BIOMEDICINE AND CHEMICAL SCIENCES
AN INTERNATIONAL PEER-REVIEWED JOURNAL

BIOMEDICINE AND CHEMICAL SCIENCES
Website: https://journals.irapa.org/index.php/BCS
e-ISSN: 2790-296X | p-ISSN:2957-5826

Original Article

We Were Left Alone": Understanding Hope, Emotional Burden, and Caregiver Experiences During End-of-Life Care in a Palliative Clinic of Kashmir

Corresponding Author:
Dr Arshi Taj

Article History:
Received on: May 10, 2026
Revised on: May 19, 2026
Accepted on: June 22, 2026
Published on: July 01, 2026

Dr Arshi Taj[1], Dr Syed Faisal Andrabi[2], Dr Syed Qazi Afaan[3], Dr Iram Rasool[4], Dr Aleesha N[5], Dr Ayushi Gupta[6]

1 Associate Professor, Department of Anesthesia Critical Care Pain and Palliative Medicine, Government Medical College Srinagar, Jammu and Kashmir, India.
2 Assistant Professor, Department of Anesthesia Critical Care Pain and Palliative Medicine, Government Medical College Srinagar, Jammu and Kashmir, India.
3 Senior Resident, Kashmir Medical Collage, Srinagar, Jammu and Kashmir, India.
4 Senior Resident, Department of Anesthesia Critical Care Pain and Palliative Medicine, Government Medical College Srinagar, Jammu and Kashmir, India.
5 Postgraduate Scholar, Department of Anesthesia Critical Care Pain and Palliative Medicine, Government Medical College Srinagar, Jammu and Kashmir, India.
6 Postgraduate Scholar, Department of Anesthesia Critical Care Pain and Palliative Medicine, Government Medical College Srinagar, Jammu and Kashmir, India.

Citation: Dr Arshi Taj *et al.* We Were Left Alone": Understanding Hope, Emotional Burden, and Caregiver Experiences During End-of-Life Care in a Palliative Clinic of Kashmir. *Biomedicine and Chemical Sciences, 5 (3): 16-20, 2026*

ABSTRACT

Background: End-of-life care goes beyond the suffering of patients and significantly impacts family caregivers who often remain silent. In resource-limited areas like Kashmir, emotional distress, social isolation, uncertainty, and loss of hope among caregivers are not well studied.

Aim: This study aims to understand the experiences, emotional burden, coping methods, and support needs of family caregivers of patients receiving palliative and end-of-life care at a tertiary care hospital in Srinagar.

Materials and Methods: Over four months, a qualitative phenomenological study was done in the palliative care clinic of a tertiary care hospital in Srinagar. Primary family caregivers of terminally ill patients were chosen using purposeful sampling. Semi-structured in-depth interviews were conducted in Kashmiri, Urdu, and English. Interviews were recorded, transcribed word for word, and analyzed using thematic analysis.

Results: Fourteen attendants took part in the study. Five main themes emerged: (1) loss of hope after recognizing an incurable illness, (2) emotional exhaustion and loneliness in caregiving, (3) fear of suffering and death, (4) financial and social burden, and (5) the need for compassionate communication and support systems. Many participants felt “left alone” during the illness despite being around relatives. Spirituality and faith served as important coping tools.

Conclusion: Family caregivers of patients receiving end-of-life care experience deep emotional pain that often goes unnoticed. Providing organized psychosocial support, caregiver counseling, and compassionate communication should be essential parts of palliative care in tertiary hospitals.

Keywords: Palliative care; caregivers; end-of-life care; caregiver burden; qualitative study; Kashmir; emotional distress; hope; terminal illness.

INTRODUCTION

Palliative care aims to improve the quality of life for patients and families dealing with life-threatening illnesses by preventing and relieving suffering.[1] While much focus is on symptom control for patients, the emotional experiences of

family caregivers often go unnoticed. Family caregivers witness a slow decline, increased dependency, uncertainty, and the approach of death. Their suffering typically remains silent, prolonged, and unsupported.

