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Experiences of family caregivers caring for cancer patients at home: A qualitative systematic review comparing evidence from HICs and LMICs

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ABSTRACT

The rising global cancer incidence and mortality rates increase burden for family caregivers of patients at home. Much research reflects Western-centric views, overlooking cultural, relational, and structural contexts worldwide. We compared experiences of family caregivers in high-income countries (HICs) and low- and middle-income countries (LMICs) through a qualitative systematic review using JBI methodology. We searched eight databases and screened articles for eligibility. We grouped article findings by HIC and LMIC and used the Transactional Model of Stress and Coping as a flexible heuristic to generate synthesized findings. Of 1067 records identified, 52 studies were included (41 HICs and 11 LMICs). Family caregivers faced high physical and psychosocial demands, inadequately addressed by healthcare and social services. The availability of resources like home-based services and financial protection differed between HICs and LMICs, but coping strategies were similar. Motivations for caring ranged from moral obligation to caregiving as an extension of relationships. Caregiving was characterized by emotional distress alongside meaning and satisfaction. Our findings show shared human responses to caregiving, despite differing healthcare access. The comparative insights underscore that caregivers, despite varying contexts are insufficiently acknowledged as vital care team members, compelling urgent health system integration into cancer care plans.

1. Introduction

The global burden of cancer continues to rise, with an estimated 20 million new cancer cases and almost 10 million cancer-related deaths worldwide in 2022, and a disproportionate mortality relative to incidence in Africa and Asia (Bray et al., 2024; WHO, 2020). Estimations indicate that by 2040, the largest increases in cancer incidence and mortality will occur in low- and middle-income countries (LMICs), where diagnosis is often late, access to treatment and supportive services is limited, and survival rates are lower than those in HICs (WHO, 2020). These trends have substantial implications not only for patients but also for family members who increasingly assume responsibility for care within the home.

In HICs, cancer care has progressively shifted from hospitals to home-based settings, with earlier discharge, outpatient treatment, and expanded use of supportive and palliative care services (Hwang et al., 2024; Nipp et al., 2022). While this trend is often considered patient-centered, it also shifts care responsibilities to family caregivers, who frequently provide complex physical, emotional, and practical care with limited preparation or support. While prior research from HICs primarily documents caregiving challenges through a Western lens of burden, stress, and unmet needs (Viana et al., 2013; Wang et al., 2018), these framings often overlook diverse cultural and structural contexts. Recent research from diverse cultural contexts has reported caregiving as a culturally embedded moral practice shaped by relationships, religious values, reciprocity, and social norms (Pharr et al., 2014; Xiao

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et al., 2024; Zarzycki et al., 2022). Caring for a seriously ill family member at home may be considered an expected and meaningful familial responsibility rather than primarily a source of strain. Experiences of stress and burden may be exacerbated by structural constraints, such as poverty, weak health systems, limited access to palliative care, and lack of social protection.

Evidence from LMICs suggests that family caregivers often provide end-of-life care with minimal formal support, limited access to pain relief and symptom control, and substantial financial and social consequences (Connor, 2020; Donkor et al., 2024; Gambe et al., 2023). Even in HICs, where palliative care services are more established, there are concerns regarding equitable access to home-based services, with patients often dying in institutional settings despite preferring home-based care (Donkor et al., 2024; Fereidouni et al., 2021). Existing palliative care programs insufficiently focus on the needs of family caregivers (Baugh et al., 2022). These findings point to shared challenges across settings while also highlighting contextual differences in the resources, expectations, and consequences of informal caregiving. While the need to understand how informal caregiving experiences are shaped by relationships, cultural norms, and health systems across diverse settings is evident, a critical gap exists in synthesizing and directly comparing these experiences between HICs and LMICs, which is essential for developing globally relevant and equitable care strategies. This review specifically addresses this gap by systematically comparing caregiving experiences in high-income (HICs) and low- and middle-income countries (LMICs) to reveal culturally sensitive insights.

For this review, we synthesized evidence of caregiving experiences using the Transactional Model of Stress and Coping (Folkman, 2013; Lazarus & Folkman, 1984), which conceptualizes an individual's stress response to a personal threat by appraising demands and available resources and employing coping strategies to manage these threats (Fig. 1). This model has been used in cancer and caregiving research to examine how individuals respond to illness-related stressors over time (Folkman, 2013; Livneh, 2000; Mukwato et al., 2010). The model's focus on appraisal, resources, and coping provides a flexible heuristic for examining how caregiving experiences are shaped by individual and contextual factors. In this review, this model is used as a lens to identify both shared patterns and context-specific meanings of caregiving across HIC and LMIC settings.

Therefore, this qualitative systematic review aimed to achieve two objectives.

- to synthesise qualitative evidence on the experiences of family caregivers caring for people with cancer at home; and
- to compare commonalities and differences in caregiving experiences, needs, resources, and coping strategies between HICs and LMICs, with explicit attention to socio-cultural and structural contexts.

By systematically elucidating both universal experiences and context-specific nuances, this comparative approach is crucial for moving beyond Western-centric interpretations and informing culturally sensitive interventions and policies.

2. Methods

2.1. Study design

We undertook a qualitative systematic review using the JBI (Joanna Briggs Institute) methodology to identify family caregivers' experiences of caring for cancer patients at home (Aromataris et al., 2024). The JBI meta-aggregation was chosen because it supports systematic synthesis of qualitative findings while maintaining fidelity to participants' meanings and producing practice-relevant outputs. This makes it well-suited to the review's aim of informing caregiver support across high- and low-resource settings (Lockwood et al., 2015).

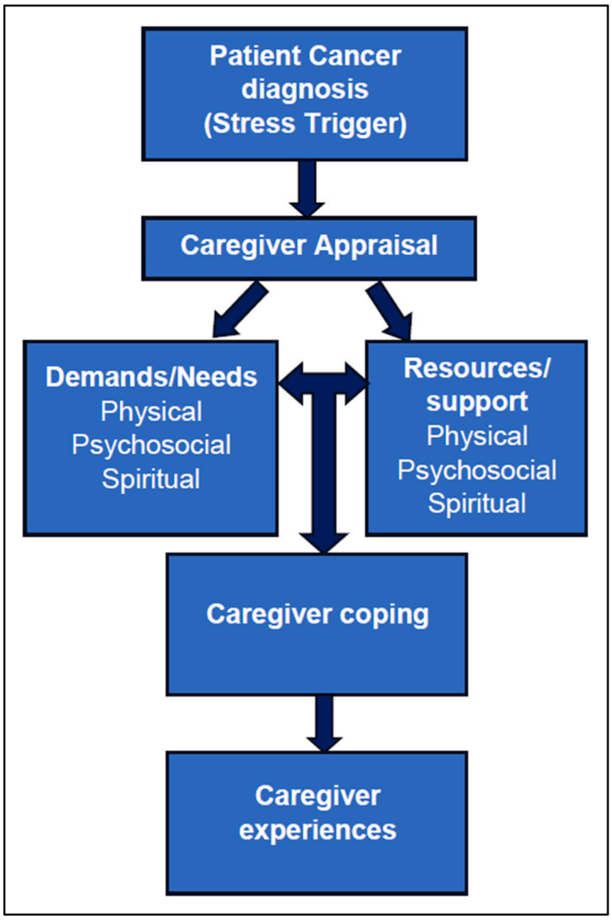

Fig. 1. The Model of Stress and Coping for family caregivers based on the Transactional Model of Stress and Coping (Folkman, 2013; Lazarus & Folkman, 1984).

2.2. Inclusion criteria

Population: Family caregivers of patients with any cancer being nursed at home, including family members and untrained caregivers.

Phenomena of interest: Family caregivers' perceptions of their roles and experiences in providing care to people with cancer at home.

Context: Experiences of caregiving at home from diagnosis to survivorship or death, including the bereavement period.

2.3. Exclusion criteria

Studies of paid and formal caregivers, such as healthcare professionals; reviews, commentaries, protocols, and conference abstracts; studies with inaccessible full-text articles; studies not addressing the phenomena of interest; and, due to limited resources, studies not published in English.

2.4. Types of studies

Qualitative studies (e.g., phenomenological, grounded theory, ethnographic, and narrative designs) which are suited to exploring in depth the meaning and complexity of family caregivers' experiences of caring for a cancer patient at home. Mixed-methods studies were included if the qualitative findings could be extracted separately.

