Original Article

Exploring Satisfaction and Support Needs of Informal Home Caregivers Using Palliative Care Services: A Mixed-Methods Study from Rwanda

Jean Claude Twahirwa[1*,2], Marg Fitch[3], Godfrey Katende[4], Madeleine Mukeshimana[1]

[1]School of Nursing and Midwifery, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda
[2] Department of Nursing and Midwifery, Faculty of Health Sciences, Kibogora Polytechnic, Rwanda
[3]Bloomberg Faculty of Nursing, University of Toronto, Canada

[4] Aga Khan University John Hopkins University

***Corresponding author:** Jean Claude Twahirwa. School of Nursing and Midwifery, College of Medicine and Health Sciences, University of Rwanda, Kigali, Rwanda. Email: twahirwajeanclaude1@gmail.com. ORCID: https://orcid.org/0009-0007-0537-7885

Cite as: Twahirwa C, Fitch M, Katende G, Mukeshimana M. Exploring Satisfaction and Support Needs of Informal Home Caregivers Using Palliative Care Services: A Mixed-Methods Study from Rwanda. Rwanda J Med Health Sci. 2026;9(1): 62-83. https://dx.doi.org/10.4314/rjmhs.v9i1.5.

Abstract

Background
Informal home-based caregivers play a key role in supporting patients with life-limiting illnesses in Rwanda, often assuming primary responsibility for daily palliative care. Despite the sense of purpose caregiving may bring, it is frequently accompanied by emotional, physical, and financial strain that affects caregivers' well-being. However, limited evidence exists regarding their satisfaction with palliative care services and their unmet support needs.

Objective
This study aimed at exploring the support needs and satisfaction levels of informal home-based caregivers regarding palliative health services in Rwanda.

Methods
A mixed-methods study design, involving twenty (20) informal home-based caregivers for the qualitative approach was employed. One hundred sixty-one (161) informal caregivers were recruited for the quantitative approach. The data was conducted in two districts of Nyamasheke and Rusizi in Rwanda. Descriptive statistics were performed on the quantitative data while structured thematic analysis was used for the qualitative data.

Results
The results revealed that informal home-based caregivers experienced significant emotional, physical, and financial strain due to inadequate training and limited support. Feelings of burnout, loss of personal time, and dissatisfaction with the caring roles as well as palliative care services were reported. Informal home-based caregivers needed better training, financial aid, and consistent medical support.

Conclusion
Training and support systems for informal home-based caregivers' satisfaction are key facets to palliative care services. Palliative policy and programmatic reforms are needed to address these issues for enhanced palliative care services in Rwanda.

Rwanda J Med Health Sci 2026;9(1):62-83

Keywords: Informal caregivers, home-based care, palliative care, support needs, caregiver- satisfaction

Background

Informal home-based caregivers provide the backbone of palliative care, often performing their roles without preparation, resources, or formal support. Their responsibilities are shaped by cultural expectations of family duty but are constrained by poverty and limited health infrastructure. Strengthening caregiver training and integrating their contributions into formal palliative care systems are essential to improve outcomes for both patients and families.[1] Although palliative care services are more established in high-income countries, significant gaps persist worldwide, particularly in terms of access, coverage, and integration into health systems. Globally, informal caregivers experience similar psychosocial challenges, such as emotional distress, caregiver burden, feelings of guilt and inadequacy, social isolation, and anticipatory grief. These challenges occur across regions and income levels but are often intensified where access to professional palliative care is limited.[2] Palliative care seeks to address the physical, emotional, social, and spiritual needs of individuals with life-limiting illnesses, with the overarching goal of improving quality of life for both patients and their families. However, access to these services remains limited in many low- and middle-income countries (LMICs), including those in Sub-Saharan Africa, which bear the majority of the global burden of life-limiting illnesses. Service availability is particularly constrained in rural areas, where most of the population resides, due to inadequate healthcare infrastructure, a shortage of trained personnel, limited access to essential medications, and weak policy implementation. Additional barriers include low awareness of palliative care, fragmented patient interventions, and the lack of integration into national health systems.[2–5]

The importance of palliative care in resource-limited settings lies in its ability to provide early, holistic interventions that support patient autonomy, enhance quality of life, and promote family well-being. Cultural sensitivities and the everyday struggles faced by families further underscore the need for patient- and family-centered care.[7]

Informal home-based caregivers are essential everywhere, but their roles are often demanding and context-dependent. Despite their critical contributions, many caregivers remain underappreciated and unsupported. Globally, policies and certifications for caregivers vary, with advocacy groups promoting caregiver rights.[8,9] The need for palliative care is increasing worldwide due to population ageing and the rising burden of non-communicable diseases such as cancer, cardiovascular diseases, and chronic respiratory conditions.[10,11] In Rwanda, home-based palliative care remains limited and is predominantly provided by unpaid family members, friends, or neighbors.[6-9] These informal caregivers play vital roles in assisting with medical tasks, managing daily patient needs, and providing emotional support.[10-11] Nevertheless, caregivers frequently face major challenges, including psychological and financial strain, inadequate training, and limited access to medical guidance.[10-11] Previous studies show that caregivers often have greater unmet needs than the patients themselves, particularly regarding information, emotional support, and physical exhaustion.[12–14] These challenges compromise caregiver well-being and, consequently, the quality of care received by patients.[15,16]

Despite the growing importance of informal home-based caregivers in end-of-life care, empirical research on their support needs and satisfaction with palliative care services in Rwanda remains limited. Understanding these factors is essential for informing policy and designing interventions that enhance both caregiver well-being and patient outcomes.[17–20] Therefore, this study aimed to explore the support needs and satisfaction levels of informal home-based caregivers regarding palliative health services in Rwanda.

Methods

Study design

This study employed an explanatory sequential mixed-methods design. The study was conducted in two distinct phases:
Phase I (Quantitative): A cross-sectional survey questionnaire was administered to informal home-based caregivers of patients receiving palliative care services to assess levels of caregiver satisfaction and support needs.
Phase II (Qualitative): In-depth interviews were conducted with a purposive subsample of survey participants to explain, elaborate, and contextualize the quantitative findings. The mixed-methods approach was chosen to first quantify the magnitude of caregiver satisfaction and support needs and then explore caregivers lived experiences in greater depth within the context of Rwanda. Integration occurred at two points:
During sampling for the qualitative phase (selection based on quantitative results). During interpretation, where qualitative findings were used to explain quantitative trends.

Study setting

The study was conducted in selected health facilities and their affiliated home-based palliative care programs in Rwanda. Specifically, the research took place in Nyamasheke and Rusizi districts, located in the Southwestern Province of Rwanda. These districts are predominantly rural and characterized by mountainous terrain, dispersed settlements, and limited access to specialized palliative care services. As such, they represent typical rural Rwandan contexts where home-based palliative care is essential and where informal caregivers assume a central role in the provision of daily care for patients with life-limiting illnesses.

The selected sites included facilities operating at different levels of Rwanda's health system to ensure contextual diversity and transferability of findings. These comprised district hospitals providing primary and secondary-level services, a provincial referral hospital offering specialized care, and a level-two teaching hospital delivering advanced tertiary services. This multilevel health system representation allowed the study to capture variations in service organization, caregiver support mechanisms, and resource availability across primary, secondary, and tertiary care settings.

Study population

The study population comprised informal home-based caregivers providing unpaid care to patients with life-limiting illnesses enrolled in home-based palliative care services. Informal caregivers were defined as family members or close relatives who assumed primary responsibility for the patient's daily physical, emotional, and supportive care without financial compensation.

At the time of data collection, a total of 200 patients were receiving home-based palliative care services across the selected hospitals in Rwanda. These patients were supported by approximately 270 informal caregivers, as some patients had more than one primary caregiver involved in their care. Therefore, the target population for this study consisted of all 270 identified informal caregivers linked to these patients. Participants were caregivers of patients diagnosed with life-threatening illnesses at advanced stages and formally enrolled in hospital-affiliated home-based palliative care programs. All caregivers included in the study were actively providing care in home settings during the study period.