In India, caregiving responsibilities are deeply embedded in family dynamics. Relatives often take on roles as nurses, counselors, decision-makers, and emotional supporters without official training or psychological preparation.[2] This burden intensifies in terminal illnesses where a cure is no longer an option, and care shifts to comfort. Caregivers may face feelings of helplessness, anticipatory grief, financial strain, social isolation, and fear of losing their loved ones.[3,4]

Kashmir faces unique psychosocial and healthcare obstacles. Emotional resilience is frequently challenged by financial limitations, limited palliative care resources, and social expectations related to caregiving. Despite this, there is little literature exploring the experiences of caregivers in palliative environments in this region.[5,6]

This study aims to explore the emotional realities, perceptions, and unmet needs of family caregivers accompanying patients receiving end-of-life care in a palliative clinic in Srinagar.

MATERIALS AND METHODS

Study design and setting

This qualitative phenomenological study took place in the palliative care clinic of a tertiary teaching hospital in Srinagar, Jammu and Kashmir, India, from January 2026 to April 2026. The phenomenological approach was selected to capture the lived experiences of caregivers in depth, consistent with established qualitative methodology.[17,18]

Participants

Primary family caregivers of patients receiving palliative or end-of-life care were eligible to participate.

Inclusion criteria

- Age over 18 years
- Primary caregiver of a terminally ill patient
- Willingness to participate
- Ability to communicate in Kashmiri, Urdu, or English

Exclusion criteria

- Attendants with a diagnosed mental illness
- Unwilling participants
- Attendants of clinically stable patients who do not require palliative support

Sampling technique

Purposeful sampling was used until saturation was reached, consistent with standard qualitative practice.[16,17]

Data collection

Semi-structured in-depth interviews lasting 20 to 40 minutes were conducted in a private area within the clinic. Open-ended questions explored:

- Emotional experiences during care giving
- Thoughts about incurable illness
- Experiences of support or isolation
- Communication with healthcare professionals
- Coping methods and spirituality

Interviews were recorded after obtaining informed consent and transcribed verbatim.

Ethical considerations

Institutional approval was obtained before starting the study. Written informed consent was collected from all participants. Confidentiality and anonymity were ensured.

Data analysis

Thematic analysis was conducted manually following the framework described by Braun and Clarke.[16] Researchers repeatedly read and coded the transcripts to identify emerging themes and subthemes collaboratively.

RESULTS

Fourteen attendants participated in the study. The group included spouses, children, siblings, and parents of terminally ill patients.

Theme 1: Loss of hope after recognition of incurable illness

Most attendants described a moment when they realized recovery was impossible, consistent with patterns of anticipatory grief described in the literature.[22,23] This realization often led to emotional collapse and a sense of helplessness. One participant shared:

"When doctors told us there was nothing more to cure, it felt like the world ended for us."

Several attendants found it hard to accept the change from curative treatment to comfort care, mirroring findings from prior studies on caregiver responses to palliative transitions.[7,13]

Theme 2: Emotional exhaustion and loneliness
Caregivers often described feeling emotionally abandoned despite being surrounded by family members.[3,4,8] This "emotional invisibility" has been documented in prior palliative care research:
"Everyone gives advice, but at night I was alone with my mother's pain."
Many attendants reported lack of sleep, anxiety, emotional numbness, and difficulty expressing their own fears. Women caregivers often mentioned neglecting their own health and withdrawing socially, consistent with published data on gender differences in caregiver burden.[11,12]

Theme 3: Fear of suffering and death
Witnessing pain, difficulty breathing, and decline caused intense distress. Anticipatory grief was common among caregivers of advanced cancer patients, corroborating existing literature.[26,27]
"I was not afraid of death itself. I was afraid of watching him suffer every day."

Theme 4: Financial and social burden
Frequent hospital visits, medical expenses, and lost jobs added to psychological pressure, reflecting well-documented economic consequences of terminal illness in low- and middle-income countries.[49,50]
"Treatment drained our savings. We stopped thinking about ourselves."
Some attendants felt unsupported by extended family during long illnesses.