2.5. Search strategy

We searched for studies published between 1 January 2000 and 29

February 2024 to include relevant literature findings reflecting current cancer care practices. This review adopted a three-step search method to identify relevant studies. 1) We conducted a limited search of PubMed to examine index keywords and text words in the title and abstracts to characterize the articles. 2) We searched eight databases: PubMed, MEDLINE (via EBSCO), CINAHL, PsycINFO, Scopus, and Proquest Nursing and Allied Health & Proquest Dissertations and Theses Global. We used “MESH” and expanded free text terms related to "family caregivers,” “cancer,” “care at home,” and “experience,” with database-specific adaptations. The full search strategies for each database are provided in Supplementary Table S1. 3. We searched the reference lists of the included studies for any relevant studies missed in the searches conducted in the second stage. The initial search was conducted across the identified databases in November 2021 and was updated in March 2024.

2.6. Article review, selection, and methodological assessment

Following the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) guidelines (Page et al., 2021), all articles were imported into Covidence 2.0 ("Covidence systematic review software, Veritas Health Innovation," 2022) where duplicates were automatically removed. Six reviewers independently screened the titles and abstracts (two per paper). Disagreements were discussed and resolved by the group. The full texts of all the included papers were retrieved and screened. Three reviewers (KM, PM, CB) assessed the methodological validity of the included studies using the standardized critical appraisal instrument from JBI for Qualitative Assessment and Review (Aromataris et al., 2024). This tool comprises ten questions, each requiring a “yes,” “no,” “unclear,” or “not applicable” response. For this review, papers that did not report a clearly stated philosophical or theoretical premise were scored as zero for Question 1. Similarly, studies reporting a qualitative approach without identifying a specific qualitative methodology were scored zero for questions 2 – 5. All studies were included, irrespective of the score, as guided by JBI (Aromataris et al., 2024) to ensure comprehensive coverage and avoid discarding valuable qualitative insights solely based on reporting quality, particularly given the nascent nature of some research areas.

2.7. Data extraction

Using Covidence, three reviewers (KM, PM, and CB) independently extracted the findings with supporting quotes. Additional data included the phenomena of interest, participant characteristics, study design, methods, and authors' conclusions. Extracted findings were assigned a level of credibility – “unequivocal,” “credible,” or “not supported”–as agreed by four independent reviewers (KM, CB, MJ, PM) (Aromataris et al., 2024).

2.8. Data synthesis

Data synthesis followed the JBI meta-aggregative approach, which aims to produce synthesized findings that are grounded in participants’ experiences while remaining suitable for informing policy and practice (Aromataris et al., 2024). The extracted findings were initially coded inductively within HIC and LMIC groupings and, through constant comparison, grouped into categories related to caregiving demands and resources, ways of coping and meaning making of their experiences.

The Transactional Model of Stress and Coping (Folkman, 2013; Lazarus & Folkman, 1984) (Fig. 1) was used as a flexible interpretative heuristic to organise and compare the findings across HIC and LMIC settings, allowing for both theory-informed analysis and the inductive emergence of new insights. Categories that did not align with the model were retained as independent findings and informed the refined conceptual interpretation. This iterative hybrid analysis is consistent with established hybrid analytic strategies used in qualitative research, which support theory-informed analysis while allowing for the inductive emergence of new insights (Kaur et al., 2025). Only findings assessed as unequivocal or credible were included in the final aggregation according to the JBI guidance.

2.9. Assessing confidence in findings

We used the JBI ConQual method to assess the level of confidence in the synthesized findings, ranging from high, moderate, and low to very low (Aromataris et al., 2024). The level of confidence was determined by the dependability and credibility of the individual findings of the included studies (Munn et al., 2014). Dependability was based on five critical appraisal questions (Q2 – Q4, Q6, and Q7) (Table 1). Credibility was determined by the congruence between the authors’ interpretation of the findings and the supporting data. These are ranked from unequivocal (the data without doubt supports the findings) to credible (the supporting data lacks a clear association with the finding) and not supported (the data does not support the finding). The rankings commence with “high” and are adjusted based on the levels of dependability and credibility.

3. Results

We identified 1067 studies of which 506 duplicates were removed, and 566 articles were screened for eligibility. We included 52 studies in this review. (Fig. 2).

3.1. Methodological quality

On critical appraisal of the 52 studies (Table 1, with the footnote providing the 10 questions (Aromataris et al., 2024)), none scored 10/10, 14 (27%) scored 8-9/10 (Barlund et al., 2021; Brazil et al., 2010; Capodanno et al., 2020; Dobrina et al., 2016; Juarez et al., 2014; Kusi et al., 2020; Maree et al., 2018; McKenzie et al., 2017; Mlaba et al., 2021; Mohammed et al., 2018; Rafii et al., 2020; Ream et al., 2013; Shanmugasundaram, 2015; Wilkinson & Wilkinson, 2020), 25 (48%) scored 5-7/10 (Beaver & Witham, 2007; Duggleby et al., 2010; Grbich et al., 2001; Heckel et al., 2018; Herring et al., 2022; Hopkinson, 2018; Houldin, 2007; Hudson et al., 2002; Janda et al., 2006; Koop & Strang, 2003; McConigley et al., 2010; Mehta et al., 2014; Mok et al., 2003; O'Brien & Steele, 2017; Rocío, 2017; Salifu et al., 2021; Seal et al., 2015; Seamark et al., 2014; Strang & Koop, 2003; Strang et al., 2002; Thomas et al., 2002; Too et al., 2023; Totman et al., 2015; Vale et al., 2019; Witham et al., 2018), with 13 (25%) scoring from 1 to 4/10 (Adejoh et al., 2021; Epiphaniou et al., 2012; Hashemi-Ghasemabadi et al., 2016; H.-T. S. Lee et al., 2014; Lopez et al., 2012; Milberg & Strang, 2004; Pottle et al., 2020; Sherwood et al., 2004; Stajduhar et al., 2008; Teschendorf et al., 2007; Ussher et al., 2011; Wennman-Larsen & Tishelman, 2002; Wong & Ussher, 2009). Only nine (17%) studies clearly stated a philosophical or theoretical perspective (Maree & Potgieter, 2018; McKenzie et al., 2017; Mohammed et al., 2018; Rafii et al., 2020; Ream et al., 2013; Salifu et al., 2021; Shanmugasundaram, 2015; Thomas et al., 2002; Wilkinson & Wilkinson, 2020). This perspective determines the methodological approach to the study design and analysis of the results. Only 18 (35%) studies reported the positionality of the authors (Adejoh et al., 2021; Barlund et al., 2021; Brazil et al., 2010; Capodanno et al., 2020; Dobrina et al., 2016; Heckel et al., 2018; Herring et al., 2022; Hopkinson, 2018; Houldin, 2007; Juarez et al., 2014; Kusi et al., 2020; H. T. Lee et al., 2014; Mlaba et al., 2021; Pottle et al., 2020; Salifu et al., 2021; Totman et al., 2015; Wilkinson & Wilkinson, 2020) and only 10 (19%) reported reflexivity (Barlund et al., 2021; Capodanno et al., 2020; Dobrina et al., 2016; Juarez et al., 2014; Kusi et al., 2020; Maree et al., 2018; Mlaba et al., 2021; Shanmugasundaram, 2015; Totman et al., 2015; Wilkinson & Wilkinson, 2020), both of which may introduce potential bias in the interpretation of the results (Wilson et al., 2022). Fifteen (29%) studies did not state a research methodology.

Table 1
Results of critical appraisal to assess methodological validity.

