

Systematic Review on Coping Strategies Used by Palliative Care Patients in South Asia

Hina Ali¹, Dave Fearon², Ismat Jabeen³

^{1,3}Aga Khan Hospital, Karachi, Pakistan

²University of Edinburgh, Scotland, UK

Abstract

Background: The number of people with life-limiting illnesses is rising in South Asia's fast-growing population. Diagnosis of a life-limiting condition is often associated with psychosocial stressors including changes in social relations, financial constraints, limited physical functioning, and anxiety about the future and death. Coping strategies employed by patients include support from family members, increased religiosity, and acceptance of their condition.

Aim: To explore how palliative care patients in South Asia cope with various psychosocial stressors experienced during their ailment.

Design and Setting: Systematic review of qualitative studies identifying and exploring coping among palliative care patients within community settings in South Asia.

Method: Searches of four electronic databases from inception to May 2022 were carried out. Extracted data included participant demographics, study characteristics, and coping strategies employed. Thematic synthesis was undertaken. This qualitative systematic review was conducted and reported according to PRISMA guidelines. The CASP checklist was used to evaluate article quality.

Results: Six studies were included. Results showed that palliative care patients often experience loss of independence, financial worries, and feelings of loneliness. Main coping strategies included social support from family, faith, and acceptance of their condition.

Conclusion: This systematic review provides a better understanding of various stressors and coping in the context of palliative care in South Asia. The patient's family and their continuous support is identified as the predominant coping strategy. Family members play a vital role in provision of community or home-based palliative care, providing personal, emotional, and monetary support in the terminal phase of life-limiting illness.

Keywords: Palliative care, End of life, Qualitative, Coping, South Asia

Correspondence: Hina Ali, Aga Khan Hospital, Karachi, Pakistan. ORCID: 0009-0006-8770-129X

INTRODUCTION

According to the WHO, palliative care is an approach that "improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual."⁽¹⁾ There are an estimated 40 million people in need of palliative care annually, 78% of whom live in low- and middle-income countries, including South Asia.⁽¹⁾

The region of South Asia includes Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka, with a collective population of almost 1.9 billion.⁽²⁾ The incidence of life-limiting illnesses, including incurable cancer, HIV, end-stage heart failure, and renal and respiratory diseases, is increasing in this region, creating a growing need for palliative care.⁽³⁾

Research suggests that from the time of diagnosis of a terminal illness, palliative care patients may experience a variety of emotional, social, and existential concerns, including changes in social relations, fears about the future and death, dependence on others, and reduced physical functioning.⁽⁴⁾

To manage psychosocial stress, patients often employ coping strategies, which may develop over time and become more or less efficacious in improving their well-being.⁽⁵⁾ Coping is defined as "the set of cognitive and behavioural strategies developed by individuals to face internal and/or external demands of the relationship between the individuals and the environment."⁽⁶⁾

Researchers have categorised coping strategies into several domains, including problem-focused (modification or resolution of the stressor), emotion-focused (reduction or regulation of distress), and meaning-focused (maintaining positive well-being), among others. Coping methods may be active/approach-oriented, aimed at managing the stressor directly, or disengagement-oriented, in which individuals tend to avoid or withdraw from dealing with the stressor.⁽⁴⁾

Palliative care is an emerging discipline with increasing coverage in South Asia.⁽³⁾ This systematic review aimed to understand how adult palliative care patients in South Asia cope with psychosocial stress.

Research Question: How do adult palliative care patients in South Asia cope with psychosocial stress?

METHOD

This systematic review was conducted according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.^(8,9) The Critical Appraisal Skills Programme (CASP) checklist was used to evaluate the quality of the included articles.

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Ethics Statement

All data were obtained from published sources, so no ethics review was required.

Search Methods

The following four databases were searched from inception to May 2024: Medline, Embase, PsycINFO, and PubMed. Searches comprised database subject headings and text words combining terms for 'South Asian' and 'palliative care' or 'end of life care' and 'coping' with the Boolean operators OR and AND. Additionally, reference checking and citation tracking of the included studies were performed.

Eligibility Criteria

The inclusion and exclusion criteria are detailed in Table 1 below.