Sampling strategy

A convenience sampling method was used to recruit informal home caregivers who were willing to participate in the study. Health providers, through a community health workers collaboration, first identified potential participants who were listed with the palliative care service as providing home-based care to a family member or relative enrolled in palliative care. Research assistants, who had been trained in the study procedures by the principal investigator, then approached these individuals in their homes, explained the purpose and procedures of the study, and obtained written informed consent from those who agreed to be part of the research study. The same research assistants were responsible for conducting the interviews and collecting all data in a consistent and ethically appropriate manner.

Sample Size

Qualitative data

For the qualitative component of the study, the sample size was determined by the study objectives, available resources, and the principle of data saturation. A total of 20 informal home-based caregivers were recruited, with five caregivers randomly selected from each district community catchment area. Although an initial target of 20 participants was proposed based on the study objectives, scope, and feasibility considerations, the final sample size was not rigidly predetermined. Rather, recruitment continued concurrently with data analysis, and the principle of data saturation guided the final number of interviews conducted. Data saturation was considered achieved when no new themes, categories, or conceptual insights emerged from successive interviews.

The decision to begin with approximately five caregivers from each district community catchment area was intended to ensure representation across geographically and structurally diverse palliative care service contexts. However, continuation or cessation of recruitment was informed by thematic redundancy rather than by a fixed numerical target.

Quantitative data

To ensure a sufficient sample of informal home-based caregivers supporting approximately 200 patients at the end of life for the quantitative data collection, the Yamane formula was applied to the total population of 270 informal home caregivers in the region.Using this formula ($n = N / [1 + N(e^2)]$), a final sample size of 161 caregivers was calculated.

This quantitative approach assessed caregivers' burden and satisfaction levels with the services provided across multiple locations: Kibogora level two teaching hospital (45 informal home caregivers), Bushenge provincial hospital (39 informal home caregivers), Mibilizi District Hospital (39 informal home caregivers), and Gihundwe District Hospital (38 informal home caregivers). This provided numerical insights into caregivers' experiences in these specific areas.

Data collection

Quantitative data

Quantitative data were collected using an interviewer-administered structured questionnaire adapted from previously validated instruments assessing caregiver burden and satisfaction. Caregiver burden was used as a proxy measure for caregivers' support needs, as burden domains emotional, physical, and financial strain directly reflect areas where caregivers require support. This approach aligns with palliative care literature that conceptualizes unmet support needs as key contributors to caregiver burden.

The questionnaire captured caregivers' socio-demographic characteristics, caregiving responsibilities, perceived support needs, and satisfaction with home-based palliative care services. The tool was reviewed by subject-matter experts to ensure content relevance and contextual appropriateness for the Rwandan setting. It was translated into Kinyarwanda and back-translated to ensure linguistic accuracy. Internal consistency reliability testing yielded a Cronbach's alpha of 0.78, indicating acceptable internal consistency for an exploratory study involving culturally adapted tools.

Qualitative Data

Qualitative data were collected through individual in-depth interviews using a semi-structured interview guide developed to explore caregivers' experiences, perceived support needs, challenges, and satisfaction with care.

No focus group discussions were conducted. The interview guide was translated into Kinyarwanda and administered by trained interviewers. Interviews were conducted in Kinyarwanda, lasted approximately 45 minutes, and were audio-recorded with participants' consent. Recordings were transcribed verbatim prior to analysis.

Data analysis

Quantitative analysis

Quantitative data were analyzed using IBM SPSS Statistics for Windows version 31.0 (IBM Corp, Armonk, NY, USA). The primary outcome measures were: Caregivers perceived support needs, operationalized through caregiver burden domain scores (emotional, physical, and financial burden),[21–23] and Caregivers' satisfaction with home-based palliative care services, measured using aggregated satisfaction item scores. Descriptive statistics including frequencies, percentages, means, and standard deviations were used to summarize caregiver characteristics and outcome measures. Inferential statistical analyses were not performed, as the primary aim of the quantitative phase was to describe patterns and distributions rather than to test hypotheses or establish causal relationships.

Qualitative analysis

Qualitative data were analyzed using reflexive thematic analysis as described by Braun and Clarke (2006), with the support of ATLAS.ti version 25, for data management and organization. An inductive, data-driven approach was applied to allow themes to emerge from participants' accounts rather than being imposed a priori. Audio-recorded interviews were transcribed verbatim, translated where necessary, and read repeatedly to ensure familiarization with the data. Initial codes were generated through systematic line-by-line coding, focusing primarily on semantic content while remaining attentive to latent meanings.Coding was conducted iteratively, with ongoing comparison across transcripts. Two researchers independently coded selected transcripts and discussed discrepancies to refine the coding framework. Codes were subsequently grouped into categories and developed into overarching themes following Braun and Clarke's six-phase process, including reviewing, defining, and naming themes to ensure coherence and distinctiveness. Data collection and analysis occurred concurrently, and saturation was considered achieved when no new codes or themes emerged from successive interviews.

An audit trail, reflexive memos, peer debriefing, and the use of verbatim quotations enhanced credibility, dependability, confirmability, and transferability. The qualitative findings were integrated with quantitative results to provide contextual depth and explanatory insight within the mixed-methods design.

Integration of quantitative and qualitative findings

Integration occurred at the interpretation stage through triangulation, whereby quantitative results were compared with qualitative themes to identify convergence, divergence, and complementarity. This integration strengthened the credibility of the findings and enabled a comprehensive understanding of caregivers' support needs and satisfaction with home-based palliative care services.

Ethical considerations

Ethical approval was obtained from the University of Rwanda College of Medicine and Health Sciences Institutional Review Board (Approval No. 506/CMHS IRB/2024) and from the ethics committees of the participating hospitals. Written informed consent was obtained from all participants prior to data collection. Confidentiality, anonymity, and voluntary participation were ensured throughout the study.

Results

The study employed a mixed methods study design integrating both quantitative and qualitative data collection techniques. Findings are presented in the two phases: firstly, the results from the quantitative analyses and followed by an in-depth exploration of the key themes identified through qualitative analysis.

Quantitative Results

The Demographic characteristics of informal home-based caregivers (N = 161)

Table 1 presents the sociodemographic and caregiving-related characteristics of the 161 informal home-based caregivers who participated in the quantitative phase of the study. The variables reported include age, sex, relationship to the patient, employment status, educational attainment, duration of caregiving, daily time spent providing care, and availability of caregiving support.

Table 1. Demographic characteristics of informal home-based caregivers

Study variables	Categories	n	%
	18-29	42	26
	30-39	41	25.5
	40-49	36	22.4
	50-59	28	17.4
	60 and above	14	8.7
Gender	Male	55	33.8
	Female	106	66.3
Relationship to the patient	Spouse	36	22.4
	Child	42	26.1
	Brother/sister	6	3.7
	Sibling	50	31.1
	Parent	23	14.3
	Friend	3	1.9
	Volunteer	1	0.6
Employment Status	Employed full-time	25	15.5
	Employed part-time	97	60.2
	Unemployed	38	23.6
	Retired	1	0.6
Educational Level	No formal education	48	29.8
	Primary education	78	48.4
	Secondary education	28	17.4
	Higher education	7	4.3
Duration of caregiving (in months)	Less than 3 months	17	10.6
	3-6 months	36	22.5
	6-12 months	21	13.1
	More than 12 months	86	53.8
Average hours spent on caregiving per day	Less than 2 hours	8	5
	2-4 hours	32	19.9
	4-6 hours	20	12.4
	More than 6 hours	101	62.7
Number of people assisting in caregiving	None	34	21.1
	1-2 people	101	62.7
	3-4 people	17	10.6
	More than 4 people	9	5.6

The demographic characteristics of informal home-based caregivers are presented in Table 1. The majority of caregivers were between 18 and 49 years of age (70.9%), indicating that caregiving responsibilities were largely assumed by individuals in their economically productive years. Smaller proportions of caregivers were under 18 years (3.1%) or aged 60 years and above (8.7%). Caregiving was predominantly undertaken by females (66.3%), while males accounted for 33.8%, reflecting the gendered nature of informal caregiving roles. With regard to the relationship to the patient, caregiving responsibilities were mainly assumed by siblings (31.1%), children (26.1%), and spouses (22.4%), followed by parents (14.3%).