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Adejoh 2021	0	0	0	0	0	1	0	1	1	1	4
Barlund 2021	0	1	1	1	1	1	1	1	1	1	9
Beaver 2007	0	1	1	1	1	0	0	1	1	0	6
Brazil 2010	0	1	1	1	1	1	0	1	1	1	8
Capodanno 2020	0	1	1	1	1	1	1	1	1	1	9
Dobrina 2016	0	1	1	1	1	1	1	1	1	1	9
Duggleby 2010	0	1	1	1	1	0	0	1	1	1	7
Epiphaniou 2012	0	0	0	0	0	0	0	1	1	0	2
Grbich 2001	0	1	1	1	1	0	0	1	1	1	7
Hashemi-Ghasemabadi 2015	0	0	0	0	0	0	0	1	1	1	3
Heckel 2018	0	1	1	1	0	1	0	1	1	0	6
Herring 2022	0	1	1	1	1	1	0	1	0	1	7
Hopkinson (2018)	0	0	1	1	0	1	0	1	1	0	5
Houldin (2007)	0	0	0	1	1	1	0	1	1	1	6
Hudson 2002	0	1	1	1	1	0	0	1	1	1	7
Janda 2006	0	1	1	1	1	0	0	1	1	1	7
Juarez 2014	0	1	1	1	1	1	1	1	1	1	9
Koop 2003	0	1	1	1	1	0	0	1	1	1	7
Kusi 2020	0	1	1	1	1	1	1	1	1	1	9
Lee 2014	0	0	0	0	0	1	0	1	1	1	4
Lopez 2012	0	0	0	0	0	0	0	1	1	1	3
Maree 2018	1	1	1	1	1	0	1	1	1	1	9
McConigley 2010	0	1	1	1	1	0	0	1	1	1	7
McKenzie 2017	1	1	1	1	1	0	0	1	1	1	8
Mehta 2014	0	1	1	1	1	0	0	1	1	1	7
Milberg 2004	0	0	0	0	0	0	0	0	0	1	1
Miranda do Vale 2019	0	1	1	1	1	0	0	1	1	1	7
Mlaba	0	1	1	0	1	1	1	1	1	1	8
Mohammed 2018	1	1	1	1	1	0	0	1	1	1	8
Mok 2003	0	1	1	1	1	0	0	1	1	1	7
O'Brien 2017	0	1	1	1	1	0	0	1	1	1	7
Pottle 2020	0	0	0	0	0	1	0	1	1	1	4
Rafii 2020	1	1	1	1	1	0	0	1	1	1	8
Ream 2013	1	1	1	1	1	1	0	1	1	1	9
Rocio 2017	0	1	1	1	1	0	0	1	1	1	7
Salifu 2021	1	0	0	0	0	1	0	1	1	1	5
Seal 2015	0	1	1	1	1	0	0	1	1	1	7
Seamark 2014	0	1	1	1	1	0	0	1	1	1	7
Shanmugasundaram (2015)	1	1	1	1	1	0	1	1	1	1	9
Sherwood 2004	0	0	0	0	0	0	0	1	1	1	3
Stajduhar 2008	0	0	0	0	0	0	0	1	1	1	3
Strang 2002	0	0	1	1	1	0	0	1	1	1	6
Strang 2003	0	0	1	1	1	0	0	1	1	1	6
Teschendorf 2007	0	0	0	0	0	0	0	1	0	1	2
Thomas 2002	1	1	1	1	1	0	0	1	0	1	7
Too 2023	0	1	1	1	1	0	0	1	1	1	7
Totman 2015	0	0	0	0	0	1	1	1	1	1	5
Ussher 2011	0	0	0	0	0	0	0	1	1	1	3
Wennman-Larsen 2002	0	0	0	0	0	0	0	1	1	1	3
Wilkinson 2020	1	1	1	1	1	1	1	1	0	1	9
Witham 2018	0	1	1	1	1	0	0	1	1	1	7
Wong 2009	0	0	0	0	0	0	0	1	1	1	3

Questions (No = 0, yes = 1).

1. Is there congruency between the stated philosophical perspective and the research methodology?.
2. Is there congruency between the research methodology and the research objectives?.
3. Is there congruency between the research methodology and the methods used to collect the data?.
4. Is there congruency between the research methodology and the representation and analysis of the data?.
5. Is there congruency between the research methodology and the interpretation of the results?.
6. Is there a statement locating a researcher culturally or theoretically?.
7. Is the influence of the researcher on the research, and vice versa addressed?.
8. Are the participants and their voices adequately represented?.
9. Is the research ethical according to current criteria, or for recent studies is there evidence of ethical approval by an appropriate body?.
10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?.

This is required to link methodological congruency with philosophy and study methods. Five (10%) studies did not clearly state a consent process or ethical approval, although the research approaches appeared ethically sound.

3.2. *Study characteristics*

The 52 studies are summarized in Supplementary Table S2. Fig. 3 geographically maps the study locations. Most studies (41) were from HICs including: Australia (n = 8) (Grbich et al., 2001; Hudson et al., 2002; Janda et al., 2006; McConigley et al., 2010; McKenzie et al., 2017; Shanmugasundaram, 2015; Ussher et al., 2011; Wong & Ussher, 2009), United Kingdom (n = 14) (Beaver & Witham, 2007; Epiphaniou et al., 2012; Herring et al., 2022; Hopkinson, 2018; Lopez et al., 2012; Pottle et al., 2020; Ream et al., 2013; Seal et al., 2015; Seamark et al., 2014; Stajduhar et al., 2008; Thomas et al., 2002; Totman et al., 2015;

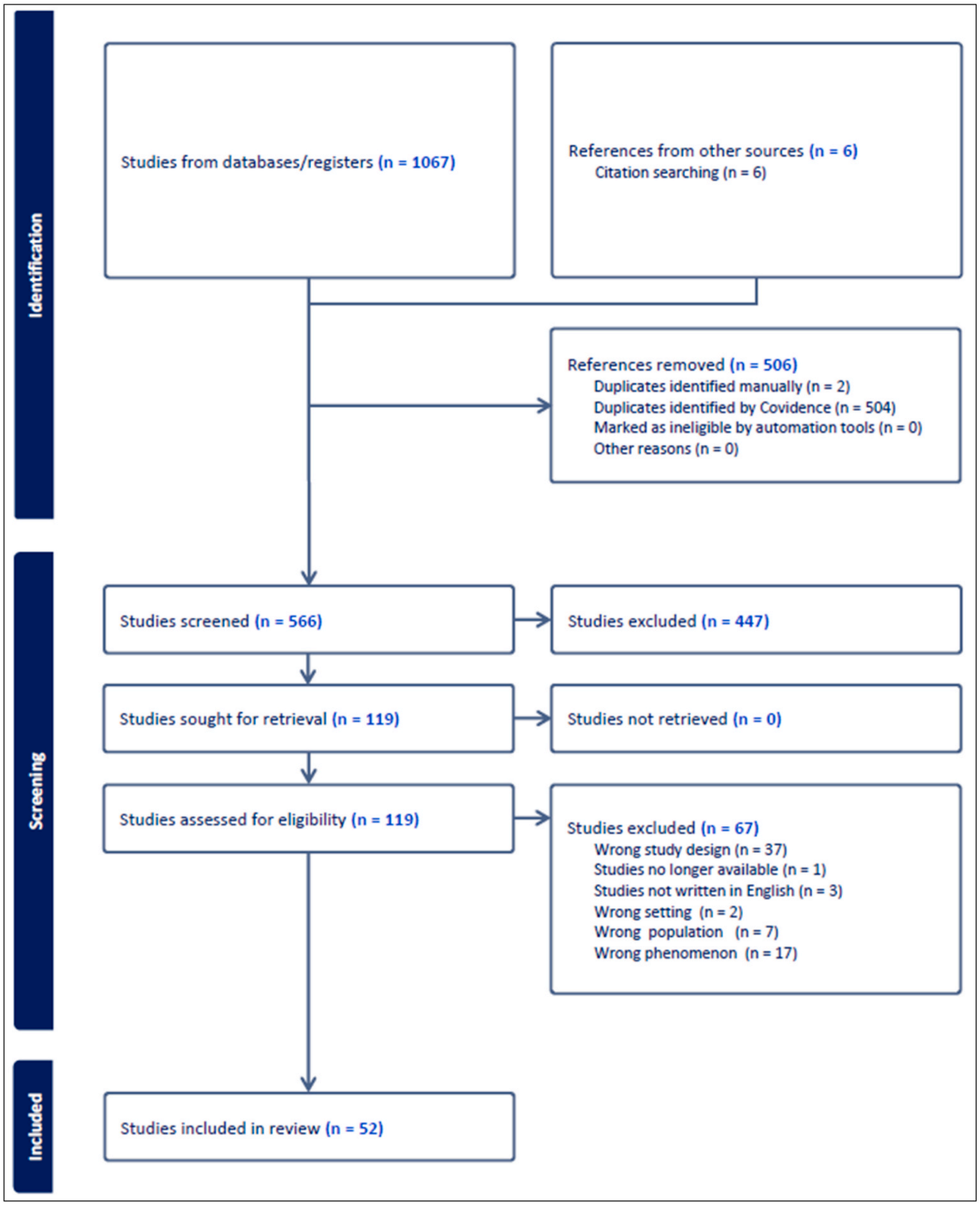

Fig. 2. PRISMA flowchart of included studies (Page et al., 2021).

