Review Article

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Sociocultural Perspectives on Palliative Care Across East African Community Countries: A Narrative Review with Thematic Synthesis

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ABSTRACT

INTRODUCTION: East African Community (EAC) partner states face a dual burden of HIV/AIDS and rapidly rising non-communicable diseases (NCDs), yet access to palliative care, including basic pain relief, remains limited, and sociocultural dynamics strongly shape how such care is understood and accepted. This review synthesized the sociocultural, spiritual, and clinical palliative care needs of patients with advanced NCDs across the eight EAC partner states, and to examine how their structural support needs differ from those of people living with HIV/AIDS.

METHODS: A structured narrative synthesis was conducted. PubMed, Scopus, and Web of Science were searched using terms combining geographic and palliative care concepts; records were screened against Population–Concept–Context criteria, and 21 core publications were thematically synthesized, with detailed data extraction performed on ten primary empirical studies.

RESULTS: Three themes emerged: (1) severe, region-wide deficits in pain and symptom management compounded by restrictive opioid regulation; (2) pervasive communication taboos and prognostic silence that obstruct disclosure and future planning; and (3) the centrality of spirituality, religious networks, and indigenous belief systems, which providers are often unprepared to engage. NCD cohorts reported acute informational deficits, whereas HIV/AIDS cohorts historically reported predominantly structural and financial needs.

CONCLUSION: Culturally grounded communication strategies, spiritual-care competence, and equitable opioid access are regional priorities; localized primary research is urgently needed in Burundi, Somalia, South Sudan, and the Democratic Republic of the Congo.

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Received: February 24, 2026
Accepted: June 25, 2026
Published: June 30, 2026

Cite this article as: Ndoli et al. Sociocultural Perspectives on Palliative Care Across East African Community Countries: A Narrative Review with Thematic Synthesis. *Rw. Public Health Bul. 2026. 7 (1): 32-39.* https://dx.doi.org/10.4314/rphb.v7i2.4

INTRODUCTION

East African countries face a challenging and evolving health issue shaped by a dual disease burden: persistent communicable diseases, particularly HIV/AIDS, alongside a rapidly rising prevalence of non-communicable diseases (NCDs) such as cancer, cardiac disease, neurological disease, and more [1,2]. This growing burden places immense pressure on already constrained health systems, while rising mortality and prolonged suffering highlight the urgent need for accessible and comprehensive palliative care services [3]. Palliative care, defined by the World Health Organization as a holistic approach addressing physical, psychological,

Potential Conflicts of Interest: No potential conflicts of interest disclosed by all authors. **Academic Integrity:** All authors confirm their substantial academic contributions to development of this manuscript as defined by the International Committee of Medical Journal Editors. **Originality:** All authors confirm this manuscript as an original piece of work, and confirm that has not been published elsewhere. **Review:** All authors allow this manuscript to be peer-reviewed by independent reviewers in a double-blind review process. **Publisher:** Rwanda Health Communication Centre, KG 302st., Kigali-Rwanda. Print ISSN: 2663 - 4651; Online ISSN: 2663 - 4653. **Website:** https://rbc.gov.rw/publichealthbulletin/

social, and spiritual dimensions of suffering [1], offers a critical response to these challenges. Yet despite its recognized benefits, access to essential palliative care including basic pain relief remains limited across much of the region, contributing to substantial unmet needs among patients and families [1].

The development of palliative care across East Africa Community countries has been uneven. Uganda and Kenya stand out for their comparatively advanced palliative care systems, largely due to early and sustained engagement from non-governmental organizations responding to the HIV/AIDS epidemic [1,4,5]. These efforts helped strengthen government involvement and expand service provision over time. In contrast, many African countries continue to show minimal or no palliative care development [4,6]. As patterns of illness shift, models originally designed to meet the acute needs of HIV/AIDS patients now face pressure to adapt to the growing, diverse demands of individuals with NCDs, a transition often hindered by limited public health resources and inconsistent system-wide commitment [1].

