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Review Article

Experiences of Adult Informal Caregivers in Palliative Care Provision for Persons with Advanced Cancer: A Meta-synthesis

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Abstract

Context. Cancer diagnoses are increasing in Sub-Saharan Africa. Diagnoses often occur at a late stage in the disease, hampering the timely initiation of palliative care. The lack of formalized palliative care provision in the region results in informal caregivers assuming most of the caregiving roles for patients. This has considerable implications for informal caregivers.

Objectives. This meta-synthesis seeks to explore how informal caregivers of persons living with advanced cancer have experienced palliative care provision in Sub-Saharan Africa.

Methods. This study was guided by Hannes' framework of meta-synthesis. A systematic search of MEDLINE, EMBASE, PsycInfo, Global Health, CINAHL, Web of Science, Scopus, and the Africa Index Medicus databases was conducted. Two authors independently performed the screening and extraction processes. Thematic synthesis guided the analysis and synthesis.

Results. Fifteen studies were retained in the study. The synthesis yielded eight analytical themes: motivations for caregiving, roles of informal caregivers, challenges and barriers of informal caregiving, quality of informal caregiving, burden and price of informal caregiving, coping strategies of informal caregivers, recommendations for improving caregiving, and the paradox of end-of-life preparation and advanced planning.

Conclusion. In Sub-Saharan Africa, informal caregivers provide the backbone of palliative care, often without preparation, resources, or formal support. Their roles are shaped by cultural expectations of family duty but constrained by poverty and limited health infrastructure. Strengthening caregiver training and integrating their contributions into developing formal palliative care systems are essential to improve outcomes for patients and families. J Pain Symptom Manage 2025;000:e1−e29.

Key words

Palliative care, end-of-life care, advanced cancer, informal caregivers, meta-synthesis

Key Message

This study synthesized relevant papers on the experience of informal caregivers in palliative care provision to advanced cancer patients.

Introduction

Cancer is one of the most common causes of death globally, accounting for approximately 10 million deaths in 2020.[1] African countries have reported lower

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prevalence of cancer than other countries,[2,3] probably due poor surveillance systems, misdiagnoses and/or missed diagnosis. This can also be attributed to factors such as lower air pollution, lower rates of tobacco and alcohol use, and lower consumption of meat, sugar, and refined foods.[4,5] However, cancer incidence has increased steadily in Sub-Saharan Africa (SSA)[2,6] with a high proportion of advanced-stage presentations resulting in poor prognoses.[7,8] For instance, cancer incidence increased by over 5.5% with about 7% associated deaths between 2020 and 2022 in Sub-Saharan Africa.[2,6]

People diagnosed at an advanced stage of disease have limited curative options and require timely palliative care.[9,10] In this study, palliative care refers to "the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life."[11] Its goal is to improve quality of life for patients, families, and caregivers through early and comprehensive identification, assessment, and management of biopsychosocial-spiritual distress.[11] While some studies define the end-of-life phase as the last six months of life,[12,13] this study adopts a broader timeframe: the final 12 months to imminent death.[14,15]

Globally, the need for palliative care is high,[16] with the greatest burden in low- and middle-income countries (LMICs), particularly in Africa, where under-resourced health systems struggle to meet demand.[10] In Africa, only about 5% of those in need receive palliative care.[17,18] Most care in Sub-Saharan Africa is home-based, delivered by both formal and informal caregivers with active community involvement.[17] Informal caregivers—family, partners, friends, or neighbor's—provide unpaid support, including medication management, daily care, and emotional and spiritual support.[19,20,21]

A Southern African cohort study of advanced cancer patients found most preferred to receive care and die at home, due to the desire for close involvement of informal caregivers.[22] Other studies reinforce the critical role of informal caregivers in home-based palliative care.[23,24,25] Consequently, they bear the greatest burden of care in the region.[19,26] Despite these challenges, specialist palliative care services are developing in countries such as Uganda, South Africa, Tanzania, Rwanda, Zimbabwe, and Kenya, although progress is constrained by limited infrastructure, funding, and access to medication.[27,28,17]

While a recent review analyzed caregivers' roles and experiences in cancer care across Africa,[29] its broad focus overlooked key regional differences. Variations in healthcare infrastructure across the continent affect palliative care integration and, consequently, caregiver experiences.[30,31,25] The review's mixed-methods approach did not clearly capture caregivers' lived experiences and focused on general cancer care rather than palliative care specifically limiting its relevance for targeted interventions.[32] Our own database search identified eight relevant studies missed in the prior review, likely due to its broad scope. Importantly, the review lacked contextual analysis for Sub-Saharan Africa, hindering local application of findings. Given rising cancer incidence, late diagnoses, and limited formal palliative care in the sub-region,[33,30,34,25] there is a pressing need for context-specific evidence. This meta-synthesis, therefore, explores the experiences of informal caregivers providing palliative care to individuals with advanced cancer in Sub-Saharan Africa.

Materials and Methods

This meta-synthesis followed Hannes'[35] framework and was reported in line with the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ)[36] and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)[37] guidelines. The protocol is registered in PROSPERO (registration number: CRD42024605301 and available from: https://www.crd.york.ac.uk/PROSPERO/view/CRD42024605301

Eligibility Criteria

Inclusion criteria were predefined and summarized in Table 1.

Search Strategy and Information Sources

A systematic search of eight databases: Medical Literature Analysis and Retrieval System Online (MEDLINE), Excerpta Medica Database (EMBASE), American Psychological Association (APA) Psychological Information (PsycINFO), Global Health, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Scopus, and the Africa Index Medicus databases was conducted using the **P**opulation, **E**xposure, and **O**utcome (PEO) framework for qualitative evidence synthesis.[38] This was framed as **Population**: (informal caregivers of adults (18+) with advanced cancer); **Exposure** (hospital, home or community-based palliative care); **Outcome** (caregiving experiences). Search terms included combinations of cancer-related terms ("neoplasms" OR cancer* OR tumour* OR neoplas* OR carcinoma*), palliative care "terminal care OR hospice care OR (end of life) OR end-of-life OR terminal OR palliative OR hospice," Sub-Saharan Africa "Africa OR (Africa South of the Sahara)," and informal caregiving terms. Searches were completed on October 21, 2024 and updated on May 11, 2025.

Table 1
Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Qualitative studies and mixed method studies that disaggregate qualitative data from quantitative data	Quantitative and mixed method studies that aggregate qualitative and quantitative data
Original/ primary articles	Secondary articles, reports from grey literature, reviews (literature, systematic, scoping, rapid, umbrella)
Studies that focus on palliative care provision	Studies that focus on medical, surgical, pharmaceutical, and diagnostics, palliative care programs
Adult population aged 18 years and over	Pediatric population aged below 18 years as they have different illness experience to that of adults.
Focused on informal caregivers of patients with any type of advanced cancer	Focused on informal caregivers of other diseases than advanced cancer
Focused on informal caregivers of patients with stage III and IV of the cancer diseases	Focused on informal caregivers of patients with stage I and II of the cancer diseases
Conducted in Sub-Saharan Africa	Conducted outside Sub-Saharan Africa
Conducted in English Language	Conducted in languages other than English
Studies conducted in the last 10 years (2014−2024) to retrieve a more contemporary studies for the synthesis.	Studies conducted beyond the last 10 years (2013 and below)

Study Screening and Selection Process

Search results were managed using Covidence software (Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). Two authors independently screened titles, abstracts, and full texts against inclusion criteria. Discrepancies were resolved through discussion. Reasons for exclusion were documented. Reference lists of included studies were hand-searched for additional articles.

Quality Assessment and Appraisal

Two authors independently appraised study quality using the critical appraisal skills program (CASP) checklist for qualitative studies.[39] Disagreements were resolved through discussion.

Data Extraction

Two authors independently extracted data using a predesigned Microsoft Word form, capturing study characteristics, context, methods, key findings, and illustrative participant quotes. A pilot extraction was conducted to ensure consistency.

Data Synthesis

Thematic synthesis followed by Thomas and Harden's[40] three-stage approach: line-by-line coding of results from primary studies; descriptive theme generation; and analytical theme development, moving beyond primary study findings. Two authors extracted the texts of the primary studies into a Microsoft Word file and imported them into NVivo v15. The authors then read the texts multiple times to familiarize themselves with the dataset and to grasp the meaning and contents of the studies and searched for similarities between them. They then proceeded to code every line of the texts of the primary studies inductively and iteratively. The codes were read several times and analyzed, paying attention to the research question to generate descriptive themes. The two authors met regularly to discuss the codes and arrived at a consensus that led to the generation of the descriptive themes. The third and last stage includes generating analytical themes by "moving beyond" the findings of the primary studies.[40] At this stage, the authors, using their judgement and understanding, then reflected on the descriptive themes while paying close attention to the research question, and "moved beyond" the findings of the primary studies to generate eight analytical themes.[40] The two authors met to discuss the entire process to reorganize and rearrange the analytical themes. All authors reviewed the synthesis, with discrepancies resolved through discussion.

Results

Database Search

A total of 320 studies were retrieved, with one additional study identified through hand-searching PubMed. After removing 85 duplicates, 236 studies were screened by title and abstract. Of these, 186 were excluded as irrelevant, and 50 were assessed for full-text eligibility. Thirty-five were excluded, with reasons documented, leaving 15 studies for the meta-synthesis. The PRISMA flow diagram (Fig. 1) illustrates this process.

Study Characteristics

The 15 studies included employed various qualitative designs, with sample sizes ranging from 10 to 48 informal caregivers. Five studies each were conducted in Kenya[41,42,43,44,45] and Ghana,[46,47,48,49,50] and one study each in Uganda,[51] South Africa,[52] Ethiopia,[53] Nigeria,[54] and a multi-country study in Nigeria, Uganda, and Zimbabwe.[55] All countries had point-of-care payment models with some government support. Caregivers provided support for patients with various cancers (e.g., lung, breast, gastrointestinal, prostate).

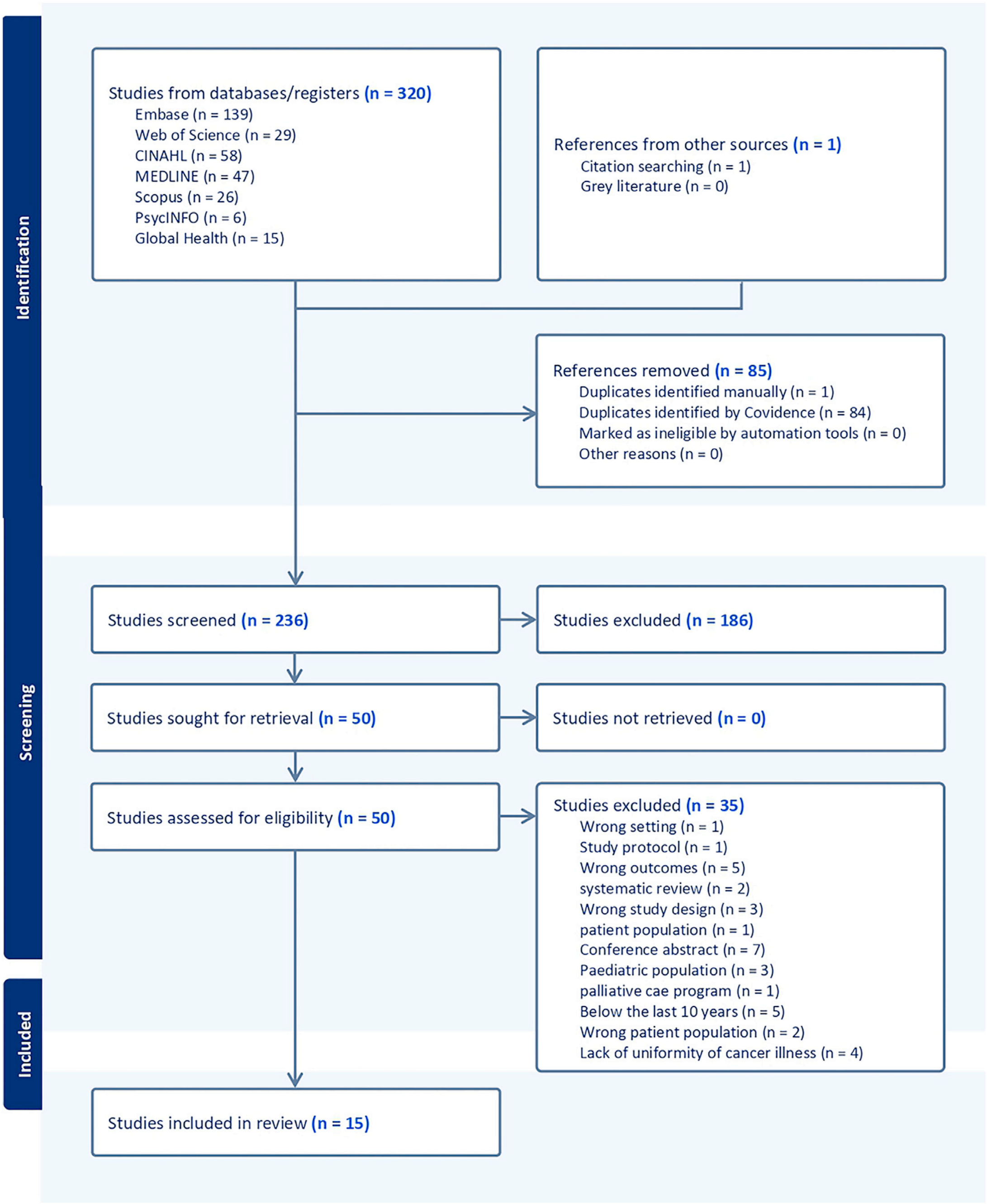

Fig. 1. PRISMA flow diagram of results.

