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Experiences of Informal Caregivers of Terminally Ill Patients in Palliative Care: A Systematic Review

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ABSTRACT

Informal caregivers play a vital role in palliative and end-of-life care. However, their experiences are rarely acknowledged or recognized formally within health care delivery systems. This systematic review examined the most recently available peer reviewed literature examining the experiences of informal caregivers caring for terminally ill patients in palliative care focusing on burden, challenges, coping, psychosocial reactions and lived experiences. Eligible studies published from 2021 forward were located via a structured search through PubMed and Google Scholar. Twenty-one studies were ultimately selected for inclusion in this synthesis. Thematic analysis was used to analyze data resulting in the identification of six themes: (1) caregiving as complex work; (2) caregiving under constraint; (3) emotional burden and psychological distress; (4) coping, meaning-making and positive adaptation; (5) role transformation and caregiver expertise; and (6) navigating uncertainty and preparing for dying. These results clearly indicate that caregiving during palliative care is multi-dimensional and influenced by practical, emotional, structural limitations and uncertainty associated with an individual's death. While many caregivers will suffer from burden and lack of adequate support, caregivers have shown the ability to develop resiliency, meaning and expertise in their caregiving roles. Overall, this systematic review supports the recognition of caregivers as both care partners and care recipients within palliative care delivery systems.

Keywords: informal caregivers; palliative care; terminal illness; caregiver experiences; thematic analysis

INTRODUCTION

Caregiving is universal. In all regions of the world, most long-term care and many forms of short-term supportive care for people with severe illnesses, disabilities, or frailty are provided by family members or close relatives. Family caregiving has been identified as a significant global and lifelong public health challenge due to demographic changes resulting from increasing longevity and improved survival rates of individuals with chronic diseases. As a result of population aging, increased dependency on unpaid family and informal caregiver labor is increasingly being utilized as a resource by health systems and governments in caring for individuals at home and within local communities (Haley & Elayoubi, 2024). Palliative care places additional importance on providing support to family members in addition to supporting the terminally ill individual, recognizing that the well-being of the family member is critical to providing quality care (World Health Organization [WHO] 2020).

The goal of palliative care is to enhance the quality of life of patients and their families experiencing a life-threatening illness by reducing physical, psychological, social and spiritual suffering (WHO, 2020). Despite the increasing demand for palliative care globally, there is currently limited access to services. Approximately 14% of those requiring palliative care receive the necessary care and services (WHO, 2020), and the burden of cancer, organ failure, neurological disease, dementia, and other life limiting conditions continues to grow internationally. Given the limitations of formal palliative care services, family and friends who are providing informal care are becoming increasingly responsible for delivering care, particularly in home and community-based care environments where much of the end-of-life support occurs.

Informal caregivers are generally perceived as family members or friends providing unpaid assistance and support to an individual with a severe or terminal illness (Auclair et al., 2022). Informal caregivers may be involved in multiple aspects of care including; monitoring symptoms; performing personal care; providing

emotional support; coordinating services; making decisions regarding the health-care needs of the individual; and advocating for the individual's needs (Abed et al., 2025; Auclair et al., 2022). While these roles contribute significantly to the delivery of care to the patient, they can also place a significant burden on the caregiver and impact the caregiver's emotional, social, economic, and physical well-being (Haley & Elayoubi, 2024; Handique et al., 2025).

Studies and reviews conducted over the past several years have demonstrated that informal caregivers in palliative and end-of-life care frequently report having experienced high levels of burden. Commonly reported difficulties include psychological distress; exhaustion; uncertainty; social isolation; inadequate support; lack of respite; and financial burden (McGuigan et al., 2024; Handique et al., 2025). Although caregivers do face hardships associated with providing care, some caregivers also indicate positive outcomes resulting from their caregiving experience including: personal growth; enhanced relationships; sense of purpose; and ability to adapt to new experiences (Cole et al., 2025; Theißen et al., 2024). These findings demonstrate that caregiving in palliative care is multifaceted and influenced by both burden and resilience.

Although research focusing on the experiences of informal caregivers is expanding rapidly, evidence synthesis remains fragmented. Several reviews have focused on specific medical conditions such as dementia or advanced stage chronic illnesses, while others have examined only one dimension of caregiving, e.g. loneliness, psychosocial interventions, or service experience (Cole et al., 2025; Lindeza et al., 2024; McGuigan et al., 2024). Moreover, some researchers have noted that evidence relating to informal caregivers in palliative and end-of-life care is often condition-specific or setting-specific which complicates developing a broad understanding of what caregivers typically experience when dealing with terminally ill patients (Auclair et al., 2022; Lung et al., 2021).

Therefore, given the existing gaps in knowledge about the experiences of informal caregivers of terminally ill patients receiving palliative care this systematic review was designed to systematically compile peer-reviewed studies examining the experiences of informal caregivers of terminally ill patients receiving palliative care. This study specifically sought to gather and synthesize evidence concerning common challenges, burdens faced by caregivers, strategies employed to cope with the caregiving experience, psychosocial responses to caregiving, and general lived experiences of informal caregivers in order to develop a clearer and more current understanding of how caregivers' function in palliative and end-of-life settings.

METHODOLOGY

Research Design

This study utilized the systematic review design to synthesize recently published research regarding the lived experiences of informal caregivers supporting terminally ill patients receiving palliative care. Specifically, this systematic review reviewed literature that identified caregiving-related challenges experienced by caregivers; caregiver burden; caregiving strategies employed by caregivers; caregiver psychosocial response(s) to their role as a caregiver; and the overall lived experience of caregivers.

In order to enhance transparency in how the results were reported, this systematic review followed guidelines outlined in the most recent version of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020), which provided current recommendations for reporting systematic reviews (Page et al., 2021).

A thematic analysis was also used to interpret data collected from all studies included in the systematic review. Thematic analysis is one of many methodologies that can be applied to systematic reviews of both qualitative and mixed-methods research and involves the process of applying codes to each finding obtained from the studies selected for inclusion in the systematic review; developing descriptive categories based upon coded findings; and ultimately creating larger analytical themes (Thomas & Harden, 2008).

