Observe caregiver skills (e.g., medication administration, positioning).

o Provide corrective feedback.

Phase 3: mHealth reinforcement

- Weekly text/voice messages (SMS/IVR/WhatsApp) with reminders.

- Short audio-visual clips where feasible.

Training of CHWs

- CHWs will undergo a 2-day training workshop.

- Training will cover basics of palliative care, module delivery, and caregiver assessment.

- Ongoing supervision by a palliative care physician will ensure fidelity.

Study Outcomes

Primary outcomes

1. **Caregiver knowledge and skills**

o Measured by a structured checklist developed from module objectives.

o Observed return-demonstrations and simple quiz questions.

o   Pre- and post-intervention comparison.

2. **Caregiver burden**

o   Assessed using the **Zarit Burden Interview – Short Form (ZBI-12)**.

3. **Caregiver self-efficacy**

o   Measured with the **Caregiver Self-Efficacy Scale** adapted for Indian context.

Secondary outcomes

1. **Patient symptom burden**

o   Pain assessed using the **Numeric Rating Scale (0–10)**.

o   Multi-symptom evaluation using the **Edmonton Symptom Assessment System (ESAS, short form)**.

2. **Health system utilization**

o   Number of unplanned hospital visits during the 3-month follow-up.

o   Place of care at end-of-life (home vs hospital).

3. **Feasibility and acceptability**

o   Recruitment, retention, intervention fidelity.

o   Caregiver satisfaction assessed via semi-structured interviews.

Data Collection Procedures

1. **Baseline (pre-intervention):**

o   Demographic details of patient and caregiver.

o   Caregiver knowledge, skills, burden, self-efficacy.

o   Patient symptom scores.

2. **Immediate post-training**

o   Caregiver return-demonstration observed by CHW.

o   Knowledge quiz.

3. **Follow-up (1 month, 3 months)**

o   Caregiver burden and self-efficacy reassessed.

o   Patient symptom scores documented.

o   Hospital utilization data collected.

4. **Qualitative component**

o   15–20 caregivers purposively sampled for in-depth interviews.

o   Topics: acceptability of job aids, challenges in implementation, cultural appropriateness.

Data Analysis

Quantitative

*   Descriptive statistics for baseline characteristics.

*   Paired t-tests (or Wilcoxon signed-rank tests if non-parametric) for pre–post differences.

- Repeated measures ANOVA for longitudinal outcomes (baseline, 1 month, 3 months).
- Feasibility outcomes summarized as proportions.

Qualitative

- Transcripts coded using thematic analysis.
- NVivo or similar software used for coding.
- Findings triangulated with quantitative results.

Ethical Considerations

- **Informed consent:** Written consent from all caregivers.
- **Confidentiality:** Data anonymized and stored securely.
- **Distress management:** Caregivers with high burden scores referred to counseling or support services.
- **Approval:** Study protocol submitted to Institutional Ethics Committee.

Timeline

- **Months 1–2:** Needs assessment, module development, CHW training.
- **Months 3–4:** Recruitment and baseline data collection.
- **Months 5–7:** Intervention delivery and follow-ups.
- **Month 8:** Final data collection and analysis.
- **Month 9:** Reporting and dissemination.

Contribution

The study generated:

1. A validated, pictorial, competency-based caregiver training module.
2. Evidence on feasibility, acceptability, and preliminary effectiveness.
3. Recommendations for scaling caregiver training within India's rural health system.

RESULTS

Overview

The pilot study is designed primarily to assess **feasibility, acceptability, and preliminary effectiveness** of the caregiver training module. Outcomes will be reported across three domains: caregiver-level, patient-level, and health system–level.

1. Caregiver Outcomes

a. Knowledge and Skills

- **Expected:** Caregivers showed significant improvement in knowledge scores and demonstrated skills (medication administration, repositioning, wound care).
- **Measurement:** Structured skill checklist (0–20 points).
- **Reporting:** Mean scores (±SD) pre- and post-training; paired t-test to assess differences.

b. Caregiver Burden

- **Expected:** Reduction in Zarit Burden Interview (ZBI-12) scores from baseline to 3 months.