Wilkinson & Wilkinson, 2020; Witham et al., 2018), Norway (n = 1) (Barlund et al., 2021), Canada (n = 7) (Brazil et al., 2010; Duggleby et al., 2010; Koop & Strang, 2003; Mehta et al., 2014; Mohammed et al., 2018; Strang et al., 2002; Strang & Koop, 2003), USA (n = 5) (Houldin, 2007; Juarez et al., 2014; O'Brien & Steele, 2017; Sherwood et al., 2004; Teschendorf et al., 2007), Hong Kong (n = 1) (Mok et al., 2003), Italy (n = 2) (Capodanno et al., 2020; Dobrina et al., 2016), Sweden (n = 2) (Milberg et al., 2004; Wennman-Larsen & Tishelman, 2002), Taiwan (n = 1) (H.-T. S. Lee et al., 2014) and Germany (n = 1) (Heckel et al., 2018). Studies from LMICs (all but three classified as upper middle-income countries) included Brazil (n = 1) (Vale et al., 2019), Ghana (n = 2) (Kusi et al., 2020; Salifu et al., 2021), Iran (n = 2) (Hashemi-Ghasemabadi et al., 2016; Rafii et al., 2020), Kenya (n = 1) (Too et al., 2023), South Africa (n = 2) (Maree et al., 2018; Mlaba et al., 2021) and Colombia (n = 1) (Rocío, 2017). One multi-country study included Uganda (a lower-income country) with Nigeria and Zimbabwe (both lower middle-income countries) (Adejoh et al., 2021). Notably, two studies from HICs included minority populations from LMICs (Mexican population in the USA and Indian population in Australia) (Juarez et al., 2014; Shanmugasundaram, 2015).

The 52 studies included 1389 family caregivers aged 18–87 years. Of the 46 studies reporting sex, 913 (73%) caregivers were female and 334 (27%) were male.

3.3. *Synthesized findings*

We extracted 328 findings (266 from HIC and 62 from LMIC studies) (Supplementary Tables S3–S8). Using the Transactional Model of Stress and Coping, the 328 findings were aggregated into 13 categories within five main synthesized findings. These were: 1) experiences triggering the onset of family caregiving (two categories), 2) relational, moral, and cultural motivations for assuming the caregiving role (two categories), 3) caregivers' appraisal of caregiving demands and available resources (four categories), 4) ways caregivers cope and make meaning of caregiving (three categories), and 5) relationally grounded caregiver experiences and personal consequences (two categories).

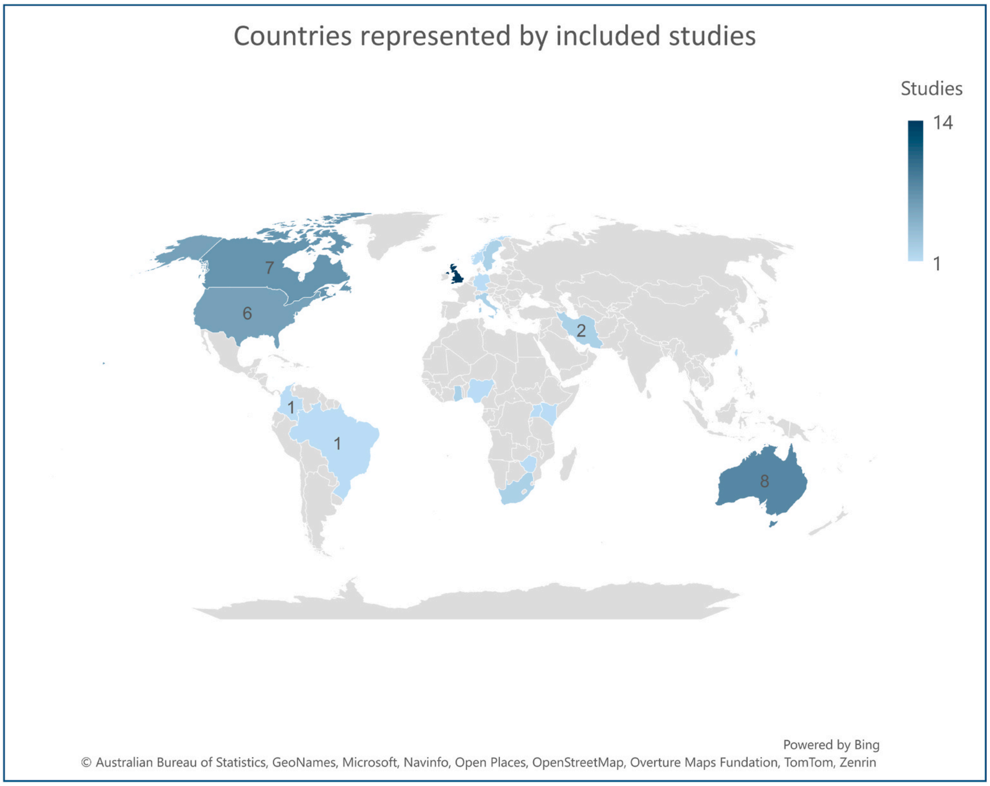

Fig. 3. Map of countries represented in the included studies.

3.3.1. Experiences triggering the onset of family caregiving

This synthesized finding consists of 17 findings grouped into two categories: 1) cancer diagnosis and 2) deterioration and transitions. The patient's diagnosis and changes in the disease trajectory were a source of severe trauma for both patients and caregivers.

3.3.1.1. Category 1. the cancer diagnosis. Globally, cancer diagnosis was described as a distressing event, commonly associated with shock *("body blow"* (Seal et al., 2015) *(HIC)*), anger, fear, and emotional distress:

> *"this ordeal has caused me so much pain and it has caused me to overthink which has led to so much stress in my life …"* (Maree et al., 2018) *(LMIC).*

In some LMIC studies, caregivers reported experiencing less shock at diagnosis when caregiving was preceded by prolonged exposure to chronic illness in the family. One caregiver described being accustomed to ongoing care responsibilities as follows:

> *"It was not a shock as I was used to taking her for check-ups …"* (Maree et al., 2018) *(LMIC).*

3.3.1.2. Category 2. deterioration and transitions. Caregivers across HIC and LMIC settings reported distress associated with multiple and worsening symptoms, including the rapid or unexpected deterioration of the patient's condition.

> *"It came too quick; the cancer spread too fast; just like a whirlwind"* (Seal et al., 2015) *(HIC).*

Uncertainty regarding disease progression and prognosis contributes to heightened anxiety.

> *"I'm just waiting all the time for the bombshell"* (McKenzie et al., 2017) *(HIC).*

Poor communication from health professionals further intensified distress during periods of deterioration and transition, particularly when news was delivered abruptly or without preparation, as reported in both HIC and LMIC studies (Hashemi-Ghasemabadi et al., 2016; McKenzie et al., 2017) (HIC, LMIC). Caregivers across settings described similar stressful experiences related to patient deterioration and transition to end-of-life care.

3.3.2. Relational, moral, and cultural motivations for assuming the caregiving role

This synthesized finding comprised 20 findings grouped into two categories: 1) obligation to provide care (six findings) and 2) personal meaning and relationship (14 findings). The motivation for caregiving ranged from a sense of obligation to loving care for the patient (Table 3). Contributing factors included the caregiver and patient's relationship, as well as community factors such as cultural and religious beliefs. This finding was inductively derived from the data and added to the stress and coping model.

3.3.2.1. Category 1. obligation to give care. Caregivers described a sense of obligation to provide care shaped by cultural, religious, and relational expectations, as well as reciprocity for prior care received.

> *"I must care for him. God will not forgive me if we abandon him because he (dad) has done a lot for the family and me … Everyone knows what my dad has done for us growing up." (Sophia, Samson's daughter)* (Salifu et al., 2021) *(LMIC).*

In other accounts, caregivers emphasized relational bonds rather than obligation as the primary motivation for caregiving, even when social expectations were acknowledged.

> *"I feel very good caring for him; I don't feel that it's my responsibility or my obligation … I still love him and care for him."* (Juarez et al., 2014) *(HIC).*

3.3.2.2. Category 2. personal meaning and relationship. Caregivers also described caregiving as a meaningful extension of their relationship with the patient.

> *"I take pleasure in caring for him because it has always been the love of my life and for me, caring for him is loving above all else". (*Vale et al., 2019*)(LMIC)*

Caring for a parent was an expression of gratitude for earlier care received. Rather than being a burden, caregiving was viewed a gift.

Maintaining a sense of normality and respecting the patient's wish to die at home, peacefully, and with dignity were also described as important aspects of caregiving.