Theme 5: Importance of compassion and communication
Participants valued healthcare workers who communicated honestly and with empathy, consistent with clinical practice guidelines for end-of-life communication.[24,25,44]
"One doctor simply sat with us and calmly explained everything. That gave us strength."
Several attendants requested counseling services and emotional support groups for caregivers, aligning with recommendations from systematic reviews of psychosocial interventions.[10,48]

DISCUSSION
This study shows the intense emotional suffering faced by caregivers of patients receiving end-of-life care. The findings highlight that care giving involves more than physical help; it includes ongoing emotional adjustments to uncertainty, suffering, and impending loss.[3,4]

Loss of hope was a central theme. Similar findings have been noted in studies about caregiver distress in advanced illnesses. Families often perceive the shift from active treatment to palliative care as "giving up," especially in cultures where caregiving is tied to hope and survival.[7]

Loneliness and emotional exhaustion were notable despite the strong family ties expected in Indian society. Caregivers frequently suppress their feelings while focusing on patient comfort. This emotional invisibility has been noted in earlier palliative care studies.[3,4,8]

Financial strain further intensified caregiver burden. In low- and middle-income countries, prolonged illness often disrupts household income and savings.[2,6] Together, the emotional and financial effects create significant suffering.[30,49]

Spirituality and faith emerged as key coping strategies, a finding supported by prior research on religious coping in advanced illness.[21,40]
Notably, participants consistently valued compassionate communication. Small gestures of empathy from healthcare workers greatly improved coping and acceptance. This underscores the need for communication skills training and psychosocial support within palliative care systems.[1,3,44]
This study adds regional insight from Kashmir, where caregiver experiences are underrepresented in the literature. Acknowledging caregiver suffering is critical for providing complete palliative care.[5]

Limitations
This study was conducted at one tertiary care center with a small sample size. Experiences may differ in community and rural areas. Social desirability bias may also have affected participant responses.

CONCLUSION
Family caregivers of terminally ill patients endure significant emotional distress, loneliness, anticipatory grief, and loss of hope.[3,4,12] Their suffering often remains hidden behind the visible illness of the patient. Compassionate communication, organized psychosocial support, and caregiver-focused interventions should be vital parts of palliative care practice.[1,34,47]
In end-of-life care, healing may not always mean a cure. Sometimes, it means ensuring no family feels abandoned while facing loss.[19,20,45]

