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Family caregivers' experience in the provision of palliative care for adult cancer patients in low-income and lower-middle-income countries: a qualitative systematic review protocol

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ABSTRACT

Introduction In many low-income and lower-middle-income countries (LMICs), palliative care services are limited and much of the care for adults with advanced cancer is provided by family caregivers. This review aims to explore the family caregiver experience in providing palliative care to adult patients with cancer in LMICs.

Methods and analysis This qualitative systematic review will be conducted using a comprehensive search strategy on PubMed (MEDLINE), Embase, CINAHL and PsycINFO without language or date restrictions. The COnnecting REpositories (CORE) database of the Open University will be searched for grey literature. Review questions will follow the PICo framework (Population, Phenomena of Interest and Context). Qualitative or mixed-method studies on the experience of family caregivers of adult patients with cancer (above 18 years) receiving palliative care in LMICs will be included. Study quality will be assessed using the Joanna Briggs Institute (JBI) critical appraisal tools. Findings will be synthesised using meta-aggregation or with a narrative synthesis if pooling is not feasible. The review process will follow the JBI methodology for systematic reviews of qualitative evidence and will be reported according to the ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) framework.

Ethics and dissemination No ethical approval is required as the study involves secondary data analysis of published literature. Ethical principles of accurate reporting and transparency will be upheld. Findings will be published in peer-reviewed open-access journals and presented at academic conferences. Recommendations will be shared with policymakers and healthcare organisations responsible for the provision of palliative care for patients with cancer in LMICs.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Four databases, as well as grey literature, will be searched using the extensive search strategy by a multidisciplinary team with expertise in systematic reviews and cancer care in low-income and lower-middle-income countries (LMICs).
⇒ A rigorous methodology will be adhered to throughout the study as per the Joanna Briggs Institute guidelines for qualitative systematic reviews.
⇒ While the language was not limited in the search, due to translation constraints, only selected non-English articles will be reviewed. This limitation may introduce language bias through the exclusion of some non-English qualitative study articles.
⇒ Due to the limited number of qualitative studies on palliative care for patients with cancer in LMICs and possible low quality of available studies, the certainty of evidence generated through this systematic review may be limited.

INTRODUCTION

Palliative care aims to improve the quality of life of patients and their families facing life-threatening illness through the prevention and relief of physical, psychosocial and spiritual suffering.[1] Palliative care for patients with cancer is a holistic approach aimed at improving the quality of life for patients with advanced cancer by addressing physical symptoms, psychological distress and spiritual concerns. This multidisciplinary care focuses on alleviating pain, managing symptoms, and providing emotional support to both patients and their families, ensuring comfort and dignity throughout the disease trajectory.[2]

A caregiver is an individual who assists persons needing help with self-care, including healthcare professionals, social service workers, family members, close companions or spiritual advisors in home or healthcare settings. Caregiving can impose significant physical, emotional and financial burden that may negatively affect both caregivers and the quality of care delivered to patients.[3–6]

Family caregivers are unpaid individuals, usually relatives, who provide physical, emotional and practical support to a loved one with a serious illness. Often lacking formal training and structured support, they experience substantial physical, emotional, social and financial burden.[6 7] Family caregivers play a critical role in the provision of palliative care, particularly in low-income and lower-middle-income countries (LMICs) where formal palliative healthcare services are limited and expensive.[8]

Palliative care services in high-income countries are often well-integrated into healthcare systems, with specialised teams and structured support systems. In contrast, in many LMICs, palliative care services are underdeveloped due to limited health financing, workforce shortages, restricted opioid availability, fragmented policy frameworks and poor integration into primary health systems; as a result, families assume substantial caregiving responsibilities with minimal formal support, within cultural contexts that strongly shape norms surrounding family obligation, death and caregiving.[9 10] These constraints, in addition to economic hardship and cultural expectations, may result in caregiving experiences that uniquely differ from high-income and upper-middle-income settings.