SOURCE OF LITERATURE AND SEARCH STRATEGY

A systematic search for literature was performed using PubMed and Google Scholar. PubMed was used as the primary bibliographic database and Google Scholar was additionally used to increase the retrieval of relevant

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studies. A search strategy was developed using pre-specified keywords and Boolean operators specific to each source. In accordance with PRISMA-S guidance, the review reported the information sources searched and the number of records derived from each source.

The search yielded 1,623 records from PubMed and 3,214 records retrieved from Google scholar for a total of 4,837 records before de-duplication and preliminary screening.

Eligibility Criteria

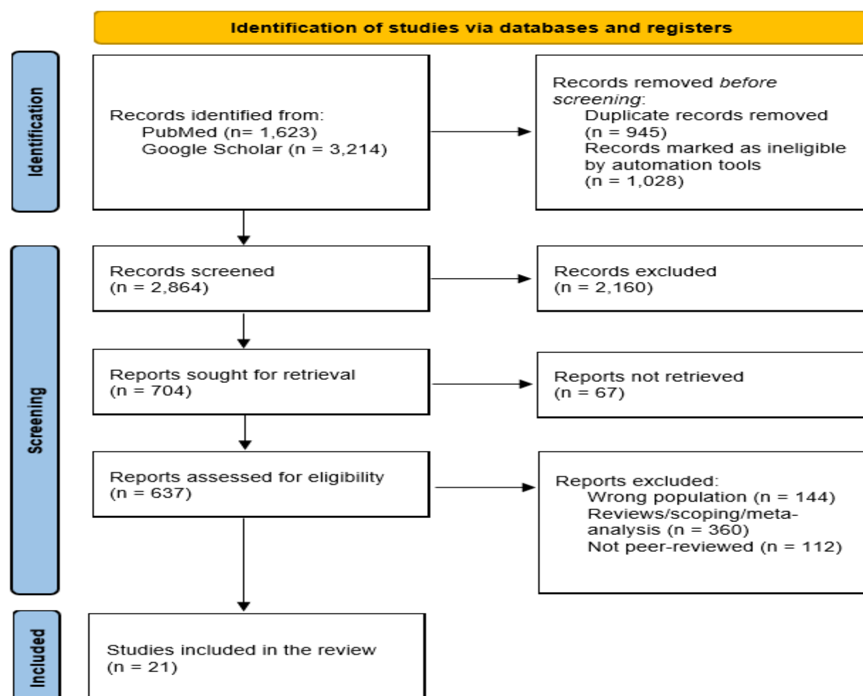
The studies that qualified for inclusion in this systematic review were peer reviewed articles from journals, published after 2020. All articles included in this review were either written in the English language or a translated version was available in English. Articles eligible for inclusion in this systematic review contained information about informal family unpaid caregivers caring for terminally ill individuals. In addition to describing the experiences of these caregivers (such as burden, challenges, coping strategies, perceptions, etc.) there were also articles in which authors reported the psychosocial effects experienced by these caregivers in the context of palliative/end of life care.

Studies were excluded if they were not available in full text, were not peer-reviewed, were published before 2020, were written in another language without English translation, or did not focus on the target population and topic of interest. Review articles, systematic reviews, meta-analyses, scoping reviews, editorials, commentaries, letters, instrument studies, and case reports were also excluded.

Study Selection

Study selection was done using the PRISMA 2020 guidelines and are shown in a PRISMA flow chart. A total of 4,837 records were found during the literature search (PubMed = 1,623; Google Scholar = 3,214). Following duplicate removal (n = 945) and removal of non-applicable records before initial screening (n = 1028), there were 2,864 remaining for title/abstract screening. Of those screened for title/abstract, 2,160 were removed with 704 report titles selected for retrieval. Sixty-seven reports could not be located, and 637 full-text versions of eligible reports were evaluated. During evaluation of full-text reports, reasons for exclusion included wrong population (n=144), and because they were reviews/scoping reviews/meta-analyses (n=360), or not peer-reviewed (n=112). Ultimately, 21 studies met inclusion criteria for the final review.

Figure. 1 PRISMA Flow diagram documenting the search process.



Quality Appraisal and Risk of Bias

The methodological quality of the studies reviewed was appraised using the appropriate design-specific Joanna Briggs Institute (JBI) Critical Appraisal Checklists; these checklists include qualitative research, analytical cross-sectional, cohort and quasi-experimental designs. These critical appraisal tools are designed to provide an evaluation of the credibility and reliability of each study included in the review.

Independent appraisal of the studies by two reviewers occurred. Any discrepancies that arose from their independent appraisal of each study were resolved through dialogue and consensus. If additional input was needed, a third reviewer would be contacted. In the context of this review, addressing potential bias associated with the included studies' methodological quality and methodological limitations provided information regarding the risk of bias.

Due to the qualitative nature of the studies that were included in this systematic review as well as being observational/quasi-experimental in design, a formal statistical analysis assessing potential publication bias was not conducted. However, consideration of potential biases was based upon evaluating both methodological strength and limitation within each study through use of the JBI appraisal process.

Data Extraction

The following data were extracted from each study using a structured format that allowed for consistency in extracting all pertinent data. This also helped to identify any missing data. The data included were author(s), year of publication, study design, setting, participant characteristics, illness context, and findings directly related to the review question.

Data Analysis

The included studies in this review were analyzed via thematic analysis. Initial codes were given to all identified data as a result of the first stage. In the second step, all data containing codes with equivalent definitions were consolidated to form higher-level categories. Categories created during the second phase were then examined and combined to create six primary themes which encapsulate the collective experience of those who provide informal care in both palliative and end-of-life settings. These steps are consistent with the typical phases associated with thematic synthesis as outlined by Thomas and Harden (2008).