Table 1. Inclusion and Exclusion Criteria

| Inclusion criteria | Exclusion criteria |
|--|--|
| South Asian adult population (India, Pakistan, Bangladesh, Afghanistan, Sri Lanka, Maldives, Nepal, Bhutan) on palliative care | Full text unavailable |
| Studies that describe stressors and experiences | Studies involving children (less than 18 years of age) |
| Coping among palliative care patients | Specifically focusing only on the carer's experience |
| Primary care or any community setting | Physician's experiences |
| Qualitative studies, descriptive, cross-sectional, and observational studies | Quantitative studies, conference abstracts, reviews, or editorials |
| Studies in the English language | Studies in languages other than English |

Study Screening and Selection

The eligibility criteria were applied to screening titles and abstracts, and reasons for excluding articles were recorded.

PRISMA Flowchart

The PRISMA flowchart⁽¹¹⁾ outlining the number of articles identified, duplicates, rejected against title or abstract, rejected against eligibility criteria, and articles accepted is shown in Figure 1. The search identified 6,051 unique articles, of which six were ultimately included in the systematic review.

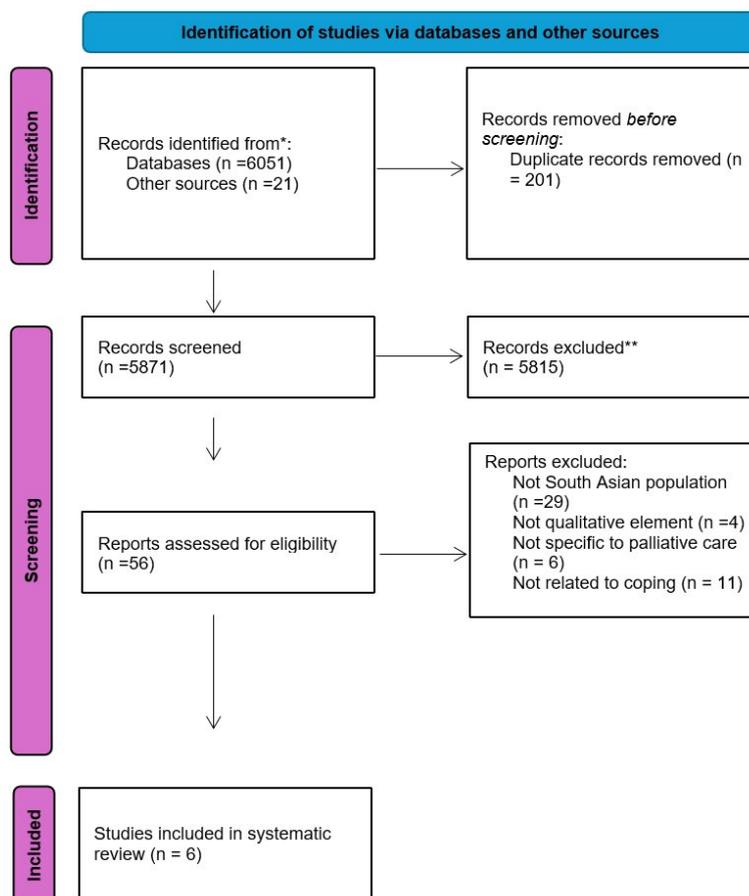


Figure 1. PRISMA flow chart

Data Extraction and Quality Assessment

Excel was used for data management and screening; EndNoteT software was used for reference management. Data were extracted using a standardized data extraction form capturing study aim and design, methods of data collection and analysis, participants' socioeconomic information, setting, number of participants, and experiences. The quality of all included studies was assessed using the CASP checklist.

Thematic Synthesis

Thematic synthesis was performed according to Thomas and Harden.⁽¹²⁾ This method enables identification, analysis, and reporting of common patterns (themes) in a secondary dataset.⁽¹³⁾ It allows inferences to be drawn based on common themes across included studies.⁽⁹⁾ Thematic synthesis is inspired by thematic analysis, an approach widely used to comprehend experiences, perceptions, or behaviours across a primary dataset.⁽¹⁴⁾

RESULTS

Study Characteristics

The search identified 6,051 unique articles, six of which were included in the systematic review. The included studies were from India (n = 4) and Bangladesh (n = 2). The articles from India represented participants from different parts of the country. No relevant studies were identified from other South Asian regions. The study characteristics are included in Table 2.

