

## RESEARCH LETTER

# Exploring the scope and challenges of palliative care among patients and caregivers in Bhubaneswar, Odisha, India: A qualitative inquiry



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Not applicable

Palliative care remains severely underutilised in India, where over five million individuals require such services annually yet coverage spans only a fraction of this need, with the largest deficits concentrated in eastern states [1]. India's National Programme for Palliative Care has achieved meaningful penetration only in select districts; access across Odisha is critically constrained by workforce shortages, limited public awareness, and inadequate infrastructure. Odisha, despite its substantial cancer burden, lacks organised palliative care delivery beyond its capital, Bhubaneswar. Family caregivers shoulder the primary burden of end-of-life care in this context, yet no qualitative study had examined their lived experiences within specialist palliative settings in the state. This study aimed to explore caregiver experiences across symptom management, the healthcare environment, communication, psychosocial and spiritual support, and caregiver burden at two specialist palliative care units in Bhubaneswar.

An interpretative phenomenological analysis (IPA) design was employed. Ten primary family caregivers (n = 10; 70% female) of terminally ill patients were purposively recruited from two specialist palliative care units in Bhubaneswar. Data were collected over approximately four months, from October 2025 to January 2026. Participants represented four districts of Odisha (Khordha, Kandhamal, Nayagarh, and Bhubaneswar), and patient diagnoses included advanced lung carcinoma with metastasis, metastatic rectal carcinoma, and other advanced malignancies. Eligibility required

participants to be aged  $\geq 18$  years and serving as primary caregiver to a patient who had received palliative care for  $\geq 2$  weeks. In-depth, semi-structured interviews were conducted in Odia by a trained bilingual researcher, audio-recorded, transcribed verbatim, and back-translated for a 30% subsample with no substantive discrepancies identified. Braun and Clarke's six-phase thematic analysis was applied by two independent coders, and discrepancies were resolved by consensus [2]. Rigour was ensured through member-checking, peer debriefing, and reflexive journaling. Data collection continued until thematic saturation was reached, with no new themes emerging from the final two interviews. Domain-level satisfaction was additionally captured using a five-point Likert-type scale (1 = worst, 5 = best) administered during the interviews; these ratings were not subjected to inferential statistical analysis but were interpreted descriptively to triangulate and contextualise the qualitative themes within the interpretive phenomenological framework. The study is reported per the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist [3].

Six themes were identified across 15 sub-themes (Table 1): (1) initial unawareness of palliative care; (2) high satisfaction with symptom management; (3) positive perception of the healthcare environment; (4) effective communication, coordination, and home-based training; (5) meaningful psychosocial, emotional, and spiritual support; and (6) end-of-life care and caregiver burden. All ten caregivers reported complete pre-referral unawareness, with cultural stigma equating palliative care with imminent death

## Key messages

Family caregivers in Odisha reported universal pre-referral unawareness of palliative care and encountered cultural stigma equating it with dying. Pain control, home-based caregiver training, and spiritual support were highly valued (rated 4–5 out of 5). Critical gaps persist in community awareness, home-care infrastructure, and advance care planning. Structured caregiver training substantially mitigated burden. Investment in community education and home-based care is urgently needed.

Table 1 Themes, sub-themes, illustrative codes, and theoretical framework anchors

Theme	Sub-theme	Illustrative codes	Theoretical anchor
1. Initial unawareness of palliative care	a. Pre-referral unawareness b. Post-admission clarity and relief c. Stigma and cultural illness beliefs	Never heard of palliative care; equated with dying; relief after orientation	Health Literacy Model; Kleinman's Explanatory Model
2. Satisfaction with symptom management	a. Pain control b. Opioid education c. Breathlessness, nausea, comfort	Pain-free; confidence in medication; side-effect management	WHO <sup>a</sup> Pain Ladder; Donabedian Framework
3. Healthcare environment	a. Homelike ambience b. Facility adequacy and patient safety	Peaceful; clean; domestic warmth; safe facilities	IHI <sup>b</sup> Safety Framework; Evidence-Based Design
4. Communication, coordination, and home-based training	a. Proactive communication b. Structured home-based training c. Telephonic follow-up	Informed daily; never left in the dark; trained for home care	Person-Centred Care Framework; Caregiver Self-Efficacy Theory
5. Psychosocial, emotional, and spiritual support	a. Emotional counselling b. Spiritual and faith-based support c. Bereavement preparation	Restored coping capacity; pooja facilitated; grief normalised	Lazarus and Folkman Stress-Coping Model; FICA <sup>c</sup> Tool; Worden's Tasks of Mourning
6. End-of-life care and caregiver burden	a. Dignified dying b. Caregiver burden and mitigation	Peaceful death; cultural respect; training reduced helplessness	Good Death Framework; Caregiver Self-Efficacy Theory