Sociocultural dynamics play a central role in shaping how palliative care is understood, accepted, and delivered throughout the region. Spirituality, traditional belief systems, communication norms, and family structures profoundly influence patients' experiences of illness and their expectations of care. For instance, the region reflects a diverse continuum of care models, ranging from family-driven and community-supported frameworks in the Democratic Republic of Congo (DRC) to deeply complex cultural attitudes toward pain expression, fatalism, and stoicism seen in Somali communities [7,8]. Furthermore, efforts to culturally ground end-of-life care are exemplified by the integration of the Ubuntu philosophy emphasizing shared humanity and interconnectedness into structural care delivery [9]. However, when these local ways of finding meaning collide with formalized healthcare systems, mismatches occur; healthcare providers frequently express discomfort or marginalize indigenous spiritual practices (such as ancestral beliefs or witchcraft) in favor of major global religions [10].

While structural integration and rapid policy development have advanced in certain nations, severe gaps remain regarding implementation capacity, clinician preparedness, and equitable resource allocation [2,11]. Crucially, historical end-of-life research in sub-Saharan Africa has predominantly focused on HIV/AIDS [12]. To address the changing epidemiological landscape, this narrative synthesis examined sociocultural perspectives on palliative care across East African Community (EAC) countries, with particular attention to Kenya, Uganda, Rwanda, Burundi, the Democratic Republic of the Congo (DRC), South Sudan, Somalia, and Tanzania. The inclusion of these nations reflects the expanding geopolitical footprint and historical health-system cross-linkages of the EAC.

METHODS

Design

This paper utilizes a structured narrative synthesis methodology to collate, analyze, and map the literature surrounding palliative care delivery across eight target East African Community nations. Given the highly qualitative, heterogeneous, and deeply contextual nature of sociocultural data, a narrative synthesis framework was selected over a rigid scoping review protocol to allow for a comprehensive thematic integration of both empirical studies and foundational regional perspective pieces.

Search Question

The core question directing this synthesis is: *What are the specific sociocultural, spiritual, and clinical palliative care needs, particularly regarding pain management and communication taboos of patients with advanced non-communicable diseases (NCDs) such as cancer, and how do their structural support needs differ from those of patients living with HIV/AIDS in the East African Community region?*

Data Sources and Search Strategy

Literature was identified using a targeted search strategy across multi-disciplinary databases (PubMed, Scopus, and Web of Science). Search strings combined terms relating to the geographic setting ("East Africa", "Rwanda", "Kenya", "Tanzania", etc.) with core concept blocks ("palliative care", "terminal care", "hospice", "cultural beliefs", "spirituality", "pain") (Table 1). Searches were completed in April 2026; of the 295 records retrieved across the three databases (Table

Table 1: *Database Search Strategy and Records Retrieved by Source*

Database	Search Terms	Records Retrieved (n)
PubMed	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	94
Scopus	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	118
Web of Science	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	83

1), duplicates and ineligible records were removed through title, abstract, and full-text screening.

Eligibility and Study Selection

Literature was evaluated using a modified PCC (Population–Concept–Context) framework: Population (Palliative care patients, family caregivers, or healthcare professionals; Concept (Sociocultural barriers, spiritual support, communication norms, or symptom management experiences; and Context (East African Community partner states). After applying eligible criteria, 10 eligible full-text stuidies were included in the synthesis.

Synthesis Approach

Using the narrative synthesis, we thematically maped insights across papers to capture the sociocultural realities of the region from 10 primary empirical studies representing the core thematic pillars of communication, spirituality, and resource shortages were subjected to detailed data extraction (Table 2). Methodological quality appraisal was not formally conducted due to the inclusion of diverse essay, perspective, and qualitative formats, which limits comparative scoring but maximizes thematic breadth.

RESULTS

Study Characteristics and Reported Sociocultural Dimensions of Palliative Care

Table 2 profiles ten empirical studies published between 2006 and 2022, spanning six settings: Kenya, Uganda, Tanzania, Rwanda, the DRC, and Somali populations (via a diaspora study), plus one multi-country regional evaluation. Designs are predominantly qualitative or descriptive — ethnography, interviews, focus groups, and field studies, alongside cross-sectional and clinician surveys and one mixed-methods study; the largest sample was 420 Rwandan clinicians. Populations covered advanced cancer patients, people living with HIV/AIDS, healthcare professionals, family caregivers, religious leaders, and policy actors.