RESULTS

Characteristics of the Included Studies

The review analyzed 21 studies (see table 1) that were all completed between 2021 and 2025. Each of the studies explored the experiences of informal or family caregivers for individuals who were terminally ill and receiving palliative and/or end-of-life care (Adejoh et al. 2021; Armstrong et al. 2022; Armstrong et al. 2025; Biney et al. 2024; Conroy et al. 2021; Conroy et al. 2023; Ibrahim et al. 2024; Kennedy et al. 2022; Maksymowicz-Śliwińska et al. 2023; McCauley et al. 2023; Najjuka et al. 2023; Nysaater et al. 2024; Poppe et al. 2022a; Poppe et al. 2022b; Read et al. 2023; Rosqvist et al. 2021; Schischlevskij et al. 2021; Song et al. 2024; Vermorgen et al. 2021; Xu et al. 2024; Zhang et al. 2023).

Studies included in this systematic review included research conducted within a variety of international settings, including Uganda, Ghana, Egypt, China, Norway, Belgium, Ireland, the Netherlands, England, Sweden, Germany, Switzerland, United States of America, and multi-country contexts within sub-saharan Africa and Europe (Adejoh et al. 2021; Biney et al. 2024; Conroy et al. 2021; Kennedy et al. 2022; Najjuka et al. 2023; Nysaeter et al. 2024; Poppe et al. 2022a; Poppe et al. 2022b; Read et al. 2023; Rosqvist et al. 2021; Schischlevskij et al. 2021; Song et al. 2024; Vermorgen et al. 2021; Xu et al. 2024; Zhang et al. 2023). Studies demonstrated considerable heterogeneity by setting — whether urban, rural, affluent or poor — which is indicative of the experience of caring for those with terminal illnesses in various income environments.

ISSN No. 2454-6186 | DOI: 10.47772/IJRISS | Volume X Issue IV April 2026

Each of the included studies employed different methodologies. Many studies utilized qualitative research methods, such as phenomenology, grounded theory, interpretive phenomenological analysis, descriptive qualitative methodology and field study design. Other studies applied mixed-methodologies, cross-sectional, longitudinal and/or quasi-experimental design methodologies (Adejoh et al. 2021; Armstrong et al. 2022; Armstrong et al. 2025; Biney et al. 2024; Conroy et al. 2021; Conroy et al. 2023; Ibrahim et al. 2024; Kennedy et al. 2022; Maksymowicz-Śliwińska et al. 2023; McCauley et al. 2023; Najjuka et al. 2023; Nysaeter et al. 2024; Poppe et al. 2022a; Poppe et al. 2022b; Read et al. 2023; Rosqvist et al. 2021; Schischlevskij et al. 2021; Song et al. 2024; Vermorgen et al. 2021; Xu et al. 2024; Zhang et al. 2023). The sample size varied from very few participants in some qualitative interview studies to large-scale multicenter studies with over one hundred caregivers/caregiver-patient dyad combinations.

Studies examining terminal illness context included cancer at an advanced stage and other conditions such as amyotrophic lateral sclerosis (ALS), dementia with Lewy bodies and late-stage Parkinson's disease (Adejoh et al. 2021; Armstrong et al. 2022; Armstrong et al. 2025; Biney et al.

Table 1. Characteristics of Included Studies

Author(s), Year	**Country**	**Study Design**	**Participants / Sample**	**Illness / Condition**	**Setting / Context**	**Key Focus / Aim**
Adejoh et al. (2021)	Nigeria, Uganda, and Zimbabwe	Secondary analysis of qualitative interviews	48 informal caregivers aged ≥18 years	Advanced cancer	Palliative care services in sub-Saharan Africa	Role, impact, and support of informal caregivers in palliative care
Armstrong et al. (2022)	United States of America	Qualitative descriptive interview study	30 family members (15 children, 13 spouses, 2 other relatives)	Dementia with Lewy bodies	End-of-life caregiving context	End-of-life experiences, roles, symptom impact, and supports
Armstrong et al. (2025)	United States of America	Observational longitudinal cohort; mixed-methods	73 caregiver–patient dyads	Dementia with Lewy bodies	Post-death follow-up (3 months after death)	Post-death caregiver experiences and factors linked to grief, depression, and quality of life
Biney et al. (2024)	Ghana	Exploratory descriptive qualitative study	20 family caregivers	Terminal illness/cancer	Palliative care unit of a teaching hospital	Challenges, coping strategies, and social support among family caregivers
Conroy et al. (2021)	Ireland, the Netherlands, and England	Multi-centre mixed-methods descriptive exploratory study	172 informal caregivers	Amyotrophic lateral sclerosis (ALS)	Three European multidisciplinary centres	Caregiver burden and perceived difficulties in ALS caregiving

Conroy et al. (2023)	Ireland	Exploratory longitudinal mixed-methods study	17 primary informal caregivers followed across five interviews	Amyotrophic lateral sclerosis (ALS)	National clinic in Dublin	Burden and positive aspects of caregiving over time
Ibrahim et al. (2024)	Egypt	Quasi-experimental pre-test/post-test study	88 Terminal cancer patients and their primary caregivers	Terminal cancer	Oncology Center, Mansoura University	Impact of a comprehensive rehabilitation palliative care program on patient and caregiver outcomes
Kennedy et al. (2022)	Ireland and the Netherlands	Exploratory mixed-methods study	134 informal caregivers (Ireland n=76; Netherlands n=58)	Amyotrophic lateral sclerosis (ALS)	Specialist multidisciplinary clinics	Burden and beneficial aspects of caregiving across two cohorts
Maksymowicz-Śliwińska et al. (2023)	Poland and Germany	Cross-sectional study	164 patient–caregiver dyads (80 Poland; 84 Germany)	Amyotrophic lateral sclerosis (ALS)	Specialized ALS centres	Quality of life and depression among primary caregivers under different cultural conditions
McCauley et al. (2023)	Ireland	Qualitative study using grounded theory	30 interviews involving 15 patients and 21 family caregivers	Advanced illness (mostly advanced cancer) in palliative care	Hospice sites	Processes of mutual support between patients and family caregivers
Najjuka et al. (2023)	Uganda	Descriptive qualitative study with a phenomenological approach	12 family caregivers	Advanced cancer (stage III or IV)	Uganda Cancer Institute	Lived caregiving experiences, burdens, supports, and perceived benefits
Nysaeter et al. (2024)	Norway	Longitudinal qualitative grounded theory study	11 adult family caregivers; 22 repeated interviews	Cancer in the late palliative phase	Home care / home death context	Family caregivers' preferences for support over time
Poppe et al. (2022a)	Switzerland	Qualitative study	36 participants: 9 current caregivers, 14 bereaved caregivers, and 13	Amyotrophic lateral sclerosis (ALS)	Swiss caregiver and professional care context	Supportive needs of informal caregivers from caregiver and professional perspectives