Friends (1.9%) and volunteers (0.6%) contributed minimally, underscoring that caregiving is largely embedded within close family networks. In terms of employment status, most caregivers were employed part-time (60.2%), while nearly one-quarter were unemployed (23.6%) and only 15.5% were employed full-time; a very small proportion were retired (0.6%). This employment pattern suggests that caregiving responsibilities may interfere with caregivers' ability to maintain stable or full-time employment. Educational attainment among caregivers was generally low. Nearly half of the caregivers (48.4%) had attained only primary education, while 29.8% had no formal education.

Those with secondary education accounted for 17.4%, and only 4.3% had attained higher education, which may affect caregivers' capacity to understand medical information and engage effectively with healthcare providers. Regarding caregiving experience, more than half of the caregivers (53.8%) had been providing care for over 12 months, while others reported caregiving durations of 3–6 months (22.5%), 6–12 months (13.1%), or less than three months (10.6%). Daily caregiving demands were substantial, with 62.7% of caregivers spending more than six hours per day on caregiving activities. Caregiving support varied considerably; while 62.7% of caregivers received assistance from one to two individuals, 21.1% reported receiving no assistance, and only 16.2% had support from three or more people.

Perceptions of support, satisfaction, and coping among informal home-based caregivers (N = 161)

Table 2 summarizes caregivers' perceptions of support, satisfaction, and coping within the context of home-based palliative care. These findings provide insight into caregivers' experiences regarding the quality of care they provide the adequacy of training and health service support, their confidence in managing patient needs, and the emotional and practical challenges associated with caregiving. Table 2 presents caregivers' perceptions of satisfaction, support, and coping in the context of home-based palliative care. Overall, caregivers reported mixed levels of satisfaction. While (30%) agreed that they were satisfied with the quality of care they provided and (13.7%) strongly agreed that they were satisfied with the quality of care they provided, a substantial proportion (55.4%) including (33%) who disagreed and (22.4%) who strongly disagreed. Feelings of appreciation from patients were more positive, with 57.8% reporting agreement or strong agreement.

Training and confidence emerged as major gaps. More than two-thirds of caregivers (72.8%) disagreed or strongly disagreed that they had received adequate training, and 75.8% reported low confidence in managing patient symptoms. Similarly, perceptions of support were limited, with 62.1% indicating they lacked a strong support system. Satisfaction with available healthcare services was also low, as 76.1% of caregivers disagreed or strongly disagreed that services were sufficient to meet their needs.

Despite these challenges, caregiving was also associated with emotional rewards. More than half of caregivers (55.4%) reported a sense of fulfilment from their caregiving role, and 64.7% expressed hopefulness about the future of their patient's care.

In terms of coping, many caregivers reported difficulties maintaining physical health (57.8%), social relationships (66.3%), and time for relaxation and self-care (53.5%). Mental health outcomes were comparatively better; with 47.8% including (41%) who agreeing and (6.8%) who strongly agreeing that they were able to maintain their mental health. Overall satisfaction with palliative care services remained low, with nearly three-quarters of caregivers (73.7%) expressing dissatisfaction.

Table 2. Perceptions of support, satisfaction, and coping among informal home-based caregivers

Items	SD n (%)	D n (%)	N n (%)	A n (%)	SA n (%)
Informal Home-Based Caregivers Satisfaction					
I feel satisfied with the quality of care I provide to my patient.	36(22.4)	53(33)	1(0.6)	49(30)	22(13.7)
I feel appreciated by my patient for the care I provide.	27(16.8)	34(21)	7(4.3)	45(28)	48(29.8)
I have received adequate training to provide the necessary care.	85(52.8)	32(20)	6(3.7)	32(20)	6(3.7)
I feel confident in my ability to manage my patient's symptoms.	64(39.8)	58(36)	1(0.6)	26(16)	12(7.5)
I feel a sense of fulfilment from being a caregiver.	31(19.3)	41(26)	0(0)	53(33)	36(22.4)
I am satisfied with the overall palliative care services available.	88(54.7)	30(19)	2(1.2)	34(21)	7(4.3)
Informal Home-Based Caregivers Needed Support					
I have a good support system (family, friends, etc.) to help me with caregiving.	71(44.1)	29(18)	2(1.2)	51(32)	8(5)
The healthcare services available to us are sufficient to meet our needs.	63(39.1)	59(37)	1(0.6)	29(18)	9(5.6)
Informal Home-based caregivers Coping					
I am able to maintain my physical health despite my caregiving duties.	27(16.8)	66(41)	6(3.7)	57(35)	5(3.1)
I am able to maintain my mental health despite my caregiving duties.	24(14.9)	59(37)	1(0.6)	66(41)	11(6.8)
I have time for relaxation and self-care.	25(15.5)	61(38)	2(1.2)	66(41)	7(4.3)
I am able to maintain social relationships despite my caregiving duties.	52(32.3)	55(34)	2(1.2)	43(27)	9(5.6)
I feel hopeful about the future of my patient's care.	24(14.9)	33(21)	0(0)	82(51)	22(13.7)

SD: Strongly Disagree; D: Disagree; N: Neutral; A: Agree; SA: Strongly Agree

Qualitative Results

Qualitative demographic characteristics of participants (N=20)

This section of Table 3 presents an overview of the demographic characteristics of the 20 informal home-based caregivers who participated in the qualitative component of the study. The profile summarizes participants' age distribution, gender, educational attainment, and socioeconomic status to provide contextual grounding for the subsequent thematic findings.

Table 3. Qualitative demographic profile of informal home-based caregivers

Demographic	Description	n(%)
Age	18–29 years	5(25)
	30–39 years	5(25)
	40–49 years	1(5)
	50–59 years	2(10)
	60+ years	7(35)
Sex	Female	12(60)
	Male	8(40)
Education Level	No formal or minimal primary education	7(35)
	Completed primary school	5(25)
	Some secondary education or higher	2(10)
Socioeconomic Status	Low-income (subsistence farming, informal labor,or dependent on donations)	17(85)
	Moderate/stable income (e.g., salaried or with property)	3(15)

The qualitative demographic profile of participants is presented in Table 3. A total of 20 informal home-based caregivers participated in the qualitative component of the study. As shown in Table 3, participants ranged in age from 20 years to over 60 years, with the largest proportion aged 60 years and above (35%), followed by those aged 20–29 years (25%) and 30–39 years (25%). Females constituted the majority of participants (60%), while males accounted for 40%.

Educational attainment among participants was generally low, as summarized in Table 3. Over one-third (35%) had no formal or only minimal primary education, 25% had completed primary school, and only 10% had some secondary or higher education. Socioeconomic status was predominantly low, with 85% of participants relying on subsistence farming, informal labor, or donations, while only 15% reported a moderate or stable income.

Beyond these demographic characteristics, qualitative findings revealed that caregiving responsibilities typically fell on close family members and were sustained over extended periods, underscoring the enduring and deeply personal nature of caregiving. As illustrated in Table 3, many caregivers were older adults and women, who often assumed caregiving roles with limited external support. One husband reflected on the prolonged nature of care, stating, *"She is under my care for two years"* (P020, Husband). Similarly, another caregiver expressed exhaustion and diminished capacity, noting, *"It is not easy to take care of my patient… the capacity and ability we had is over"* (P019, Sister). Financial strain emerged as a pervasive theme among participants, particularly among those from low socioeconomic backgrounds identified in Table 3. One husband described the severe economic sacrifices involved: *"We sold our crops, our hens, and cows; we are left with nothing"* (P003, Husband). Another caregiver highlighted dependence on external assistance, stating, *"We live from the donation of good people and from cultivation"* (P015, Grandchild).