Table 2. Study Characteristics

| Settings | Design | Aim | Title | Authors/Country |
|---|--|---|---|---------------------------------|
| Palliative care patients and caregivers in community-based palliative care project | Qualitative, ethnographic | Explores experiences of palliative patients and caregivers in community-based project | Solidarity and suffering: terminal patients' and caregivers' experiences of community-based palliative care in urban slum of Bangladesh | Akter et al., 2022 Bangladesh |
| Palliative care | Cross-sectional observational | Understand psychosocial and spiritual needs of patients with advanced incurable illness in Bangladesh | The Psychosocial and Spiritual Experiences of Patients with Advanced Incurable Illness in Bangladesh | Doherty et al., 2019 Bangladesh |
| Palliative Care Clinic, Trivandrum, Kerala and patients' homes | Semi-structured qualitative interviews | Investigate psychosocial and spiritual problems of terminally ill patients in Kerala | Psychosocial and spiritual problems of terminally ill patients in Kerala, India | Elsner et al., 2020 India |
| Hospice and palliative care centre inpatients | Descriptive and cross-sectional | Study influence of spiritual well-being on distress and quality of life in advanced cancer patients | Spirituality, distress, depression, anxiety, and quality of life in patients with advanced cancer | Kandasamy et al., 2011 India |
| Terminally ill cancer patients undergoing palliative care | Observational, cross-sectional | Identify effective coping strategies leading to life satisfaction among terminal cancer patients | Coping styles and life satisfaction in palliative care | Garg et al., 2018 India |
| Advanced cancer patients in Pain and Palliative Care Unit, regional centre, New Delhi | Observational | Identify prevalence of psychosocial concerns in advanced cancer patients | Psychosocial concerns in patients with advanced cancer: An observational study at the regional cancer centre, India | Mishra et al., 2010 India |

Quality Appraisal

The quality appraisal of the studies according to the CASP criteria is outlined in Figure 2. This instrument incorporates 10 questions answered as yes (✓), no (x), or cannot tell (?).

| | | | | | | |
|--|---------|--------|------------|--------|--------|-------|
| Was there a clear statement of the aims of the research? | Green | Green | Green | Green | Green | Green |
| Is a qualitative methodology appropriate? | Green | Green | Green | Green | Green | Green |
| Was the research design appropriate to address the aims of the research? | Green | Green | Green | Green | Green | Green |
| Was the recruitment strategy appropriate to the aims of the research? | Green | Green | Green | Green | Green | Green |
| Was the data collected in a way that addressed the research issue? | Green | Green | Green | Green | Green | Green |
| Has the relationship between the researcher and participants been adequately considered? | Yellow | Yellow | Yellow | Yellow | Yellow | Red |
| Have ethical issues been taken into consideration? | Green | Green | Yellow | Yellow | Yellow | Red |
| Was the data analysis sufficiently rigorous? | Green | Yellow | Yellow | Yellow | Yellow | Red |
| Is there a clear statement of findings? | Green | Green | Green | Green | Green | Green |
| Is the research valuable? | Green | Green | Green | Green | Green | Green |
| | 1 | 2 | 3 | 4 | 5 | 6 |
| | Studies | | | | | |
| | Green | Yellow | Yellow | Yellow | Yellow | Red |
| | Yes | | Can't tell | | | No |

Figure 2. Quality appraisal

FINDINGS

Thematic synthesis identified six themes related to coping in palliative care contexts: three related to the challenges to be addressed and three related to coping styles (Table 3).