ISSN No. 2454-6186 | DOI: 10.47772/IJRISS | Volume X Issue IV April 2026

			healthcare professionals			
Poppe et al. (2022b)	German-speaking Switzerland	Qualitative constructivist grounded theory study	23 informal caregivers	Amyotrophic lateral sclerosis (ALS)	Home-based palliative and end-of-life caregiving trajectories	Caregiving work and trajectory of informal caregiving in ALS
Read et al. (2023)	England	Explorative qualitative study	11 family caregivers	Late-stage Parkinson's disease	Family caregiving and service provision context in England	Lived experience of caregiving and perceptions of service provision
Rosqvist et al. (2021)	Sweden	Qualitative substudy using directed content analysis	20 participants (11 patients and 9 informal caregivers)	Late-stage Parkinson's disease	Swedish arm of a European multicentre project	Experiences and perceptions of care and support in late-stage Parkinson's disease
Schischlevskij et al. (2021)	Germany	Prospective cross-sectional multicentre study	249 patient–caregiver dyads	Amyotrophic lateral sclerosis (ALS)	17 specialized clinics	Caregiver burden, predictors, and consequences on health and work
Song et al. (2024)	China	Exploratory qualitative phenomenological study	19 primary caregivers	Advanced cancer in palliative treatment	Oncology ward in a tertiary hospital, Wuhan	Benefit finding and positive experiences during palliative caregiving
Vermorgen et al. (2021)	Belgium (Flanders)	Qualitative study using interpretative phenomenological analysis	30 primary family carers	Life-limiting chronic illness (cancer, heart failure, and dementia)	Home care setting	Collaboration between family carers and professional carers in end-of-life care
Xu et al. (2024)	China	Descriptive phenomenological	15 family caregivers	End-of-life cancer	Transition from tertiary hospital to home	Experiences, needs, and coping during hospital-to-home transition

ISSN No. 2454-6186 | DOI: 10.47772/IJRISS | Volume X Issue IV April 2026

		qualitative study			palliative care	
Zhang et al. (2023)	China	Field study using qualitative content analysis	25 family caregivers	Dying or terminally ill patients receiving home care	Beijing; two hospitals and four communi ties	Needs and coping strategies of family caregivers caring for dying patients at home

Quality Appraisal of Included Studies

Methodological quality was assessed using appropriate for the design JBI critical appraisal tool (Table 2). In total, there were 20 studies that are rated to be of high quality and one of the studies was rated as moderate.

Qualitative studies had considerable similarity amongst each other concerning aims of the research, methods employed, data collected and analyzed, along with an excellent depiction of the views of participants. There were also limitations such as little reflexivity discussed by participants, secondary data limitations and transferability issues in single site and/or context specific studies.

Cross sectional studies and cohorts generally utilized valid measuring instruments and provided a clear description of the population studied, however many did not adjust well for confounders. The one moderate quality study was a longitudinal mixed-methods cohort study in which significant attrition existed and limited adjustments were made for confounders resulting in less robust methodology.

The quasi-experimental study clearly sequenced temporally and utilized valid measurement tools, however no control group existed limiting causal interpretations. Overall, the results from the appraisal suggest a relatively robust evidence base to synthesize. A detailed review is located in table 2.

Table 2. Methodological quality appraisal of included studies using JBI critical appraisal checklists

Study	**Study design**	**JBI checklist used**	**Key appraisal findings**	**Overall quality**
Adejoh et al. (2021)	Secondary analysis of qualitative interviews	JBI Qualitative Research Checklist	High congruity between research aims, qualitative methodology, and data collection. Participant voices well represented through verbatim quotations. Limitation related to secondary analysis, as further participant clarification was not possible.	High
Armstrong et al. (2022)	Qualitative descriptive interview study	JBI Qualitative Research Checklist	Clear alignment between descriptive qualitative approach and study objectives. Data saturation achieved with independent coding and consensus procedures. Member checking was not conducted.	High
Armstrong et al. (2025)	Observational longitudinal cohort; mixed-methods	JBI Cohort Checklist	Use of validated outcome measures and longitudinal follow-up strengthened internal validity. Potential confounders were considered in sensitivity analyses. Baseline recruitment numbers were not fully reported, limiting assessment of attrition.	High

ISSN No. 2454-6186 | DOI: 10.47772/IJRISS | Volume X Issue IV April 2026

Biney et al. (2024)	Exploratory descriptive qualitative study	JBI Qualitative Research Checklist	Strong congruity between exploratory aims and qualitative methods, with rich representation of participant voices. Limited explicit discussion of researcher reflexivity.	High
Conroy et al. (2021)	Multi-centre mixed-methods descriptive exploratory study	JBI Analytical Cross-Sectional Checklist	Clear description of settings and use of validated instruments. Inclusion criteria were explicit. Limited statistical adjustment for potential confounding between national cohorts.	High
Conroy et al. (2023)	Exploratory longitudinal mixed-methods study	JBI Cohort Checklist	Longitudinal design and validated instruments supported credibility. High attrition and limited adjustment for confounding factors reduced methodological robustness.	Moderate
Ibrahim et al. (2024)	Quasi-experimental pre-test/post-test study	JBI Quasi-Experimental Checklist	Clear temporal sequencing between intervention and outcomes, with use of multiple validated measures. Absence of a control group limited control for external confounding.	High
Kennedy et al. (2022)	Exploratory mixed-methods study	JBI Analytical Cross-Sectional Checklist	Use of validated instruments and detailed participant descriptions strengthened rigor. Quantitative analysis relied on group comparisons without multivariable adjustment for confounding.	High
Maksymowicz-Śliwińska et al. (2023)	Cross-sectional study	JBI Analytical Cross-Sectional Checklist	Large sample size and comprehensive use of validated instruments supported credibility. Limited multivariable adjustment for identified confounding factors.	High
McCauley et al. (2023)	Qualitative study using grounded theory	JBI Qualitative Research Checklist	Strong congruity between grounded theory methodology and study aims, with rich participant representation. Methodological limitations related to remote interviewing were transparently addressed.	High
Najjuka et al. (2023)	Descriptive qualitative study with a phenomenological approach	JBI Qualitative Research Checklist	High methodological rigor with strong ethical oversight, clear analytic processes, and proactive management of potential researcher bias.	High
Nysaeter et al. (2024)	Longitudinal qualitative grounded theory study	JBI Qualitative Research Checklist	Rigorous longitudinal data collection and systematic coding enhanced credibility. Use of memos and team discussions supported reflexivity and analytic consistency.	High
Poppe et al. (2022a)	Qualitative study	JBI Qualitative Research Checklist	Clear congruity between objectives and methods, with systematic analysis and strong representation of participant perspectives.	High