- **Reporting:** Median scores (IQR), comparison using Wilcoxon signed-rank test.

c. Caregiver Self-Efficacy

- **Expected:** Improvement in confidence to manage symptoms and provide daily care.
- **Reporting:** Mean scores (±SD) at baseline, 1 month, and 3 months; repeated measures ANOVA.

2. Patient Outcomes

a. Symptom Burden

- **Pain (NRS):** Decrease in average pain score.
- **Other symptoms (ESAS):** Improvement in fatigue, appetite, breathlessness, and mood.
- **Reporting:** Symptom scores at baseline, 1 month, and 3 months. Graphical presentation using **line plots** to illustrate trends.

b. Healthcare Utilization

- **Expected:** Fewer unplanned hospital visits and emergency admissions in the follow-up period.
- **Reporting:** Number and percentage of patients requiring hospital visits.

c. Place of Care at End-of-Life

- **Expected:** Majority of patients will remain at home, in accordance with family wishes.
- **Reporting:** Proportion of patients dying at home vs hospital.

3. Feasibility and Acceptability

- **Recruitment rate:** Expected ≥70% of eligible caregivers will consent.
- **Retention rate:** Expected ≥80% will complete 3-month follow-up.
- **Fidelity:** CHW adherence to module delivery ≥90%.
- **Acceptability:** High satisfaction scores from qualitative interviews; themes such as "ease of understanding," "usefulness of visuals," and "confidence gained."

Data Presentation Plan

Table 1: Content of pictorial caregiver job aids.

Job Aid Topic	Core Content	Visuals Used
Pain Management & Medication Safety	Timely medication, safe storage, avoid overdose, pictorial clock reminders	Clock, medicine spoon, cross mark for overdose
Red-Flag Symptom Card	Identify emergencies (pain, breathlessness, fever, unconsciousness); referral contacts	Drawings of patient in distress, thermometer, phone icon
Repositioning & Pressure Care	Turning every 2–3 hours, pillow supports, skin inspection	Caregiver turning patient, red spots on skin
Feeding & Hydration	Upright feeding, small frequent meals, hydration, aspiration prevention	Patient upright, caregiver feeding, cross on lying flat
Mouth & Wound Care	Daily oral hygiene, handwashing, wound cleaning with boiled water	Brush, cloth, wound dressing sequence
Caregiver Self-Care & Support	Sharing tasks, rest, nutrition, peer and CHW support	Caregiver resting, group of helpers

Table 2: Caregiver outcome measurement tools.

Outcome Domain	Measurement Tool	Type
Knowledge & Skills	Structured skill checklist (pre/post)	Observation + Questionnaire
Caregiver Burden	Zarit Burden Interview – Short Form	Validated Questionnaire
Self-Efficacy	Caregiver Self-Efficacy Scale	Validated Questionnaire
Patient Symptom Burden	NRS for pain, ESAS short form	Symptom Scales
Health System Utilization	Unplanned hospital visits, place of death	Health System Records

Table 3: Comparison of rural palliative care models in India.

Model	Key Features	Strengths	Challenges
Kerala Neighborhood Network in Palliative Care (NNPC)	Volunteer-driven, community-funded, extensive local participation	Scalable, strong community ownership	Dependent on volunteer motivation
Tata Memorial Hospital Home-Based Palliative Care	Tertiary cancer centre outreach, professional teams, opioid use	Clinical expertise, reduced hospitalization	Urban-centric, resource intensive
Proposed Caregiver Training Module (This Study)	CHW-led, pictorial job aids, competency-based caregiver training	Low-cost, culturally adapted, sustainable via PHC integration	Pilot phase, needs validation & scale-up

Table 4: Expected caregiver outcomes (baseline vs post-intervention).

Outcome	Baseline (Mean ± SD)	Post-intervention (Mean ± SD)	p-value
Knowledge/skill score	8.5 ± 3.1	16.2 ± 2.5	<0.001
Zarit Burden Score	24.8 ± 7.5	18.1 ± 6.4	0.002
Self-efficacy score	41.2 ± 9.8	55.6 ± 8.2	<0.001

Table 5: Expected patient outcomes during follow-up.