Most caregivers were family members, including spouses, children, and siblings. Study characteristics are detailed in Table 2.

Quality Appraisal Results

All studies clearly stated the study aims and used the appropriate designs as well as data collection and analysis. All studies obtained ethical clearance and findings were fully described. Detailed information about the quality appraisal is found in Supplement file 1.

Findings

The synthesis process yielded eight analytical themes: motivations for caregiving, roles of informal caregivers, challenges and barriers of informal caregiving, quality of informal caregiving, burden and price of informal caregiving, coping strategies of informal caregivers, recommendations for improving caregiving, and the paradox of end-of-life preparation and advanced planning. The themes are further discussed in detail below. Table 3 presents the overview of findings from the synthesis with supporting participants' quotes.

Table 2
Characteristics of Included Studies

S. No	Study Reference and Country	Aim(s) of Study	Study Design/Setting/ Sampling Strategy	Participants Characteristics. Sample Size Male/Female Mean or average age of included participants	Data collection and Analysis	Summary of key Findings Reported by the Authors
1	Biney et al.[46] (Ghana)	To identify the challenges family caregivers face and how they cope with the care of patients with terminal illnesses who are on admission or have been recently discharged at a teaching hospital in Ghana.	**Design**: Explorative Descriptive qualitative **Setting**: Korle-Bu Teaching Hospital (Palliative care center)	Family caregivers **Sample size**: 20 **Male/Female**: 5/15 **Age range**: 28 and 58 years	**Data collection procedure:** Semi-structured interviews **Data analysis**: Thematic analysis	Caregivers reported challenges, coping strategies, and social support in caring for a terminally ill person with cancer. These themes encompassed financial burden, bad health conditions, faith and prayer, and support from health professionals. Notwithstanding that caregiver narrated that providing care was a difficult task, they never gave up, citing responsibility, the importance of family, and religious beliefs as the primary motivations for doing so.
2	Adejoh et al.[55] Nigeria, Uganda, and Zimbabwe	To explore the experiences of informal caregivers in palliative care provision for patients diagnosed with advanced cancer.	**Design**: Multi-center qualitative design **Setting**: Palliative care multi-center study	Family caregivers **Sample size**: 48 **Male/Female**: 24/24 **Age range**: 19 to 75 years, mean age 37 years old.	**Data collection procedure:** Semi-structured interviews **Data analysis**: Thematic analysis	Family caregivers coordinates emotional, practical, and health service issues; Caregiving presents personal, social, and fiscal costs and challenges; Caregivers receive and require practical and emotional assistance; Caregivers' experience of interacting and liaising with palliative care team/ services; Recommendations regarding improving access to palliative care.
3	Kusi et al.[50] Ghana	To explore the caregiving experiences and motivations of family caregivers of advanced cancer patients.	**Design**: Exploratory descriptive phenomenological design **Setting**: Komfo Anokye Teaching Hospital (KATH)- Oncology directorate	Family caregivers **Sample size**: 15 **Male/Female**: 7/8 **Age range**: 25 to 73 years.	**Data collection procedure:** Semi-structured interviews **Data analysis**: Colaizzi's Thematic analysis	Family and socio-cultural commitments and reciprocity motivates caregiving; Caregivers address self-care and psychosocial support encompassing activities of daily living, spiritual, emotional, and financial supports to patients; Caregivers control and monitor symptoms of illness such as wound dressing and care at home, medication and pain management, evaluating symptoms and act as advocates for patients.
4.	Boamah Mensah et al.[48] Ghana	To explore the experiences of spouses of advanced breast cancer women and their coping strategies.	**Design**: Exploratory descriptive qualitative design **Setting**: Komfo Anokye Teaching Hospital (KATH)- Oncology Unit	Husbands of patients **Sample size**: 15 **Male/Female**: 15/0 **Age range**: 34 and 55 years.	**Data collection procedure:** Semi-structured interviews **Data analysis**: Thematic analysis	Husbands encountered difficulties that stressed them including threatening their marriages and considering divorce, losing friends and inability to attend social functions, job instability, and depts and financial challenges. Husbands relied on resources to cope such as marital commitment and children welfare, informal support from family and friends, formal support from healthcare professionals, and relying on their spirituality.
5	Ketlogetswe et al.[52] South Africa	To describe the experiences of caregivers of diagnosed with cancer and receiving hospice care.	**Design**: qualitative descriptive design **Setting**: Hospice in Gauteng Province, South Africa	**Participants:** Family caregivers **Sample size**: 22 **Male/Female**: 3/19 **Age range**: 23 to 84 years, mean age 52 years old.	**Data collection procedure:** in-depth interviews **Data analysis**: Qualitative content analysis	Satisfying the caregiver duties through coping with the caregiving duties and coping with the end of life of patient; The individual costs of caregiving including physical burden, financial burden, and social consequences of caregiving responsibilities; Spiritual concerns related to caregiving such as deriving strength through faith and dissonance between faith and reality.

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Table 2
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S. No	Study Reference and Country	Aim(s) of Study	Study Design/Setting/ Sampling Strategy	Participants Characteristics. Sample Size Male/Female Mean or average age of included participants	Data collection and Analysis	Summary of key Findings Reported by the Authors
6	Salifu et al.[49] Ghana	To explore the experiences of family caregivers of cancer patients in palliative and end of life care provision at home.	**Design**: Interpretive phenomenological design **Setting**: Tertiary hospital in Kumasi, Ghana	**Participants:** Family caregivers **Sample size**: 23 **Male/Female**: not specified **Age range**: not specified.	**Data collection procedure:** semi-structured interviews **Data analysis**: thematic analysis	Practical and emotional concerns of providing care such as feelings of anxiety and fear related to abrupt deteriorating of patients' health; Limited formal support and training/preparation to navigate care at home, caring by reciprocity; Challenges relating to pain assessment, access to pain medications, and use of herbal medicines at home.
7	Too et al.[41] Kenya	To explore the experiences of family caregivers of advance cancer patients towards their perceived readiness, resilience, and continual unmet needs in executing their caregiving duties.	**Design**: Interpretive phenomenological design **Setting**: Outpatient palliative unit, Kijabe Hospital, Kenya	**Participants:** Informal family caregivers **Sample size**: 12 **Male/Female**: 4/8 **Age range**: 21 to 67 years.	**Data collection procedure:** individual interviews **Data analysis**: interpretive phenomenological analysis	Informal caregivers lacked training and preparation to execute their caregiving roles; Informal caregivers developed resilience through spiritual practices such as prayer and marital obligations; Informal caregivers continued to face challenges in their caregiving roles including limited network for support, hopelessness and helplessness related to worsened state of patient's health.
8	Najjuka et al.[51] Uganda	To explore family caregivers' experiences of providing care to advanced cancer patients.	**Design**: descriptive phenomenological design **Setting**: Uganda Cancer Institute, Uganda.	**Participants:** family caregivers **Sample size**: 12 **Male/Female**: 6/6 **Age range**: 19 to 49 years.	**Data collection procedure:** individual in-depth semi-structured interviews **Data analysis**: thematic analysis	Caregivers assume their caring roles including assisting with activities of daily living, coordinating care, and making care decisions; Caregivers experience burdens associated with the caring responsibilities which includes financial burden, physical drain, psychological distress, socio-cultural- spiritual difficulties; Caregivers are caught in role conflict including failure in employment and educational duties and conflict in caring roles and family obligations; Caregivers experience tensions from system tensions which includes the admission process, hospital environments, and healthcare professionals; Caregivers receive assistance and motivation from deity (God), other informal caregivers, community, church members. Also, caregivers receive support needs such as financial and psychological; Caring profits, lessons, and recommendations including social and spiritual/ religious benefits.
9	Salifu et al. 2023[47]	To explore how advanced prostate cancer impacts on men's masculine identity from the perspective of patients and their caregivers.	**Design:** Qualitative exploration **Setting:** A tertiary hospital in Ghana	**Sample size**: $N = 23$ dyads Male/Female – Patients were all men. **Age range**: 49 – 88 years	**Data collection:** Individual interviews **Analysis approach:** Thematic analysis	Prostate cancer affected men's perception of their masculine identity. It impacted their masculinity in terms of:[1] physical changes,[2] sexual ability,[3] socio-economic roles and[4] expressing emotions. Thus, changes in physical appearance, feeling belittled, having no active sexual life and the inability to continue acting as provider and protector of the family was of great concern to participants.

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Table 2
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S. No	Study Reference and Country	Aim(s) of Study	Study Design/Setting/ Sampling Strategy	Participants Characteristics. Sample Size Male/Female Mean or average age of included participants	Data collection and Analysis	Summary of key Findings Reported by the Authors
10	Githaiga[45] (Kenya)	To interrogates the complexities of the family cancer caregiver role in the context within the framework of the model of palliative care in sub-Saharan Africa.	**Study design:** A qualitative interpretive phenomenology **Setting**: Urban Nairobi Hospice	**Sample size**: $N = 20$ **Mean age**: Not stated	**Data collection:** Individual semi-structured in-depth interviews and Focused group. **Analysis**: Interpretive analysis	Narratives portrayed caregiving as a gendered role ascribed to women and as a service rendered on the basis of familial loyalty. Women family cancer caregivers took on non-traditional roles such as single-parenting and full-time professions. Beyond the tension of competing roles, role reluctance is of particular interest in this cultural set-up where caregiving is linked with gender and kinship expectations. Some participants were coerced into their caregiving roles. Reluctance to care for ill family members is likely to be perceived as socially and culturally objectionable behaviour.
11	Githaiga[43] (Kenya)	To describe the lived experiences of women caring for a family cancer patient at home.	**Study design:** A qualitative interpretive phenomenology **Setting**: Urban Nairobi Hospice	**Sample size**: $N = 20$ **Mean age**: Not stated	**Data collection:** Individual semi-structured in-depth interviews and Focused group. **Analysis**: Interpretive phenomenology analysis	Caring for ill parents was motivated by a sense of obligation to reciprocate parental care. It was seen as a moral responsibility for children to care for their ill health parents. Married women who housed ill family members from their families of origin in their marital homes experienced role-related tension. Some took on their caring roles fully aware that they were breaching traditions.
12	Abate et al.[53] (Ethiopia)	To explore barriers to the continuum of palliative care from facility to household for cancer patients in Addis Ababa	**Study Design:** Explorative deductive qualitative approach **Setting**: Households within the Community in Addis Ababa.	Sample size: $N = 25$ **Male/Female**: 15/10 Age: 40	Data collection: Face-to-face individual interviews Analysis: Thematic analysis guided by Tanahashi's framework	The key barriers to continuity of palliative care included opioid scarcity and turnover and shortage of healthcare workers. A shortfall of diagnostic materials, cost of medications, lack of government backing, and home-based center's enrollment capacity hampered accessibility. Care providers were instruments of cultural barriers in delivering appropriate end-of-life care, on the other hand, patients' preference for conventional medicine hindered acceptability. Lack of community volunteers, failure of health extension workers to link patients, and spatial limits fraught utilization
13	Githaiga and Swartz[44] (Kenya)	To examine the content and contexts of family end-of-life conversations and decisions based on the retrospective accounts of bereaved women family cancer caregivers	**Design:** Interpretative phenomenological analysis **Setting:** Nairobi Community (Family carers)	**Sample size**: 13 **Male/Female**: 0/13 **Mean age**: Not stated	**Data collection:** Focused group discussion **Data analysis**: Interpretative phenomenological analysis	Two themes featured in focus group discussions amongst bereaved family caregivers: advance directives as indicators of preparedness for death (or lack thereof) and who initiates end-of-life conversations. Sometimes end-of-life conversations generated misunderstanding amongst patients and family members: (a) in home settings, when there were conflicts around emotional and psychological readiness for 'death talk' at a more pragmatic level versus cultural beliefs rendering such conversations taboo (b) in health-care settings where there appeared to be inconsistencies in how healthcare personnel supported families of dying patients.

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Table 2
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S. No	Study Reference and Country	Aim(s) of Study	Study Design/Setting/ Sampling Strategy	Participants Characteristics. Sample Size Male/Female Mean or average age of included participants	Data collection and Analysis	Summary of key Findings Reported by the Authors
14	Githaiga[42] (Kenya)	To explore therapeutic pluralism as a reclaiming of lay agency in the context of late-stage cancer diagnoses drawing from experiential narratives of women family cancer caregivers	**Design:** Interpretive phenomenology approach **Setting:** Urban Nairobi	**Sample size**: $N = 20$ **Female/male**: 0/20 Mean age: Not stated	**Data collection:** Individual Semi-structured in-depth interviews and focused groups **Data analysis:** Interpretive phenomenological analysis	Findings show that therapeutic pluralism was largely collective – (family and community focused), rather than individual – (primary caregiver or patient) focused. Decisions on therapy choices were influenced by socio-cultural understandings of cancer propagated informally through family and community networks. Therapeutic pluralism in this context marks a reclaiming of agency as lay caregivers, family and community members collectively got involved in caring for ill members by sourcing for available therapeutic resources.
15	Agom et al.[54] (Nigeria)	To explore how cancer patients and family members and healthcare professionals construct meaning of cancer illness and its impact on the palliative care provision and usability.	**Design:** Exploratory ethnographic approach **Setting:** University of Nigeria Teaching Hospital in South-Eastern Nigeria	**Sample size**: $N = 39$ (10 family members) **Female/male**: not stated Mean age: Not stated	**Data collection:** participant observation, informal conversations, individual semi-structured in-depth interviews **Data analysis:** Spradley's ethnographic data analysis framework (Spradley, 2016)	The general cultural belief about spiritual causality of cancer; and The impact of these cultural beliefs on palliative care utilisation.