Gendered expectations strongly influenced caregiving dynamics. Female caregivers often assumed responsibility due to social and familial norms. A daughter explained, *"I was the only one available at home; others are married and gone"* (P004, Daughter), illustrating how caregiving roles frequently defaulted to women. In fewer cases, male caregivers also assumed responsibility, as one son shared, *"My wife and I are the ones caring for him… others are far and married"* (P014, Son).

Low educational attainment further affected caregivers' ability to navigate caregiving demands, particularly in understanding medical information. As reflected in Table 3, several participants had no formal education. One caregiver admitted, *"I have never been to school and I am not able to read"* (P016, Wife), while another explained, *"I never went to school, so it's hard to understand all these medical things"* (P013, Daughter-in-law). These narratives highlight how limited education compounded caregiving challenges, especially in managing complex health information and interacting with healthcare providers.

Thematic analysis of informal home-based caregivers' needs, coping strategies, and caregiving satisfaction

Table 4 presents the qualitative findings from the thematic analysis. Eight interrelated themes emerged, illustrating how caregivers' coping strategies are closely shaped by unmet systemic, financial, informational, and psychosocial needs.

Table 4.Thematic analysis of informal home-based caregivers' needs, coping strategies, and caregiving satisfaction

Code	Theme	Sub-theme	Illustrative Quote
Caregivers' Needs & Suggestions for Home-Based Care Services Improvement	Need for Professional Support & Follow-up	Home consultation and follow-up	"They should provide consultation even at home, call back after visits, and follow up on how the patient is doing." (P001, Daughter-in-law)
		Poor communication with providers	"They never call us back. They should be closer to us and available on call." (P004, Daughter)
		Regular home visits	"Home visits should be done regularly, with prescription updates and medication availability." (P016, Wife),
	Training and Information Needs	Education on illness and symptoms	"They should give all information related to the patient's illness, symptoms, and how to manage them." (P001, Daughter-in-law)
		Caregiving skills training	"Provision of materials and training to correct faults and strengthen attitudes." (P003, Husband)
		Managing caregiver distress	"Caregivers should be trained on self-behavior to avoid distress and know how to manage it." (P011, Daughter)
	Material and Medication Support	Provision of supplies	"My patient bleeds always; we need kits, medication, feeding support, and regular assistance." (P015,Grandchild)
		Poverty and lack of materials	"Due to poverty, we use substandard dressing and clothes; there is no specific support." (P006, Granddaughter)
	Financial and Livelihood Support	Income-generating activities	"Support should help caregivers earn income, like small crops, while staying near the patient." (P008, Son)

Table 4. Continued

Code	Theme	Sub-theme	Illustrative Quote
Caregivers' Needs & Suggestions for Home-Based Care Services Improvement	Financial and Livelihood Support	Livestock and food security	"Crops and animals can provide milk, eggs, and income for patient care." (P009, Daughter)
		Job and income support	"Job support and income generation are needed because depression is common." (P014, Son)
	Health System Organization	Structured support systems	"There should be an organized framework for support and community health insurance." (P012, wife)
		Dedicated contact persons	"There should be specific hospital personnel who care for us and respond quickly." (P017, wife)
		Reliable diagnosis and planning	"Reliable diagnosis is needed before assigning caregivers, and caregivers should be evaluated and supported." (P020, husband)
	Psychosocial & Spiritual Support	Counseling and emotional support	"We need counseling because advice from relatives is full of myths." (P014, son)
		Spiritual accompaniment	"Spiritual support and accompaniment of the patient up to the end is important." (P015, Grandchild)
Coping with Home-Based Caregiving Burdens	Emotional Distress and Depression	Feelings of sadness and hopelessness	"I feel alone, depressed, and unhappy; life is not beneficial to us." (P004, Daughter)
		Crying and hidden emotions	"I cry but hide it from my patient; you try your best and feel incapable." (P019, Sister)
	Patience and Acceptance	Acceptance as survival	"Patience and acceptance are the only ways to cope, together with prayer." (P001, Daughter-in-law)
		Endurance without choice	"It is very disturbing, but there is no choice—we have to cope." (P006, Granddaughter)
	Spiritual and Faith-Based Coping	Prayer and reliance on God	"I ask God for patience; otherwise, it is very frustrating." {P002 Wife of uncle}
		Shared faith with patient	"Praying together helps us remain calm and stable." (P007, son)
	Anger and Emotional Control	Suppressed anger	"Sometimes I feel extremely angry, but it is the grace of Jesus that controls me." (P005, Daughter)
		Emotional restraint	"I try to be calm and patient even when the situation is very difficult." (P010, Wife)

Eight interrelated themes emerged from the thematic analysis, illustrating how caregivers' coping strategies are closely shaped by unmet systemic, financial, informational, and psychosocial needs. In the absence of adequate formal support, caregivers relied heavily on patience, acceptance, emotional suppression, and faith to sustain their caregiving roles are presented in Table 4.

The themes are organized into two overarching domains: (1) Caregivers' Needs and Suggestions for Improving Home-Based Care Services and (2) Coping with Home-Based Caregiving Burdens. Together, these findings demonstrate how gaps within the health system directly influence caregivers' emotional, psychological, and spiritual coping experiences. Verbatim quotes and participant identifiers provide strong empirical support for each theme.

(1) Caregivers' needs and suggestions for improving home-based care services

Need for professional support and follow-up

Caregivers consistently emphasized the need for accessible, responsive, and continuous professional support, particularly through home consultations and follow-up. Many expressed the importance of ongoing engagement beyond hospital visits. As one caregiver stated, "They should provide consultation even at home, call back after visits, and follow up on how the patient is doing" (P001, Daughter in law). Conversely, poor communication from healthcare providers intensified distress, as illustrated by a participant who reported repeated unsuccessful attempts to seek assistance: *"They never call us back. They should be closer to us and available on call"* (P004, Daughter). *Regular home visits were viewed as critical for continuity of care and medication management* (P016, Wife).

Training and information needs

Inadequate knowledge about illness progression, symptom management, and caregiving techniques contributed significantly to caregivers' anxiety and uncertainty. Participants highlighted the need for clear, comprehensive information and practical training. One caregiver noted, *"They should give all information related to the patient's illness, symptoms, and how to manage them"* (P001, Daughter in law), while another emphasized skills-building through hands-on training (P003, Husband). Training was also perceived as essential for managing caregivers' own emotional well-being and preventing distress (P011, Daughter).

Material, medication, and financial support needs

A lack of essential supplies, medications, and financial resources emerged as a major challenge. Caregivers described difficulties managing symptoms such as bleeding due to inadequate materials (P015 Grandchild) and reported resorting to unsafe alternativesbecause of poverty (P006, Granddaughter). Participants suggested income-generating activities that would allow caregivers to remain close to patients, such as small-scale farming or livestock support, to improve financial stability and care continuity (P008, son, P009, Daughter).

Health system organization and coordination

Caregivers expressed a need for a more structured, accountable, and coordinated health system to support home-based care. Participants called for organized frameworks, improved community health insurance coverage, and designated healthcare personnel responsible for caregiver support (P012sister in law, P017, wife). Concerns were also raised about the lack of proper diagnosis and caregiver assessment before assigning caregiving roles, underscoring the need for systematic evaluation and follow-up (P020, Husband).

Psychosocial and spiritual support needs

Beyond technical and material assistance, caregivers highlighted a strong need for emotional counseling and spiritual support. Participants reported that reliance on advice from relatives often reinforced misinformation and myths (P014, son). Spiritual accompaniment, particularly during end-of-life care, was viewed as essential for both patients and caregivers (P015, Grandchild).