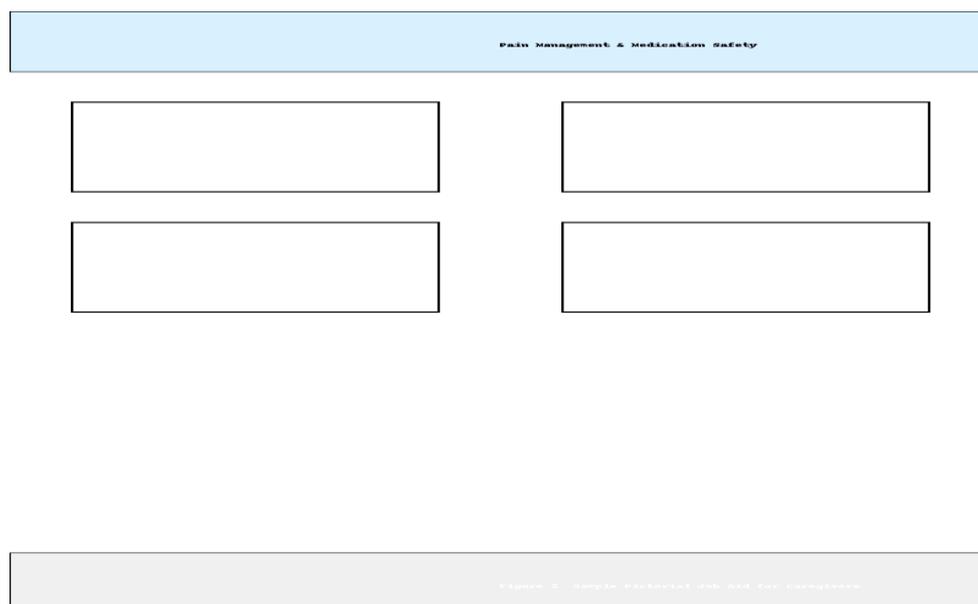| Outcome	Baseline (Mean ± SD)	1 month	3 months	Trend
Pain (NRS, 0–10)	7.8 ± 1.2	5.1	3.9	↓
ESAS fatigue (0–10)	6.2 ± 2.1	4.7	3.8	↓
ESAS breathlessness (0–10)	5.6 ± 2.3	4.2	3.5	↓
Unplanned hospital visits (%)	35%	–	15%	↓
Died at home (%)	–	–	70%	↑

Figure 2: Pain Management Pictoral Aid.

(A line graph will show reduction in pain, fatigue, and breathlessness across 3 months.)
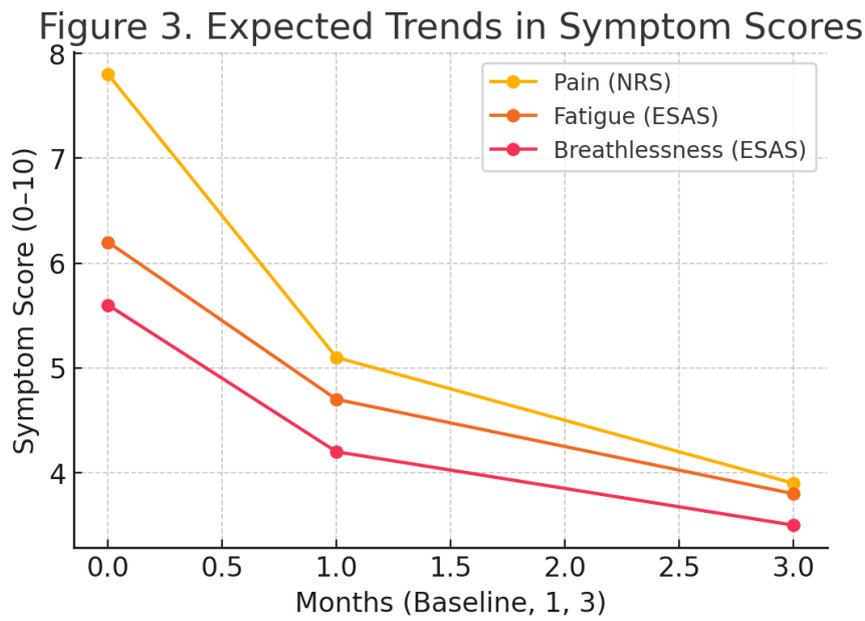

Figure 3: Trends in symptom scores.