Collectively, the studies document severe unmet pain and information needs, heavy financial and nutritional strain on families, entrenched taboos against discussing death, provider discomfort with indigenous spiritual practices, misconceptions among religious leaders, cultural expectations of stoicism, and persistent gaps between rapid policy expansion and actual service delivery, with community-based oral morphine programs and nurse-led task-sharing emerging as the most promising responses.

Cross-National Symptom Management and Clinical Deficits

Across all EAC nations, the management of physical symptoms, most notably severe pain, presents a uniform clinical crisis compounded by structural limitations [1]. Pain is consistently validated as the most distressing problem for advanced cancer patients in Kenya and Uganda [13] and matches the 43% unmet pain relief need reported by HIV-positive cohorts in Rwanda [11]. While community-based oral morphine initiatives have shown remarkable localized success in transforming rural care across Kenya and Uganda, systemic barriers such as restrictive opioid legislation and interrupted supply chains remain a persistent barrier throughout the broader continent [4,16]. Although Grant et al. [16] also report

Table 2: *Characteristics and Key Sociocultural Findings of the Ten Primary Empirical Studies Included in the Synthesis*

#	Study Details	Country Focus	Study Design & Setting	Population / Disease Focus	Key Sociocultural & Palliative Care Findings
1	Harding et al. (2014) [13]	Kenya, Uganda	Multi-center, self-report clinical survey	Advanced Cancer patients	Pain is identified as the most severe physical problem. Severe information deficits exist; lack of information for future planning is a critical unmet need. Higher spiritual well-being correlates with older age.
2	Uwimana & Struthers (2007) [11]	Rwanda	Descriptive cross-sectional survey	People Living with HIV/AIDS (PLWHA)	High unmet structural and clinical needs: 77% required financial assistance, 44% required nutritional support, and 43% reported lacking effective pain relief.
3	Lewis et al. (2017) [14]	Tanzania	Qualitative interview study in hospital settings	Healthcare professionals (HCPs) and general inpatients	Revealed a profound cultural taboo against discussing death or terminal prognosis ("We never speak about death"). Hospitals are culturally viewed as superior environments for acute symptom control.
4	Kale (2011) [10]	Uganda	Qualitative ethnographic study at Hospice Africa Uganda	Palliative care workers and spiritual counselors	Providers are comfortable addressing mainstream global religions but experience high discomfort with indigenous spiritual expressions (e.g., witchcraft/cursing), leading to patient marginalization.
5	Rialem et al. (2020) [15]	Kenya	Mixed-methods: Survey and Focus Group Discussions	Community-based religious leaders	Religious leaders are vital partners for talking about dying, but severe misconceptions persist, such as the belief that palliative care actively hastens death.
6	Grant et al. (2011) [16]	Uganda, Kenya, Malawi	Rapid evaluation field studies in rural settings	Rural healthcare providers and palliative care patients	Confirms that community-based deployment of oral morphine serves as a vital intervention that significantly benefits patients and empowers rural staff.
7	Luyirika et al. (2022) [2]	Regional (Multi-country update)	Multi-country policy and health system progress evaluation	National health infrastructure, ministries, and policy leaders	Documents rapid policy expansion and integration of palliative care into Universal Health Coverage frameworks, while noting major persistent gaps in local service delivery.
8	Lofandjola et al. (2017) [17]	Democratic Republic of Congo (DRC)	Qualitative descriptive field study in Kinshasa	Families and extended kinship networks caring for advanced illness	Captures how resource deficits turn care into an informal system; care is driven heavily by family and religious communities to compensate for systemic healthcare gaps.
9	Finnström et al. (2006) [7]	Somalia (diaspora study, Sweden)	Qualitative conceptual exploration	Somali community perspectives on pain	Documents a pervasive cultural expectation of stoicism regarding pain expression, which extends down to children (ages 6–8) who are expected to mask physical suffering.
10	Moreland et al. (2021) [3]	Rwanda	Quantitative clinician survey across health facilities	420 medical clinicians (physicians and nurses)	Assessed educational gaps; indicates nurses score higher than physicians in communication, ethical knowledge, and family-centered care, showing strong potential for task-sharing models.

findings from Malawi, only the Uganda and Kenya components of that evaluation were drawn on here, consistent with the EAC-bounded scope of this review.