(2) Coping with home-based caregiving burdens

Emotional distress and depression

Caregiving was frequently described as emotionally overwhelming, leading to sadness, loneliness, depression, and feelings of hopelessness. One caregiver stated, *"I feel alone, depressed, and unhappy; life is not beneficial to us"* (P004, Daughter). Others concealed their emotional suffering to protect patients, resulting in unexpressed distress (P019, sister).

Patience, acceptance, and faith-based coping

Patience and acceptance emerged as dominant coping strategies, often reinforced through religious faith.

Caregivers described enduring their circumstances as unavoidable, sustained by prayer and spiritual beliefs. As one participant explained, *"Patience and acceptance are the only ways to cope, together with prayer"* (P001, Daughter in law). Faith provided emotional stability and shared meaning between caregivers and patients (P002, uncles wife, P007, son).

Anger regulation and emotional control

Despite experiencing anger and frustration, caregivers actively regulated their emotions to continue providing care. Faith and conscious emotional restraint played a key role in managing these feelings. One caregiver noted, *"Sometimes I feel extremely angry, but it is the grace of Jesus that controls me"* (P005, Daughter), while another emphasized deliberate calmness in difficult situations (P010, wife).

Integrated display of quantitative and qualitative findings on informal home-based caregiver characteristics, needs, and coping

Table 5 presents the integrated findings from the quantitative and qualitative phases of the study. The integration reveals strong convergence across caregiver demographics, unmet needs, caregiving intensity, and coping strategies.

Table 5. Integrated display of quantitative and qualitative findings on informal home-based caregiver characteristics, needs, and coping

Quantitative Findings	Qualitative Themes	Illustrative Quotes	Integrated Interpretation (Meta-Inference)
66.3% of caregivers were female	Gendered caregiving roles	*"I was the one available to care for her at home because other relatives were married and had their own homes."* (P004, Daughter)	Female caregivers disproportionately shoulder caregiving responsibilities, reinforced by cultural norms assigning care duties to women, increasing emotional and physical burden.
70.9% aged 18–49 years	Endurance and suppressed distress	*"I am still young, but my life has completely changed. I have no time for myself, no future plans, I just endure."* (P015,Grand daughter)	Caregiving occurs during economically productive years, contributing to role strain, emotional suppression, and acceptance-based coping due to limited alternatives.
29.8% no formal education; 48.4% primary education	Training and information needs	*"No one explained clearly what my patient is suffering from or what I should expect. I just do what I think is right."* (P013,Daughter in law)	Low educational attainment limits understanding of illness and care procedures, explaining strong demand for training, information, and repeated guidance.
60.2% part-time employed; 23.6% unemployed	Financial and livelihood support	"We sold all our land and cows because of the illness. Now we have nothing, and I cannot work because I must stay with the patient." (P008, Son)	Employment disruption due to caregiving explains financial distress, poverty-driven coping, and requests for income-generating activities compatible with home care.

Table 5. Continued

Quantitative Findings	**Qualitative Themes**	**Illustrative Quotes**	**Integrated Interpretation (Meta-Inference)**
53.8% caregiving >12 months	Acceptance, patience, faith-based coping	*“There is no choice. You become patient with time, and praying is the only way to continue.”* (P006, Granddaughter)	Prolonged caregiving leads caregivers to normalize burden and adopt long-term coping strategies centered on faith, endurance, and emotional control.
62.7% provide >6 hours/day of care	Emotional distress and depression	*“Sometimes I cry alone so the patient cannot see me. I am exhausted, but I must stay strong.”* (R019, sister)	High caregiving intensity aligns with reported exhaustion, sadness, hidden crying, and psychological strain.
21.1% receive no caregiving assistance	Isolation and lack of professional support	*“No one comes to check on us. We are alone, and we manage everything by ourselves.”* (P012, sister-in-law)	Limited support networks exacerbate loneliness and reinforce reliance on self-coping strategies rather than formal health system assistance.
72.8% report inadequate training	Training and information needs	*“The short talk at the hospital was not enough. I had to search on the internet to learn how to care for my patient.”* (P011, Daughter)	Quantitative dissatisfaction with training directly converges with qualitative calls for education on symptoms, caregiving skills, and self-care.
75.8% lack confidence in symptom management	Need for professional follow-up	*“When symptoms worsen, I don’t know what to do. There is no one to call, and no home visit.”* (P013, daughter in law)	Lack of confidence reflects absence of follow-up, poor communication, and minimal home visits reported qualitatively.
76.1% dissatisfied with healthcare services	Health system organization gaps	*“They promise to come, but they never come. There is no clear contact person for us.”* (P004, Daughter)	Systemic weaknesses (poor coordination, unclear contact points) explain dissatisfaction and caregivers repeated unmet needs.
55.4% report caregiving fulfilment	Meaning-making through faith	“Being a Christian helps me. Caring for him gives my life meaning despite the suffering.” (P007, son)	Despite hardship, caregivers derive fulfilment through spiritual meaning, reinforcing resilience and emotional endurance.
73.7% dissatisfied with overall palliative care	Reliance on faith over formal systems	“If you don’t rely on God, you cannot survive this situation.” (P017, wife)	Weak health system support shifts coping toward spiritual resources rather than institutional care.

Integration of quantitative and qualitative findings revealed strong convergence across caregiver demographics, unmet needs, caregiving intensity, and coping strategies. Quantitative data demonstrated high caregiving intensity, prolonged duration of care, limited training, employment disruption, and widespread dissatisfaction with health services are presented in Table 5. These patterns were consistently corroborated by qualitative themes describing systemic gaps in professional support, training, material resources, follow-up, and health system coordination. In the absence of structured and reliable formal support, caregivers relied heavily on patience, acceptance, emotional suppression, and faith-based coping strategies. This reliance was particularly pronounced among women, caregivers with low educational attainment, and those providing long-term, high-intensity care, indicating that coping strategies were shaped less by personal preference than by structural and systemic constraints within home-based palliative care.

The predominance of female caregivers (66.3%) quantitatively reflects entrenched gendered caregiving roles, which were qualitatively attributed to cultural norms, family expectations, and availability rather than choice. Women frequently assumed primary caregiving responsibilities due to the absence of alternative caregivers, thereby experiencing heightened emotional, physical, and social burden. Most caregivers were within the economically productive age group (18–49 years; 70.9%), a life stage typically associated with employment, family formation, and future planning. Qualitative narratives revealed that caregiving during this period resulted in endurance-based coping, emotional suppression, and resignation, as caregivers perceived limited alternatives to their role. This contributed to role strain, disrupted life trajectories, and postponed personal aspirations. Low educational attainment nearly one-third with no formal education (29.8%) and almost half with primary education only (48.4%) was closely aligned with qualitative reports of limited understanding of illness, symptom progression, and caregiving techniques. Caregivers consistently expressed a need for repeated explanations, practical demonstrations, and structured training, explaining the high quantitative levels of dissatisfaction with training and low confidence in symptom management.

Employment instability was widespread, with 60.2% part-time employed and 23.6% unemployed, reflecting caregiving-related disruption of income generation. Qualitative findings highlighted severe financial strain, asset depletion, and reliance on subsistence activities, prompting caregivers to request income-generating support compatible with home-based caregiving. More than half of caregivers (53.8%) had provided care for over one year. Prolonged caregiving led to a normalization of burden and adoption of long-term coping strategies grounded in patience, acceptance, and faith. While these strategies enabled emotional survival, they also masked unmet psychosocial and mental health needs, which remained largely unaddressed.

