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The True Accompaniers: An Exploration of CHWs' Navigation of Life and Death in the Burera District A Qualitative Study

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Abstract

Background

Palliative and end-of-life care in sub-Saharan Africa is often assessed through Western biomedical frameworks emphasizing prognostic transparency and individual autonomy. In Rwanda, Community Health Workers (CHWs) frequently serve as the primary point of contact for terminally ill cancer patients discharged from referral hospitals, yet their role in end-of-life care remains poorly characterized. This qualitative study explored the experiences, knowledge, and perspectives of CHWs caring for patients with advanced cancer discharged from the Butaro Cancer Center of Excellence (BCCOE) in Burera District, Rwanda, to inform the development of a hospital-affiliated palliative care program.

Methods

Semi-structured interviews were conducted in Kinyarwanda with eleven CHWs across five health centers in Burera District who had cared for a BCCOE-discharged patient with a terminal cancer diagnosis within the preceding two years. Interviews were audio-recorded, translated into English, and analyzed using thematic analysis in MAXQDA, combining a priori and inductively developed codes.

Results

Three central themes emerged. First, CHWs performed expansive, morally complex labor as embodied caregivers and cultural brokers, providing hands-on physical care, emotional support, and community mediation that extended well beyond their formal mandate and continued through funerals and bereavement. Second, CHWs practiced hope-centered, spiritually grounded accompaniment, deliberately deferring direct prognostic disclosure to physicians while sustaining patients' dignity and morale through presence, encouragement, and prayer. Third, CHWs functioned as informal interpreters of structural gaps in the health system, articulating how poverty, unmanaged pain, and inadequate nutrition, transportation, equipment, and compensation constrained the care they could provide, while proposing concrete remedies.

Conclusions

CHWs in Burera District act as the true accompagnateurs of the dying, sustaining a form of end-of-life care that is relational, spiritually attuned, and protective of hope rather than centered on prognostic transparency. Palliative care programming at BCCOE should be built around, rather than against, this existing model of accompaniment—equipping CHWs with disease-specific training, essential supplies, nutritional and transportation support, and fair compensation, rather than retraining them into a purely biomedical disclosure-centered role.

Background

Palliative care is often described through a Western biomedical lens—a specialty focused on relieving suffering and improving quality of life for individuals facing life-limiting illness (World Health Organization, 2020). The term *palliative* was introduced in the 1970s by physician Balfour Mount, who sought to merge the hospice philosophy of holistic comfort with hospital-based care (Mount, 1976). Yet the Western language of palliative care—centered on clinical transparency, patient autonomy, and individual decision-making—does not fully capture how different cultures experience the complex transition between life and death (Zaman et al., 2017). In many African societies, including Rwanda, death is not simply a medical event; it is a communal and spiritual process, interwoven with relationships, ancestry, and collective responsibility (Wright and Clark, 2006).

Nestled in the mountains of rural Burera District stands the Butaro Cancer Center of Excellence, a national referral site for complex cancer care built through a partnership between Partners In Health (PIH) and the Rwanda Ministry of Health (Binagwaho et al., 2014). While the facility represents a meaningful expansion of oncology services in rural Rwanda, thousands of patients still present with advanced cancers due to late detection, financial barriers, and limited awareness of early symptoms. At this stage, curative treatment may no longer be possible, leaving pain control and emotional and spiritual support as the primary forms of care.

A central question therefore arises: what constitutes a dignified death? Is such a death defined universally, or is it shaped by culture, community, and faith? In many high-income Western contexts, a "good death" is characterized by prognostic transparency, autonomy in decision-making, and advance planning (Institute of Medicine, 2015). In Rwanda and similar contexts, however, direct disclosure of a terminal prognosis may be considered spiritually harmful or spiritually inappropriate; families often request that patients be protected from knowing the full severity of their illness (Holmes and Illing, 2021). Palliative care thus becomes not only a clinical challenge but also a cultural negotiation.

For families living in poverty, the decision to invest limited resources in care that cannot cure the disease is an excruciating one. Choosing between transportation, food, school fees, and morphine is a moral dilemma that few in higher-income settings ever encounter (Rubagumya et al., 2023). While the Butaro Cancer Center of Excellence can provide virtually cost-free oncological care to its patients, this is far from the reality of many other patients across the continent of Africa and the globe.

It is within this landscape that Community Health Workers (CHWs) operate every day. Rwanda's CHW system is a nationally structured network of elected community members responsible for delivering preventive care, home-based follow-up, and patient accompaniment (Condo et al., 2014). While they are not formally trained palliative specialists, CHWs often become the primary witnesses to patients' final days—walking for hours to remote homes, mediating family conflict, offering counseling shaped by culture and spirituality, and frequently providing the only consistent support a dying patient receives (Krakauer et al., 2018; Thomson et al., 2014).

They operate without titles, salaries, or adequate equipment—sometimes lacking basics such as rain boots, flashlights, or reliable transportation. Yet despite these structural constraints, CHWs serve simultaneously as educators, advocates, cultural interpreters, emotional companions, and spiritual guides—roles rarely acknowledged in formal public health discourse. They are, in many ways, the true *accompanateurs* of the dying.