Poppe et al. (2022b)	Qualitative constructivist grounded theory study	JBI Qualitative Research Checklist	Strong methodological congruity and transparent researcher positioning. Inability to conduct full theoretical sampling limited refinement of some categories.	High
Read et al. (2023)	Explorative qualitative study	JBI Qualitative Research Checklist	Strong alignment between aims and methods, thorough ethical documentation, and rich participant quotations.	High
Rosqvist et al. (2021)	Qualitative sub study using directed content analysis	JBI Qualitative Research Checklist	Clear congruity between objectives and methods, multidisciplinary validation of analysis, and reflexive consideration of researcher influence.	High
Schischlevskij et al. (2021)	Prospective cross-sectional multicenter study	JBI Analytical Cross-Sectional Checklist	Large multicenter sample and use of validated instruments strengthened credibility. Confounding factors were addressed using multivariable regression analysis.	High
Song et al. (2024)	Exploratory qualitative phenomenological study	JBI Qualitative Research Checklist	Strong alignment between phenomenological design and study aims, with extensive participant quotations. Single-site recruitment may limit transferability.	High
Vermorgen et al. (2021)	Qualitative study using interpretative phenomenological analysis	JBI Qualitative Research Checklist	High congruity between interpretative phenomenological approach and research objectives, with rich participant representation. Potential selection bias was acknowledged.	High
Xu et al. (2024)	Descriptive phenomenological qualitative study	JBI Qualitative Research Checklist	Strong congruity between aims and phenomenological approach, with clear reflexivity and ethical oversight. Single-institution setting may limit broader applicability.	High
Zhang et al. (2023)	Field study using qualitative content analysis	JBI Qualitative Research Checklist	High methodological rigor supported by data triangulation, reflexive practice, and comprehensive ethical documentation.	High

Findings of the Review

The thematic analysis generated six final themes that describe the experiences of informal caregivers of terminally ill patients in palliative care. These themes, together with their brief descriptions and supporting studies, are presented in Table 3. To provide greater analytic transparency, Table 4 shows the categories grouped under each final theme and the illustrative focus of each category.

Table 3. Final Themes and Supporting Studies

Final Theme	**Brief Description**	**Supporting Studies**
Caregiving as Complex Work: Coordinating,	Describes the practical work of caregiving, including hands-on care, care coordination, symptom	Adejoh et al. (2021); Conroy et al. (2021); Ibrahim et al. (2024); Maksymowicz-Śliwińska et al. (2023); Najjuka et al. (2023); Poppe et al.

ISSN No. 2454-6186 | DOI: 10.47772/IJRISS | Volume X Issue IV April 2026

Managing, and Delivering Care	management, service navigation, technical care tasks, and continuity of care across settings.	(2022); Read et al. (2023); Rosqvist et al. (2021); Vermorgen et al. (2021); Xu et al. (2024); Zhang et al. (2023)
Caregiving Under Constraint: Time, Financial Strain, and System Barriers	Captures the material and structural pressures surrounding caregiving, such as financial hardship, work disruption, time pressure, inadequate respite, and institutional barriers.	Adejoh et al. (2021); Biney et al. (2024); Conroy et al. (2021); Conroy et al. (2023); Kennedy et al. (2022); Maksymowicz-Śliwińska et al. (2023); Najjuka et al. (2023); Nysaeter et al. (2024); Poppe et al. (2022); Schischlevskij et al. (2021); Vermorgen et al. (2021); Zhang et al. (2023)
Emotional Burden and Psychological Distress Across the Caregiving Trajectory	Reflects the emotional and psychological costs of caregiving, including anxiety, depression, guilt, grief, fatigue, and distress intensified by patient deterioration and symptom burden.	Armstrong et al. (2022); Armstrong et al. (2025); Conroy et al. (2021); Ibrahim et al. (2024); Maksymowicz-Śliwińska et al. (2023); Nysaeter et al. (2024); Poppe et al. (2022); Schischlevskij et al. (2021); Vermorgen et al. (2021)
Coping, Meaning-Making, and Positive Adaptation	Represents constructive responses to caregiving demands, including faith, coping strategies, social support, resilience, benefit finding, relationship strengthening, and adaptation over time.	Adejoh et al. (2021); Armstrong et al. (2022); Armstrong et al. (2025); Biney et al. (2024); Conroy et al. (2023); Ibrahim et al. (2024); Kennedy et al. (2022); McCauley et al. (2023); Najjuka et al. (2023); Nysaeter et al. (2024); Poppe et al. (2022); Rosqvist et al. (2021); Song et al. (2024); Xu et al. (2024)
Role Transformation, Identity Change, and Caregiver Expertise	Highlights how caregiving reshapes identity and daily life, as caregivers become advocates, decision partners, organizers, and informal experts while balancing changing roles and routines.	Armstrong et al. (2022); Nysaeter et al. (2024); Poppe et al. (2022); Read et al. (2023); Rosqvist et al. (2021)
Navigating Uncertainty, Decision-Making, and Preparation for Dying	Focuses on future-oriented caregiving, including information needs, shared decision-making, advance care planning, recognizing dying, and practical and emotional preparation for death.	Armstrong et al. (2022); Kennedy et al. (2022); McCauley et al. (2023); Nysaeter et al. (2024); Poppe et al. (2022); Vermorgen et al. (2021); Xu et al. (2024); Zhang et al. (2023)

Table 4. Categories Organized Under the Final Themes

Final Theme	**Category**	**Illustrative Focus**
Caregiving as Complex Work: Coordinating, Managing, and Delivering Care	Activities of daily living and practical care	Hands-on support with daily care, comfort, mobility, and routine caregiving tasks.
	Care coordination and navigation	Managing appointments, liaising with professionals, and navigating formal care systems.
	Hospice and palliative service access and quality	How the availability or quality of services shapes caregivers' ability to provide care.