Caregiving intensity was high, with 62.7% providing more than six hours of care daily, corresponding to qualitative accounts of exhaustion, sadness, hidden crying, insomnia, and depressive symptoms. Emotional distress was often concealed to protect patients, further intensifying caregivers' psychological strain. A substantial proportion of caregivers (21.1%) reported receiving no caregiving assistance. Qualitative narratives emphasized isolation, abandonment, and minimal professional follow-up, forcing caregivers to rely on self-coping mechanisms and informal social or spiritual support networks rather than formal health system assistance. Training gaps were prominent, with 72.8% reporting inadequate training and 75.8% lacking confidence in symptom management. These findings converged with qualitative reports of insufficient instruction, poor communication, lack of continuity of care, and minimal home visits, underscoring significant weaknesses in health system responsiveness. High dissatisfaction with healthcare services (76.1%) and overall palliative care (73.7%) was explained by organizational and structural gaps, including unclear referral pathways, inconsistent contact points, and unmet promises of home visits. In this context, caregivers increasingly turned to faith-based meaning-making, which also explains why 55.4% reported caregiving fulfilment despite substantial hardship. Spiritual coping emerged as a critical source of resilience and emotional endurance, compensating for weak institutional support.

Discussion

This study explored the support needs, satisfaction levels, and coping experiences of informal home-based caregivers providing palliative care in rural Rwanda using a mixed-methods design. By integrating quantitative measures of caregiver satisfaction, support, and coping with qualitative narratives of lived experience, the study provides a comprehensive understanding of how systemic gaps in palliative care services shape caregiver outcomes. The findings offer important implications for policy reform, service delivery, and future research aimed at strengthening palliative care in resource-limited settings.

One of the most salient findings was the widespread lack of formal training and information among informal home-based caregivers. Quantitatively, more than two-thirds of caregivers reported dissatisfaction with training and low confidence in managing patient symptoms, while qualitatively, caregivers consistently described uncertainty, anxiety, and fear related to insufficient knowledge of illness progression and caregiving techniques similar to other researches.[24,25] These unmet informational needs were directly linked to lower satisfaction with palliative care services, suggesting that caregiver competence and confidence are key determinants of perceived service quality.[21] These findings align with studies from other low- and middle-income countries, which have shown that caregivers often assume complex clinical tasks without adequate preparation, resulting in distress and dissatisfaction with healthcare systems.[17,26,27] Importantly, the high proportion of caregivers who nonetheless reported a sense of fulfilment highlights a paradox frequently observed in caregiving literature: emotional meaning and personal satisfaction may coexist with significant unmet support needs.[28] This underscores the need for structured caregiver education programs that not only enhance clinical skills but also validate caregivers' roles as essential partners in palliative care delivery.

The quantitative results revealed that caregiving was highly intensive, with most caregivers providing care for more than 12 months and spending over six hours per day on caregiving activities mean that all of their time in the year is spend int caring for patient at home. These demands were mirrored in qualitative accounts of physical exhaustion, emotional burnout, social isolation, and neglected personal health.[29,30] High caregiving intensity was associated with poorer physical and psychosocial coping outcomes, including limited time for self-care and strained social relationships.[31] Consistent with existing literature, prolonged and intensive caregiving in the absence of institutional support has been linked to caregiver burden, depression, and declining health.[32] The convergence of quantitative and qualitative findings in this study reinforces the notion that caregiver burden in palliative care is multidimensional, encompassing physical, emotional, social, and economic domains. These results highlight the importance of incorporating caregiver burden screening and routine psychosocial assessment into palliative care services.[33]

Financial hardship emerged as a central determinant of caregiver stress and dissatisfaction. Quantitatively, a large proportion of caregivers were unemployed or engaged in part-time work, while qualitatively, participants described selling livestock, land, and household assets to finance patient care. These coping strategies reflect deep structural vulnerability and align with findings from other low-income settings, where caregiving frequently leads to long-term economic insecurity.[34–36] In Rwanda, limited access to community-based health insurance in rural areas that focus on home based care, inconsistent donor funding, and the absence of government-funded home-based palliative care programs exacerbate caregivers' financial burden. Without targeted economic interventions such as caregiver stipends, transport vouchers, conditional cash transfers, or income-generating initiatives compatible with home caregiving caregivers risk falling into chronic poverty. Addressing financial strain is therefore not only a social protection issue but also a prerequisite for sustainable palliative care delivery.[37,38]

Caregivers reported substantial dissatisfaction with professional healthcare engagement, particularly regarding poor communication, lack of follow-up, and limited home visits. Quantitative findings indicated low satisfaction with healthcare services overall, while qualitative narratives illustrated how inconsistent provider engagement eroded trust and heightened caregiver distress. These findings are consistent with prior studies emphasizing the importance of continuity of care, empathetic communication, and accessible professional support in palliative care settings.[34–36,39–45] Notably, many caregivers described feeling abandoned after hospital discharge, highlighting a critical disconnect between facility-based care and home-based caregiving realities. This gap suggests the need for a more integrated model of care that includes designated care coordinators, structured follow-up mechanisms, and clear communication pathways between caregivers and healthcare providers. In the absence of adequate formal support, caregivers relied heavily on patience, acceptance, emotional suppression, and faith-based coping. Quantitatively, many caregivers reported maintaining hope and finding fulfilment despite high levels of dissatisfaction and burden. Qualitatively, spiritual practices and shared faith with patients emerged as central sources of emotional resilience and meaning.[46–48] The role of spirituality as a coping mechanism is well documented in palliative care literature, particularly in low-resource and culturally collectivist contexts.[49,50] While spiritual coping can buffer stress and foster resilience, this study reinforces the argument that spirituality should complement not replace professional medical and psychosocial support. Overreliance on spiritual networks in the absence of institutional care reflects systemic failure rather than caregiver preference. Integrating spiritual care providers, such as faith leaders or trained chaplains, into multidisciplinary palliative care teams may offer a culturally responsive approach to caregiver support.[33,37–39]

Collectively, these findings underscore the urgent need for a comprehensive, integrated palliative care framework in Rwanda that explicitly recognizes and supports informal home-based caregivers. Such a model should include structured caregiver training, routine psychosocial assessment, financial protection mechanisms, and coordinated home-based follow-up. Importantly, caregivers should be formally recognized as key stakeholders within the health system, rather than invisible extensions of patient care.[51] Innovative approaches such as community health worker led caregiver training, mobile health follow-up systems, caregiver support groups, and public private partnerships for livelihood support could offer scalable solutions tailored to rural contexts. When culturally adapted and systematically implemented, these strategies have the potential to improve caregiver well-being, enhance patient outcomes, and strengthen the overall palliative care system. [52,53]

Strengths of the study

This study used a mixed-methods design, allowing triangulation of quantitative and qualitative data for a comprehensive understanding of informal caregivers' experiences. Maximum variation sampling and in-depth interviews provided rich, diverse insights, and verbatim quotes preserved participants' authentic voices. Focusing on underrepresented informal caregivers in home-based palliative care adds original contributions, particularly in low-resource rural settings, and the findings are relevant for healthcare practitioners and policymakers.

Limitations of the study

The study was conducted in only two rural districts of Rwanda, limiting generalizability to other regions, particularly urban areas. Convenience and purposive sampling, self-reported data, and the use of caregiver burden tools as a proxy for support needs may have introduced bias or failed to capture all dimensions of support needs. Translation and transcription may have affected nuance, and the cross-sectional, descriptive design cannot establish causality or capture changes over time. Despite these limitations, the underlying data are available upon reasonable request.

Conclusion

Informal home-based caregivers in Rwanda face multiple challenges while providing palliative care at home, which are further compounded by inadequate support networks. Some caregivers reported dissatisfaction with their caregiving roles and the palliative care services available, citing several factors that contributed to this dissatisfaction. To address these issues, there is a need for a multi-faceted program that includes caregiver training, regular home visits, access to medical supplies, financial protection, and mental health support to improve both caregiver and patient quality of life. Prioritized actionable recommendations include implementing structured caregiver training programs to enhance skills and confidence, and establishing regular home-based support visits by healthcare professionals to provide guidance, monitor patient care, and reduce caregiver burden. Strengthening caregivers' support systems and networks, alongside policy reforms that recognize and support informal caregivers, is imperative for sustainable improvements in palliative care delivery.