Therefore, understanding the needs and experiences of family caregivers is essential for addressing challenges in palliative care and improving the quality of life for patients and their families in LMIC settings.[11] A qualitative approach is suggested for exploring experiences and perspectives that are difficult to quantify. It enables participants to express their thoughts, emotions and experiences in their own words, offering a deeper and more comprehensive understanding of the phenomenon under investigation.[12]

A growing body of qualitative systematic reviews explores the experiences of family caregivers in the provision of palliative care for adult patients with cancer, highlighting common themes of emotional burden, lack of support, communication needs and resilience. Five published systematic reviews are based on primary studies conducted in upper-middle-income or high-income countries, including North America, Australia, Western Europe and parts of East Asia.[13–18] These reviews provide insights into caregiving within strengthened healthcare systems where caregiver support mechanisms are in place. Differences in health system structures, sociocultural norms, financial protection mechanisms and the availability of specialist palliative services limit the transferability of these existing findings to the LMIC context.

This proposed review aims to explore and synthesise the lived experiences of family caregivers providing palliative care to adult patients with cancer in LMICs. Within these experiences, particular attention will be given to perceived challenges, coping strategies and expressed support needs, as these are embedded dimensions of caregiving experience rather than separate outcome categories. This review differs from previous syntheses since it exclusively focuses on caregiving experience within a cancer palliative care context in LMIC settings.

With the above scope, the review aims to generate contextually relevant findings to inform policy and service development in LMICs. However, due to the stark variation in health literacy, cultural norms and health systems even within these LMICs, a significant heterogeneity is expected in the primary qualitative studies that will be captured in this proposed review.

The findings of this review are significant at multiple levels. At the individual level, they can help develop interventions to enhance the well-being and coping strategies of caregivers. At the community level, strengthening community-based palliative care services can alleviate the burden of caregivers. At the policy level, the insights can inform the creation of supportive policies, including financial assistance, training programmes and mental health support for family caregivers.

Review question

This systematic review aims to answer the following question: "What are the experiences of family caregivers providing palliative care for adult cancer patients in LMICs?"

This question is framed using the PICo mnemonic:

- Population (P): family caregivers (informal, unpaid caregivers such as relatives, spouses or children).
- Phenomena of Interest (I): the experience of caregiving in palliative care settings for adult patients with cancer.
- Context (Co): low-income and LMICs, where access to formal palliative care services is often limited.

Inclusion criteria

Inclusion criteria were developed based on PICo elements.

Participants

Family caregivers who provide or have provided palliative care for adult (more than 18 years of age) patients with cancer will be considered as participants in this review. Family caregivers will include parents, spouses, children, siblings or other relatives who play a major role in the provision of palliative care for the patient with cancer. The WHO definition of palliative care will be used in the identification of studies suitable for the review.

Phenomena of interest

This review will consider studies that explore common themes related to caregiving experiences, including, but not limited to, challenges related to access to healthcare services, financial burdens and social support, coping mechanisms, emotional, physical and psychological impact of caregiving, expectations and perceived support needs.

Context

Studies conducted in all types of settings in LMICs, including healthcare facilities and homes of patients, will be selected for this review. To determine the income category to identify LMICs, the World Bank income classification at the time of publication of the particular

article will be used, as it provides a standardised and widely applied economic categorisation in global health research. However, income classification of a country alone does not fully capture within-country variations in health system capacity, cultural norms, social protection policies or palliative care infrastructure: facilities in urban settings may significantly differ from those in rural settings. Furthermore, countries within the same income band may differ substantially in ways that influence caregiver experiences. These contextual differences will be considered during data synthesis and interpretation.