Table 3

Participants’ Quotes Supporting Findings from the Synthesis

Analytical Theme	Descriptive Theme	Participants’ Quotes
Motivations for Caregiving	Internal motivations for caregiving	*It [caregiving] just grows on you. I think it just grows on you. Somewhere, somehow, we must have picked it from our mothers [] I think women in their nature are just, are more caring; more feeling [] I think it comes from the fact that we care for our children right from when they are young”* (Githaiga, 2015).
		“You know women, I think, are made to care. When you’re not caring for your children then you now have all the time to care for your husband and he got very good attention because I would care for him all the time [laughs]” (Githaiga, 2015).
	Caregiving inspired by culture and tradition	*“considering the obligation towards my wife in situations like this. . . There is nothing to do than to accept the situation and support my wife and ensure the wellbeing of our children”* (Boamah Mensah et al., 2021).
		“You know there is one thing: on our wedding day, we said this- in the day of trouble I will look after him, I’ll be with him. Now this time if I leave him on the day he’s in trouble, really, do I fulfill the word of God? So I will just stay and serve him until the last day” (Too et al., 2023).
		“I am a woman and her mother and it is my cultural duty to take care of her. As our culture demands, I have to take care of her. It is just my duty as her (patient) family member” (Kusi et al., 2020).
		“Hmmm..! As the eldest daughter, it is my cultural duty to take care of her. I have no other option than to take care of her” (Kusi et al., 2020).
		“The love, commitments and our memories have helped me to deal with the situation” (Boamah Mensah et al., 2021).
		“Oh! She is my wife. . . if I don’t take care for her, who will? It is just my social obligation as a husband to take care of her” (Kusi et al., 2020).
		“She is my mother, my family. . . it is actually my socio-cultural responsibility to take care of her. . . That is the reason I am the one taking care of her” (Kusi et al., 2020).
	Caring inspired by a sense of reciprocity	*“I am the last born in a family of 10 . . . I have sisters, I have brothers but they can’t help . . . I feel happy coz whatever he [father] did for me when I was small he can see me repay – he can see it repay for him. He can see the need of [value of] having a child. Right now if he did not have me, tell me, who would have cared for him?”* (Githaiga, 2017b).
		“We want to show him love and support by giving back what he did for us when we were young and fragile” (Salifu et al., 2021).
		“I have no problem with taking care of him because this man has really been there for me. Personally, my husband died when I was still young. He has been the one taking care of my children and me...Even giving them school fees. I don’t see any other way I can repay him” (Najjuka et al., 2023).
		“We are also men; a similar thing (prostate cancer) might happen to us. You can’t tell what will happen. Can you?” (Salifu et al., 2021).
		“Caring about others is important because we are all prone to vulnerability and you can’t know what might happen tomorrow” (Najjuka et al., 2023).
		“I feel it is my responsibility to look after him [father] now that he is unwell. After all he’s looked after me from when I was a child. If I don’t give back now when he cannot look after himself, [pause] what kind of a child am I being? . . . it’s our responsibility as children to give back to them . . . I’m actually number five out of six [siblings]” (Githaiga, 2017b).
		“He (dad) has done a lot for the family and me. Everyone knows what my dad has done for us growing up” (Salifu et al., 2021).
Roles of Informal Caregivers	Administration of medications, pain and symptom management	*“When we have been told to buy drugs, which are not inside here [UCI], it’s me who moves out to buy the drugs for him”* (Najjuka et al., 2023).
		“*Whenever she is feeling pain I will ask her what is wrong with you she will tell me she is feeling pain, then I will ask her to take drugs so that the pain will come down. Sometimes she will tell me that no, I will still plead with her that she should take the drugs, she will take the drugs, sometimes she will be vomiting, I will still run to her, give her water I will be telling her sorry, sorry so that she will feel better and be happy”* (Adejoh et al., 2021).
		“Per the doctor’s instruction, she was supposed to take 100 mg *tramadol two times daily and 1 gram paracetamol three times daily. But the pain was still unbearable so I had to give her more than the prescribed medicine. Now, I give her 200mg tramadol to relieve her pain and also help her to sleep”* (Kusi et al., 2020).
		“One tablespoon (10mg) Morphine three times daily is what they (doctors) prescribed for her. But, normally, she complains of pain in the breast. The breast is ulcerated so she really feels the pain. So I administer two tablespoons (20mg) to her in the house anytime she complains of pain. I don’t stick to the prescribed dosage because it just couldn’t relieve her pain” (Kusi et al., 2020).
		“Where we were staying, we had no fan. So whenever she cried and complained of pain, I fan her to reduce the pain and further promote her comfort” (Kusi et al., 2020).
		“Due to this, I do not administer the drug daily per the prescription . . . I administer the drug to her when the pain is too much” (Kusi et al., 2020).
		“You know, it’s hard. After giving all the medicines to him, and he still complains of pain” (Salifu et al., 2021).
		“Sometimes when she complains of pain, I intentionally play her favorite program on TV for her to watch and it really helps to take her mind off the pain” (Kusi et al., 2020).
		“We had a family meeting on Sunday . . . my brother Sempo met with a woman who had supposedly gone to Dr Tiba [a renowned herbalist] and been cured of cancer. So we ended up going to see him and he said all the things my mum wanted to hear: ‘No, you don’t need surgery . . . God will heal you and we believe in God. Cancer is curable. The West doesn’t tell you that. I have the cure and you do not need surgery . . . ’. He gave my mum eleven medicines that were worth 100,000 Kenyan Shillings [approximately $1,000] per week and we were in shock; but he sold it so well that everybody latched onto it for 4–5 months!” (Githaiga, 2017a).
		“Witchcraft is prohibited in our religion [Islam] . . . but if you are sick and hospitalized and the illness is indigenous, the one that requires traditional medication, that is allowed . . . I talked with . . . a friend of mine . . . she used to sell herbal medicine. I asked her, ‘Would you have cancer medicine?’ She told me, ‘Ah, if it’s cancer, there’s another place called Hospice. I can take you there and you can get help for your sister’.. . . ” (Githaiga, 2017a).
		“*Her arm was always swollen and I sent her to an herbalist who put some herbs in a horn and blew it on the swollen arm”* (Kusi et al., 2020).
		“. . .After I give him his medication” (Najjuka et al., 2023).
		“Mostly, when I give her the morphine, she becomes relaxed and sleeps. . ..” (Biney et al., 2024).
		“Because I have to know the time for his medication and be present then. . . ” (Too et al., 2023).
		“I always make sure that I communicate with her and encourage her to forget about the breast cancer so that she can be happy all the time” (Kusi et al., 2020).

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Table 3
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Analytical Theme	Descriptive Theme	Participants' Quotes
		"I also chat with her and try to recollect some of our childhood memories, the doctor said that can help my sister and it helps me as well. So normally chatting with her this way helps me a lot and I forget that she is even sick at times. When I am happy, I like to tell stories" (Biney et al., 2024).
		"In about three months the cancer had spread to her lungs . . . then, um, so chemo is failing; so what do most people do? They go for some herbal [sounds of agreement from participants] treatment" (Githaiga, 2017a).
		"I sent her to an herbal center at Asokwa" (Kusi et al., 2020).
		"We thought that the immediate solution was to go to another country so that we can get the first treatment. Until when my father decided to wait, we were planning to go to Kenya for an urgent solution" (Najjuka et al., 2023).
		"We got some herbal medicines from a woman who is known to be an expert in that field" (Salifu et al., 2021).
	Physical hands-on care	*"I had to cover him with a lesso[cotton cloth] then tell my son, 'go remove for me the trousers, get this warm water and do like this'. I [gave] him some gloves . . . so he did it for me and then I took the clothes, washed [them], changed the bedding"* (Githaiga, 2017b).
		"I fetch and boil water for her every day. I also groom her every day because she becomes very weak whenever she goes for therapy (chemotherapy)" (Kusi et al., 2020).
		"Early in the morning, when Mzei [my father] has woken up, . . .I clean him in the mouth and then the body, and because he cannot move out, I dress him from here, so I have to remove the pumpers and change him into clean ones. Now when he is clean, I lay the bed . . .silence. . . after that, I then start to look for what to feed him, ... I feed him. Sometimes I massage him to make him feel relaxed" (Najjuka et al., 2023).
		"She just has different issues, for example, if she needs to relieve herself, I take her to the toilet, she just goes there and sits. When she is done, I go for her . . ." (Too et al., 2023).
		"I have no maid, I don't have any money to employ one. . .. I cook for her; I boil for her drinking water . . .. I do her laundry" (Too et al., 2023).
		". . .coz he'd soil his bed, and I know he'd feel very embarrassed about it so I'd have to wash his bed sheets every day and wash his underpants . . . and I'd have to go [do it] quietly" (Githaiga, 2017b).
		"She cannot wash her dirty cloths because her hand is always swollen and heavy (lymphedema). So, I am the one who does all her laundry" (Kusi et al., 2020).
		"I wake up, if he wants to eat, I get him breakfast, then I see what he wants to eat for lunch. Sometimes I prepare juice. I wash, I bathe him when he is weak, when he is unable to move, and we use a bucket" (Najjuka et al., 2023).
		"There was a time he could not turn himself on the bed. You are the one to turn him" (Too et al., 2023).
		"I take care of her. . . just like I went to the store to help her there, then after I come back from the store I still help her at home" (Adejoh et al., 2021).
		"I need to assist her bath, tidy up the house, cook, and prepare the children for school before I can go to work" (Boamah Mensah et al., 2021).
	Psychosocial care provision	*"I told him there is a God in heaven who will help you"* (Too et al., 2023).
		"Although I worry a lot about her condition every day, I try to be cheerful when I am with her. I get time to listen to her and console her when she is lonely" (Kusi et al., 2020).
		"So you see I'd rather stay here helping him until he gets well" (Too et al., 2023).
		"There is a day she said she was about to die, I told her that she will not die but that will live and take care of her children . . .." (Too et al., 2023).
		"My husband is very particular about his physical appearance and the clothes he wears. As a man, one needs to look strong and healthy. His cancer treatment plus the disease has resulted in excessive weight loss. He is worried about the weight loss and his social status, but I reassured him" (Salifu et al., 2023).
		"I always make sure that I communicate with her and encourage her to forget about the breast cancer so that she can be happy all the time" (Kusi et al., 2020).
		"I will be telling her sorry, sorry so that she will feel better and be happy" (Adejoh et al., 2021).

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Analytical Theme	Descriptive Theme	Participants' Quotes
	Spiritual care provision	*"Considering the places my sister has gone for treatment, but her case was not healed whereas other people with similar cases were healed, I, therefore, believed it is a spiritual problem"* (Agom et al., 2019).
		"We have tried medical but "it is not working." I requested for discharge because we need to go make a sacrifice to appease the gods" (Agom et al., 2019).
		"I told him there is a God in heaven who will help you" (Too et al., 2023).
		"I still pray for her to get well, so that she can bring up her children because I cannot bring up her children the way she would have. . . It's better for her to stay here with us as long as we are able to see her, even if she remains weak. . . I want her to recover…" (Too et al., 2023).
		"Now she (patient) does not cry anymore because I always encourage her that God is on the throne and that He will heal her. I pray and share God's words with her. These have really increased her faith in God" (Kusi et al., 2020).
		"My pastor's wife is always calling to encourage me and pray with me as well, and I'm grateful for that. Even though it's hard to know your mother is dying, I think it's better than not knowing. My pastor's wife told some of the prayer warriors in our church to check up on me and to call me to pray with me always" (Biney et al., 2024).
		"Like I said earlier, our doctor at the hospital is also our pastor at church, he has been supporting us. . . he helps in prayers, he has informed the church about it and requested they pray for me and my husband all the time. The financial support is coming from the pastor and the church as well" (Biney et al., 2024).
		*"Every Friday evening, our Imam visits us at home to offer prayers for me and my sister. Sometimes he recites the Quran, and other times when he is unable to come, he sends a representative to come to us on his behalf. His representative will always encourage me that Allah is in this, so I shouldn't worry (*she burst into tears and smiled a little after*) At times, some of the believers come to see us when we are home, especially on Fridays, to encourage us"* (Biney et al., 2024).
		"*Our landlord is a witch. She even killed her own sisters with cancer and caused this breast lump to my sister*" (Agom et al., 2019).
		"I just pray that God my heal her so that she may raise her children" (Too et al., 2023).
		"I pray for her and share healing messages in the Bible with her. This has really helped her to have some inner peace now" (Kusi et al., 2020).
		"let us pray he shall be delivered'. We pray then we take him to the hospital because God helps those who are in hospital rather than those who are at home. He'll heal him when he is in hospital. So I took him and brought him here [Nairobi] to Simba Hospital" (Githaiga, 2017a).
		"My only hope is for God to answer my prayers. Every day I fast for my son and I pray every morning and night time. I pray for him. I say. . .(God it is you to heal my child because you are the most doctor, you are one that created him) and I pray for him like that" (Najjuka et al., 2023).
		". . . the chief Imam in our community organizes regular prayer sessions for my father in our house whenever he is called upon" (Biney et al., 2024).
		"Our pastor and the church do visit and pray with us and also share the word of God with the family which is helping us to cope with the situation" (Boamah Mensah et al., 2021).
		"I asked my pastor to pray with me because it is hard to pray when you are in that situation; all you see is a dark cloud. It is also important to have someone to support you spiritually, who will constantly remind you about God and remind you that he can see your situation" (Ketlogetswe et al., 2022).
		". . . I have family members, church members and friends who are helping me. Church members have come home, like three or four times. They come as a group, and they sit with us, whatever they have, they give it to us" (Najjuka et al., 2023).
		"the church members come to pray for her, and tell her that she will recover" (Too et al., 2023).
	Coordinating roles	*"After the first cycle of chemotherapy, they told us she will vomit and also have diarrhea. But the vomiting was too much for three consecutive days. So, I called the doctor and told him about it and he said it is the side effect of the chemotherapy. But I told the doctor that the vomiting was too much. So, he told us to send her to the nearest hospital"* (Kusi et al., 2020).
		"One of the major activities I do are: to move Mzei around, if he is supposed to go to another ward, or at the OPD, I have to take him on a wheel chair and I move him around. When it is time for waiting for results, I have to make sure that I keep around to get the results. When we have been told to buy drugs, which are not inside here [UCI], it's me who moves out to buy the drugs for him" (Najjuka et al., 2023).
		"My day is organized depending on doctors' ward round schedule because very early in the morning they ask me how he is and how he slept, and I tell them what has happened and they note it" (Najjuka et al., 2023).
		"I don't know whether it was because of the drugs she was taking. She was always complaining "my stomach, my stomach". When she complains of the stomach pains, she usually feels like vomiting so I called the doctor and told him about what was happening" (Kusi et al., 2020).
		"…. I made a decision after two months in the clinic with no change. . . I said . . . let me look for another way forward. Then I went to the hospital and found a senior doctor, he examined the swelling and then used an Ultrasound scan. He later told me that I needed to come to national referral hospital for further management and I decided to bring my child to this hospital" (Najjuka et al., 2023).
		"I always remind the church leaders every month about the Holy Communion. I make sure that they always bring her bread and wine in the house" (Kusi et al., 2020).
		"Sometimes, I arrange pastoral visits for her. The Osofo (Reverend) comes in to pray with her" (Kusi et al., 2020).