Areas for further research include evaluating the effectiveness of structured training and support interventions for informal caregivers, exploring long-term psychosocial and economic impacts of caregiving, and examining strategies to integrate caregiver support into national palliative care policies. Additionally, studies could investigate the role of community-based and digital interventions in expanding access to support and reducing caregiver burden in rural settings.

Authors' contribution

J C T: Conceptualized the study, led data collection and analysis, drafted the manuscript, and coordinated the overall research process.

MM, MF, KG: Conceptualized the study, led data analysis, provided methodological guidance, critically reviewed the manuscript, and contributed to data interpretation, contributed to critical manuscript revisions and supported ethical compliance and quality control.

Conflict of interest declaration

Non-conflict of interest declared

Reference

1. Anago EK, Mcfeely C, Bayuo J. Experiences of Adult Informal Caregivers in Palliative Care Provision for Persons with Advanced Cancer: A Meta-synthesis. *J Pain Symptom Manage.* 2026;71(1):e40-e68. https://doi.org/10.1016/j.jpainsymman.2025.08.042

2. Peeler A, Afolabi OA, Sleeman KE, Akoum M El, Gafer N, Hammerich A, et al. Confronting global inequities in palliative care. *BMJ Glob Health.* 2025;10(5):e017624. https://doi.org/10.1136/bmjgh-2024-017624
3. Slatyer S, Aoun SM, Hill KD, Walsh D, Whitty D, Toye C. Caregivers' experiences of a home support program after the hospital discharge of an older family member: A qualitative analysis. *BMC Health Serv Res.* 2019;19(1):220. https://doi.org/10.1186/s12913-019-4042-0
4. Agom D, Onyeka T, Iheanacho P, Ominyi J. Barriers to the provision and utilization of palliative care in Africa: A rapid scoping review. *Indian J Palliat Care.* 2021;27(1):3–17. https://doi.org/10.4103/IJPC.IJPC_355_20
5. Lung EYL, Wan A, Ankita A, Baxter S, Benedet L, Li Z, et al. Informal Caregiving for People With Life-Limiting Illness: Exploring the Knowledge Gaps. *J Palliat Care.* 2022;37:233–41. https://doi.org/10.1177/0825859720984564
6. Abu-Odah H, Molassiotis A, Liu J. Challenges on the provision of palliative care for patients with cancer in low- And middle-income countries: A systematic review of reviews. *BMC Palliat Care.* 2020;19:1–16. https://doi.org/10.1186/s12904-020-00558-5
7. Soumya Liz Jacob1 , Malathi G. Nayak1 LSGLM and PLB, Abstract. Experiences and perspectives by family caregivers on a palliative care journey : A case report from India. *Sage Journals.* https://doi.org/10.1177/26323524251355286
8. Genet N, Boerma WG, Kringos DS, Bouman A, Francke AL, Fagerström C, et al. Home care in Europe: A systematic literature review. *BMC Health Serv Res.* 2011;11:207. https://doi.org/10.1186/1472-6963-11-207
9. Mills J, Abel J, Kellehear A, Patel M. Access to palliative care: the primacy of public health partnerships and community participation. *Lancet Public Heal.* 2021;6:e791–2. https://doi.org/10.1016/S2468-2667(21)00213-9
10. Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FEM, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care ? Population-based projections of place of death. *Sage Journals.* 2018; https://doi.org/10.1177/0269216317734435
11. Salikhanov I, Connor SR, Kunirova G, Khashagulgova F. Challenges for Developing Palliative Care Services in Resource- Limited Settings of Kazakhstan. *Public Health Rev.* 2023;44:1–7. https://doi.org/10.3389/phrs.2023.1605672
12. Souza TJ, Coelho AGMS, Lima LLC, Assis JMV, Pires JCS, Lima SS. Nurses conduct in palliative care: an integrative review. *Palliative care.* 2021;24:6116–20. https://doi.org/10.36489/nursing.2021v24i280p6000
13. Theißen T, Ullrich A, Oechsle K, Wikert J, Bokemeyer C, Schieferdecker A. "Being an informal caregiver – strengthening resources": mixed methods evaluation of a psychoeducational intervention supporting informal caregivers in palliative care. *BMC Palliat Care.* 2024;23:1–17. https://doi.org/10.1186/s12904-024-01428-0
14. Gómez-Batiste X, Murray SA, Thomas K, Blay C, Boyd K, Moine S, et al. Comprehensive and Integrated Palliative Care for People With Advanced Chronic Conditions: An Update From Several European Initiatives and Recommendations for Policy. *J Pain Symptom Manage.* 2017;53:509–17.https://doi.org/10.1016/j.jpainsymman.2016.10.361
15. Van Den Noortgate NJ, Verhofstede R, Cohen J, Piers RD, Deliens L, Smets T. Prescription and Deprescription of Medication during the Last 48 Hours of Life: Multicenter Study in 23 Acute Geriatric Wards in Flanders, Belgium. *J Pain Symptom Manage.* 2016;51:1020–6. https://doi.org/10.1016/j.jpainsymman.2015.12.325
16. Van den Block L, Smets T, van Dop N, Adang E, Andreasen P, Collingridge Moore D, et al. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries. *J Am Med Dir Assoc.* 2016;17:566.e1-566.e7. https://doi.org/10.1016/j.jamda.2016.03.008

17. Kreyer C, Stecher B, Pleschberger S, Ewing G. What individual needs do family caregivers have in palliative home care and how are they supported? A qualitative study of a supportive intervention. *Support Care Cancer.* 2024;32:733. https://doi.org/10.1007/s00520-024-08904-6
18. Kirtania M, Katta A. Essential Elements of Home-based Palliative Care Model: A Rapid Review. *Indian J Palliat Care.* 2023;29:359–67. https://doi.org/10.25259/ijpc_227_2022
19. Care P, Luymes N, Williams N, Garrison L, Goodridge D, Silveira M, et al. " The system is well intentioned , but complicated and fallible " interviews with caregivers and decision makers about palliative care in Canada. *BMC Palliat Care.* 2021;1–12. https://doi.org/10.1186/s12904-021-00843-x
20. Meneguin S, Ribeiro R, Ferreira M de LSM. Comfort of formal and informal caregivers to palliative care patients in primary health care. *Rev da Rede Enferm do Nord.* 2017;17:797. https://doi.org/10.15253/2175-6783.2016000600010
21. Kochuvilayil A, Varma RP. Understanding caregiver burden and quality of life in Kerala 's primary palliative care program : a mixed methods study from caregivers and providers 'perspectives. *International Journal for Equity in Health.*2024;1–15. https://doi.org/10.1186/s12939-024-02155-x.
22. Katsarou A, Intas G, Pierrakos G. Investigating the Needs of Caregivers of Patients Suffering from Chronic Diseases : A Mixed-Method Study. *Indian Journal of Palliative Care* .2023;29:285–91. https://doi.org/10.25259/IJPC_179_2022
23. Onuorah CC, Oriji SO, Omoaregba JO, Aina FO, Erohubie PO, Anaje OD. Caregiver Burden And Its Correlates In Caring For Adults With Epilepsy In A Nigeria Tertiary Hospital : A Cross-Sectional StudY. *Nigerian Journal of Psychiatry.* 2024;22:39–50. https://doi.org/10.5455/NJP.195207
24. Fikre K. Caregivers ' experiences : major challenges families ' face in caring for people with chronic illnesses in Ethiopia. *Cogent Public Heal.* 2025;11. https://doi.org/10.1080/27707571.2025.2457840
25. Yu Z, Shao Q, Hou K, Wang Y. The experiences of caregivers of children with epilepsy : A meta-synthesis of qualitative research studies. *Frontiers in Psychiatry.2022.* https://doi.org/10.3389/fpsyt.2022.987892
26. Kumar GS, Thomas PT, Arun M, Mohandas RP, Arshad F, Alladi S. A Qualitative Exploration of Caregiving in Advanced Dementia : Caregiver Perspectives on Unmet Needs in Low- and Middle-income Setting. *IJPC.* 2025;31:250–8. https://doi.org/10.25259/IJPC
27. Nyati Z, Sebit MB. Burden of mental illness on family members, care-givers and the community. *East Afr Med J.* 2002;79:206–9. https://doi.org/10.4314/eamj.v79i4.8880
28. Roxburgh E, Taylor BL, Rammou A, Hodgekins J. Experiences of informal caregivers supporting individuals diagnosed with bipolar disorder : a systematic review and thematic synthesis. *Springer Berlin Heidelberg.* 2025; https://doi.org/https://doi.org/10.1186/s40345-025-00391-w
29. Onyeneho CA, Ilesanmi RE. Burden of Care and Perceived Psycho - Social Outcomes among Family Caregivers of Patients Living with Cancer. *Asia-Pacific Journal of Oncology Nursing.* 2021;2–8. https://doi.org/10.4103/2347-5625.308678
30. Bongelli R, Pacifico A, Fabiani M, Guarascio C, Sofritti F, Lamura G, et al. Caregiving burden , social support , and psychological well-being among family caregivers of older Italians : a cross-sectional study. *Front. Public Health.* 2024;1–20. https://doi.org/10.3389/fpubh.2024.1474967
31. Rodríguez-núñez A, Pérez-cruz PE. Objective burden , caregiver psychological distress , and patient religion and quality of life are associated with high-intensity burden of care among caregivers of advanced cancer patients in a Latino population. *Palliat Support Care.* 2024. doi: 10.1017/S1478951523000834