	Medical skills and equipment	Learning and performing technical care tasks and using equipment in home care settings.
	Transition and continuity of care	Managing care across hospital, home, and end-of-life transitions while maintaining continuity.
Caregiving Under Constraint: Time, Financial Strain, and System Barriers	Financial and employment impact	Financial burden, reduced work participation, and employment disruption caused by caregiving.
	Institutional and policy barriers	Structural challenges such as weak systems, bureaucracy, and policy-level limitations.
	Time pressures and role restrictions	Loss of personal time, restricted social life, and competing role demands.
	Respite and relief	Need for breaks, relief, and temporary support from continuous caregiving demands.
	Escalating support needs (Time pressures)	Increasing intensity of caregiver demands as the patient's condition deteriorates.
Emotional Burden and Psychological Distress Across the Caregiving Trajectory	Burden and mental health outcomes	Psychological strain including stress, anxiety, depression, grief, and emotional exhaustion.
	Patient behavioral and neurocognitive impact	Distress associated with patient symptoms such as behavioral changes, confusion, or neurocognitive decline.
	Emotional support and validation (when unmet)	Psychological burden linked to feeling unsupported, unseen, or insufficiently acknowledged.
Coping, Meaning-Making, and Positive Adaptation	Benefit finding and meaning making	Perceived gains, redefined purpose, gratitude, and positive meaning derived from caregiving.
	Coping strategies and faith	Use of faith, prayer, relaxation, and practical coping strategies to manage caregiving demands.
	Adjustment / adaptation (Benefit finding)	Active adaptation and psychological adjustment to the ongoing demands of caregiving.
	Perseverance / duty (Benefit finding)	Endurance rooted in love, commitment, obligation, and responsibility.
	Being present (Emotional support)	Emotional presence and relational support as part of coping and sustaining the caregiving role.
	Social support and community resources	Support from family, peers, religion, and community resources that helps sustain caregivers.
	Emotional support and validation (when supportive)	Validation and encouragement functioning as a protective or strengthening factor.
Role Transformation,	Caregiver identity, role and advocacy	Shifts in identity as caregivers become advocates, coordinators, and central care actors.

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Identity Change, and Caregiver Expertise	Skill acquisition and becoming expert	Development of practical knowledge and expertise through caregiving experience.
	Holding the balance (Adjustment)	Maintaining equilibrium between caregiving, self, family life, and normalcy.
	Home environment and adaptations	Changes to home life, routines, and environment to sustain caregiving at home.
	Medical skills and equipment (identity / expertise emphasis)	Use of medical knowledge and equipment as part of becoming an informal care expert.
Navigating Uncertainty, Decision-Making, and Preparation for Dying	Decision making and involvement	Participation in care decisions and efforts to remain informed and involved in planning.
	Information needs and tailored communication	Need for clear, timely, and understandable information from healthcare professionals.
	Advance care planning and end-of-life guidance	Need for guidance regarding future care, dying, and practical end-of-life planning.
	Death preparation and rituals	Preparation for dying, recognition of final hours, and management of ritual or funeral-related tasks.

Caregiving as Complex Work: Coordinating, Managing, and Delivering Care

The first theme presents caregiving as a form of complex practical work. Across the included studies, caregivers were not only providers of emotional support but also active managers of daily care, symptom monitoring, service coordination, and care transitions (Adejoh et al., 2021; Conroy et al., 2021; Ibrahim et al., 2024; Maksymowicz-Śliwińska et al., 2023; Najjuka et al., 2023; Poppe et al., 2022a; Read et al., 2023; Rosqvist et al., 2021; Vermorgen et al., 2021; Xu et al., 2024; Zhang et al., 2023). This theme was supported by categories such as activities of daily living and practical care, care coordination and navigation, hospice and palliative service access and quality, medical skills and equipment, and transition and continuity of care, as shown in Table 4.

Caregiving Under Constraint: Time, Financial Strain, and System Barriers

The second theme illustrates how structural and material limitations can influence a caregiver's ability to provide care. Most caregivers also experienced a variety of physical and financial challenges that limited their ability to take on the role of caring for another person. These have been identified by researchers such as Adejoh et al. (2021), Biney et al. (2024), Conroy et al. (2021), Conroy et al. (2023), Kennedy et al. (2022), Maksymowicz-Śliwińska et al. (2023), Najjuka et al. (2023), Nysaeter et al. (2024) and others, as including both physical challenges (e.g. providing enough assistance with basic activities of daily living, or time needed to assist) and economic ones (e.g. loss of income due to time away from work, etc.). As the patient became sicker and required increasing amounts of assistance, most caregivers experienced additional stressors and pressures which further reduced the amount of available time they had to continue assisting them.

Emotional Burden and Psychological Distress Across the Caregiving Trajectory

The third identified theme reflects an individual's mental/psychological experience of being a caregiver. Stress, anxiety, and fatigue are common for caregivers, along with feelings of depression, guilt, grief, and emotional exhaustion throughout the illness continuum and sometimes after the death of their loved one (Armstrong et al., 2022; Armstrong et al., 2025; Conroy et al., 2021; Ibrahim et al., 2024; Maksymowicz-Śliwińska et al., 2023; Nysaeter et al., 2024; Poppe et al., 2022a; Schischlevskij et al., 2021; Vermorgen et al., 2021). These negative emotions were often increased due to a decline in the patients' condition, the presence of behavioral issues or

excessive symptom burden, and uncertainty about what the future will be like. Categories that helped guide this theme included burden and mental health outcomes, the effect of the patients' behaviors on them as caregivers, and lack of emotional support/validation from others.