The findings across studies indication that the primary divergence between patient populations relates to structural vs. acute clinical resource strains.

Socioeconomic and Structural Exhaustion

Patients navigating long-term illness face severe, compounding structural deficits. For instance, data from Rwandan cohorts demonstrates that financial strain (77%) and nutritional insecurity (44%) often eclipse standard medical care needs, demonstrating how chronic illness drains family resources over time [11]. These HIV/AIDS cohort data, however, predate the large-scale expansion of antiretroviral therapy in Rwanda and should be read as a historical benchmark rather than a contemporary comparison. This matches patterns in the DRC, where scarce painkiller access turns palliative care into an informal, economically draining family survival model [8,17].

Clinical Communication Gaps

Advanced NCD cohorts (such as cancer patients) display a higher vulnerability to severe information deficits regarding their disease trajectory and future planning, frequently driven by institutional and familial communication failures [13].

Communication Taboos and Prognostic Silence

A dominant sociocultural barrier across the region is the pervasive cultural taboo surrounding explicit discussions of death, dying, and terminal prognoses [14,18]. In qualitative investigations within Tanzania, healthcare providers explicitly noted an institutionalized silence, summarizing the cultural norm as: "We never speak about death" [14]. This silence directly triggers severe clinical consequences; patients facing terminal NCDs in Kenya and Uganda identify the lack of clear prognostic information as one of their most damaging unmet needs, directly preventing them from executing essential future planning [13].

This protective silence is further complicated in settings like Somalia. While direct clinical palliative care studies within the country are absent, proxy sociocultural data collected among Somali diaspora women living in Sweden demonstrates a rigid cultural expectation of stoicism regarding physical suffering [7]. This strict expectation of pain control and endurance extends even down to children between the ages of 6 and 8, which heavily impacts symptom communication and underscores the necessity for healthcare providers to develop deep cultural competence during clinical end-of-life mapping [7].

Spirituality, Religious Networks, and Indigenous Belief Systems

Across the synthesized literature, spirituality emerged as a central organizing framework through which patients and families interpret serious illness, suffering, and death. In Kenya and Uganda, higher spiritual well-being among advanced cancer patients was associated with older age, suggesting that spiritual resources operate as culturally embedded coping assets that accumulate across the life course [13]. In the DRC, religious communities function as a de facto arm of the care system itself, providing material, emotional, and spiritual support that compensates for profound gaps in formal service delivery [17].

The evidence nevertheless reveals a marked asymmetry in provider preparedness. Ethnographic work at Hospice Africa Uganda found that palliative care workers were comfortable engaging patients' mainstream global religious traditions but expressed substantial discomfort when confronted with indigenous spiritual expressions such as ancestral beliefs, cursing, or witchcraft — a discomfort that can result in the marginalization of patients whose meaning-making draws on these frameworks [10]. This tension is consequential in a region where biomedical systems and local cosmologies coexist, and where culturally grounded models such as the Ubuntu philosophy of shared humanity have been proposed as bridges between the two [9].

Religious leaders themselves represent both a critical asset and a potential barrier. In Kenya, community-based religious leaders were identified as vital partners in initiating conversations about dying, yet serious misconceptions persisted among them, including the belief that palliative care actively hastens death [15]. Taken together, these findings indicate that spiritual-care competence — including structured engagement with indigenous belief systems and deliberate partnership with faith leaders — is as fundamental to palliative care delivery in the region as clinical symptom control.