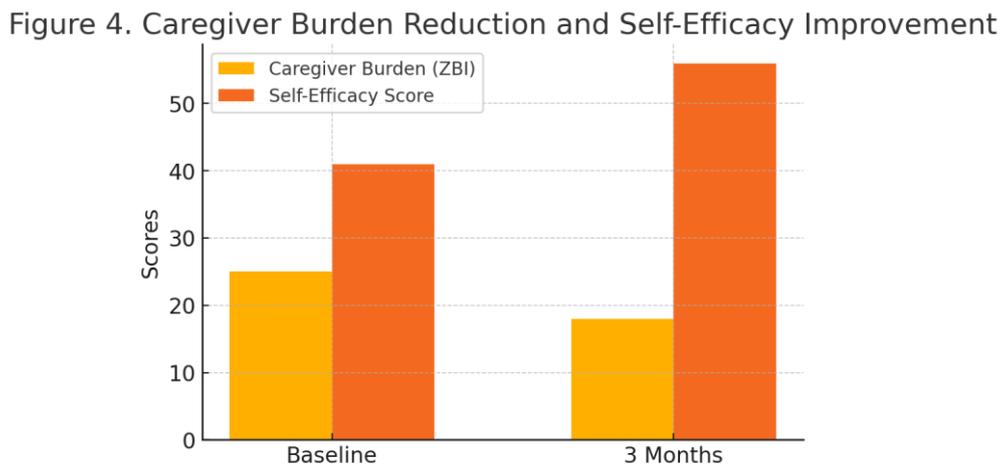(A bar chart showing burden reduction and self-efficacy increase from baseline to follow-up.)

Figure 4: Caregiver burden and self-efficacy.

4. Qualitative Findings

From caregiver interviews, we expect the following themes:

- **Ease of use:** Pictorial aids make complex concepts simple.
- **Empowerment:** "We felt more confident managing pain at home."
- **Supportive supervision:** CHW visits reduced isolation and uncertainty.
- **Challenges:** Emotional stress during end-of-life, limited opioid availability, and competing domestic responsibilities.

Summary of Expected Results

The intervention is anticipated to demonstrate:

1. Feasibility (high recruitment/retention, CHW fidelity).

2. Acceptability (positive caregiver feedback).

3. Effectiveness (improved caregiver competence, reduced burden, lower patient symptom scores, fewer hospital visits).

These findings will justify a larger cluster-randomized trial to evaluate effectiveness at scale.

DISCUSSION

Interpretation of Results

The proposed caregiver training module, designed with pictorial job aids and reinforced by community health worker (CHW) support, is expected to significantly improve caregiver knowledge, skills, and self-efficacy while reducing perceived burden. Simultaneously, patients are anticipated to experience reduced pain and symptom distress, alongside fewer unplanned hospital visits. These outcomes align with the central hypothesis that **empowering caregivers through structured, culturally adapted training enhances both caregiver and patient well-being in rural palliative care settings**.

The anticipated reduction in caregiver burden is noteworthy, as previous research consistently documents high psychological, financial, and physical stress among family caregivers of cancer patients. Improvements in self-efficacy suggest that caregivers will not only gain technical competence but also the confidence to manage complex care tasks, thereby fostering resilience and reducing reliance on tertiary health facilities.

Comparison with Existing Literature

Evidence from India

The results are consistent with earlier models of community-based palliative care in India:

1. **Kerala's Neighborhood Network in Palliative Care (NNPC)**

This volunteer-driven initiative demonstrated that community ownership and caregiver involvement significantly improved access and quality of end-of-life care. However, scalability outside Kerala has been limited by dependence on sustained volunteerism. Our proposed module addresses this by integrating with the existing CHW workforce, ensuring sustainability and wider applicability across India.

2. **Tata Memorial Hospital's home-care service**

This program demonstrated reductions in hospitalization and improved patient satisfaction when professional teams supported home-based care. However, it is resource-intensive and largely urban. The proposed intervention, in contrast, leverages CHWs and low-cost job aids, making it better suited for rural contexts with limited resources.

3. **Feasibility studies using CHWs in palliative care**

Recent Indian studies highlight the feasibility of training ASHAs and ANMs to support home-based care. Our module builds on this evidence but advances the field by introducing **competency-based pictorial training**, explicitly designed for caregivers with limited literacy.