Coping, Meaning-Making, and Positive Adaptation

The fourth theme illustrated that caregiving is much more than a burden. In addition to many of the burdens associated with caregiving, some caregivers reported positive adaptations such as coping and resilience to the demands of caring for someone else. This positive adaptive behavior is characterized as "faith," "social support," "personal growth," "strengthened relationship" or "gratitude" or attempts to "find meaning" in their caregiving experience. As can be seen from Table 4, these positive behaviors are categorized into seven subcategories including; Benefit Finding/ Meaning Making, Coping Strategies/Faith, Adjustment/Adaptation, Perseverance/Duty, Being Present, Social Support/Community Resources.

Role Transformation, Identity Change, and Caregiver Expertise

The fifth theme identified that a caregiver's daily activities and routines were transformed by their experience with caregiving. Caregivers across many different research projects have reported taking on roles such as advocate, decision partner, organizer, and informal expert in patient care (Nysaeter et al., 2024; Armstrong et al., 2022; Read et al., 2023; Poppe et al., 2022a; Poppe et al., 2022b; Rosqvist et al., 2021). These transformations can include learning new skills or adjusting their living space to accommodate a family member or friend needing care. They also may find it difficult to juggle all of their responsibilities and find they are able to define themselves differently than before.

Navigating Uncertainty, Decision-Making, and Preparation for Dying

The sixth theme is that palliative and end-of-life caregivers are uncertain about their work. These caregivers often indicated a need for clarity of information, participation in decisions regarding future care, and guidance on how to manage the last stages of an illness and death (Armstrong et al., 2022; Kennedy et al., 2022; McCauley et al., 2023; Nysaeter et al., 2024; Poppe et al., 2022a; Vermorgen et al., 2021; Xu et al., 2024; Zhang et al., 2023). Many stated they wanted to understand what it would be like when someone's illness progressed, and when someone is dying. They also needed help with supporting loved ones through end-of-life planning and ritualizing. This theme was reflected in four categories including decision making and involvement, information needs and tailored communication, advance care planning and end-of-life support, and death preparation and rituals (see Table 4).

DISCUSSION

The results of this systematic review revealed six primary themes among the experiences of informal caregivers of terminally ill patients receiving palliative care. These themes were: caregiving as complex work; caregiving under constraint; emotional burden and psychological distress; coping, meaning-making and positive adaptation; role transformation and caregiver expertise; and navigating uncertainty and preparing for dying. Together, these themes illustrate how caring for terminally ill individuals in the context of palliative and end-of-life care is a dynamic, multi-faceted, and constantly changing role influenced by the responsibilities inherent in providing care for a loved one (i.e. practical/physical), emotional stress and strain, social environment/community, and the conditions provided by healthcare systems (Armstrong et al., 2022; Conroy et al., 2021; Adejoh et al., 2021; Najjuka et al., 2023). Additionally, these findings further emphasize the importance of conceptualizing palliative care as supportive for both patients and their families - not just patients (World Health Organization [WHO], 2020).

One of the most significant findings of this systematic review was that caregivers engage in a wide range of complex care activities which extend well beyond the provision of social companionship or general support. The majority of studies reviewed demonstrated how caregivers engaged in coordinating service, monitoring the health status of those they cared for, completing technical tasks such as administration of medications, managing care transition, and advocating on behalf of their family members/care recipients with other healthcare

professionals when navigating through complex and often fractured systems of care. Caregivers' ability to complete these types of functions were largely dependent upon whether they were providing care from the comfort of their own homes, or in resource-poor environments. (Poppe et al., 2022; Read et al., 2023; Xu et al., 2024) A finding that supported existing palliative care literature suggesting that informal caregivers are at the heart of delivering care and many times function as "hidden" providers of care in both community-based and home-based models of care (Schutter et al., 2025; Auclair et al., 2022). Therefore, while caregiving in palliative care can be defined by relational elements, it is also an element of organizational/structural and clinical practice and, thus, may be performed by caregivers without formal education/training, nor institutional recognition of the extent to which they have assumed responsibility for performing quasi-clinical roles (Read et al., 2023; Auclair et al., 2022).

On the other hand, the review found that there is always a sense of being constrained as a caregiver. Constraints such as economic burden on families and caregivers, loss of job due to caring responsibilities, no time for rest, restrictions from society, and lack of access to institutions were found among all disease types and within all the different environments where care takes place (Schischlevskij et al., 2021; Biney et al., 2024; Zhang et al., 2023; Kennedy et al., 2022). These results confirm those of previous studies concerning the experiences of many palliative care givers, particularly in the community-based setting who report experiencing chronic fatigue, decline in their physical health, lack of adequate support systems, and financial strain (McGuigan et al., 2024; Handique et al., 2025). The repeated experience of these constraints in the current study indicates that caregiver strain is both an individual and family issue as well as a structural issue related to the way in which palliative care is organized, funded and provided. Therefore, providing caregiver support needs to go beyond just offering emotional reassurance. It must include development of policies and programs that provide time off for the caregiver, financial support, access to respite and continuum of care (WHO, 2020; Handique et al., 2025).

The third theme has been identified as emotional burden and psychological distress. The literature examined within this review demonstrates that caregivers' mental health and emotional wellbeing can be affected significantly through their role as a caregiver. Caregivers have described experiencing anxiety, depression, guilt, grief, emotional exhaustion and an on-going level of distress prior to the patient's death and after (Armstrong et al., 2025; Conroy et al., 2021; Maksymowicz-Śliwińska et al., 2023; Nysaeter et al., 2024) This aligns with larger research evidence indicating that palliative caregivers are at risk for developing clinical levels of distress, reducing quality of life and having unmet psychosocial needs particularly in home based care situations and during transitions from early stages of illness to end-of-life (Ullrich et al., 2025; Theißen et al., 2024). Importantly, the findings of this review also demonstrate that distress is not limited to any single point in time during caregiving. Distress tends to accumulate throughout the continuum of the patient's illness trajectory and may persist post-bereavement if caregivers felt they were not adequately supported or prepared, or felt overwhelmed by the complexity of caring for their loved one (Armstrong et al., 2025; Ullrich et al., 2025).