32. Yustisia N, Aprilatutini T, Utama TA, Masdar M. The Burden Experience of Family Caregiver of Older Adults with Chronic Illness. *Res Community Public Heal Nurs.* 2023;34:85–95. https://doi.org/10.12799/rcphn.2022.00304
33. Lapa L, Cardoso M. Informal Caregiver Burden in Palliative Care and the Role of the Family Doctor : A Scoping Review. *Healthcare.* 2025;1–17. https:// doi.org/10.3390/healthcare13080939
34. Herrera-Abián M, Castañeda-Vozmediano R, Antón-Rodríguez C, Palacios-Ceña D, González-Morales LM, Pfang B, et al. The caregiver's perspective on end-of-life inpatient palliative care: a qualitative study. *Taylor & Francis.* 2023;55. https://doi.org/10.1080/07853890.2023.2260400
35. Sharkiya SH. Quality communication can improve patient-centred health outcomes among older patients: a rapid review. *BMC Health Serv Res.* 2023;23:1–14. https://doi.org/10.1186/s12913-023-09869-8
36. Lai DWL. Effect of financial costs on caregiving burden of family caregivers of older adults. *SAGE Open.* 2012;2:1–14. https://doi.org/10.1177/2158244012470467
37. Hebdon MCT, Thi C, Phan T, Phillips C, Wan S, Doyon K, et al. Financial interventions for family caregivers of individuals with chronic illness : a scoping review protocol. *BMJ Open.* 2022;1–5. doi: 10.1136/bmjopen-2022-061667
38. Machado DB, Jôse F, Alves O, Patel V. Economic interventions for the prevention of mental health problems: the role of cash transfers. *Am J Orthopsychiatry.* 2025;94:477–84. doi: 10.1037/ort0000764
39. Zhang X, Xu T, Qin Y, Wang M, Li Z, Song J, et al. Exploring the needs and coping strategies of family caregivers taking care of dying patients at home: a field study. *BMC Palliat Care.* 2023;22:1–11. https://doi.org/10.1186/s12904-023-01315-0
40. Galvin M, Corr B, Madden C, Mays I, McQuillan R, Timonen V, et al. Caregiving in ALS - A mixed methods approach to the study of Burden. *BMC Palliat Care.* 2016;15:1–12. https://doi.org/10.1186/s12904-016-0153-0
41. Choi, J.Y.; Lee, S.H.; Yu, S. Exploring Factors Influencing Caregiver Burden: A Systematic Review of Family Caregivers of Older Adults with Chronic Illness in Local Communities. *Healthcare.* 2024, 12, 1002. https://doi.org/10.3390/healthcare12101002
42. Sausman J, Arif A, Young A, MacArtney J, Bailey C, Rajani J, et al. Healthcare professionals' perspectives of the management of people with palliative care needs in the emergency department of a UK hospital. *BMC Palliat Care.* 2023;22:1–13. https://doi.org/10.1186/s12904-023-01248-8
43. Khouban-Shargh R, Mirhosseini S, Ghasempour S, Basirinezhad MH, Abbasi A. Stress management training program to address caregiver burden and perceived stress among family caregivers of patients undergoing hemodialysis: a randomized controlled trial study. *BMC Nephrol.* 2024;25:350. https://doi.org/10.1186/s12882-024-03795-5
44. Alanazi MA, Shaban MM, Ramadan OME, Zaky ME, Mohammed HH, Amer FGM, et al. Navigating end-of-life decision-making in nursing: a systematic review of ethical challenges and palliative care practices. *BMC Nurs.* 2024;23:1–15. https://doi.org/10.1186/s12912-024-02087-5
45. Guo J, Xu X, Liu C, Wang Y, Chen Y. Perspectives of telemedicine-based services among family caregivers of patients with end-of-life cancer: a qualitative study in mainland China. *BMC Palliat Care.* 2024;23:16. https://doi.org/10.1186/s12904-024-01347-0
46. Vidinioti C, Konstanti Z, Gouva M, Kourakos M. Self-Care , Hope , and Life Meaning as Predictors of Psychological Resilience in Informal Caregivers of Hemodialysis Patients : A Systematic Review. *cureus.* 2026;18:1–9. https://doi.org/10.7759/cureus.100630

47. Lee CW, Hwang IC, Lee YJ. Spiritual Well-Being and Care Burden among Families of Patients with Terminal Cancer: Is Emotional Distress a Crucial Thing?. *J Hosp Palliat Care.* 2025;28:115-119. https://doi.org/10.14475/jhpc.2025.28.3.115
48. Sharif L, Basri S, Alsahafi F, Altaylouni M, Albugumi S. An Exploration of Family Caregiver Experiences of Burden and Coping While Caring for People with Mental Disorders in Saudi Arabia — A Qualitative Study. Int J Environ Res Public Health. 2020;17(17):6405. doi: 10.3390/ijerph17176405
49. Woodworth J. Exploring networks of care in the end-of-life context through eco maps: feminist perspectives on caregiving in between family, community, and professionals in Sweden. *Community, Work Fam.* 2024;1–20. https://doi.org/10.1080/13668803.2024.2303998.
50. Owokuhaisa J, Kamoga R, Musinguzi P, Muwanguzi M, Natukunda S, Mubangizi V, et al. Burden of care and coping strategies among informal caregivers of people with behavioral and psychological symptoms of dementia in rural south-western Uganda. *BMC Geriatr.* 2023;23:1–9. https://doi.org/10.1186/s12877-023-04129-0.
51. Koo A, Low M, Yeo Z, Ee J, Chong P. Caregiver needs in end-of-life care are diverse , yet invisible : a narrative review. *Public Health in Palliative Medicine and Palliative Care.* 2025;14:160–71. https://doi.org/10.21037/apm-24-151.
52. Palumbo N, Tilly A, Namisango E, Ntizimira C, Thambo L, Chikasema M, et al. Palliative care in Malawi: a scoping review. *BMC Palliat Care.* 2023;22:1–11. https://doi.org/10.1186/s12904-023-01264-8.
53. Curcio F, El Khabir H, Chelo G, Puggioni S, Soddu M, Lucchetta MR, et al. Transcultural Perspectives in Nursing: Understanding the Role of Healers and the Evil Eye in Modern Healthcare. *Nurs Reports.* 2024;14:2443–55. https://doi.org/10.3390/nursrep14030181.