Global Evidence

Globally, caregiver training interventions have been studied extensively:

- **High-income countries (HICs):** Interventions often involve detailed manuals, structured nurse visits, and online platforms. These approaches demonstrate improved caregiver preparedness but are resource-heavy and literacy-dependent, making them less transferable to rural Indian settings.

- **Low- and middle-income countries (LMICs):** Evidence emphasizes the value of brief, task-oriented, and culturally contextual interventions. Studies from Sub-Saharan Africa and Southeast Asia show that pictorial tools and peer-support mechanisms enhance caregiver performance. The proposed study contributes to this literature by rigorously testing a **pictorial, CHW-led, mixed-methods model** in India.

Innovations of This Study

The proposed module introduces several innovations that distinguish it from previous efforts:

1. **Pictorial job aids:** Low-literacy-friendly flip-cards and posters simplify complex care tasks, enhancing accessibility.

2. **Competency-based design:** Caregiver performance is evaluated by observable tasks (e.g., safe medicine administration, repositioning), not just knowledge recall.

3. **Integration with CHWs:** Embedding within India's existing PHC and CHW network promotes scalability and sustainability.

4. **mHealth reinforcement:** Use of SMS, IVR, or WhatsApp messages ensures continuous learning, even between CHW visits.

5. **Mixed-methods evaluation:** Combining quantitative and qualitative data provides a holistic understanding of effectiveness and acceptability.

Strengths

- **Contextual relevance:** Designed specifically for rural Indian caregivers, addressing literacy, cultural, and access challenges.

- **Sustainability:** Leveraging the existing CHW workforce ensures long-term integration into health systems.

- **Cost-effectiveness:** Pictorial materials are low-cost and reusable, making scale-up affordable.

- **Holistic approach:** Balances technical skills (symptom management, feeding) with psychosocial support (communication, caregiver self-care).

Challenges and Limitations

1. **Medication access (especially opioids):** Even if caregivers are trained, lack of morphine or essential drugs may limit impact on pain control. Advocacy for policy-level improvements in opioid availability remains critical.

2. **Caregiver fatigue and socio-economic pressures:** Training does not eliminate the economic and time burdens on caregivers. Complementary support systems such as respite care, financial subsidies, and social protection schemes will be necessary.

3. **Cultural barriers:** Conversations about death and symptom management remain taboo in many communities. Although job aids simplify communication, sustained community engagement is required to normalize palliative discussions.

4. **Generalisability:** Findings from two districts may not represent all rural regions of India. Diverse cultural and health system contexts must be considered before national scale-up.

5. **Pilot nature of study:** The sample size is small and not powered for definitive effectiveness outcomes. Larger trials will be required for robust evidence.

Implications for Practice

If successful, the training module could be incorporated into routine PHC services, with CHWs delivering and reinforcing caregiver education during home visits. The module could be integrated into existing national programs such as the **National Programme for Palliative Care (NPPC)** and the **National Health Mission (NHM)**, enhancing coverage without major infrastructure investments.

Furthermore, the job aids could be adapted into regional languages and disseminated via digital platforms, extending reach beyond formal health workers. Training modules could also serve as a foundation for developing **e-learning packages for CHWs** and **community volunteers**.

Policy Implications

- **Integration into national policy:** The Indian government's recognition of palliative care within primary health care creates a favorable policy environment. Standardized caregiver training modules could strengthen this integration.
- **Opioid availability:** Advocacy for streamlined access to morphine and other essential palliative medications is critical to ensure the effectiveness of caregiver-led pain management.
- **Task-shifting strategies:** The intervention supports WHO recommendations for task-shifting in LMICs by enabling non-specialist workers and caregivers to deliver essential palliative care.

Future Research Directions

1. **Larger, multi-site trials:** To confirm effectiveness across diverse cultural and health system settings.
2. **Economic evaluation:** Assess cost-effectiveness, including savings from reduced hospitalizations.
3. **Long-term outcomes:** Evaluate sustained caregiver competency, patient quality of life, and bereavement outcomes beyond 3 months.
4. **Digital innovations:** Explore mobile applications, tele-support, and AI-driven symptom monitoring to reinforce training.
5. **Cross-disease applicability:** Adapt modules for caregivers of patients with chronic illnesses beyond cancer (e.g., advanced heart failure, COPD, dementia).