> *"I continued to live my usual life, with just two people at home, one of which severely ill."* (Capodanno et al., 2020) *(HIC).*

> *"This is his home, of course he should be here.*"(Wennman-Larsen & Tishelman, 2002*) (HIC).*

3.3.3. Caregivers' appraisal of caregiving demands and available resources

This synthesized finding comprised 180 study findings across four categories: (1) information demands, (2) practical and physical demands, (3) psychosocial and spiritual demands, and (4) resources supporting caregiving across domains. Family caregivers of individuals with cancer face complex practical, physical, psychosocial, and emotional demands influenced by healthcare system responsiveness, cultural contexts, and available support networks. Although demands differ across HICs and LMICs, family caregivers in both contexts experience many similar challenges.

Tables 3.1–3.4 provide a summary of the caregivers' reported informational, practical, psychosocial, and spiritual demands and the available resources. Because resources may support more than one demand, these are summarized in a single integrated table (Table 3.4). Full study-level findings and supporting quotations are provided in Supplementary Tables S5 and S6.

Table 3.1
Information demands reported by caregivers.

Type of information demand	Focus of demand	Context	Example studies
Understanding the illness	Cancer diagnosis, disease progression, prognosis	HIC	(Beaver & Witham, 2007; Duggleby et al., 2010)
Treatment-related information	Treatment effects, symptom management, side effects	HIC	Beaver and Witham (2007)
Preparation for caregiving	What to expect at home; preparation for transitions	HIC	(O'Brien & Steele, 2017; Ream et al., 2013)
End-of-life information	Talking about death; preparation for the dying phase	HIC	(Barlund et al., 2021; Beaver & Witham, 2007)
Personal implications	Genetic risk, sexuality, caregiver self-care	HIC	Mok et al. (2003)
Navigating information sources	Where and how to obtain reliable information	HIC	(Heckel et al., 2018; Mehta et al., 2014)
Basic cancer knowledge	Understanding cancer and how to respond to illness	LMIC	Maree et al. (2018)
Earlier provision of information	Preparation for care at home; changes in the patient's condition	HIC	(Janda et al., 2006; Lopez et al., 2012)

3.3.3.1. Category 1. information demands. Caregivers frequently feel overwhelmed due to insufficient knowledge about managing distressing symptoms and treatment side effects, often resorting to a *"trial and error"* approach (Hudson et al., 2002) (Table 3.1). Timely, clear, and individualized information is essential, especially concerning the dying phase and the transition from hospital to home. One caregiver recalled,

> "*… if we would have known more of what to expect, what the symptoms are … if we had known before, it would have been a lot easier."* (Duggleby et al., 2010) *(HIC).*

Inadequate responses from healthcare providers often force caregivers to seek information independently, such as via the Internet, which can increase distress.

> "The only information I got was from the Internet." (Mehta et al., 2014) (HIC), and "… recently I started to go on that support website … but I found … that for me more unsettling than helpful …" (Janda et al., 2006) (HIC).

Information needs in LMICs are less documented; one study highlighted caregivers' profound lack of understanding of cancer*:*

> *"We don't know what cancer is and we have only seen it in white people, so we don't know it at all … when he starts to get sick we don't know what to do …"* (Maree et al., 2018) *(LMIC).*

3.3.3.2. Category 2. practical and physical demands. Caregivers in both HICs and LMICs often assume extensive post-discharge caregiving responsibilities without adequate training or support (Table 3.2). The severity of the patient's symptoms and functional decline intensify these demands. An LMIC caregiver described dealing with relentless pain as follows:

> *"The pain seems worse, yes, because it often does not stop – not even at night. Perhaps only once it would cease but the rest of the time it would not, at dawn the pain would calm down for some time and he was well without pain, but it would return again.*"(Rocío, 2017) *(LMIC).*

Similarly, HIC caregivers report feeling unprepared to manage complex medical interventions at home.

> *"He had so much tubing and drains and analgesic pump and epidural in his back and- (…) Yeah, I didn't have the competence to manage that."* (Barlund et al., 2021) *(HIC).*

Table 3.2
Practical and physical demands reported by caregivers.

Type of demand	Focus of demand	Context	Example studies
Care coordination and system navigation	Navigating fragmented health and social care systems; advocacy and liaison roles	HIC, LMIC	(Adejoh et al., 2021; Mohammed et al., 2018; Strang & Koop, 2003)
Communication with services	Limited inclusion in consultations; lack of acknowledgement of caregiver expertise	HIC, LMIC	(Adejoh et al., 2021; Juarez et al., 2014; Strang & Koop, 2003; Witham et al., 2018)
Increased care workload	Managing personal care, household tasks, finances, and additional responsibilities	HIC	(Houldin, 2007; Sherwood et al., 2004)
Managing complex symptoms	Pain, deterioration, and intensive care needs without adequate preparation	HIC, LMIC	(Adejoh et al., 2021; Barlund et al., 2021; Rocío, 2017)
Lack of preparedness and skills	Feeling unqualified to manage medical tasks and symptom escalation	HIC, LMIC	(Barlund et al., 2021; Hashemi-Ghasemabadi et al., 2016)
Disrupted continuity of care	Poor informational and organisational continuity across services	HIC, LMIC	(Mohammed et al., 2018; Rocío, 2017)
Barriers to accessing care	Long queues, transport difficulties, delayed attendance	LMIC	Adejoh et al. (2021)

Table 3.3

Psychosocial and spiritual demands reported by caregivers.

Type of demand	Focus of demand	Context	Example studies
Emotional isolation and lack of recognition	Feeling alone, unsupported, or emotionally invisible while providing care	HIC, LMIC	(Mlaba et al., 2021; Teschendorf et al., 2007)
Relational and family system impacts	Relationship changes, conflict, loss of intimacy, role renegotiation	HIC, LMIC	(Salifu et al., 2021; Ussher et al., 2011)
Role transition and identity strain	Transition to caregiver role, loss of previous identity, increased responsibility	HIC, LMIC	(Totman et al., 2015; Vale et al., 2019)
Supporting patient's emotional distress	Managing patient anxiety, fear, mood changes, existential concerns	HIC	(Ream et al., 2013; Totman et al., 2015)
Socioeconomic and livelihood strain	Employment disruption, financial stress, caregiving-related financial burden	HIC, LMIC	(Brazil et al., 2010; Maree et al., 2018)
Limited access to psychosocial services	Lack of formal emotional or social support services	HIC, LMIC	(Heckel et al., 2018; Mlaba et al., 2021)

The physical burden is compounded by additional household responsibilities.

> *"I have to manage the whole house, earn all the money, pay all the bills."* (Houldin, 2007) *(HIC).*

Poor communication and coordination within healthcare services exacerbate these challenges. HIC caregivers expressed frustration with the fragmented communication:

> *"The most not helpful was the poor communication between the doctor and the health care nurses … we really got into some wrong medication and stuff."* (Strang & Koop, 2003) *(HIC).*

Navigating multiple providers was also stressful.

> *"I will tell you that it's a morass to try and work through the various providers."* (Mohammed et al., 2018) *(HIC).*

In LMICs, barriers such as long queues and transport difficulties limit timely access to care, causing treatment delays.

> *"… when you are seated there your heart is divided. You know what you have left behind, the person is in terrible pain … I wish I could get oral morphine something I have come for and leave this place."* (Adejoh et al., 2021) *(LMIC).*

Missed appointments due to transport or perceived lack of necessity further complicate caregiving:

> *"Sometimes we fail to fulfil the appointments due to sometimes transport, and at times when we see there is really no necessity."* (Adejoh et al., 2021) *(LMIC).*

3.3.3.3. Category 3. psychosocial and spiritual demands. Caregivers in both settings experienced significant emotional strain, social isolation, and financial pressure (Table 3.3). Many sacrifice employment or social roles to provide care.

> *"I left my family and devoted myself totally to my mother … It's a very difficult time for me because I left my job, I stopped being a housewife, mother, wife, to dedicate 24 hours to my mother."* (Vale et al., 2019) *(LMIC).*

While caregivers provide emotional support for patients, their own suffering often remains unacknowledged.

> *"And he [Personnel Officer] said, 'just how are you coping?' I said, 'I don't know'. He said, 'well you've got to be strong' … I feel like I'm taking it all on my shoulders."* (Thomas et al., 2002) *(HIC).*

Family support varies; some caregivers benefit from frequent contact and shared responsibility, whereas others face strained relationships or lack emotional support.

> *"Well my one sister called, I said, 'well [sister], you want to come?' But none of my family would come at the end to be with me."*(Brazil et al., 2010) *(HIC).*

Illness-related changes in the patient's personality further challenge caregivers emotionally.

> *"We are very close … but with the illness and his mood swings, it's not easy but we are understanding the pain he is going through."* (Mlaba et al., 2021) *(LMIC).*

Caregivers from minority or immigrant backgrounds in HICs report additional isolation.