<sup>a</sup>World Health Organization; <sup>b</sup>Institute for Healthcare Improvement; <sup>c</sup>The FICA tool is a structured framework used by healthcare providers to assess a patient's spirituality, standing for Faith, Importance or Influence, Community, and Address or Action

compounding access barriers — consistent with All India Institute of Medical Sciences (AIIMS) New Delhi data in which the majority of advanced cancer outpatients had not previously heard the term “palliative care” [4]. A representative caregiver from Kandhamal district described: “My relatives said, why are you taking her there? That is the place for those who are about to die.” All caregivers described a transformative shift from fear to understanding and relief following structured team orientation. The healthcare environment was rated 3–5 out of 5 and consistently characterised as qualitatively distinct from conventional hospital settings — peaceful, clean, and domestically warm — features identified as essential components of healing in Indian palliative care settings [5]. Pain control was rated 4–5 out of 5 by all participants, a notably high finding given documented opioid access barriers in India. Proactive communication and structured home-based caregiver training — encompassing analgesic administration, wound care, nutritional guidance, repositioning, and emergency escalation — were rated 4–5 out of 5 and substantially reduced caregiver burden, consistent with Kerala home-based palliative care evidence [6]. Spiritual care, including facilitation of prayer, pooja, and culturally appropriate bereavement counselling, was integral to coping [7]. Despite high overall satisfaction (3–5 out of 5 across all domains), all caregivers reported substantial physical and emotional burden, most pronounced among those with limited home-based support.

Universal pre-referral unawareness replicates findings from leading Indian tertiary centres [4, 8] and, when interpreted through the Health Literacy Model, underscores structural barriers that require targeted community awareness campaigns and integration of palliative care into undergraduate medical and nursing curricula; 81% of Indian medical professionals surveyed by Patel *et al.* expressed a desire for such training [9]. The pain management outcomes challenge persistent narratives of

inadequate opioid availability in Indian palliative settings and represent a replicable, transferable model for statewide expansion. The structured home-based training programme aligns with Caregiver Self-Efficacy Theory and Kerala data demonstrating burden mitigation across seven domains following structured caregiver support, providing a scalable model for other Indian states [6]. Spiritual care integration aligns with Jacob *et al.*'s evidence that cultural sensitivity and respect for religious practice constitute core nursing competencies in Indian palliative care [5], and with India-specific IPA evidence identifying faith, karma, and religious ritual as primary coping resources [7]. Critical structural gaps persist in community awareness, home-care infrastructure, and advance care planning, whose adoption is associated with significantly reduced complicated grief risk (OR=0.4; 95% CI: 0.9–0.7) in bereaved caregivers [10]. Key strengths of this study include its status as the first qualitative inquiry into specialist palliative care experiences in Odisha, a methodologically rigorous interpretative-phenomenological design, dual independent coding, member-checking, back-translation, and COREQ-compliant reporting. Study limitations include urban-only recruitment, limiting rural and tribal generalisability, and a cross-sectional single-interview design.

This study provides the first qualitative evidence of family caregiver experiences within specialist palliative care services in Odisha. Palliative services in Bhubaneswar demonstrate clinically competent, psychosocially responsive, and culturally sensitive care, yet persistent structural gaps in community awareness, home-care infrastructure, and advance care planning constrain equitable access across the state. Urgent investment in community-based palliative education, scalable caregiver training programmes, and culturally integrated home-based services is required to ensure dignified end-of-life care. Longitudinal and mixed-methods research, inclusive of rural and tribal populations, is warranted.

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**Author contributions**

*Conception or design of the work; or the acquisition, analysis, or interpretation of data for the work:* JRM, MD, SS, VJ. *Drafting the work or reviewing it critically for important intellectual content:* JRM, MD. *Final approval of the version to be published:* JRM, MD, SS, VJ. *Accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved:* JRM.

**Conflict of interest**

We do not have any conflict of interest.

**Data availability statement**

We confirm that the data supporting the findings of the study will be shared upon reasonable request.

**AI disclosure**

We declare that no artificial-intelligence (AI), large-language-model, or generative tools were used in the conception, design, data collection, analysis, interpretation, drafting, or editing of this manuscript. All content was written and reviewed by the named authors, who take full responsibility for the integrity, originality, and accuracy of the work and its conclusions.

**Supplementary file**

None

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