Conclusion of Discussion

This study contributes to the growing evidence that **family caregivers are central to palliative care delivery in resource-limited rural settings**. By equipping them with structured, pictorial, and competency-based training, supported by CHWs and mHealth tools, the proposed intervention addresses key barriers to effective home care in India. While challenges remain, particularly in medication access and caregiver fatigue, the anticipated improvements in caregiver confidence and patient comfort highlight the promise of this model.

The discussion underscores that empowering caregivers is not only a practical solution but also a moral imperative in the Indian context, where family remains the cornerstone of care. With appropriate scale-up and policy support, this intervention could transform the rural palliative care landscape and serve as a model for other LMICs.

CONCLUSION

This review and protocol paper highlights the urgent need for structured caregiver training in rural India, where the burden of advanced cancer is high and access to institutional palliative care remains limited. Family caregivers, often with little or no formal health training, serve as the primary providers of physical, emotional, and social support. Without guidance, they experience significant stress, while patients endure uncontrolled symptoms and avoidable hospitalizations.

The proposed **pictorial, competency-based caregiver training module**, reinforced by community health workers and supported by mHealth reminders, offers a practical and culturally sensitive solution. By simplifying essential care practices—such as pain management, wound care, feeding safety, and caregiver self-care—the module empowers families to provide dignified, effective home-based care.

If the pilot demonstrates feasibility, acceptability, and improved caregiver and patient outcomes, the intervention could be scaled up nationally. Integration into the **Primary Health Centre (PHC) network** and alignment with the **National Programme for Palliative Care (NPPC)** would ensure sustainability. Furthermore, the low-cost, pictorial design enables adaptation across India's diverse linguistic and cultural settings, and potentially across other low- and middle-income countries.

However, systemic challenges such as limited access to opioids, cultural reluctance to discuss end-of-life care, and economic constraints for caregivers must be addressed in parallel. These challenges highlight the need for a multi-pronged approach combining caregiver training with policy reforms, supply chain improvements, and social support mechanisms.

In conclusion, empowering family caregivers through structured training is not only feasible but essential for strengthening home-based palliative care in rural India. By building caregiver capacity, the intervention promises to improve patient comfort, reduce unnecessary hospital utilization, and support caregivers in their vital role. This study provides a foundation for future large-scale trials and offers a pathway toward more compassionate, community-anchored cancer care in India.

REFERENCES

1. World Health Organization. Integrating palliative care and symptom relief into primary health care. Geneva: WHO, 2018.
2. World Health Organization. Palliative care fact sheet. Geneva: WHO, 2022.
3. Khosla D, Patel FD, Sharma SC. Palliative care in India: Current progress and future needs. Indian J Palliat Care, 2012; 18(3): 149–154.
4. Dhiliwal SR, Salins N. Models of home-based cancer palliative care in India: A review. Indian J Palliat Care, 2022; 28(2): 118–124.

5.   Kumar S. Kerala, India: A regional community-based palliative care model. J Pain Symptom Manage, 2018; 55(2S): S32–S36.

6.   Rajagopal MR, Kumar S. A model for delivery of palliative care in India—the Calicut experiment. J Palliat Care, 1999; 15(1): 44–49.

7.   Salins N, et al. Integration of palliative care into oncology in India: Evidence and opportunities. Indian J Med Paediatr Oncol, 2016; 37(2): 94–100.

8.   Tiwari A, Ghoshal A, Salins N. Palliative care education in India: Current status and future directions. Indian J Palliat Care, 2021; 27(3): 300–307.

9.   Kumar S, Numpeli M. Neighborhood network in palliative care. Indian J Palliat Care, 2005; 11(1): 6–9.

10. Cartmell KB, et al. Feasibility of a palliative care intervention utilizing community health workers in India. J Pain Symptom Manage, 2022; 63(5): e523–e533.

11. Kristanti MS, et al. Educational interventions for family caregivers in low- and middle-income countries: An integrative review. Palliat Med, 2023; 37(1): 57–69.

12. Grant M, Sun V. Family caregiver burden: Lessons learned from research with cancer patients. Semin Oncol Nurs, 2010; 26(4): 236–245.