> *"I have no one here in Melbourne with me to support and care for my children. All my families are in India … they cannot help me with anything."* (Shanmugasundaram, 2015) *(HIC).*

Role shifts within families, such as assuming dual parental roles, add

Table 3.4

Resources and supports available to family caregivers across informational, practical, and psychosocial domains.

Resource type	Description	Primary domains supported	Context	Example studies
Healthcare professionals	Verbal explanations, guidance, ongoing contact	Informational; psychosocial	HIC	(Hudson et al., 2002; McKenzie et al., 2017; Stajduhar et al., 2008)
Written or structured guidance	Written materials on symptom management and dying	Informational	HIC	Hudson et al. (2002)
Internet-based information	Online searches and websites	Informational	HIC	(Janda et al., 2006; Mehta et al., 2014)
Telephone helplines	Advice and information outside routine care	Informational; practical	HIC	(Hudson et al., 2002; Seamark et al., 2014)
Family and community support	Shared caregiving, emotional presence, companionship	Practical; psychosocial	HIC, LMIC	(Barlund et al., 2021; Duggleby et al., 2010; Epiphaniou et al., 2012)
Home-based health services	Home care, equipment, professional support	Practical; psychosocial	HIC	(Capodanno et al., 2020; Sherwood et al., 2004)
Responsive nursing care	Timely pain relief and symptom control	Practical; psychosocial	HIC	Shanmugasundaram (2015)
Caregiver experiential knowledge	Symptom recognition and anticipation	Informational; practical	LMIC	Rafii et al. (2020)
Caregiver agency and initiative	Problem-solving, learning through experience	Practical; psychosocial	HIC, LMIC	(McConigley et al., 2010; Rocío, 2017)
Informal and traditional care practices	Herbal remedies and indigenous practices	Practical; psychosocial	LMIC	(Kusi et al., 2020; Salifu et al., 2021)
Emotional and spiritual practices	Prayer, faith, meaning making	Psychosocial	LMIC	Kusi et al. (2020)

to the caregiver burden:

> *"Now I'm playing the role of mom and dad at the same time … it's not that easy*." (Juarez et al., 2014) *(LMIC).*

In HICs, caregivers often manage patients' anxiety about deterioration and death.

> *"She came to me in the middle of the night and said 'Mum, what will happen if this doesn't work and I don't get better and I die?' … I didn't notice much support in this area."* (Ream et al., 2013) *(HIC).*

This emotional demand was less commonly reported in LMICs, where family conflicts over treatment choices, especially between traditional and biomedical approaches, were more prominent.

> *"Some were pushing him to undergo chemotherapy while others vehemently opposed it … we are divided about what to do."* (Salifu et al., 2021) *(LMIC).*

Financial strain is pervasive, especially in LMICs, where caregiving costs can be devastating.

> *"By 2016, I lost, we lost, we were not able to pay accommodation … we had to go to friends … a church member just allow her to stay at the balcony … Rain she is there, sun she is there, night, mosquito everything."* (Adejoh et al., 2021) *(LMIC).*

In contrast, while some HIC caregivers faced costs for additional support, such as private nursing, transportation, and treatment costs, these were generally manageable.

3.3.3.4. Category 4. resources supporting caregiving across domains. Family caregivers draw on a diverse range of resources that support their caregiving roles, including formal health and social systems, family and community networks, and individual coping strategies. These resources differ markedly between HICs and LMICs, reflecting disparities in healthcare infrastructure, cultural practices and available support.

3.3.3.5. Information resources and support. In HICs, caregivers appreciate access to healthcare professionals who provide advice and reassurance, often via phone follow-ups.

> *"She [nurse] phones and says, 'Well, how are things?' I think it does help because you're not alone. You feel like there is somebody there if you need them." (*Stajduhar et al., 2008) *(HIC).*

Telephone helplines and online resources are also commonly used, although their quality and responsiveness vary (Capodanno et al., 2020; Seamark et al., 2014).

In LMICs, formal information resources are either scarce or underdeveloped. Caregivers may rely on indigenous knowledge, traditional healers, and community networks for guidance on symptom management (Kusi et al., 2020; Salifu et al., 2021). There is a clear reported need for improved communication and accessible, culturally appropriate information tailored to caregivers' contexts.

3.3.3.6. Caregiver knowledge and skills. In LMICs, caregivers often develop substantial practical skills to manage physical symptoms and provide direct care, sometimes performing complex tasks without professional supervision. One caregiver described,

> *"When he had the catheter, I would administer the medicine … I help him with the curing procedures, all that, help him to vacate the colostomy and those things I have already learnt how to manage."* (Rocío, 2017) *(LMIC).*

Another caregiver recognized subtle pain cues:

> *"When I see him frowned, stared at one spot, and silent, I know that he is in pain … but I know how severe is that bit of pain." (*Rafii et al., 2020) (*LMIC).*

This experiential knowledge facilitates early symptom recognition and management, thereby easing patient discomfort and caregiver stress.

Caregivers in HICs also seek information to manage symptoms but tend to rely more on healthcare professionals for direct care. Access to trained nurses who administer treatments such as opioid injections, enables timely pain relief and reduces caregiver burden. One caregiver recounted,

> *"My wife was in pain for a long time … Finally, a nurse gave her morphine injection. I could not see her suffering."* (Shanmugasundaram, 2015) *(HIC).*

3.3.3.7. Formal health and social system resources. Caregivers in both HICs and LMICs value formal health services that effectively respond to their needs. In many HICs, access to home care support and healthcare professionals for symptom management is an essential service. Regular follow-ups and the availability of healthcare staff provide emotional reassurance and reduce caregiver isolation. As one caregiver noted,

> *"She [nurse] phones and says, 'Well, how are things?' I think it does help because you're not alone. You feel like there is somebody there if you need them." (Stajduhar* et al.*, 2008) (HIC).*

In LMICs, formal palliative care services exist but are often constrained by poor communication, fragmented coordination, and transport difficulties, which negatively impact the quality of life of both patients and caregivers. Consequently, caregivers frequently supplement formal care with traditional therapies and indigenous knowledge. For example, a caregiver explained,

> *"I sent her to an herbal center at Asokwa. The herbal doctor usually grinds some green leaves for us to apply on the wound at home and it has really reduced the malodor."* (Kusi et al., 2020) *(LMIC), and another shared,*
>
> *"I usually mix charcoal with clay and apply it on her swollen hand and by the next day, the hand will be better."* (Kusi et al., 2020) (*LMIC).*

3.3.3.8. Family and community support. Families and communities serve as essential sources of practical and emotional support, especially in areas where formal services are limited. Frequent contact with family members through visits or calls offers emotional relief and shares the caregiving responsibilities. One caregiver reflected,

> *"Her brother comes round every week, her sister phones up all the time, my oldest daughter phones up. When we speak with my son in the US he always asks."* (Epiphaniou et al., 2012) *(HIC).*

Nonetheless, caregiving can also strain family dynamics when patient and caregiver needs conflict with those of other relatives.

Community support, often rooted in spiritual and emotional encouragement, further strengthens caregiver resilience. A caregiver noted,

> *"I pray for her and share healing messages in the Bible with her. This has really helped her to have some inner peace now."* (Kusi et al., 2020) *(LMIC).*

3.3.3.9. Psychosocial and spiritual resources. Psychosocial support varies across different settings. Caregivers in HICs may access formal social services, although administrative demands can limit their utilization. A caregiver described,

> *"It's a demanding system because you have to plan when to take out days and everything … so, therefore, it was barely used."* (Barlund et al., 2021) *(HIC).*

In LMICs, formal social support is often lacking, and caregivers express a need for financial assistance programs, such as caregiver grants.

> *"I think the social worker department should have something, a caregivers' grant or something … will be of some help."* (Mlaba et al., 2021) *(LMIC).*

Spiritual resources are especially prominent in LMICs, where caregivers commonly use prayer and share healing messages to provide emotional and spiritual support to patients, enhancing their psychosocial well-being (Kusi et al., 2020).

3.3.4. *Ways caregivers cope and make meaning of caregiving*

This synthesized finding comprised 51 findings grouped into three broad coping orientations: (1) engagement strategies, (2) disengagement strategies, and (3) spiritual or transcendent coping. These orientations were fluid and overlapping, not discrete, with caregivers often drawing on multiple strategies within the same period or across different stages of the cancer journey.

Family caregivers of individuals with cancer employ diverse coping strategies to manage the multifaceted demands of caregiving, including engagement, disengagement, and spiritual approaches. These strategies reflect caregivers' efforts to find meaning and sustain resilience in the face of physical, emotional, and practical challenges.