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Analytical Theme	Descriptive Theme	Participants' Quotes
Challenges and Barriers of Informal Caregiving	Financial constraints and employment challenges	*"In the hospital, many of the drugs are not covered by insurance and as the man of the house, it is my duty to pay for the treatment of my wife, children school fees and other family bills"* (Boamah Mensah et al., 2021).
		"The treatment is capital intensive, money is a challenge and the insurance system is not working as perceived" (Boamah Mensah et al., 2021)."
		"My wife's situation has brought great financial difficulty" (Boamah Mensah et al., 2021).
		"At the hospital, all the little money on me has been spent on her treatment because the NHIS covers only the folder and some of the infusions but all the other medications, I have to buy them" (Kusi et al., 2020).
		"I have borrowed a lot of money and now, I don't know how I can pay my creditors. As I am talking to you now, I owe people up to the tune of GH¢ 20,000.00 (USD ≈ 3700.00)" (Boamah Mensah et al., 2021).
		"We didn't have that 12 000 [Kenyan Shillings − $120] [for surgery] and we have no way/means of getting it . . ." (Githaiga, 2017a).
		"We are very poor and now it is worse. I had to stop working to take care of her, no one could do it and I obviously had no money to pay a caregiver. . ." (Ketlogetswe et al., 2022).
		"The National Health Insurance Scheme (NHIS) does not cover all the cost of the treatment. So, the little I get, I spend it all on my mother's drugs and living expenses" (Kusi et al., 2020).
		"I was working but now, ever since my mother fell sick, I am not working. At my work place they used to give me some days off but my return days would coincide with patient's review dates. And my mother could not go for review alone, so I got confused of what to do. I decided to leave the job and take care of my mother, my patient" (Adejoh et al., 2021).
		"Because of this, I have become slow in my business. I don't take a lot of orders. At first, I was taking the orders and allowing the girls who work for me to take over, but they were spoiling it for me, so now I take only small orders, which is not very helpful because now I'm losing a lot of money" (Biney et al., 2024).
		"I used to gain some small funds from playing the keyboard at church and other functions, but currently, I don't have such opportunities anymore" (Biney et al., 2024).
		"Because of my wife's condition, at times I don't go to work at all, the time involved in her care sometimes cause my absence at the workplace. I am not able to meet my deadlines. I have received a lot of warnings and query letters from my boss" (Boamah Mensah et al., 2021).
		"I have not been able to sew and sell clothes since his condition became worse. I earn a living through this business, but now. . ." (Ketlogetswe et al., 2022).
		"My farm is just bare, yes even here there's one of my own that is not ploughed, because of the work of taking care of him. …. I even had a hotel I was operating, hotel business is good, but I had to stop it" (Too et al., 2023).
		"Mum had a plot of land, we sold it; it is what has been keeping us here all this time" (Najjuka et al., 2023).
		"Sometimes we have to sell some sheep to get money for the medicine. … My grandmother and I are even so scared that this place may one day be auctioned. ….Grandma has borrowed a lot of loans" (Too et al., 2023).
		"The children, in fact, I have to withdraw the children from private school. They all going to public school just to in fact just to give myself little degree of mouth. (. . .)" ((Adejoh et al., 2021).
		". . .as I mentioned earlier, I had to close my shop, stop selling the "kente" and stay home to take care of my mother-in-law. Salesgirls are not trustworthy lately" (Biney et al., 2024).
	Challenges Faced with Formalized Palliative Care System	*"I think that is why there is a long waiting time"* (Abate et al., 2023).
		"There are people I know that died while waiting to be called at the hospital" (Abate et al., 2023).
		"Because we sleep outside, something dangerous can come, I fear snakes so when am outside I fear. . . because somebody can even use a stone to hit me" (Najjuka et al., 2023).
		". . .because at times, these people, there are services they need and hospice cannot give. . . there are medicines they need that hospice do not have" (Adejoh et al., 2021).
		"Is not that easy because once you are trying to share anything with them they are either walking away or attending to someone telling you to hold on, at last they won't later have that time again, they will say they are in hurry or going to somewhere else, that so, there are so many times, they are so many attempts are being made even if you are trying to see them self in their various offices they might say they have somewhere to go, they have a meeting to attend to, I have something to attend to, so it has not been easy" (Adejoh et al., 2021).
		"I think it is good if hospitals like TASH and Minilk give this service, there is a shortage of health care providers like doctors it is hard to have 2−3 doctors for all these patients" (Abate et al., 2023).
		"Yes, we take a lot of time seated in the sitting room, then you wait for the receptionists to call you and you go through the process you end up to leave late" (Adejoh et al., 2021).
		"At booking, the waiting period is too long for the sick person, you find someone is so sick but they are giving him a long period of time to come in order to make a treatment plan. If you go up for booking to see a senior health professional, it can take you like three months before you see them" (Najjuka et al., 2023).
		"Sometimes it's a bit difficult to get medicine, like this called Bicalutamide is hard to get it. There is no place to get it here in the rural areas, so we have to go to Nairobi to get it" (Too et al., 2023).
		"Ah! There were so many doctors. One day one doctor said this, the other doctor said that . . . so it was just like, ah! What have they said now, you know, what are they saying? And then all that time us guys were thinking coz of all the chemo, we were thinking that it's treatment. But then it turned out the doctors had already said that there was no treatment . . . 'Are you a doctor?'" (Githaiga, 2017a).
		"It depends on the two parties say the doctor or. . . the patient may be a Lugbara [one of the tribes in Uganda], they don't know English and the doctor doesn't know Lugbara so there is language barrier. One explains things the other doesn't understand; so you need an interpreter. . . yes" (Adejoh et al., 2021).

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Analytical Theme	Descriptive Theme	Participants' Quotes
	Barriers to Accessing Formalized Palliative Care	"*. . ..* Ahhh maybe there are times when you don't have that money that they ask for to get [stoma] bags. The contribution. . . because there is a fee that you have to pay to get the bags. You just forego and you wait until you get that money and then you go. . . like, you can't do without the bags it's a daily thing so we need them, if they are finished you really need them as soon as possible" (Adejoh et al., 2021). "Well, we've been given appointments so we could follow the appointments, but sometimes we fail to fulfil the appointments due to sometimes transport, and at times when we see there is really no necessity. if he has no... like, too much pain, or the condition is not bad, at times we find that we have to miss the appointment" (Adejoh et al., 2021). *"The transport is difficult because we use public transport; we use a taxi from the village to this side [UCI]. Transport fee is too much"* (Najjuka et al., 2023). *"Because you see when we are using a matatu (public means) it stops at all stages and it makes her very dizzy and uncomfortable. . .. And we cant afford a private care"* (Too et al., 2023). "Another issue would be time. More especially when you are supposed to go, you are supposed to travel to hospice, you know you have also work to do. Now at times you try to manage time, and then say, maybe you are employed, then your employers need you at a certain time, and then hospice, by the time you will be leaving your work hospice will be closed" (Adejoh et al., 2021). *". . .it is very expensive, because the distance is very far"* (Adejoh et al., 2021). *"the roads are very bad, and also during the rainy season the roads get flooded and the vehicles can't pass. . ."* (Adejoh et al., 2021). *"the taxi passes on a bad road"* (Najjuka et al., 2023). *"The road is not good for cars to pass through. So she uses a motorbike up to where the car is, and the journey is usually difficult for her"* (Too et al., 2023).
	Breach of Privacy and Theft of Valuables	*". . .unfortunately, on the 15th when the CT scan was supposed to be done at the emergency department, early in the morning, my bag which had my property and the personal file which contained the appointment letter to do the CT scan and to meet the doctor was stolen, so meaning that I had to start tracing the file, which meant scheduling another appointment"* (Najjuka et al., 2023). *"The other thing is that because she's sick, I'm not able to spend as much time with her alone as I used to. There's always somebody in the background; someone who's come to visit – always people. Yeah. So that's been a little hard in the sense that I am there more often but the time is not really quality time as such. Yeah coz you know the African thing – when you're sick people really want to visit you. And I guess especially when it's this kind of sickness which people tend to know is terminal, they want to do their bit. I used to drop hints: 'Don't you get tired? Visitors every day? Isn't it expensive?'"* (Githaiga, 2015). *"Even the extended family like aunts, I mean you go and find the house is full of guys. Aunts from all over the place have come [] buzzing around like I don't know what to call them [] then you're like 'who the hell are you anyway?' [] You feel like kicking them out – you want to shout 'get out!' then lock the door and lock the gate but you can't. You just feel bad because they're there. You can't get to them [ill loved one] personally – there's always somebody around"* (Githaiga, 2015). *"When we were at the hospital, we were robbed. A bag with our money, phones, and medical cards was stolen"* (Najjuka et al., 2023). *"All these people who come from left, right and center; and you feel that these people have robbed you out of your parent completely. I don't recall a day when I had a one- on -one with my fathe r or my siblings for that matter because there were always all these people coming"* (Githaiga, 2015).
	The Hurdles of Culture and Tradition	*"I'm not supposed to see the nakedness of my father as a daughter. Yes. So now I had a lot of problems because 'who will it do it for me?' 'Who will do it for me?' [Silence] and my son is small – he's seven years. He can't do it for the grandfather. But there was no choice. I had to cover him with a lesso[cotton cloth] then tell my son, 'go remove for me the trousers, get this warm water and do like this'. I [gave] him some gloves . . . so he did it for me and then I took the clothes, washed [them], changed the bedding"* (Githaiga, 2017b). *"And there're things which I think children should not do for mothers; it is seeing their nakedness but we had to . . . can you imagine holding your mother's leg wide open so that the nurse can put in the catheter? . . . You can see she's resisting from body language [silence] but there you are. Either that or you do the diapers but it's still not good to put a diaper on your mother. It was ai! Aa, I cannot understand this disease. It just turns everything that you know upside down"* (Githaiga, 2017b). "Bathing my mother bothers me, but she is my mother. My culture does not allow bathing a parent, it is even worse if it is an opposite sex but for a girl it is somehow acceptable. In our case even if I were a boy, I would still do it" (Najjuka et al., 2023). *"By the way it is taboo for us Kikuyu women to see your father's nakedness . . . he's supposed to be under my brothers' care. Because if he's in a situation like that [incontinence] they are the ones who are supposed to take care of him . . . coz he'd soil his bed, and I know he'd feel very embarrassed about it so I'd have to wash his bed sheets every day and wash his underpants . . . and I'd have to go [do it] quietly"* (Githaiga, 2017b).
Quality of Informal Caregiving	Lack of training and preparation	*"You see my sisters, they are far away. You know I cannot always rely on them. . .. and at other times I do not know what to do. . .. I haven't been taught how to care for him, but I just look and try and see what's the best thing"* (Too et al., 2023). *"The health professionals gave me words of encouragement and education on breast cancer. They calmed me down. . ., they are professionals. I feel in control because of this support"* (Boamah Mensah et al., 2021). *"I have not gotten any training to take care of her. It just comes from my willingness"* (Too et al., 2023). *"It is not easy managing her wound and pain at home. I had no skills for this care"* (Boamah Mensah et al., 2021). *It's mostly trying one thing or the other to see which one works best. We do 'trial and error' most times honestly. We are on our own when we are at home. Healthcare is not my field of training; mine is in accounting, and I don't know how to nurse big wounds"* (Salifu et al., 2021).