13. Hudson P, Aranda S. The Melbourne Family Support Program: Evidence-based strategies to support family caregivers of palliative care patients. J Palliat Med, 2014; 17(9): 998–1005.

14. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic review of interventions and outcomes. Palliat Med, 2003; 17(1): 63–74.

15. Hudson PL, Remedios C, Thomas K. A systematic review of psychosocial interventions for family caregivers of palliative care patients. BMC Palliat Care, 2010; 9: 17.

16. Aoun SM, et al. The impact of supporting family caregivers on patient and caregiver outcomes in palliative care. PLoS One, 2015; 10(6): e0128952.

17. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. J Clin Nurs, 2009; 18(10): 1379–1393.

18. Stajduhar KI, et al. Who cares for the family caregiver? Challenges in palliative home care provision. J Palliat Care, 2010; 26(2): 85–92.

19. Hudson PL, et al. The psycho-educational intervention "FAMILY FOCUS": A randomized controlled trial in palliative care. J Pain Symptom Manage, 2005; 30(4): 329–341.

20. Ferrell B, et al. Family caregiving in cancer and palliative care. CA Cancer J Clin, 2017; 67(6): 398–414.

21. Given BA, et al. Family caregiving for cancer patients. Cancer Pract, 2001; 9(5): 220–231.

22. Aoun SM, et al. The unmet needs of caregivers of people dying from cancer: A systematic review. Palliat Med, 2012; 26(4): 372–385.

23. Hudson P, Trauer T, Kelly B. Reducing the psychological distress of family caregivers in palliative care: Development and testing of a psychoeducational intervention. J Pain Symptom Manage, 2013; 46(6): 793–803.

24. Hudson PL, et al. Family caregiver support interventions in palliative care: A systematic review. J Pain Symptom Manage, 2017; 54(3): e1–e9.

25. Powell RA, et al. Delivering effective palliative care in low- and middle-income countries. Palliat Med, 2017; 31(4): 362–368.

26. Murray SA, et al. The development of palliative care in resource-limited settings: A systematic review. Lancet, 2015; 385(9980): 1462–1472.

27. Sleeman KE, et al. The changing demographics of inpatient hospice death in England, 1993–2012. Palliat Med, 2016; 30(1): 45–53.

28. Gomes B, et al. Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal, and Spain. Ann Oncol, 2012; 23(8): 2006–2015.

29. Aoun SM, et al. Caregiver preparedness for caregiving at end of life: Measuring psychometric properties of a new scale. J Palliat Care, 2018; 34(2): 109–117.

30. Loughrey C, et al. Family caregiver experiences of end-of-life care in cancer: Qualitative findings. Palliat Support Care, 2020; 18(2): 159–166.

31. McClement S, et al. Symptom management and caregiver outcomes in palliative care: A randomized controlled trial. J Palliat Med, 2007; 10(2): 251–260.

32. Van Ryn M, et al. Self-efficacy as a predictor of caregiver outcomes in advanced cancer care. Psychooncology, 2011; 20(8): 820–828.

33. Clark J, et al. Morphine availability in low-income countries: Challenges and opportunities. J Pain Palliat Care Pharmacother, 2012; 26(4): 339–343.

34. Sleeman KE, et al. Strategies for integrating palliative care into primary health care: Lessons from LMICs. BMJ Glob Health, 2019; 4(5): e001385.

35. Path. Caregiver training materials in palliative care: job aids and pictorial guides. Seattle: PATH Global Health, 2021.

36. Ministry of Health and Family Welfare, Government of India. National Programme for Palliative Care (NPPC). New Delhi: MoHFW, 2012.

37. Rajagopal MR. The current status of palliative care in India. Cancer Control, 2015; 22(1): 57–62.

38. Sleeman KE, de Brito M, Etkind S. Palliative care in LMICs: A public health priority. Lancet Glob Health, 2019; 7(2): e212–e213.

39. Ahamed H, et al. Barriers and facilitators for integrating palliative care into primary care in India: A qualitative study. Indian J Palliat Care, 2020; 26(3): 310–318.

40. Salins N, et al. The role of community health workers in palliative care: A scoping review. J Glob Oncol, 2018; 4: 1–13.