3.3.4.1. Category 1. engagement strategies. Caregivers actively respond to evolving caregiving demands by accepting responsibilities and adapting their lives. One caregiver reflected,

> *"Once I heard he had advanced cancer and then [metastasis] to the bone, I jumped into action. It was just a natural thing for me to take over, since it was what needed to be done."* (O'Brien & Steele, 2017) *(HIC).*

Others described redefining their lives to accommodate caregiving.

> *"At first, it was hard; I was faced with new problems. Finally, I forced myself to believe that I have to live with this situation. I tried to define a new plan for my new life." (*Hashemi-Ghasemabadi et al., 2016) *(LMIC).*

Self-care practices, such as listening to music, prayer, or brief moments of respite, were important for emotional well-being.

> *"I had a chair in there [in the dying person's bedroom] and I [would] put my headphones on, listen to music ….burn some sweet grass or incense, [do some] visualization … other people I was praying for … and breathe, and it doesn't take a long time for that to work … and it'd make all the difference."* (Lopez et al., 2012) *(HIC).*

3.3.4.2. Category 2. disengagement strategies. Caregivers also employed disengagement to cope with overwhelming stress, including wishful thinking and avoidance of stressors. One caregiver shared,

> *"I wish I had a normal life; working and staying with my baby."* (Dobrina et al., 2016) *(HIC).*

Others denied their feelings to maintain hope*:*

> *"I cry when I am alone. How can I cry in front of her when I am trying to give her hope? I pretend that everything is ok, but inside I am devastated."* (Hashemi-Ghasemabadi et al., 2016) *(LMIC).*

Burnout and emotional withdrawal were reported as follows:

> *"I could not go near the bed … I sat there near the door on the chair because I could not go near him. I didn't feel up to it."* (Capodanno et al., 2020) *(HIC).*

Neglecting personal health was common.

> *"I stopped taking care of myself, of my health. I do not go to the doctor anymore, I do not go out for walks, I do not study anymore, I do not work, I do not care, you know?. There are times when I arrive at the end of the day, I have not even showered, just taking care of her." (*Vale et al., 2019*) (LMIC).*

3.3.4.3. Category 3. religious and spiritual coping. Spirituality and faith were vital coping resources across contexts. Caregivers turned to prayer for strength:

> *"You just have to pray to God to give you strength, you just need God's intervention so that He can give you strength because it is something we haven't planned for ….*"(Maree et al., 2018) *(LMIC).*

Faith offered a framework for meaning-making and endurance:

> *"Knowing that everyone's got their cross to bear and this is mine or this is my family's. So, from a faith standpoint, that's where my faith comes in. If I didn't believe that we're only here for a short period of time and that there's a better life after, when we pass away, I don't know if I'd be able to deal with things the way I deal with them now because I realize that this isn't the be-all, end-all.*" (Houldin, 2007) *(HIC).*

However, spiritual beliefs sometimes prolonged denial of the prognosis.

> *"There is a day she (the patient) said she will die, I told her no, she will not die but live … I still pray for her to get well, …the church members come to pray for her and tell her that she will recover."* (Too et al., 2023) *(LMIC).*

3.3.5. *Relationally grounded caregiver experiences and personal consequences*

This synthesized finding comprises 51 findings in two categories: 1) relational impacts (18 findings) and 2) personal consequences of caregiving (33 findings). Caregivers' experiences and meaning making were grounded in their relationships with the patient. While many caregivers described profound emotional, physical, and identity-related costs, others simultaneously articulated experiences of affirmation, meaning, gratitude, and personal growth, often coexisting with distress rather than replacing it. Caregivers' accounts of personal impact were frequently ambivalent, encompassing profound strain alongside experiences of meaning, fulfilment, and strengthened relationships with the care recipient.

3.3.5.1. Category 1. relational impacts. Caregivers reflected on changes in their relationships with the patient and family, highlighting both the strain and unity. Feelings of guilt and frustration emerged in the relational dynamics.

> *"Sometimes when I am busy she has expectations and demands that frustrate me and I mistreat her. Later I am saddened and distraught because I am not a good caregiver."* (Hashemi-Ghasemabadi et al., 2016) *(LMIC).*

The caregiving journey also fostered closer family bonds, as one caregiver noted,

> *"Well, I think it's the … the unity of the family, we feel more together, well, closer to her (patient)*." (Juarez et al., 2014) *(HIC).*

Caregivers mourned the loss of personal relationships and social connections.

> *"When I look back, I see that I have lost many opportunities. I did not live my life; I just took care of my sister and thought about her." (*Heckel et al., 2018) (*HIC).*

3.3.5.2. Category 2. personal consequences of caregiving. Caregivers described emotional and psychological burdens, including helplessness and despair.

> *"… you see, it's hard, very hard, emotionally its breaking me … everything is a nightmare …" (*Maree et al., 2018*) (LMIC).*

> *"I was suddenly totally helpless. I was seized with deep powerlessness when I understood that I couldn't do anything to help my wife." (*Milberg & Strang, 2004*) (HIC).*

Relief accompanied by guilt was also common.

> *"… I felt the pressure was off of me when he was in the hospital. Like when he was in [name of hospital] and they were looking after him I thought oh thank God I've got, at night, but I don't have to worry about getting up quickly and seeing to him"(*Brazil et al., 2010*) (HIC).*

While some caregivers reported a sense of personal fulfilment, caregiving was also associated with a disruption of life continuity, reflected not only in the loss of their loved one but also in losses to their own life trajectories.

> *"When I look back, I see that I have lost many opportunities. I did not live my life; I just took care of my sister and thought about her." (*Hashemi-Ghasemabadi et al., 2016*) (LMIC)*

Positive personal outcomes included feelings of pride and satisfaction in managing caregiving duties.

> *"I'm happy. Happy with myself that I could do it. It felt good I was able to manage, and I was happy that I managed and I enjoyed managing. I mean. I did get … it gave me a good feeling inside and she appreciated it."* (Grbich et al., 2001*) (HIC).*

Gratitude for quality time and the impact of palliative care were expressed as follows:

> *"I thought that the death of my mother is a good death because she died without pain from cancer or any discomforting symptoms … it was really important for us and we were appreciate what you (the hospice home care team) have done for us …" (son)* (H. T. Lee et al., 2014) *(HIC).*

4. Discussion

This qualitative systematic review provides a comprehensive synthesis of the lived experiences of family caregivers of patients with cancer, offering critical insights into their emotional, physical, and systemic burdens, which coexist with a sense of responsibility, meaning, and commitment to family roles. This review reveals the profound strain experienced by caregivers in both HICs and LMICs and the structural disparities in the caregiving landscape. However, caregiving also emerged as a relational experience embedded in individual family structures and within communities with social and cultural expectations.

4.1. Comparing experiences of family caregivers in HICs and LMICs

Despite differences in the availability of formal services and sociocultural contexts, several similarities in caregiving experiences were observed. A consistent finding across settings was the significant psychological distress triggered by the patient's diagnosis and disease progression, initiating distressing uncertainty about the future and their ability to cope with it. These moments often marked the onset of caregivers' emotional and existential burdens, which is compounded by inadequate communication from health providers.

Caregiving is often motivated by deep relational bonds, or a sense of duty often framed as a societal or familial obligation, or cultural and religious obligations. Caregivers frequently require information about the physical and psychological effects of cancer and its treatment, as well as adequate skills and preparation to manage the patient's needs, including administering medication, performing complex medical tasks, and supporting activities of daily living. Receiving sufficient timely information and support fundamentally empowers caregivers to cope with the demands of patient care at home.

Limited access to palliative care services, medical information, and symptom management support created a vacuum in which caregivers had to 'learn by doing. In HICs, formal support services are usually available, including medical, social, supportive, and palliative care facilities. However, these services could be poorly coordinated and not adequately responsive to individual needs. Caregivers experienced challenges in navigating health systems and social services while feeling unacknowledged as vital partners in patient care. Caregivers in LMICs face numerous challenges owing to limited formal health and social service support. They frequently reported limited access to pain relief, inadequate symptom management, and minimal formal home-based or palliative care services. Financial strain was often pronounced, reflecting out-of-pocket health expenditures, income loss, and limited access to social protection. With inadequate access to health services, some caregivers would consult traditional healers or rely on knowledge of indigenous practices to alleviate the patient's physical suffering; a poorly acknowledged local source of support. Globally, caregivers sought support from their families and communities, although families sometimes offered financial rather than emotional support. Importantly, the presence or absence of emotional, informational, and practical support for caregivers often shapes the extent to which their caregiving is experienced as a meaningful role or a debilitating burden. Many caregivers described feeling unprepared, overwhelmed, and excluded from formal care discussions, further exacerbating their sense of powerlessness. This underscores the importance of health systems in recognizing and actively supporting caregivers, not merely as passive bystanders but as essential contributors to patient care.