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Analytical Theme	Descriptive Theme	Participants' Quotes
		"To be honest I cannot say I have been doing a great job of caring for my father, I cannot even take care of myself now…it is just a trial-and-error situation. It feels like I am not doing enough" (Ketlogetswe et al., 2022).
		"I was scared she might die while sleeping. For this reason, I didn't give her the morphine. I waited for my husband and pretended to have forgotten so he would remind me. If anything happens to this woman with me alone in the house, I won't know how to handle or explain it to them (husband's family)" (Biney et al., 2024)
		"I told the sister [nurse] I wanted to stay on for the night. And I knew they allowed people because there were other patients that were allowed to have a close member of the family with them when they became very sick, and she was adamant; she refused [emphatic] [] maybe she, they knew he was going and I felt very [emphatic] bad because they refused to allow me to, and then because they called me at 3.00 a.m. [Silence] to tell me that he had passed on at 1.00a.m., could I go to the hospital and I said 'no, I'll come in the morning'. I mean, I couldn't even drive" (Githaiga and Swartz, 2017).
		"The nurses help me a lot. They ask me sometimes if I need any help. I should feel free to inform them. All this depends on the good ones on duty (she burst into laughter slightly)" (Biney et al., 2024).
		"I like the way they attended to me when they realized I was not comfortable; they took time in the consulting room to counsel me and taught me how to clean and dress the wound at home using normal saline and home-made Metronidazole (Flagyl) cream. It would have been difficult to cope with the situation had it not been their support" (Boamah Mensah et al., 2021).
	Sense of fulfilment in caregiving	*"I don't think I have been affected taking care of mum. And even though it had, I wouldn't know because I can't see or feel it"* (Too et al., 2023).
		"The small things I do for her makes me happy" (Ketlogetswe et al., 2022).
		"I don't think I have been affected taking care of mum. And even though it had, I wouldn't know because I can't see or feel it" (Too et al., 2023).
		"I normally don't sleep well, I just sleep here on the couch, so that I can be able to respond to him when he calls" (Too et al., 2023).
Burden and Price of Informal Caregiving	Biopsychosocial-spiritual burden of caregiving	*"I have been taking medicine for hypertension, but since my husband's condition changed or got worse; my BP has never dropped. I am always at 170/100* mm/Hg. *I even forget to take my medicine sometimes"* (Biney et al., 2024).
		"I am tired! I am tired. Like I said, I used to have a couple of hours of sleep when he could still sleep, but now I hardly sleep and my body has taken a lot of strain. I can feel it…" (Ketlogetswe et al., 2022).
		"I don't feel all that good because she is unwell. I feel chest pain and sometimes when I think a lot, like when you are seated and start thinking, what if my aunt dies, you are always worried. I even get headache" (Najjuka et al., 2023).
		"One time I was very sick. I was in tears; my body was weak. I had even gone to Gatundu level five, and the doctor did some tests on me. He told me that I was overwhelmed by stress and told me not to think a lot… I was just crying by myself, I couldn't cry where my kids or husband were" (Too et al., 2023).
		"We experience body pain because we sleep on the floor. The body becomes weak and tired. Because of this, one can even fall sick yet they are ideally the caretakers" (Najjuka et al., 2023).
		"Even the children were stressed from the eldest to the smallest. All of them. Even the teachers were asking me what is wrong with the children. I told them (the teachers) to let them be because they are seeing the way their father is in pain. Because they saw him vomiting after eating anything. I don't know what to do with the children" (Too et al., 2023).
		"Psychologically, I have been affected because I wonder what next. I wonder when I have gone to work and left him, will I find him? When I find him in the bedroom, I tell God thank you ….. I cannot accept to be affected physically, because I will not be able to care for him when I am affected" (Too et al., 2023).
		"I was mocked a lot by people, saying I would not succeed in fundraising money to take him to hospital. I was tolerating all these because I had hope but he had given up hope" (Too et al., 2023).
		"…as the head of the family, when you see what you are supposed to do being done by someone else, you become irritated and sometimes that person does certain things without telling you, you feel despised" (Najjuka et al., 2023).
		"Her diagnosis has placed a lot of restrictions on my social life and now even some of family members and friends are angry with me" (Boamah Mensah et al., 2021).
		"You know that we the Muslims cherish our activities such as naming ceremonies (Suuna), funerals (Adua). But now I cannot attend all these community programs because my wife needs my services at home" (Boamah Mensah et al., 2021).
		"I was very angry at God because my husband has never enjoyed his life…he did not have a life that he would have loved to have. So, I got angry. The spiritual feeling I had before faded away…" (Ketlogetswe et al., 2022).
		"Sometimes I could talk to him but he isn't talking. It was hard……" (Too et al., 2023).

(*Continued*)

Table 3

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Analytical Theme	Descriptive Theme	Participants' Quotes
		“I am unsure if I have pissed him off or something. I don't figure out why he refuses his best food. I can't tell. He might be annoyed, or he is doing that intentionally to end his life” (Salifu et al., 2021).
		“The demand has changed our relationship, life style and expectations. I sometimes feel like ending the marriage” (Boamah Mensah et al., 2021).
		“I thought of leaving her when I got discouraged. I felt it was too difficult for me alone to be caring for her and the kids” (Boamah Mensah et al., 2021).
		“I was tempted to think about the possibility of divorce” (Boamah Mensah et al., 2021).
		“Anytime there is a small quarrel, then he says I've changed my attitude because he is now impotent. No! No! Far from that. He's paranoid. I'm not the type of woman who will divorce their husband because of impotence. But there have been times I wondered whether he will ever be able to regain his erectile function. It's a pity this has happened to us” (Salifu et al., 2023).
		“Even I do not sleep in. . .. normally I sleep here on the couch so that when he calls I can hear. . . .” (Too et al., 2023).
		“I have been having severe knee discomfort, backaches, and hypertension I have not had it easy” (Biney et al., 2024).
		“I have lots of pain in my body. I can't sleep. . .I have this pain on my whole left side. . .” (Ketlogetswe et al., 2022).
		“At times if the patient is badly off, you can't sleep. Throughout the night, you may rest for only two hours” (Najjuka et al., 2023).
		“There times also when you yourself the care giver you are unwell. . .There are times when you can also be unwell and you can't, moving or travelling to the hospital you are not feeling fine” (Adejoh et al., 2021).
		*“...it's not comfortable doing that all by myself. I need to ensure that I direct the affairs relating to care to avoid confusion and all that [*addressing different duties all at the same time]. *The task is not as simple as that”* (Salifu et al., 2021).
		“For me, I serve two masters. . .. In addition to the farm work, I take care of guka (grandfather) who has cancer (prostate cancer with spine metastasis and paraplegia) and cucu (grandmother) who had a spinal cord injury and even she cannot walk” (Too et al., 2023).
		“um, who else would take care of my mum? [] the neighbours would come, especially the women: they would come in the evening and even when I wasn't there coz I was working during the day. So they'd come in the evenings at least or even afternoons, sing with my mum and then just sit with her, you know, do nice things for her yeah [] It was also stressful coz you're trying to cope with visitors and you're trying to cope with the sick person, yeah and then we lived with eh, we've always lived with relatives so that time we were living with, my cousins from my dad's side [] the girl was, I don't know, she was so unhelpful” (Githaiga, 2015).
		“...it is quite stressful; always dealing with a terminally ill person is tough for us culturally to cope with such a circumstance and discuss the end of life care” (Abate et al., 2023).
		“Sometimes I cry because of stress. . . .Not that he is sick, but I'm even stressing myself to take care of him. I am tired all the time and always feel light within myself” (Biney et al., 2024).
		“Like psychologically it has weighed him down, he tends to think almost every time whenever he is alone, he is in his room he thinks a lot that is the major reason we don't like leaving him alone because we know he will start thinking, start feeling somehow that is why we to play with him, check on him” (Adejoh et al., 2021).
		“especially, when I see my mother, who produced me and took care of me, in this very bad situation. I really feel stressed and worried” (Najjuka et al., 2023).
		“It is so difficult for me. I am anxious all the time. It is hard to let him go. I do not know how I am going to do without him. . .” (Ketlogetswe et al., 2022).
		“the stress now is you know we have been explained to that there is no treatment. She cannot be treated again. Now the stress is there because you know its any time. . .. because now if the patient is not being treated and is physically ill, what would you conclude for yourself?..... and even sometimes when she lacks sleep she tells God to come and take her now. . .. .” (Too et al., 2023).
		“It reaches a time when I feel unwell. When I see the situation that my mother passes through, when she cannot walk, there is a time when she cannot feed herself, so it has affected me so much because I feel sad.. . .” (Najjuka et al., 2023).
		“. . .least I attracts gossips and stigma. You know our society, the gossips and people's attitudes. . .” (Boamah Mensah et al., 2021).
		“I was stressed because, in Kenyatta, I was told that he would die, and even he (the patient) seemed to agree. . ..” (Too et al., 2023).
		“Of late he is not cheerful, not even a fake smile, and this makes us all sad. It's difficult seeing him this way because he wasn't like this . . . He has always been brave and endured strong emotions” (Salifu et al., 2023).
		“How will I even be respected? A married man with children without a job? How will the society even see me. . . It is not easy, hmmm. . ..” (Boamah Mensah et al., 2021).
		“I don't have time with my friends, now like this time am with her, comforting her” (Najjuka et al., 2023).
		“. . .. And you see even if it's going out, I cannot go out for long hours, Because I have to know the time for his medication and be present then” (Too et al., 2023).
		“I don't have any social life again. I'm always occupied with caring for her” (Biney et al., 2024).
		“I am not praying now as I was before, but I usually do when I am going to eat or sleep. I cannot move away from home to go to church because I cannot leave the patient, and I go for prayers. I really feel bad because I was used to going to church” (Najjuka et al., 2023).
		“I was angry with God. I really was, because you go through life believing [you can] call to God when you need help, but when you call and you really need help there is no help. . .” (Ketlogetswe et al., 2022).

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Table 3
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Analytical Theme	Descriptive Theme	Participants' Quotes
		“. . . I'm not able to go to church. I can't visit friends like I used to do. When I try to go to church and the church service is about to end, I begin to think of the problem at home. So, I prefer not to go anywhere” (Biney et al., 2024).
		“Because of her situation I must always stay home, I cannot attend family meetings although compulsory for all family members; I don't go to church any more” (Boamah Mensah et al., 2021).
		“He ‘dies’ and ‘resurrects’ most of the time. His condition has thrown us [the family] into a state of confusion. We don't know what to do” (Salifu et al., 2021).
		“When she was first told she had cancer, we were not taught what type of food to eat and what not to eat, so I was finding it difficult to cook the right food for her. I would cook two separate meals, not even knowing which one was okay for her to eat. Till now, the doctors and nurses haven't said anything. I asked some people to help me with the diet issues, so I am on it” (Biney et al., 2024).
		“I thought of leaving this marriage initially. I nearly broke our marriage vows but. . .” (Boamah Mensah et al., 2021).
		“One day, I thought of running away and leaving him there. . .I was tired of being in that situation. . . and thought running away will make me feel better. . .” (Ketlogetswe et al., 2022).
		“I feel a little bit guilty because I'm now neglecting my husband. Okay, my kids are grown up but they still need my time; but especially my husband - I feel like I spend more time and focus on my mother than on my husband . . . it just so happens that I also have a grandchild and I want to be in his life as well. So the other day he [husband] was saying ‘you know, these days your weekends are about your grandchild and about your mother and yeah, I don't know where I fit in’. So yeah, it's an issue” (Githaiga, 2017b).
		“Hmmm, sex is not my main worry now but rather how he [husband] will be healthy so that we have a happy life together. But my husband is worried! He's ashamed. Yes, I note he is unhappy about it because he asked how I feel about his situation [his inability to have sex]” (Salifu et al., 2023).
Coping Strategies of Informal Caregivers	Positive reframing	*“I have got new friends from the hospital. Also, it [caring for the patient] has united us as a family, like mum being sick has created a good relationship within the family. There are relatives from mum's side, I was telling them to come and visit us. . . . They came as a group; we were so happy as a family. It has also improved the relationship between us as the children at home because they all gather and come to take care of mum because in the past, we were distant, but it has united us as a family that makes me so happy”* (Najjuka et al., 2023).
		“. . .but overall I would say, that her illness has brought us together as a family, we are working as a team because the demands are so many, even those relatives who used not be to in touch can now call us to know about her condition, it would be harder if I was the only one doing this” (Najjuka et al., 2023).
		“I have learnt to give medicines, like sometimes when the nurse is not around and water (Intravenous drip) gets finished, I just remove it by myself” (Najjuka et al., 2023).
		“I think it changed my life because there are circumstances that come and I think, we thank God, I thank God because of an opportunity to take care for her and I thank God for probably it is not good but also good coming to hospital and interacting with other patients and also working with the doctors and nurses also seeing this as a part of life! You know when everything is comfortable you may not get to know the other part of life; what people go through. Yah, I can say it's been a blessing in disguise and also learning more about cancer” (Adejoh et al., 2021).
		“. . .There is no cure, but I am managing and adjusting to the situation. Each day that comes and passes is a blessing. Indeed, I am managing, and I don't speak to the doctors anymore because it's the same thing they will tell you every time. . .” (Biney et al., 2024).
		“I think we have bonded a lot since I spend most of the time with her” (Ketlogetswe et al., 2022).
		“I learnt how to wash wounds, to clean him in time, to change. Most especially I learnt how to perform proper wound care” (Najjuka et al., 2023).
	Avoidance and diversional therapy	*“When I'm exhausted, I'll lie down and sleep. I can choose that option. . . .I can occasionally decide to disregard work when I am drained instead of doing it, I will go to bed. I balance my options and prioritize which tasks I need to complete for my father, my family, and myself”* (Biney et al., 2024).
		“I also chat with her and try to recollect some of our childhood memories, the doctor said that can help my sister and it helps me as well. So normally chatting with her this way helps me a lot and I forget that she is even sick at times. When I am happy, I like to tell stories” (Biney et al., 2024).
		“I lie on the bed and take my mind off all these issues before I can sleep. I must relax. I need it. When I am awake, I feel so good, and I regain most of my lost energy. This is how I cope with the ones I have control over” (Biney et al., 2024).
		“I always make sure that I communicate with her and encourage her to forget about the breast cancer so that she can be happy all the time” (Kusi et al., 2020).
		“I simply return to a state of calm when this occurs. Because if I'm tired, I always tell myself to rest so that when I have rested enough, I can do the work” (Biney et al., 2024).
		“Sometimes when she complains of pain, I intentionally play her favorite program on TV for her to watch and it really helps to take her mind off the pain” (Kusi et al., 2020).
	Familial and societal support	*“My children and husband support me by attending to my father when I may be doing something. Sometimes I instruct my children to do other things, and they are always available. I have observed for some time now, they* (children) *stay at home and even ask Mummy, “Can I help you with something?””* (Biney et al., 2024).
		“My friends are very helpful; can you imagine two of my friends took loans for me to pay for my wife's' treatment? I could not have coped without this” (Boamah Mensah et al., 2021).
		“I do a lot of video calls with my wife and children when they are not around, so I keep in contact with them. My wife also calls me on a video call to encourage me that there are blessings in what I am doing. I call in to see my kids and ask if they need anything and tell them that they will see me soon and that everything will be over soon. Grandma will be fine. (Bows his head and shakes it)” (Biney et al., 2024).
		“Family members are very supportive, visiting, giving us some money and sometimes foodstuffs. We get money monthly from her elder sister who is a nurse in the UK, she is very supportive. This has helped me cope with the situation” (Boamah Mensah et al., 2021).
		“Everybody tries to participate to help me. I would not make it without my family. . .” (Ketlogetswe et al., 2022).