Table 3. Themes

| Challenges | Coping Styles |
|---|------------------------------------|
| Theme 1: Loss of independence | Theme 4: 'Finding strength in....' |
| Theme 2: Debt | Theme 5: 'I pray' |
| Theme 3: 'There is no one to take care of me' | Theme 6: Wish for death |

Challenges

Theme 1: Loss of Independence

Many palliative care patients are bedbound and reliant on family members for their daily activities and physical, emotional, and financial support. This often resulted in feelings of guilt, as patients considered themselves an enormous burden on their families. The ongoing need for family medical and non-medical support, including treatment costs, created feelings of frustration and helplessness among patients.⁽¹⁵⁾

"All these days, I have lived an active, independent life. I could earn my livelihood. Now, I'm incapacitated; I have to depend on others for everything."

This was found to be more challenging for male patients who were previously breadwinners and could no longer provide the same level of support, resulting in loss of social status within the family system.⁽¹⁵⁾

"I feel very helpless. My wife is also sick, yet I must depend on her." (Patient, Male, 55–60 years old)⁽¹⁵⁾

Theme 2: Debt

During illness, many patients experience loss of income due to disease severity or physical impairment. The ongoing cost of treatment and livelihood may result in depletion of savings and increasing debt.⁽¹⁶⁾ Many patients discontinued hospital-based care due to unaffordability.

"I used to sell bread, and I did very well in the business. I earned a lot of money, but now my business is over, and the money is finished." (Patient, Female, 60–65 years old)⁽¹⁵⁾

Worries regarding children's future, including education and marriage, were also commonly reported among patients who were unable to afford accommodations or experienced poor nutrition due to unemployment.

Theme 3: 'There is no one to take care of me'

Most patients considered themselves socially isolated and lonely, as they remained at home due to illness. Reduced ability to meet friends and family, and inability to play an active role in community activities, contributed to social seclusion. Perceived lack of care from family and friends and feelings of abandonment further compounded their loneliness.⁽¹⁵⁾

"There is no one to take care of me. I sit in a corner all day long; I bring my medicine and clothes by myself. There is no one even to cool my head with water if needed." (Male patient 60–70 years old)⁽¹⁵⁾

Coping

Theme 4: 'Finding Strength in...'

Family members were considered the main source of support during illness. In the majority of cases, family members provided physical and emotional care throughout the various stages of disease.⁽¹⁵⁾ Participants associated family as a source of psychological and spiritual support; talking with family was the most commonly reported coping activity. One study described the spouse as the primary caregiver, followed by children and parents. Living with an extended family was associated with greater hopefulness and optimism compared to living with a spouse only.⁽¹⁷⁾

Some patients employed active coping strategies, such as spending time in the community. Male patients who were not bedridden regularly walked to shops or religious places, or chatted with neighbours. Discussions with healthcare workers also helped participants gather courage and find strength to face their disease.⁽¹⁵⁾

Theme 5: 'I Pray'

A strong theme among South Asian palliative care patients was coping through faith in God. Many patients were spiritually connected with their faith and held a firm belief that God would help them. This faith eased their fight against disease, reducing anxiety and fear.

"After going to the prayer, I am getting relief, and I also get good sleep. When I have pain, I pray to God, and after the prayer, I do not know where the pain is gone."⁽¹⁶⁾

In one study, all participants believed in God and had found peace through religious practice.⁽¹⁵⁾ After diagnosis, participants often reported feeling closer to God. Many patients accepted their disease or death as God's plan and began preparing for death with dignity.

"Sufferings come from Allah, and only He can relieve them. Therefore, I do pray all the time for my recovery." (Patient, Female, 75–80 years old)⁽¹⁵⁾

Theme 6: Wish for Death

Significant anxiety was found among patients regarding fear of pain, suffering, and death. In one study, almost one-third of participants wished for death to alleviate their suffering.⁽¹⁸⁾

"Why doesn't Allah take me to Him, so I do not suffer anymore?" (Patient, Male, 55–60 years old)⁽¹⁵⁾

In another study, several participants reported their wish to die. Some patients were awaiting death, accepting it as God's will; some had already attempted suicide, while others would have liked to do so but were unable.