DISCUSSION

This review indicates that the sociocultural architecture of palliative care in the EAC region rests on three interlocking realities: unrelieved physical suffering, culturally patterned silence around death, and spiritually mediated meaning-making.

The convergence of these themes across otherwise heterogeneous national contexts suggests that clinical models imported without cultural adaptation are unlikely to succeed. The documented communication taboos [13,14] do not merely delay disclosure; they actively prevent patients from executing future planning, settling family and financial affairs, and accessing goal-concordant care. Approaches to truth-telling therefore need to be renegotiated within, rather than against, local norms — for example through gradual, family-mediated disclosure and through the involvement of trusted religious leaders [15].

The findings also carry direct workforce and policy implications. Evidence from Rwanda that nurses outperform physicians in communication, ethics, and family-centered care domains [3] supports task-sharing models in which nurses anchor community-level palliative care, an approach consistent with the demonstrated success of community-based oral morphine programs in rural Uganda and Kenya [16].

At the policy level, the rapid integration of palliative care into Universal Health Coverage frameworks [2] has not yet been matched by local service-delivery capacity, echoing the region's wider implementation gap [4]. Finally, the divergence identified between the historically documented structural needs of HIV/AIDS cohorts [11] and the informational needs of NCD cohorts [13] should be interpreted cautiously, given that the available HIV evidence predates modern antiretroviral scale-up; contemporary comparative studies are needed.

This review showed some literature gaps to consider. The first is the constrained and highly uneven distribution of the available empirical literature across the eight studied nations, which prevents drawing sweeping, uniform conclusions for the entire East African Community region. While countries like Uganda and Kenya benefit from a relatively robust corpus of documented palliative care frameworks and empirical assessments [1,5], the evidence base for a significant portion of the bloc remains severely limited or indirect.

The structural and geographical gaps in the regional evidence base are characterized by the following specific limitations: Complete absence of local primary evidence in Burundi, where direct, localized primary literature on the sociocultural or clinical dimensions of palliative care is entirely absent. Consequently, assertions regarding patient-provider dynamics or healthcare system integration in Burundi must rely on broader, translated sub-Saharan regional models, rather than verified domestic data.

There is a lack of Direct Palliative Care Research in Somalia: The available literature for Somalia does not capture direct palliative care or hospice delivery systems. Instead, the evidence base is restricted to proxy sociological explorations of cultural attitudes toward pain expression, fatalism, and general healthcare interactions within Somali communities, largely conducted among diaspora populations outside Somalia [7,19]. While these insights are vital for building cultural competence, they lack direct clinical application to end-of-life care pathways.

Although formal palliative care guidance has been articulated for South Sudan [20], there is a profound scarcity of active field research detailing how these guidelines translate to patient experiences. The expected barriers are inferred primarily from broader maternal and antenatal health utilization studies rather than dedicated end-of-life evaluations [21].

Despite its massive geographical and population footprint within the expanded EAC, the DRC remains deeply underrepresented in global palliative care literature. Extant data is heavily localized to qualitative snapshots within urban centers like Kinshasa, capturing informal family survival models but failing to reflect the diverse rural realities of the wider nation [8,17].

Acknowledging these extensive empirical limitations is essential. They highlight that the findings presented in this synthesis represent a fragmented regional landscape rather than a single, uniform East African reality. Rather than undercutting the value of this review, these profound gaps underscore an urgent, explicit mandate for localized, country-specific primary research and clinical intervention studies across these underrepresented nations.

CONCLUSION

Palliative care needs across the EAC partner states are shaped as much by sociocultural and spiritual dynamics as by clinical resource constraints. Pain relief remains the most urgent and universal unmet clinical need, but its resolution is inseparable from communication norms that silence prognostic discussion and from spiritual frameworks that providers are frequently unprepared to engage. Strengthening regional palliative care will require culturally negotiated communication strategies, structured spiritual-care training that includes indigenous belief systems, nurse-led task-sharing, and sustained investment in opioid access. Above all, the profound evidence gaps in Burundi, Somalia, South Sudan, and the DRC constitute an explicit mandate for localized, country-specific primary research.

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