As observed in our synthesized findings explicit descriptions of coping strategies were more prevalent in studies from HICs than in those from LMICs. This likely reflects differences in how caregiving experiences are conceptualized, expressed, and reported in research from these contexts, rather than an actual absence of adaptive responses in LMICs (Bamodu & Chung, 2024; Giebel et al., 2022; Murphy et al., 2019). Coping frameworks commonly used in caregiving research are largely derived from Western psychological models that emphasize individual agency and conscious strategy use (Aronowitz et al., 2015; Falzarano et al., 2021; Yuan et al., 2023). However, coping with caregiving in other contexts may also be embedded in collective familial, social, religious, or cultural practices and not expressed as coping strategies in the literature.

Caregiving presents mental, physical, and emotional challenges in any setting. Although access to support varies by region, caregivers generally employ similar strategies of engagement and disengagement, with religious or spiritual coping more frequently reported in LMICs echoing findings of studies on caregivers in mental health (Marimbe et al., 2016). Caregivers' coping strategies are diverse, both individually and throughout the cancer journey, ranging from proactive engagement to emotional suppression and disengagement as well as religious coping which can signify either engagement or disengagement. While these strategies may reflect personal resilience, they also highlight unmet support needs among caregivers. Even in HICs with formal support structures, caregivers experience emotional isolation, role strain, and a lack of recognition by professionals, emphasising the universal need to strengthen supportive caregiver policies. Studies of caregiver coping indicate that engagement coping strategies lead to improved social support (Biney et al., 2024; Litzelman et al., 2016; Mosher et al., 2015) and better caregiver quality of life (Dionne-Odom et al., 2017; Long et al., 2021), while caregiver well-being affects cancer patients' perceived quality of care (Litzelman et al., 2016) and a higher caregiver burden has been shown to negatively affect patient survival (Dionne-Odom et al., 2016). In several LMIC studies, caregiving is not primarily seen as a burden but as an expected moral, familial, relational, or spiritual obligation. Distress often stems not from caregiving itself, but from structural issues such as poverty, inadequate pain relief, fragmented services, transportation difficulties and lack of financial protection. Thus, what may be perceived as 'caregiver burden' in Western contexts might in some settings, reflect the interplay between deeply valued caregiving roles and insufficient structural support.

Although meaning and personal growth were more frequently articulated in HIC studies, LMIC studies more often foregrounded the overwhelming effects of poverty, social disruption, and inadequate support systems, which may have constrained opportunities for such reflections. This stark contrast highlights the transformative potential of accessible and responsive palliative care services and the ethical imperative to invest in caregiver-centered cancer care support in LMICs. Indeed, those who received palliative support coped better with the practical challenges of caring for the patient but felt that their emotional and social needs were still not adequately addressed.

4.2. Model fit and usefulness

The Transactional Model of Stress and Coping proved to be a good fit for the findings and provided a novel focus on family caregivers' coping. One additional domain, namely the caregiver's motivation to adopt their role, was added. We found that stress triggers reoccurred throughout the cancer trajectory as the patient's condition changed or deteriorated. With the increase in life-prolonging treatments and the dynamic nature of cancer care (Thana et al., 2021), caregivers may experience repeated triggering events that require re-appraisal of new demands, available resources, and coping strategies. By employing this model as an analytic heuristic to explore caregivers' experiences and meaning making, we identified common human responses of family caregivers to the challenges of caring for a patient with cancer at home. Although contexts, demands, and resources may differ, the stresses, motivations for caregiving, and coping mechanisms, shaped by socio-cultural and individual beliefs, are universally shared. Caregivers' access to information, practical, psychosocial and spiritual support will affect caregiver coping and the impact of the stressors on the caregivers. This model may serve as a blueprint for the development of individualized assessment of caregivers' needs, available resources, and coping strategies, which would inform the interventions required to ensure the best possible support for them and the patient, which may improve survival and quality of life outcomes.

4.3. Implications for policy, practice and research

Informal or family caregivers are central role players in the care of cancer patients at home. Caregivers' coping affects their ability to access resources, their burden of care, and their psychosocial well-being, which in turn impacts patient outcomes. Caregivers' roles in managing cancer patients should be acknowledged, and they should be included in decision-making and care planning with caregiver-sensitive communication. Caregiver integration in discharge planning for older patients reduced the costs of post-discharge care, increased time to readmission, and reduced the length of hospital stay (Rodakowski et al., 2017), while a 2-h caregiver training offered by a nurse pre-discharge improved caregiver self-efficacy and stress management. However, as with other studies, we found that caregivers require ongoing support after discharge (Hendrix et al., 2016).

Caregiver support interventions must be context-sensitive and culturally appropriate. Integrating formal health services and psychosocial support with digital technologies to extend access may be feasible in HICs; however, in LMICs, strengthening and integrating existing community strengths and services for palliative care while adopting task-sharing approaches in the formal health system may be more culturally and contextually appropriate and sustainable in the long term.

This review highlights significant gaps in the evidence regarding the experiences of caregivers, especially from LMICs. Future qualitative research should focus on the unique contextual and cultural experiences to gain a deeper understanding of caregivers' meaningful interpretations of their experiences, supports, and coping with challenges in all contexts. This research will inform sustainable strategies for developing interventions that are responsive to the unique needs of family caregivers across diverse settings.

4.4. Strengths and limitations of the review

This review has some limitations that may impact the transferability of the findings. Only papers published in English were included, which may limit access to research published in other languages, especially from diverse cultural perspectives. While the studies in the review represent all WHO regions, they are concentrated in a few HICs and even fewer LMICs, which may not represent the global experiences of caregivers. Acknowledging that meta-aggregation is an interpretative synthesis of findings, we recognized the potential influence of the researchers' positionality on the data analysis and implemented measures to enhance the congruency between the original study findings and the synthesized findings. A notable limitation of this review stems from the methodological quality of the primary studies included. As detailed in Table 1, a substantial number of studies did not explicitly state their philosophical or theoretical perspectives, nor did they adequately report on researcher positionality or reflexivity. These elements are crucial for establishing the rigor and trustworthiness of qualitative research. Thus, the overall lower methodological quality of a significant portion of the evidence base may limit the depth and nuance of the synthesized findings, particularly concerning the interaction of cultural contexts and caregiving experiences. Future research could benefit from more robust reporting standards in primary qualitative studies to enhance the richness of subsequent syntheses.

5. Conclusion

In conclusion, the findings highlight the importance of viewing caregiver experiences through a global lens to avoid missing important relational and practical supports available to caregivers and their different coping mechanisms that may be missed with a deficit-oriented view. While access to resources may differ across settings, caregivers report common human responses to the triggering need for caregiving in a cancer diagnosis. Coping strategies depend on individual responses and contextual resources and serve to either access resources to minimize stress or protect the caregiver from an overwhelming stress response. Despite the differences in resources, the similarities in care responses indicate an urgent need for health systems in HICs and LMICs to integrate caregivers more fully into the continuum of cancer care. This includes (i) developing caregiver-inclusive communication protocols, (ii) ensuring access to timely, individualized information and training, (iii) establishing community-based support services, including financial protection, and (iv) embedding culturally sensitive psychosocial interventions into routine care. In doing so, we can shift the caregiver experience from one of silent suffering to one of empowered partnership and ensure that those who care are also cared for.

CRediT authorship contribution statement

Charmaine L. Blanchard: Writing – original draft, Validation, Project administration, Formal analysis, Data curation, Conceptualization. **Keletso Mmoledi:** Writing – original draft, Validation, Project administration, Data curation, Conceptualization. **Maureen Joffe:** Writing – review & editing, Validation, Formal analysis, Data curation, Conceptualization. **Shane Norris:** Writing – review & editing, Validation, Supervision, Conceptualization. **Patricia McInerney:** Writing – review & editing, Validation, Supervision, Data curation, Conceptualization.

Ethics statement

This review uses data from previously published, publicly available sources; therefore, ethical approval was not required.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this manuscript, the authors used Paperpal (version Extensive 2.0, October 2025]; https://paperpal.com/) for editing assistance to improve spelling, grammar, clarity, and readability. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

Declaration of generative AI and AI-assisted technologies in the writing process

The authors declare that there was no use of AI and AI-assisted technologies in the writing process.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2026.100773.

Data availability

Data will be made available on request.

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