"I hesitate to take my own life thinking of the complications it would create for my family."⁽¹⁶⁾

DISCUSSION

This systematic review offers a new understanding of coping in people with life-limiting ailments in South Asia by combining evidence from several studies. Life-limiting conditions are associated with various types of physical, emotional, and financial suffering. Findings echoed the literature that participants are more likely to perceive themselves as a burden on their families due to loss of income and inability to care for themselves.⁽²¹⁾ Other concerns include physical symptoms, adverse effects of treatment, loss of functioning, and constant feelings of uncertainty.^(21,22)

Qualitative studies have facilitated understanding of patients' experiences from diagnosis to end of life. Multiple factors — social isolation, dependency on family, and financial hardships — impact coping.⁽¹⁵⁾ The coping framework developed by Lazarus and Folkman (1984) describes coping as "efforts to deal with adaptational demands and emotions," with skills learned through experience.⁽²⁰⁾

In response to social and psychological stressors, patients initially rely on existing coping mechanisms to manage distress.⁽²³⁾ Strategies evolve as patients find ways of living with disease, often combining emotional support, active coping, and religion.^(24,27) The palliative care experience can stimulate broader meaning-making and personal growth towards end of life.^(25,26)

Coping in palliative care is a dynamic process across the disease trajectory, often affected by patient context.⁽²⁸⁾ Many individuals do not adhere strictly to one coping strategy; instead, they employ a range of methods that evolve with symptom severity. Acceptance emerged as the most prevalent coping strategy, closely followed by seeking emotional support, active coping, and religious support.^(30,31)

Few palliative care patients resort to unhealthy negative coping mechanisms such as behavioural disengagement, denial, and self-blame. Self-distraction and venting were the most frequently reported maladaptive strategies, associated with higher levels of emotional distress. Denial and self-blame were associated with decreased quality of life and elevated pain and depression.^(31–33)

Strengths and Limitations

To the authors' knowledge, this is the first systematic review to explore how palliative care patients cope in South Asia. This review highlights a gap between the psychosocial support needs of this population and the services provided by healthcare professionals, with potential to improve service provision through early recognition and management of psychosocial stressors.

A limitation is that findings may not apply to all patients in South Asia given the region's diverse geography, dialects, and religious beliefs. Data are from only two countries (India and Bangladesh), limiting generalizability. The included studies did not sufficiently address negative coping strategies such as substance abuse, denial, venting, and self-blame. A deductive approach was used in thematic synthesis, which may result in loss of data not fitting predefined themes.

CONCLUSION

The acknowledgement of the psychosocial needs and coping strategies of terminally ill patients is highly important for the provision of effective palliative care. It is recommended to incorporate screening tools designed to detect maladaptive or avoidant coping strategies, followed by confidential clinical interviews conducted by primary care physicians, psychologists, or psychiatrists. Recognising patients who resort to unhealthy or avoidant coping methods is crucial for guiding appropriate psychological support and promoting healthier coping strategies.

Ethics Approval: As this review included only already published data, no specific ethical approval was required.

Availability of Data: The datasets used and/or analysed are available from the corresponding author on reasonable request.

Competing Interests: The authors declare that they have no competing interests.