While the review has demonstrated that caregiving is more than burden, it also has shown how many caregivers have used their faith and personal values and their ability to make meaning and develop social support as ways to adapt positively (Song et al. 2024; Xu et al. 2024) to caregiving. Some caregivers reported experiencing personal growth, stronger family bonds, increased appreciation/gratitude for life and/or a new sense of purpose in addition to caring for another person (Conroy et al. 2023; Song et al. 2024). Findings from these studies were supportive of previous research that have identified both hardship and benefit finding aspects of caregiving (Theißen et al. 2024), and that having a positive appraisal of caregiving could potentially mitigate some negative impacts associated with burden (Neller et al. 2024). Practically speaking, this indicates that while caregiver-based interventions focused solely on alleviating distress are important, it would be equally valuable to identify and amplify those factors that contribute to an individual's resilience/meaning/connection in their role as a caregiver.

This review adds a new perspective through recognizing how caring for another person can affect a person's own perception of themselves. As identified in this review, many caregivers develop a role as an advocate/organizer/decision partner/expert role while caring for the love one. (Read et al., 2023; Armstrong et al., 2022; Poppe et al., 2022b) While developing such roles may be viewed positively as a means of increasing competency, there is the possibility that caregivers will lose autonomy and independence in their role within the family, and experience disruption in the way they typically perceive themselves. These concerns have been

similarly addressed in literature regarding how families navigate through fractured healthcare systems, and how families support individuals when the formal healthcare structure fails them. (Haley & Elayoubi, 2024; Kim et al., 2023) This systematic review identified that the expert knowledge of caregivers needs to be recognized and supported by health practitioners in a palliative care setting. Practitioners need to view the caregiver as more than just an extension of the family's responsibilities; instead, practitioners need to see the caregiver as a knowledgeable partner who has developed a set of skills that require validation and support (Vermorgen et al., 2021; Kim et al., 2023).

The final theme highlights the need for caregivers to have access to relevant information, facilitate open communication, prepare through advance care planning and practical preparations as they navigate their loved ones' final stages of illness (Nysaeter et al., 2024; Xu et al., 2024; Zhang et al., 2023; Mc Cauley et al., 2023). This theme is especially important since uncertainty presented itself both as a clinical concern and as an emotional/relational challenge. Caregivers had difficulty understanding what were clear guidelines about how the disease would progress, what caregiving needs there may be down the road, what death may look like, and the "practical" aspects of providing end of life care from home. This finding is consistent with previous reviews which demonstrated that including caregivers in decision-making processes and using open communication helped to decrease relational tension and supported reaching agreement regarding their care preferences (Quigley & McCleskey, 2020; Symmons et al., 2022). In addition, this supports the notion that preparing for death is a process and it will require that caregivers receive timely information, have opportunity for open communication, and are provided emotional support along the entire illness trajectory (Unesoko et al., 2024; Symmons et al., 2022).

In addition to being an important resource for patients, families need to have their individual needs, risks, abilities, etc. evaluated by palliative care staff. Caregivers should receive support proactively during the illness process and before they reach a point of crisis, such as at the time of a patient's death. Support to caregivers can take many forms including, providing them with emotional support, clear communication regarding a patient's condition, providing caregivers with respite opportunities, educating caregivers on how to provide practical support to a patient and acknowledging the contributions caregivers make to patient care plans.

There are several limitations to this review that need to be addressed. One limitation of the current review is that the search was only conducted using PubMed and Google Scholar. While this approach generated a large volume of recent literature, it is possible that some studies reported in other databases may have been overlooked. A larger search involving multiple databases would be easier to replicate. PRISMA and PRISMA-S suggest that researchers provide transparent reporting of all information sources searched and the number of records identified from each source, which emphasizes the value of conducting a thorough search when developing systematic reviews.

Another limitation of this review is that the focus of the review is on studies published in English or with an English translation and published since 2020. Therefore, previous studies and/or evidence in languages other than English may have been omitted. Additionally, the heterogeneity of the design and context of the studies included in the review may limit the ability to compare directly caregiving contexts and trajectories of illness. However, the variety of the included studies provided an enriched synthesis; therefore, while there are limitations associated with the diversity of study types included, they also contribute positively to the development of future research.

The quality assessment revealed that, although most of the studies included in the review were determined to have a high level of methodological quality, many of the studies had at least one serious limitation relative to their methodology (e.g., lack of reflexivity, poor transferability, potential confounders and/or high levels of attrition). In addition, one longitudinal mixed-methods cohort study was rated as "moderate" due to its substantial loss to follow-up and failure to adjust for known confounds.

While these limitations exist, this review does represent a helpful compilation of recent literature regarding informal caregivers within palliative care. Confidence in the majority of the major themes developed during the course of this review can be increased by the fact that the majority of studies included in this review were found to be methodologically strong.

As such, future research should conduct searches across a wider range of databases and if possible, consider studies in a greater number of languages and from a longer span of years. Future research should give priority to designing longitudinal comparative intervention studies in order to reduce issues with attrition and confounding.

CONCLUSION

This systematic review has shown that informal caregivers caring for terminally ill patients in palliative care are important but generally unrecognized contributors to the continuum of care. According to this review, caregiving was found to be an ever-changing, multifaceted experience that is influenced by the practical needs of the caregiver; emotional burden; structural barriers to support; ability to adapt; changes in their sense of identity; and uncertainty related to death. While many informal caregivers experience high levels of burden and lack of adequate support; however, they may develop resilience; meaning; and caregiving skills throughout the course of caregiving. These results suggest that palliative care practices should begin to include an understanding of informal caregivers as care partners and care recipients, and therefore require a shift from a patient-centric approach towards a more inclusive family-centered approach.

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