Type of studies

This review will consider qualitative studies exploring the experiences of family caregivers providing palliative care for patients with cancer, including, but not limited to, designs such as grounded theory, phenomenology, ethnography, action research and qualitative descriptive. In addition, the qualitative component of mixed-method studies will be considered for inclusion if they contain a clearly defined qualitative component that addresses the review question. The qualitative component must be explicitly described, including details of data collection and analysis methods, and present interpretable qualitative findings (eg, themes, categories or narrative accounts supported by participant quotations).

Methods

The proposed systematic review will follow the Joanna Briggs Institute (JBI) methodology for systematic reviews of qualitative evidence.[19] The completed review will be reported according to the ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) framework.[20] This protocol followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocol (PRISMA-P) guidelines in reporting.[21] The review has been registered with PROSPERO (CRD 420251010556).

Patient and public involvement

Neither patients nor the public were involved in this protocol preparation.

Search strategy

A preliminary search was conducted to tailor specific search terms. Once the strategy is finalised, a comprehensive search will be conducted across PubMed (MEDLINE), Embase, CINAHL and PsycINFO databases using the Ovid platform. Studies published from the inception of the database to May 2025 will be considered for this review. The detailed search strategy for each database is attached in online supplemental file 1.

The proposed search strategy for MEDLINE is given below:

((“family caregiv*“[Title/Abstract] OR “informal caregiv*“[Title/Abstract] OR “family member*“[Title/Abstract] OR “caregiving relative*“[Title/Abstract] OR “carer*“[Title/Abstract] OR “spouse caregiv*“[Title/Abstract] OR “parent caregiv*”[Title/Abstract])

AND

(“Palliative care”[Title/Abstract] OR “end-of-life care”[Title/Abstract] OR “terminal care”[Title/Abstract] OR “hospice care”[Title/Abstract] OR “supportive care”[Title/Abstract] OR “advanced cancer care”[Title/Abstract] OR “home-based palliative care”[Title/Abstract]) AND (“experience*“[Title/Abstract] OR “perception*“[Title/Abstract] OR “perspective*“[Title/Abstract] OR “burden*“[Title/Abstract] OR “challenge*“[Title/Abstract] OR “coping”[Title/Abstract] OR “expectation*“[Title/Abstract] OR “need*“[Title/Abstract] OR “support need*“[Title/Abstract] OR “quality of life”[Title/Abstract] OR “psychosocial impact*“[Title/Abstract] OR “mental health”[Title/Abstract] OR “burnout”[Title/Abstract] OR “psychological*"[Title/Abstract])

AND

(“cancer*“[Title/Abstract] OR “neoplasm*“[Title/Abstract] OR “oncology patient*“[Title/Abstract] OR “malignan*“[Title/Abstract] OR “advanced cancer*“[Title/Abstract] OR “metastatic cancer*“[Title/Abstract] OR “terminal cancer*"[Title/Abstract])) AND ((humans(Filter)) AND (alladult(Filter)))

In addition to database searches, the reference lists of all retrieved studies will be manually reviewed to identify further relevant articles for inclusion. Furthermore, our search strategy will also include grey literature relevant to the subject of this review. First, the COnnecting REpositories (CORE) database by the Open University will be searched, and second, advanced Google searches will be conducted on relevant key terms with results limited to PDF files and .edu, .gov or .org website domains. The first 5 pages of each search will be screened for potentially relevant documents.

The search strategy will use two filters, adult and human, to restrict the search to be more focused on the study population. At the initial stage, the search will include all the qualitative studies published in peer-reviewed journals related to the topic without any language filters to obtain an idea of the breadth of published literature in different languages. Google Translate will be used to translate the titles and abstracts published in languages other than English to check their eligibility for the next step, full-text screening. However, due to resource constraints, only studies published in the English language will be screened for eligibility at the full-text screening stage. The number of studies that were excluded due to language restrictions will be presented in the PRISMA flow chart and will be acknowledged as a limitation of the review during the discussion.