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Table 3
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Analytical Theme	Descriptive Theme	Participants' Quotes
	Spiritual or religious coping	*"I listen to some gospel tunes to encourage myself. My home speakers are always on because my husband loves music and so do I. I try not to keep the environment too quiet; otherwise, he starts getting angry. So, for music, it has helped a lot in this situation. . . . at times, depending on the weather and the level of pain, he demands a particular genre of music. But mostly, we listen to gospel and reggae"* (Biney et al., 2024).
		". . .but when I told my pastor's wife about it, she motivated me to go ahead and not listen to the insults. She said we all have a cross to carry. Maybe mine is like this. I should focus and keep on praying and she will remember me in prayers and inform the prayer group in the church about it" (Biney et al., 2024).
		"There is one thing that I know! God is powerful and answers prayers. It is the prayer that has helped me to accept the situation and is keeping me on. I have placed my hopes and trust in Him and I know He will heal my wife" (Boamah Mensah et al., 2021).
		"I have a closer relationship with God than before. This is because devoid of God, I would not have had this strength. God is my pillar. I have faith in him as a healer and this calms me down with peace" (Boamah Mensah et al., 2021).
		"There is one thing that I know! God is powerful and answers prayers. It is the prayer that has helped me to accept the situation and is keeping me on. I have placed my hopes and trust in Him and I know He will heal my wife" (Boamah Mensah et al., 2021).
		"I just pray to God for help with my thoughts to go away" (Too et al., 2023).
		"To get rid of all the plenty thoughts in my mind, . . . I also read the Quran and recite my tasbih. . . .Whenever I start crying then I pick up my Tasbih and start reciting" (Biney et al., 2024).
		"It's because only God gives me strength, only the higher power. No medication on earth can help. . ." (Ketlogetswe et al., 2022).
		"I am a Muslim, my trust and faith in Allah have been keeping me on. 'Issha Allah' (meaning it shall be well)" (Boamah Mensah et al., 2021).
Recommendations for Improving Caregiving		*"According to my personal observation caregivers need psychologists to talk to them because I have seen on several occasions, like yesterday when I was on the ward, a caregiver slapped a sick person due to frustration"* (Najjuka et al., 2023)
		"Uhm, it has been somehow easy, much as. . . it may be quite different because for example, at hospice, I wish they could assign only one medical personnel to a patients, because it's easy, it might be easy today I go to hospice I find maybe a male medical officer, next time see a different face and the other one will be so different face, so different faces sometimes becomes a little bit harder. Sometimes they ask what you went through, sometimes something is very distressing, for her to remember the history of the patient and all that, but it would be much better, it may be easier if a patient is assigned to one, knowing that am going to hospice, am going to find so and so" (Adejoh et al., 2021).
		". . .just the patient to be able to explain in details and their time not to be in a hurry and even if they are in a hurry to give us other time we can, we can actually reach them ok maybe, ha I am busy now I need to attend to 1 million patient, okay, but because you are, can call me at this time or you can call at this time then we will have enough time to talk to him. I think so just the patient to be able to explain in details and their time not to be in a hurry and even if they are in a hurry to give us other time we can, we can actually reach them ok maybe. . ." ((Adejoh et al., 2021).
		"I think they should focus on counselling more than anything else especially for the patients. Ah, as for the caregivers, yes, personally I'm also starting to think that. So, my mum, so, my mum, even all her other children begin to think about it but the issue. . .they are supposed to counsel the patient herself more. . . and physio [physiotherapy] could be done. A person might get to walk but it is counselling that is important" (Adejoh et al., 2021).
		"One thing that would really help me is if you had someone to talk to me, and counsel someone on how I can stay with someone who is sick, so that even if someone is overwhelmed by the disease, I can know how to handle her. That counselling would be very important" (Too et al., 2023).
		". . .how I wish all the services were within here, because now Mzei is weak, but you have to take him down, or up, he comes back with almost no energy. We were up and down, we came back on a motor cycle and Mzei almost collapsed, so how wish all these services were just within this hospital such that we don't have to move a lot of distances, sometimes you have to call for an ambulance, and the ambulance not for free" (Najjuka et al., 2023).
		"It depends on the two parties say the doctor or. . . the patient may be a Lugbara [one of the tribes in Uganda], they don't know English and the doctor doesn't know Lugbara so there is language barrier. One explains things the other doesn't understand; so you need an interpreter. . . yes" (Adejoh et al., 2021).
		"If there is any way hospice can pass through the government and there is some fund they give to, from the government to hospice, because at times, these people, there are services they need and hospice cannot give. . . there are medicines they need that hospice do not have. And these people buy them. And these people, these cancer people, it takes. . .most of them are really broke – many of them, by the time you contact, or you go to hospice, you are really broke... financially broke or bankrupt, because as I told you before, that this is a sickness which is very expensive. Sometimes, because there are drugs, medicines which they get from hospice, but not that every medicine a cancer patient needs hospice has it" (Adejoh et al., 2021).
		". . .the government can support caretakers by giving them money when a person is sick. Money for buying drugs. Like some medicine that the government can't provide, you have to buy them outside the hospital. Those ones are very expensive" (Najjuka et al., 2023).
		"If there is any way hospice can pass through the government and there is some fund they give to, from the government to hospice, because at times, these people, there are services they need and hospice cannot give. . . there are medicines they need that hospice do not have. And these people buy them. And these people, these cancer people, it takes. . .most of them are really broke – many of them, by the time you contact, or you go to hospice, you are really broke... financially broke or bankrupt, because as I told you before, that this is a sickness which is very expensive. Sometimes, because there are drugs, medicines which they get from hospice, but not that every medicine a cancer patient needs hospice has it" (Adejoh et al., 2021).

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Table 3

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Analytical Theme	Descriptive Theme	Participants’ Quotes
The Paradox of End-of-Life Preparation and Advanced Planning	Unpreparedness for end-of-life preparation and advance planning	*“. . .because my mother didn’t do that and it left us in disarray [] I think that’s very helpful because reality is reality whether you like it or not [] and I kept on telling my sisters this and actually they thought I was an enemy. At one point they just told me ‘you want your mother to die’ which is not the case [] I didn’t know the date but from my senses I could tell that this is not the road to Jahazi Town [parents’ current residence]. This is the road to Mpakani Town [rural home] where the grave was going to be put [] and this is where I really feel as a family we went wrong and we did not support my mum because we were not giving her strength to, to, to be dignified”* (Githaiga and Swartz, 2017). *“I actually remember telling my husband to write a will or to discuss with me what he wants with his, with the properties [] because my son kept on telling me ‘mum, you people have to write a will.’ And I kept on talking to my husband [silence, then lowers voice] and his mouth was tight-lipped. He wouldn’t; he wouldn’t say [] he wouldn’t say a single thing [brief silence] and in fact I, I felt like I was pressurizing him because my children were also telling me ‘talk to him, ask him [spoken in whispers but emphatic] has he got a will?’ but he wouldn’t talk [silence] he would not say a thing”* (Githaiga and Swartz, 2017). *“I was scared because I was told grandpa’s life is about to end. I just felt scared. I just felt. . . I just say like he had departed...... and he is nearing the end. . . . . . Someone once you’ve spent time with them then you are told their life is in trouble- you go into denial”* (Too et al., 2023). *“He did not believe in wills. No. He wouldn’t talk at all; he wouldn’t say. And I realized now I am pushing him or I am making him say things he doesn’t want to say because he would just keep quiet and look at me”* (Githaiga and Swartz, 2017). *“He even asked me to look for village elders so that he may talk to them about final rites but I refused. . ...he said to me “ I love you all but my life has to me to an end” but I told him there is a God in heaven who will help you”* (Too et al., 2023).
	Preparing and initiating end-of-life discussions and advanced planning	“Before he [husband] went to the hospital we sat with the family and he was telling us ‘now very soon you’re going to have one parent and it’s good you start adjusting. Mum cannot afford the rent. Now, she’s going to look for a smaller house [] And the little money which I’m going to leave will educate the ones who are in school’ [] And he said ‘Jumuia [daughter] take that book and write what I’m saying.’ [] And then after that he was saying ‘it’s not that I’m dying now, right now [] But you know my sickness; you know it’s cancer and there’s no cure’ [] I wouldn’t have managed but he really prepared us very well” (Githaiga and Swartz, 2017). “Yes, I just wanted to identify with eh, Auntie [Elimu]. For me, I think what helped us as a family is being prepared. Dad has been sick for a long time but it wasn’t until last year June that he sat us [family] down and told us ‘I want you people to walk with us this journey’. I remember sharing with a friend and I’m telling her ‘hĩĩ! The way this man has shared, it’s like he’s going to die the next minute’[] so he wrote his life story – he actually gave it to us [] and so we safeguarded the family history. He told us where he wants to be buried [] when I heard you [Baraka] talk, I was thinking your mum hid so much. She didn’t want to see you in pain and sometimes for a woman it’s harder. For a man I think he’s feeling like ‘if I leave my family like this everything will be, you know, in disarray’” (Githaiga and Swartz, 2017). “Now this is where the decision was very difficult [] I, I, signed and after the doctor had gone my daughter cried, sobbed, ‘mummy how can you do [emphasis] that? [] I wish he had told me before so that I consult the members of the family [] She was very bitter: ‘How can you do that? Sign our daddy out?’” (Githaiga and Swartz, 2017). “he [the doctor] called me and said ‘Mrs Fikira I want you to sign here. If your husband deteriorates at night I want you to give us consent that we don’t take him to ICU. If he was my father that’s what I would have done- he was a young doctor - because he is going to be on a life machine and this doesn’t help. But just tell me what you want” (Githaiga and Swartz, 2017). “He [doctor] told us ‘tomorrow, Monday, come and see me with members of the family.’ We went on a Monday. He told us ‘we have done everything and now medically we’re not doing anything; it’s only nursing care. And there’re two things – you take him home or we take care of him in hospital: which one do you choose? Many people would like to see their person go [die] at home and even when they go home sometimes they get better.’ So we chose for him to come home [] on Wednesday he came home [] Friday he went - he died peacefully” (Githaiga and Swartz, 2017). “so we were asked []‘should the heart stop what would you like us to do?’ That was the hardest question and nobody was ready to answer it so we all kept quiet. We looked at him until I realized until I said something nobody would. So I said ‘we’ll go by his [the doctor’s] word and then we went round - every member of the family said ‘we’ll do what mum has said’ [] that was on Monday night. He passed away on [] Thursday night” (Githaiga and Swartz, 2017). “. . .there is no way out. . .I think she is going to die. . .I have made peace that she is dying. . .I cannot change it. I mean you have to accept what is in the plate. . .” (Ketlogetswe et al., 2022). “sometimes I could talk to him but he isn’t talking. It was hard. . .. . . I thought he was now going” (Too et al., 2023). “. . .sometimes, too, she can squeeze my hand and tell me, “Do not be scared, my son, death is there for everyone.” Whenever she makes such comments, I feel as though she is saying her goodbye” (Biney et al., 2024).