REFERENCES

1. World Health Organization. WHO definition of palliative care. Geneva: WHO; 2002.
2. Glajchen M. The emerging role and needs of family caregivers in cancer care. J Support Oncol. 2004;2(2):145-155.
3. Hudson P, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. J Palliat Med. 2004;7(1):19-25.
4. Kristjanson LJ, Aoun S. Palliative care for families: Remembering the hidden patients. Can J Psychiatry. 2004;49(6):359-365.
5. Milberg A, Strang P. Exploring comprehensibility and manageability in palliative home care: An interview study of dying cancer patients' informal carers. Psychooncology. 2004;13(9):605-618.
6. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: At what cost? Palliat Med. 2005;19(7):551-555.
7. Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C. Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research. Palliat Med. 2010;24(6):594-607.
8. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. Palliat Med. 2003;17(1):63-74.
9. Given BA, Given CW, Sherwood P. Family and caregiver needs over the course of the cancer trajectory. J Support Oncol. 2012;10(2):57-64.
10. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. CA Cancer J Clin. 2010;60(5):317-339.
11. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. JAMA. 2014;311(10):1052-1060.
12. Stajduhar KI. Burdens of family caregiving at the end of life. Clin Invest Med. 2013;36(3):E121-E126.
13. Hudson P, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. J Palliat Med. 2004;7(1):19-25.
14. Kristjanson LJ, Aoun S. Palliative care for families: Remembering the hidden patients. Can J Psychiatry. 2004;49(6):359-365.
15. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and caregivers. Cochrane Database Syst Rev. 2013;(6):CD007760.
16. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101.
17. Creswell JW. Qualitative inquiry and research design: Choosing among five approaches. 3rd ed. Thousand Oaks: Sage Publications; 2013.
18. Finlay L. "Outing" the researcher: The provenance, process, and practice of reflexivity. Qual Health Res. 2002;12(4):531-545.
19. Cassell EJ. The nature of suffering and the goals of medicine. N Engl J Med. 1982;306(11):639-645.
20. Chochinov HM. Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. BMJ. 2007;335:184-187.
21. Breitbart W. Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. Support Care Cancer. 2002;10(4):272-280.
22. Kübler-Ross E. On death and dying. New York: Macmillan; 1969.
23. Stroebe M, Schut H. The dual process model of coping with bereavement: Rationale and description. Death Stud. 1999;23(3):197-224.
24. Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness. Med J Aust. 2007;186:S77-S108.
25. Cherlin E, Fried T, Prigerson HG, et al. Communication between physicians and family caregivers about care at the end of life. J Palliat Med. 2005;8(6):1172-1181.
26. Waldrop DP. Caregiver grief in terminal illness and bereavement: A mixed-methods study. Health Soc Work. 2007;32(3):197-206.
27. Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C. Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research. Palliat Med. 2010;24(6):594-607.
28. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review. Palliat Med. 2003;17(1):63-74.
29. Payne S, Hudson P, Grande G, Oliviere D, Tishelman C. White paper on improving support for family carers in palliative care. Eur J Palliat Care. 2010;17(5):238-245.
30. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: At what cost? Palliat Med. 2005;19(7):551-555.
31. Milberg A, Strang P. Exploring comprehensibility and manageability in palliative home care. Psychooncology. 2004;13(9):605-618.
32. Proot IM, Abu-Saad HH, ter Meulen RH, et al. The needs of terminally ill patients at home. Palliat Med. 2004;18(1):53-61.
33. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. Int J Palliat Nurs. 2004;10(2):58-65.
34. World Health Assembly. Strengthening of palliative care as a component of integrated treatment throughout the life course. Geneva: WHO; 2014.

35. Ferrell BR, Coyle N, Paice JA. Oxford textbook of palliative nursing. 5th ed. Oxford University Press; 2019.
36. Glajchen M. The emerging role and needs of family caregivers in cancer care. J Support Oncol. 2004;2(2):145-155.
37. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database Syst Rev. 2011;(6):CD007617.
38. Ugalde A, Krishnasamy M, Schofield P. The relationship between self-efficacy and anxiety and general distress in caregivers of people with advanced cancer. J Palliat Med. 2014;17(8):939-941.
39. Gysels M, Evans N, Menaca A, et al. Culture and end-of-life care: A scoping exercise in seven European countries. PLoS One. 2012;7(4):e34188.
40. Balboni TA, Vanderwerker LC, Block SD, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences. J Clin Oncol. 2007;25(5):555-560.
41. Aoun SM, Breen LJ, Howting DA, et al. Who needs bereavement support? A population based survey. PLoS One. 2015;10(3):e0121101.
42. Grande GE, Stajduhar KI, Aoun SM, et al. Supporting lay carers in end-of-life care: Current gaps and future priorities. Palliat Med. 2009;23(4):339-344.
43. Kissane DW, Bloch S, Burns WI, McKenzie D, Posterino M. Psychological morbidity in the families of patients with cancer. Psychooncology. 1994;3(1):47-56.
44. Selman LE, Brighton LJ, Hawkins A, et al. The effect of communication skills training for healthcare professionals working with palliative care needs: A systematic review. Patient Educ Couns. 2017;100(4):621-635.
45. Mount BM, Boston PH, Cohen SR. Healing connections: On moving from suffering to a sense of well-being. J Pain Symptom Manage. 2007;33(4):372-388.
46. Cherny NI, Fallon MT, Kaasa S, Portenoy RK, Currow DC. Oxford textbook of palliative medicine. 5th ed. Oxford University Press; 2015.
47. Ferrell B, Twaddle M, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th edition. J Palliat Med. 2018;21(12):1684-1689.
48. 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.
49. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness. JAMA. 2000;284(19):2476-2482.
50. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284(19):2476-2482.