The list of countries under each income category changes annually based on World Bank data. Since this review explores the experiences of palliative caregivers in LMICs at the time of publication of each study—rather than at the time of this review—no search filters were used to identify LMICs during the initial search. Instead, the country of origin for each study will be assessed manually using the World Bank classification corresponding to the year the study was published.

The authors will re-run the search strategy 3 months before the submission of the manuscript to keep the review updated.

Study selection

All collected citations will be stored in the reference management software EndNote by Clarivate, London, UK. Following the removal of duplicate records, the titles and abstracts of studies identified in the initial search will be independently screened by two reviewers (two independent pairs as GG and VRU, and YI and KK) using predefined inclusion/exclusion criteria to determine their relevance. This screening will be conducted on the Rayyan web application by Rayyan Systems Inc., Cambridge, Massachusetts, USA.[22] The initial screening process will be broad, aiming to capture the full spectrum of studies that align with the eligibility criteria, thereby ensuring a comprehensive overview of the literature on the experiences of family caregiver providing palliative care for patients with cancer in LMICs. Discrepancies will be resolved through discussion. In case of disputes, a third reviewer (MS) will be consulted for arbitration.

Full-text versions of studies that appear to meet the eligibility criteria will be obtained and assessed for relevance by two independent reviewers (two independent pairs as GG and VRU, and YI and KK). Any discrepancies regarding the inclusion of studies will be resolved through discussion and consensus between the reviewers. In cases where consensus cannot be reached, a third reviewer (MS) will be consulted to resolve the disagreement and determine final eligibility.

Assessment of methodological quality

The methodological quality of the included qualitative studies and the qualitative strand of the mixed-methods studies will be assessed using the JBI Critical Appraisal Checklist for Qualitative Research, which includes 10 items to evaluate research methodology and other domains of reporting.[19] This tool evaluates key aspects such as study design, transparency in reporting, risk of bias and reliability of findings. The critical appraisal process will adhere to the approach outlined in the published JBI systematic reviews of qualitative evidence guidelines to ensure methodological rigour and consistency.

Two independent reviewers (two independent pairs as GG and VRU, and YI and KK) will conduct the critical appraisal. Discrepancies in quality assessment will be resolved through discussion, and if necessary, a third reviewer (MS) will be consulted. Additional information will be sought from study investigators if the required information is unclear or unavailable in the study publications/reports. The final quality assessment results will not influence study inclusion but will be considered in the synthesis and interpretation of findings. The evaluation results will be judged by the number of items that meet the standard requirement. Critical appraisal results will be reported in narrative form, and all studies, irrespective of the rating, will be included in data extraction and synthesis. A rating of 5 or lower will be considered weak (C), 6–8 will be considered medium (B), and 9–10 will be considered strong (A). Risk of bias due to missing results and certainty of findings will not be assessed.

Data extraction

A standardised data extraction sheet will be developed according to the JBI guidelines for qualitative systematic reviews[19] and piloted on a subset of included studies to ensure consistency and comprehensiveness. The extraction sheet will capture: bibliographic details (author and year of publication); study characteristics (country, study aims and qualitative design); setting (eg, community, primary care, hospital and residential care); participant characteristics, including caregiver demographics (age, sex/gender, relationship to care recipient, ethnicity where reported, education level, employment status and socioeconomic indicators), and relevant characteristics of care recipients where applicable; sampling strategy and recruitment methods; data collection methods (eg, in-depth interviews, focus groups and observations) and duration; qualitative analytical approach (eg, thematic analysis, grounded theory, phenomenology and content analysis); use of theoretical or conceptual frameworks; and key findings, including themes, subthemes and supporting participant quotations related to caregiving, such as emotional burden, physical and psychological challenges, coping strategies and social support. For mixed-methods studies, only the qualitative findings will be extracted unless quantitative findings are required to contextualise them. The conclusions from the studies will be extracted verbatim and carefully assessed through a thorough reading and re-reading of the studies. Details relevant to methodological rigour (eg, reflexivity, data saturation and ethical considerations) will also be recorded to inform quality appraisal (online supplemental file 2).