Motivations for Caregiving

Studies reported filial piety[56] as what motivated informal caregivers to provide on-going palliative care to their loved ones albeit in challenging moments.

Internal Motivations for Caregiving. The majority of informal caregivers were women.[45,44,52,46] Providing palliative care was viewed as a natural extension of their wider caregiving roles within the family despite many women also engaging in paid employment in addition to the caregiving roles. They were motivated internally to assume caring responsibilities through heritage. They believed that the duty to care for family members lies in women right from childbirth where the mother is the main carer for the child.[45]

Caregiving Inspired by Culture and Tradition. Studies found a common cultural expectation that individuals would provide caring support to their relatives. For some, this was associated with duty and wanting to help loved ones and is strengthened by marital vows taken during marriage ceremonies.[50,48,41] Shared memories of love inspired participants to provide care for their loved ones in difficult and challenging moments.

The cultural expectation that families would provide caring support to people at their end-of-life was associated with duty bounded by parental ties and familial obligations. Taking care of parents were participants' socio-cultural responsibilities; a role they could not avoid.[50,51] Neglecting a sick relative is culturally considered inappropriate and unacceptable in several African societies and has consequences or punishment in the afterlife.

Caring Inspired by a Sense of Reciprocity. Informal caregivers were motivated and inspired to provide palliative care to their family members by a sense of duty and a wider sense of reciprocity where if the informal caregiver required help in the future, they would receive it.[49,51] For them, uncertainty and unpredictability of the future motivates them to provide care and same be reciprocated to them when needed.

Moreover, some informal caregivers were inspired by the need to reciprocate and extend good deeds and kind gestures to loved ones.[43,49] For these informal caregivers, their loved ones (patients) before ailments, were the bread winners of their families. Hence, in their ailments, the opportunity to reciprocate was essential to these informal caregivers.

Roles of Informal Caregivers

Studies reported varied roles of informal caregivers in providing palliative care to patients including medical, pain and symptom management, physical hands-on care, psychosocial care, spiritual care, and coordinating roles.

Administration of Medications, Pain and Symptom Management. Pain and symptom management formed the largest part of the caring role involving administering medications when patients' complained of pain. Sometimes, patients' complain of pain became so intense and unbearable that informal caregivers had to increase the dosages of patients' medications without doctors' approval or consultation and in addition, consoled patients.[50,55,49,51,41,46] In some instances, patients' complain of pain persisted even after the dosages of their medications had been increased. Even in the hospital setting, informal caregivers were left with responsibility for this care amidst a context of limited resources and a lack of availability of effective analgesia such as morphine in the hospital pharmacy. In consequence, informal caregivers had to purchase these limited medications outside the hospital.

Moreover, informal caregivers alleviated patients' pain through providing diversional therapies to divert patients' attention from the pains through story-telling and watching television.[50,46]

Additionally, the pain and symptom management of the caring role of informal caregivers involved dressing wounds and managing nausea, vomiting, and loss of appetite. In consequence, informal caregivers often sought alternative care through traditional medicine, which was more accessible in the communities.[42,50,49,51]

Physical Hands-On Care. Physical care entailed maintaining the personal hygiene of patients (bathing and assisting in toileting), assisting with positioning and mobility and providing nutrition. In addition, informal caregivers provided support in caring for the wider environment (housekeeping, laundry and maintaining the garden).[43,50,55,48,51,41] Sometimes, informal caregivers provided physical care amidst limited resources such as poverty; thus, informal caregivers improvised in providing palliative care to patients.[41]

Psychosocial Care Provision. Psychosocial care provided by informal caregivers to patients included being by patients' side until recovery, actively listening to patients and offering consolation and reassurance through story-telling and communication.[50,55,47,41] Informal caregivers promised not to leave patients' side until patients had recovered to mitigate patients' feelings of isolation. There were moments when patients were emotionally drained and experienced feelings of sadness and sorrow while others felt like they were dying. Informal caregivers reassured and consoled patients through words of encouragement and sometimes, reassured them of the ability of a higher power (God) to heal them.

Spiritual Care Provision. Informal caregivers provided spiritual care to support patients through praying for patients, sharing messages of hope, encouragement and inspiration from the Bible or Quran with patients.[42,50,51,47,41] This was mostly inspired by the perceived meta-physical causes of cancer.[54]

While some informal caregivers offer prayers for patients, others were exhausted by the burden of caregiving roles and were incapable of providing spiritual support to patients. Consequently, informal caregivers and patients received spiritual support from family, friends, and religious leaders and communities. Some informal caregivers reported that this gave them strength to continue their caregiving role; others appreciated the support with prayer when they themselves found it challenging but some reported a loss of faith and feelings of anger and disappointment in their God for allowing the suffering.[50,55,48,52,51,41,46]

Coordinating Roles. Informal caregivers became the liaisons between patients and healthcare professionals by reporting sudden changes in patients' health status to healthcare professionals. Additionally, informal caregivers coordinated patients' treatments and activities at the hospital including moving of patients from one ward to another ward.[50,51] Informal caregivers at home would call physicians to report unexpected changes in patients' health and transport patients to the hospital when necessary. Also, informal caregivers coordinated patients' religious or spiritual practices and activities by arranging pastoral visits and prayers.[50]

Challenges and Barriers of Informal Caregiving

Informal caregivers encountered several challenges and barriers in providing palliative care to their patients including financial constraints and employment challenges, challenges faced with formalized palliative care system, barriers to accessing formalized palliative care, breach of privacy and theft of valuables, and the hurdles of culture and tradition.

Financial Constraints and Employment Challenges. Consistent across this study was informal caregivers providing palliative care amidst limited financial resources. Most informal caregivers were grappled with financial handicap or poverty and could not afford patients' medications and treatments, hence, had to borrow money from friends and neighbours.[42,50,48,52,51,41] Those who borrowed had to auction their properties and family assets such as houses to repay their creditors. Some informal caregivers had to reduce paid employment commitments, thus, lost their employment or businesses and a reduction in their children's access to education.[45,42,55,48,52,51,41,46] Financial constraints were exacerbated by lack of insurance cover for patients' treatments and medications, hence, informal caregivers had to pay out of pocket for hospital services.

Challenges Faced with Formalized Palliative Care System. Informal caregivers encountered numerous challenges with the formal palliative care system at the hospitals including lack of space or accommodation and shelter for informal caregivers, shortage of healthcare professionals, longer waiting time, and shortage of medicines.[55,53,51,41] For some informal caregivers, engagement with healthcare professionals was limited due to lack of continuity of care, limited specialist physicians, ambiguous instructions from healthcare professionals, language barriers and a lack of interpreters to support the interaction.[42,55] It was difficult for informal caregivers to arrange and schedule one-to-one appointment with healthcare professionals for discussions.

Barriers to Accessing Formalized Palliative Care. Informal caregivers identified a number of practical barriers to accessing available formal palliative care. Poverty was a consistent challenge in accessing available care. For example, lack of mobile phones (or credit to make calls) and lack of transportation to access centralized urban services from rural areas, consistently prevented patients from accessing formal palliative care and informal caregivers from accessing information or resources to improve the effectiveness of the care they provided.[55,51,41] In addition, some informal caregivers found it difficult to be released from paid work to support patients to attend hospital appointments.[55]

Rurality in itself presented challenges as, in addition to cost, there were issues with the infrastructure or poor road networks and the ability of the patient and or informal caregiver to tolerate long journeys. Most informal caregivers and their patients live in rural areas and could not afford what formal palliative care services there is.[55,51,41] For the largely rural samples, lack of personal vehicle and funds to access transportation to attend clinic and hospital settings for clinical appointments was a challenge.

Breach of Privacy and Theft of Valuables. Studies noted support from the wider community for people with advanced cancer and informal caregivers. This included providing transport to hospital appointments and social contact in the home. However, some informal caregivers advised that visits were not always supportive as frequent visits could feel like an invasion of privacy and some feared visitors might steal from their homes.[45,51] Other informal caregivers had their valuables stolen while at the hospital. Informal caregivers felt that the intrusion of the wider family members and friends deprived them of quality time with their sick family members.

The Hurdles of Culture and Tradition. Informal caregivers provided palliative care amidst strong socio-cultural huddles and taboos. Caring for parents and being exposed to certain parts of parents' body (private parts) is deemed inappropriate and a taboo in informal caregivers' cultures and societies.[43,50,51] For instance, culture and tradition does not permit children to bath their parents.

Quality of Informal Caregiving

Informal caregivers navigated and provided palliative care with lack of training and preparation. However, there was a sense of fulfilment in the caregiving provided.

Lack of Training and Preparation. Informal caregiving to patients were suboptimal. Due to the lack of relevant skills, competency, and training in executing caregiving roles such as pain relief, medication, and symptom management and physical hands-on care were poor. Informal caregiving was largely based on "trial and error."[48,49,52,41,46]

Perceived favoritism from the healthcare providers limited the caring duties of informal caregivers at the hospital. Participants in the study by Githaiga and Swartz[44] reported denial of the opportunity of staying with their patients at near death while other family caregivers were allowed at the hospital. This left informal caregivers frustrated and felt that their informal caring roles were undervalued and inadequate by the formal palliative care team. However, some informal caregivers providing palliative care at the hospital received some form of support from healthcare professionals including pain and symptom management.[48,46]

Sense of Fulfilment in Caregiving. Notwithstanding the limited skills and competency and lack of training and preparation in providing informal palliative care, some informal caregivers felt happy and satisfied with the care they provided to their patients (family members).[48,49,52,41,46] The fact that they were able to provide care to their family members gave them a sense of fulfilment and joy in their hearts. Some informal caregivers also developed numbness to any impact of the caregiving roles on them.

Burden and Price of Informal Caregiving

Caregiving responsibilities placed significant burden on informal caregivers including biopsychosocial-spiritual burdens.

Biopsychosocial-spiritual Burden of Caregiving. The burden of caring is multidimensional with informal caregivers describing the labor of providing physical care; the workload when balancing caring with paid employment and other responsibilities; the financial burden of paying for treatment or loss of earnings associated with providing care; the emotional burden of witnessing, and being unable to relieve the suffering of the patient and the psychological burden of the imminent loss of a loved one.

For some informal caregivers, the physical aspects of care (e.g. personal care, moving and handling) were demanding and exhausting. Informal caregivers reported high levels of fatigue, discomfort, back and knee pain, insomnia, headache, and hypertension.[55,48,52,51,41,46] Balancing caring with paid employment and other responsibilities without receiving any help from other family members intensified the burden on participants' physical health.[45,49,41] Participants' felt like they were "serving two masters."

In particular, informal caregivers reported anxiety and fear about the imminent death of their loved one and failing health of their family members; they experienced heightened stress if they noted periods of breathlessness or inactivity, and were unsure of what to do.[55,48,52,53,51,41,46] In some instances, the stress extended to the children of informal caregivers. In addition, informal caregivers were unable to bear and cope with the psychological burden and stress. They reported sorrows, stigma, shame, grief, hopelessness, and uncertainties about living without the loved one which drained participants emotionally.[55,48,51,47,41]

For some informal caregivers, they reported losing their social status as "heads of their families" because they could no longer afford the cost of treatment for their wives (patients).[48,51,41,46] In a traditional patriarchal patrilineal society like Africa, men or husbands are seen as the head of the family and as such, are the bread winners of the family including paying for treatments for any family member who may be sick.

The caregiving responsibilities disrupted participants' religious or spiritual practices. Some could not pray and attend religious and social functions. Also, some informal caregivers felt that God had betrayed and paid deaf ear to their prayers by not healing their family members.[48,52,51,46] This resulted in dissonance and conflict between informal caregivers and God. Moreover, communication between informal caregivers and patients were often poor due to the deterioration in the patient's condition and the fatigue experienced by participants. This left informal caregivers confused and frustrated, exacerbated by limited education on cancer from healthcare professionals.[49,41,46]

Finally, the burden of caregiving caused some informal caregivers to contemplate divorce and abandon sick family members. For some participants, caring responsibilities for their sick family members (for instance, brothers, parents) denied them of sexual intimacy and quality time with their husbands which created tension in their homes.[43,48,52,47]

Coping Strategies of Informal Caregivers

Informal caregivers adopted varied coping mechanisms including positive reframing, avoidance and diversional therapy, family and societal support, and spiritual or religious coping.

Positive Reframing. Notwithstanding the enormity of challenges and burden experienced by informal caregivers, several of them found it refreshing and fulfilling in performing their caregiving duties. Informal caregivers learnt and acquired new skills such as wound dressing and managing patients' medications and an enhanced family bond and relationships.[55,52,51,46] Informal caregivers found value in every second and minute that passes and counted everyday as blessing.

Avoidance and Diversional Therapy. Informal caregivers adopted strategies to cope and deal with the overwhelming burden of caregiving by avoiding stressful situations or emotional triggers and used diversional therapy such as sleeping, communication with the patient and watching television.[50,46]

Familial and Societal Support. Participants received practical emotional and physical supports from family and friends through video calls and face-to-face who encouraged participants to continue in their caregiving journey.[46,51,52,48,45] Some participants received support from friends while others also receive financial support from siblings overseas.