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REFERENCES

- World Health Organization (2020). WHO palliative care. Retrieved from <https://www.who.int/news-room/factsheets/detail/palliative-care>
- WHO Definition of Palliative Care. Retrieved from <http://www.who.int/cancer/palliative/definition/en>
- Singh T, Harding R. Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes. *BMC Research Notes*. 2015;8:1–5.
- Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson VA. Understanding and addressing the role of coping in palliative care for patients with advanced cancer. *Journal of Clinical Oncology*. 2020;38(9):915.
- Mosher CE, Ott MA, Hanna N, Jalal SI, Champion VL. Coping with physical and psychological symptoms: a qualitative study of advanced lung cancer patients and their family caregivers. *Supportive Care in Cancer*. 2015;23:2053–60.
- Sapeta P, Centeno C, Belar A, Arantzamendi M. Adaptation and continuous learning: integrative review of coping strategies of palliative care professionals. *Palliative Medicine*. 2022;36(1):15–29.
- Garg R, Chauhan V, Sabreen B. Coping styles and life satisfaction in palliative care. *Indian Journal of Palliative Care*. 2018;24(4):491.
- Arya S, Kaji AH, Boermeester MA. PRISMA reporting guidelines for meta-analyses and systematic reviews. *JAMA Surgery*. 2021;156(8):789–90.
- Purssell E, Gould D. Undertaking qualitative reviews in nursing and education: method of thematic analysis for students and clinicians. *International Journal of Nursing Studies Advances*. 2021;3:100036.
- Rathbone AP, Todd A, Jamie K, et al. A systematic review and thematic synthesis of patients' experience of medicines adherence. *Research in Social and Administrative Pharmacy*. 2017;13(3):403–39.
- Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *International Journal of Surgery*. 2021;88:105906.
- Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*. 2008;8(1):1–10.
- Kiger ME, Varpio L. Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical Teacher*. 2020;42(8):846–54.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101.
- Akter S, Sarker M, Hossain P, Ahmad N, Zaman S. Solidarity and suffering: enrolled terminal patients' and their caregivers' experiences of the community-based palliative care programme in an urban slum of Bangladesh. *Palliative Care and Social Practice*. 2022;16:26323524221095104.
- Elsner F, Schmidt J, Rajagopal MR, Radbruch L, Pestinger M. Psychosocial and spiritual problems of terminally ill patients in Kerala, India. *Future Oncology*. 2012;8(9):1183–91.
- Doherty ME, Power L, Rahman R, et al. The psychosocial and spiritual experiences of patients with advanced incurable illness in Bangladesh: a cross-sectional observational study. *Indian Journal of Palliative Care*. 2019;25(4):487.
- Mishra S, Bhatnagar S, Philip FA, et al. Psychosocial concerns in patients with advanced cancer: An observational study at regional cancer centre, India. *American Journal of Hospice and Palliative Medicine*. 2010;27(5):316–9.
- McPherson CJ, Wilson KG, Murray MA. Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine*. 2007;21(2):115–28.
- Folkman S, Lazarus RS, Gruen RJ, DeLongis A. Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology*. 1986;50(3):571.
- Liao YC, Liao WY, Sun JL, et al. Psychological distress and coping strategies among women with incurable lung cancer: A qualitative study. *Supportive Care in Cancer*. 2018;26:989–996.

22. Sterba KR, Zapka J, Gore EI, et al. Exploring dimensions of coping in advanced colorectal cancer. *Journal of Psychosocial Oncology*. 2013;31:517–539.
23. Walshe C, Roberts D, Appleton L, et al. Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. *PLoS One*. 2017;12:e0169071.
24. Thompson GN, Chochinov HM, Wilson KG, et al. Prognostic acceptance and the well-being of patients receiving palliative care for cancer. *Journal of Clinical Oncology*. 2009;27:5757–5762.
25. Moreno PI, Stanton AL. Personal growth during the experience of advanced cancer: A systematic review. *Cancer Journal*. 2013;19:421–430.
26. Sand L, Olsson M, Strang P. Coping strategies in the presence of one's impending death from cancer. *Journal of Pain and Symptom Management*. 2009;37:13–22.
27. Kandasamy A, Chaturvedi SK, Desai G. Spirituality, distress, depression, anxiety, and quality of life in patients with advanced cancer. *Indian Journal of Cancer*. 2011;48(1):55–9.
28. Dein S. Religious healing and mental health. *Mental Health, Religion & Culture*. 2020;23(8):657–65.
29. Dev R, Reddy AS, Arthur JA, et al. Adaptive and maladaptive coping strategies among patients with advanced cancer. 2021.
30. Fearon DM, Hughes S, Brearley SG. Women's experiences of advanced breast cancer in a resource-limited Arab context. *Psycho-Oncology*. 2021;30(10):1720–7.
31. Dev R, Agosta M, Fellman B, et al. Coping strategies and associated symptom burden among patients with advanced cancer. *The Oncologist*. 2024;29(2):166–75.
32. Amonoo HL, Daskalakis E, Deary EC, et al. Relationship between longitudinal coping strategies and outcomes in patients with acute myeloid leukemia. *Journal of the National Comprehensive Cancer Network*. 2022;20(10):1116–23.
33. Nipp RD, El-Jawahri A, Fishbein JN, et al. The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer*. 2016;122(13):2110–6.