Data will be extracted by two trained reviewers independently (two independent pairs as GG and VRU, and YI and KK) to ensure consistency and accuracy. Any discrepancies between the two reviewers during data extraction will be resolved through discussion or, if necessary, by consulting a third reviewer (MS) to achieve consensus.

Data synthesis

For qualitative synthesis, findings will be organised using a structured data extraction sheet (Microsoft Excel V.2602), supplemented by the custom tagging and note features of Rayyan. The data synthesis will follow a meta-aggregation approach using findings from the studies that were screened and categorised. For mixed-methods studies, qualitative findings will be synthesised alongside those from standalone qualitative studies. Quantitative results will not be included in the synthesis unless required to contextualise the qualitative findings.

First, all individual qualitative findings from included studies will be extracted from the results sections. These findings will be in the form verbatim extracts of author

interpretations that are supported by an illustration, which are participant quotations or field observations. The extracted qualitative findings will be systematically organised and categorised into distinct groups based on shared meanings. These categories will reflect various aspects of the caregiving experience in palliative care settings, including, but not limited to, emotional strain, coping mechanisms and social support. The custom tagging and note features of Rayyan will be used in this categorisation process for efficient classification and data retrieval.

Next, a level of credibility will be assigned to each finding in adherence to the Conqual approach (Confidence in Qualitative research) as recommended by JBI.[19] This will be based on the congruence between the data presented and the interpretation of authors. The categorisation will be as follows.

- Unequivocal—evidence beyond reasonable doubt, including findings that are clearly observed/directly reported and are not open to challenge.
- Credible—findings that are accompanied by an illustration, but the association with the findings are not clearly established, and hence are open to challenge.
- Not supported—when findings are not supported by data and neither of the first two apply.

Only unequivocal and credible findings will be included in the aggregation stage. This will be followed by the development of categories aggregating two or more findings based on similarity in meaning and context. The categories will be accompanied by a category description conveying their whole inclusive meaning. Two independent reviewers will develop these categories (YI and VRU) and disagreements will be resolved through discussion or consultation with a third reviewer (MS).

Next, synthesised findings will be developed, which are overarching descriptions of a group of categories that capture their shared patterns. These synthesised findings will be expressed as indicatory statements that will provide conclusions on the experiences of family caregivers in LMIC palliative care settings,

If textual pooling is not feasible, findings will be presented narratively in a detailed and rich description of the experiences of caregivers. This approach will allow for a deeper exploration of the key themes, contextual factors and insights from individual studies.

A sensitivity analysis will be performed to explore the impact of study quality on the synthesised findings. This will involve the temporary exclusion of studies categorised as having low methodological quality (scoring less than 6/10 on the JBI Critical Appraisal Checklist) to determine if the synthesised findings remain robust. When interpreting the results, careful attention will be paid to whether methodologically strong or weaker studies mainly support the conclusions. If certain findings are derived mostly from lower-rated studies, this will be acknowledged in the discussion.

Given the heterogeneity expected across LMICs, contextual details will be recorded during data extraction and taken into account during synthesis. Geographical region, availability and organisation of formal palliative care services, features of healthcare systems, cultural and societal norms surrounding palliative care and relevant policy information will be considered when interpreting the results. The findings will be examined for patterns pertaining to these contextual moderators to identify variations in caregiver experiences based on them. Where sufficient data is available, subgroup comparisons will be made to guarantee that our conclusions represent the variety of LMIC caregiving contexts.

Ethical considerations

As this study involves secondary data analysis, no ethical approval is required. However, ethical principles of accurate reporting and transparency will be upheld.

Dissemination plan

Findings will be published in an open-access peer-reviewed journal to facilitate access to the relevant stakeholders at LMICs and will be presented at academic conferences. Recommendations will be shared with policymakers and healthcare organisations responsible for the provision of cancer care services.

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