Spiritual or Religious Coping. Participants drew from their internal spiritual or religious resources of faith and belief in a higher power (God or Allah) to cope with their caregiving burden. Others also relied on prayers and supplication to God and reading religious books such as Quran or Bible as well as listening to music, usually gospel songs to cope with caregiving burden.[46,41,52,48]

Recommendations for Improving Caregiving

There was a general lack of aspects of palliative care services and specialists such as psychologists, physiotherapists and counselling services in various palliative care centres.[41,51,55] Informal caregivers and their patients were usually referred to other hospitals for those services, incurring additional costs to participants. Therefore, availability of these services in the various hospitals and palliative care centers would enhance palliative care provision. Moreover, due to language barrier encountered, availability of interpreters would enhance communication between staff, patients, and family members.[55]

The lack of insurance package to cover cost of treatments for patients provides an avenue for governmental policies to capture the cost of cancer treatments in the health insurance packages.[51,55] This would help ease the financial burden on informal caregivers and their family members.

The Paradox of End-of-Life Preparation and Advanced Planning

This theme identified the paradox where, on one hand, informal caregivers and their loved relatives were unwilling to discuss issues of wills and death, and on the other hand, informal caregivers and their patients initiated and discussed issues of wills and advanced planning towards imminent death.

Unpreparedness for End-of-Life Preparation and Advance Planning. One aspect of palliative care is preparing the individual for death and considering legal or financial matters. Informal caregivers were unable to bear and cope with the psychological burden regarding the imminent death of their loved relatives. This became a source of discord between the patient and caregiver. Moreover, discussion of wills was perceived as wishing the sick individual dead rather than preparing for the inevitability of imminent death.[41,44] Consequently, this was rarely discussed and dying individuals were reluctant to discuss any issues about wills or to give advance directives due to their unbelief in wills.

Preparing and Initiating End-of-Life Discussions and Advanced Planning. Though difficult, some informal caregivers anticipated and were able to come to terms and made peace with the imminent death of their loved ones. Those who achieved end of life discussions received some sort of support from the formal palliative care team members and engaged the wider family members.[46,41,52,44] Informal caregivers and the wider family members were able to discuss advanced directives about the place of death of their loved ones. They preferred that their loved ones die at home instead of the hospital.

Discussion

This synthesis explored the experiences of informal caregivers in palliative care provision for persons with advanced cancer in Sub-Saharan Africa. Evidence in Sub-Saharan Africa indicates that people wish to be at home at the end of life, cared for by and with people they know.[57,22] This corroborates with the finding of this synthesis where informal caregivers preferred to provide palliative care for their loved ones at home. This is consistent worldwide among advanced cancer patients and their families' preferred wish for palliative care and death at home in a global umbrella review[59] and a global systematic review and meta-analysis[58] although significant minority prefer hospitals and hospice care settings.

A key finding from this synthesis is the willingness of informal caregivers to provide support for their loved ones, motivated by filial piety. This is mirrored in a quantitative study in the U.S.[60] and a global qualitative systematic review and meta-synthesis[61] which found that informal caregivers were inspired by filial piety to provide palliative care for their loved ones in the terminal stage of cancer illness. However, the lack of resources and support (including fundamental information about the disease, symptom management and dying) for informal caregivers creates the burden of caring, reduces the quality-of-care provision and deterioration of informal carer's health and social circumstances which is also noted in the Sub-Saharan Africa.[62,28] Musonda et al.[63] highlighted the challenges faced by informal caregivers in Zambia, particularly the lack of training and support for home-based palliative care. This issue is echoed in Effendy et al.'s[64] global scoping review. Given informal caregivers' willingness to help, supporting them may be a more feasible short-term solution than expensive formal palliative care systems. Psychosocial interventions, such as those found in Guan et al.'s[65] systematic review of Sub-Saharan Africa, offer promising strategies, though a significant gap remains in educational support for caregivers and patients.

The scarcity of specialist palliative care services in Sub-Saharan Africa is well documented.[66,67] Access is further hindered by poor infrastructure, high transportation costs, and financial barriers.[68,69] Similar challenges exist globally, especially in rural areas. Ndiok and Ncama[70] suggest that community and home-based palliative care, including telehealth, can improve access and outcomes, as demonstrated in an European, American, and Asian scoping review.[71]

Poverty remains a significant barrier to formal palliative care in Sub-Saharan Africa, where out-of-pocket costs for care are a major financial strain on patients and caregivers.[68,69,72] Limited access to medical supplies often drives caregivers to seek traditional remedies, a common response in the region.[68,73] Cultural beliefs, such as the metaphysical interpretation of cancer, and religious factors influence this reliance on traditional treatments.[74] Additionally, the potential interactions between traditional and conventional treatments need further exploration.[75,76]

The nature of physical care required by people with advanced cancer in this study is consistent with the palliative care needs of patients with other diseases such as Acquired Immune Deficiency Syndrome (AIDS).[77] Therefore, the findings from this study might be transferrable to other informal providers of end-of-life care in Sub-Saharan Africa and other low to middle-income countries. This synthesis found that provision of physical care needs at home was associated with fatigue, exhaustion, insomnia and reduced physical functioning in informal caregivers, alongside a negative impact on their emotional and psychological wellbeing, echoed in research on AIDS and cancer care in this region.[77,78]

Furthermore, this review identified the bio-psycho-social-spiritual burden of caregiving experience on informal caregivers. Whilst some informal caregivers found a source of strength and support from the community and used internal spiritual resources, others reported a loss of faith and spiritual distress. The physical, psychological, social, financial, and spiritual toll is reported in a recent systematic review of family provision of palliative care globally[79] in which strong evidence is presented for all informal caregivers to receive financial support and importantly, disease-specific information to enable them to better care for themselves and their relatives. Moreover, this is consistent with the findings of a recent meta-synthesis of spiritual care provision for advanced cancer patients in Sub-Saharan Africa[74] in which patients and family members received spiritual care and support from the religious community and at the same time, experienced spiritual distress.

Strengths and Limitations

Restricting studies to the past ten years and those studies conducted in English may have excluded some relevant studies. English Language and those published from 2013 and below, therefore, omitted studies published in other languages and after 2013 that could have added richer data and findings to the review.

Conclusion

In Sub-Saharan Africa, limited formal palliative care services and practical barriers to accessing recently developed provision mean that informal caregivers frequently assume primary responsibility for care. They take on roles spanning pain and symptom management, physical, emotional, spiritual, and financial support, often without preparation, training, or supervision. Caregiving is shaped by cultural expectations of family duty but occurs in contexts of poverty and fragile health infrastructure, exposing caregivers to financial hardship, stress, poor physical health, and spiritual distress. Despite these challenges, relatives and friends remain willing to contribute to the care of people with advanced cancer. Strengthening palliative care in Sub-Saharan Africa therefore requires investment in culturally appropriate caregiver training and support, alongside the development of formal services that recognize and complement the indispensable role of informal caregivers.

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Quality Appraisal of Studies using CASP Tool

Results of Quality Appraisal of Studies

Study Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Positive/Methodologically Sound	Negative/Relatively Poor Methodology	Unknowns
Biney et al.[46]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	There is a clear objective that matches with the methods used; Clear inclusion criteria for participants and the principle of data saturation used.	The same author conducted interviews in different languages – English, Ga and Akan. His/her background and level of proficiency in these languages have not been discussed	It remains unclear whether interviews conducted in local language were transcribed in the original language before being translated to English for analysis. The authors relationship with participants prior to research is unclear.
Salifu et al.[47]	Y	Y	Y	C	Y	C	Y	C	Y	Y	The study had a clear focus/aim and design was appropriate	Very scanty information on recruitment process, not very explicit on data analysis methods. This information perhaps is in the larger study mentioned by the author but needed to be highlighted here too.	No information provided on whether interviews conducted in the local language were transcribed in local dialect before being translated to English for analysis. No information provided on steps taken to endure credibility of the data.
Githaiga[45]	Y	Y	N	Y	Y	C	Y	N	Y	Y	There is a clear objective and recruitment strategies was robust.	The authors used interpretative phenomenological analysis (IPA), meanwhile the study framework was the African palliative HBC model. The HBC model was again used to draw their conclusions. Therefore, data analysis process could benefit more from a framework analysis guided by the HBC model.	It not known what informed the number of individual interviews and focus groups that were conducted. It is unclear how data from focus groups and individual interviews data were integrated
Githaiga[42]	Y	Y	Y	Y	Y	C	Y	C	Y	Y	Conscious effort was made to diversify participants to include current caregivers and former caregivers (those whose sick relatives are deceased).	Limited / small sample size for interviews with no justification provided. Limited information provided on how data trustworthiness was ensured	It is not known who conducted the interviews /moderated the focus group and the persons background or relationship with participants. Unclear how individual interviews and focus group data was combined.
Abate et al.[53]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	There is detail description of data collection, data saturation and translation of transcripts by experts	Accuracy of transcribed data could have been confirmed by study participants instead to ensure confirmability of data and findings.	Though there is a clear inclusion criterion, is not known how the participants were approached for inclusion – face to face, telephone calls, other?
Githaiga and Swartz[44]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	There is clear objective that matches research methods.	No description of efforts made to ensure data confirmability and trustworthiness.	It is unclear the background and training provided to the research assistant who wrote the notes during the focus group discussions.
Githaiga[43]	Y	Y	Y	Y	Y	C	Y	N	Y	Y	Clear research objective and recruitment process.	There is no mention of how data credibility/ trustworthiness or confirmability was ensured since is only one author. Not clear how data from individual interviews was integrated with the focus groups to arrive at themes.	It is unclear who moderated the focus group and how data was taken during focus group – notes making or recording or other.

(*Continued*)

Continued

Study Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Positive/Methodologically Sound	Negative/Relatively Poor Methodology	Unknowns
Adejoh et al.[55]	Y	Y	C	Y	Y	N	Y	Y	Y	Y	There was a clear statement of research question and objective as well as recruitment. Multi-country study with large sample size with clear inclusion criteria. Country selection was based on consultation with the African Palliative Care Association. Moreover, interview guide was piloted and changes made where necessary.	Although data saturation was predicted to inform sample size in each country, this was not practically done across the countries. Also, relationship between researcher and participants was not clear.	The study design used was not clear. It is unknown how participants were excluded from the study. It is not clear whether the piloted interviews were included in the analysis or not and the reason.
Boamah Mensah et al.[48]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	Exploratory qualitative study appropriate for the research question as there is not sufficient evidence on the research question in Ghana. Inclusion and exclusion criteria clearly defined. Sample size determined by data saturation. Interview guide piloted before data collection.	No relationship between researchers and participants described. It is not clear how participants were recruited.	It is not clear whether the piloted interviews were included in the analysis or not and the reason.
Ketlogetswe et al.[52]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Qualitative methodology, descriptive qualitative design, recruitment, data collection and analysis appropriate. Three authors involved in the coding of data.	Sample size determination was not justified as there was no mention of data saturation. Researcher who conducted interviews was a student nurse at the setting, hence, might have influenced participants' decision to participate.	It is not clear whether the researchers developed interview guide to guide the interviews.
Kusi et al.[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Methodology and design appropriate to answer research question. Inclusion and exclusion criteria clearly stated. Interview guide was piloted at the center of the study. Member checks conducted as transcribed interviews were sent to participants for verification. Interviews conducted in the local language were transcribed then back-back translated.	Recruitment process was not done by researchers but by nurses. This might have influenced participants' decision to participate. It is clear why the piloted interviews were included in the data for analysis.	It is not clear whether sample size was based on data saturation as it was not provided.
Najjuka et al.[51]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	Research method, design and question are appropriate and clear. Inclusion and exclusion criteria clearly stated. Sample size was determined by data saturation. Independent translator performed the back-back translation of interviews conducted in Luganda (local language)	Two days given to participants to self-determinate is short, could have been at least 72 hours. Transcripts were not returned to participants for confirmation. Researcher and participants' relationship not clear.	It is not clear whether the piloted interviews were included or excluded from the analysis.

(*Continued*)

Continued

Study Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Positive/Methodologically Sound	Negative/Relatively Poor Methodology	Unknowns
Salifu et al.[49]	Y	Y	Y	C	Y	C	Y	C	Y	Y	The study had a clear focus/ aim and design was appropriate. Study had a clear inclusion criteria. Interviews in local language verified translated transcripts.	Relationship between researcher and participants was not clearly established prior to data collection. Not very explicit on data analysis methods.	It remains unclear how researchers excluded participants from the study. It is not clear if interviews in local language were transcribed in the local language before translation.
Too et al.[41]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	Qualitative methodology appropriate to answer research question. Interpretive design appropriate for study objective. Data collection and analysis appropriate. Reflexivity, member checking, audit trails dully followed.	Relationship between researcher and participants not described. Inclusion and exclusion criteria not very explicit.	It is not clear who identified participants (whether palliative care team researchers).
Agom et al.[54]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	The use of triangulation in data collection as well as participants enhanced the credibility and transferability of the findings. Data analysis was rigorous. Prolonged engagement and persistent observation enhanced the credibility of the findings. The authors also used reflexivity in the data collection and analytical processes.	Relationship between researcher and participants are not described.	It is not clear whether sample sizes were determined by data saturation.

Key
Y – Yes; N – No; C – Can’t tell.
Q1 - Was there a clear statement of the aims of the research?
Q2 - Is a qualitative methodology appropriate?
Q3 - Was the research design appropriate to address the aims of the research?
Q4 - Was the recruitment strategy appropriate to the aims of the research?
Q5 - Was the data collected in a way that addressed the research issue?
Q6 - Has the relationship between researcher and participants been adequately considered?
Q7 - Have ethical issues been taken into consideration?
Q8 - Was the data analysis sufficiently rigorous?
Q9 - Is there a clear statement of findings?
Q10 - How valuable is the research?