Methods

Study Design and Setting

This qualitative case study was conducted in villages within Burera District, a rural region in Rwanda's Northern Province. Burera District is home to the Butaro Cancer Center of Excellence (BCCOE), a referral facility providing advanced cancer care and support services for patients across Rwanda and neighboring countries. BCCOE's patients fall within the catchment area of Butaro Level Two Teaching Hospital (BL2TH), which extends across multiple districts. This study focused on this catchment area to assess the role of Community Health Workers (CHWs) in supporting the continuum of care for patients discharged from BCCOE with a terminal illness.

Aim and Objectives

The aim of this study was to understand the experiences, knowledge, and perspectives of CHWs regarding palliative and end-of-life care for cancer patients in Burera District, in order to inform the development of the BCCOE palliative care program and the potential role of CHWs within it. Three objectives guided the study: (1) to describe CHWs' experiences interacting with patients discharged from BCCOE with a terminal diagnosis, in order to understand current practices and the structural factors influencing palliative care provision; (2) to explore CHWs' knowledge and perspectives on palliative care in order to gain insight into local cultural attitudes and contextual factors shaping care; and (3) to identify opportunities for integrating palliative care within the existing CHW model, in order to inform future education and program development.

Participants and Sampling

The target population comprised CHWs within Burera District who had experience caring for patients discharged from BCCOE with a terminal illness. Purposive sampling was used to identify CHWs meeting specific experience and demographic criteria. Eligible CHWs had provided care for a BCCOE-discharged patient with a confirmed cancer diagnosis (pediatric or adult) within the preceding two years and had at least one year of experience in their position; both men and women aged 18 years or older were eligible. CHWs who had not worked in Burera District, or who lacked experience with BCCOE-discharged cancer patients, were excluded. Participants were recruited through the University of Global Health Equity (UGHE) Social Medicine and Community Health Department's existing network of CHWs, who were approached via established contacts within the network and invited to voluntarily participate. Eleven

CHWs were enrolled, serving five health centers (Butaro, Kirambo, Rwerere, Rusasa, and Ndogozi) within the BCCOE catchment area.

Data Collection

Semi-structured interviews (SSIs) were conducted with all eleven participants using an interview guide developed to explore CHWs' knowledge of and attitudes toward palliative care, their roles and responsibilities in caring for terminally ill patients, the strengths of the community in providing end-of-life care, and structural challenges to that care. Interviews lasted approximately 45–60 minutes and took place in the private setting of participants' homes or another location chosen by the participant within Burera District. Interviews were conducted in Kinyarwanda, the participants' language of choice, by the study's co-principal investigator (CR) together with a Kinyarwanda-speaking data collector contracted through the UGHE Department of Community Health and Social Medicine, who translated in real time. With participants' written consent, interviews were also audio-recorded for later transcription and analysis, and transcripts were subsequently translated into English. The original study protocol also proposed a follow-up participant-observation component with two selected CHWs; this was not carried out, and all findings reported here are drawn from the semi-structured interviews only.

Data Management

Each participant was assigned a study ID used to label audio files and transcripts. Audio files and transcripts were stored on a password-protected, secure server accessible only to the research team. Recordings were transcribed verbatim in Kinyarwanda and translated into English by trained data officers. Each transcript was reviewed by the principal investigator to identify and redact personally identifiable information prior to analysis; after analysis, identifiable data were deleted. A single document linking participant names to study IDs was stored securely and separately, accessible only to study investigators.

Data Analysis

Interview transcripts were examined using thematic analysis and coded in MAXQDA Standard 2022. Three members of the research team (AF, KF, CR) developed a preliminary codebook using a priori codes drawn from the literature and interview guide (e.g., "spiritual care," "pain management challenges," "coordination with family caregivers"), with inductive codes added iteratively as they emerged from the data — including demographic codes (age, religious affiliation, CHW designation, years of experience, additional employment) applied to each transcript. AF, KF, and CR independently open-coded the English-translated transcripts, immersing themselves in the data through multiple readings and re-listening to key interview segments. Individual codebooks were compared and discussed to develop a finalized, cohesive codebook; AF's and CR's coding was checked against KF's for agreement, and discrepancies were resolved by consensus. All transcripts were then coded using the final codebook.

Results

Eleven CHWs were enrolled across five health centers in Burera District (Butaro, Kirambo, Rwerere, Rusasa, and Ndogozi). Full interview and demographic data were available for all eleven participants. Eleven interviews took place between February 28th 2025 and March 14th 2025. Among the elven participants, CHW experience ranged from 5 to 21 years (median 12.5 years). Age was recorded for four participants (range 41–60 years). Religion was recorded for nine participants: six identified as Catholic, two as Adventist/Seventh-day Adventist, and one as Christian without further specifying denomination. CHW designation was recorded for nine participants, with several describing themselves as binômes working in integrated care and others focused specifically on disease prevention. One participant (#501 E) described caring for a patient approximately ten years before the interview, outside the two-year window specified in the study's eligibility criteria; this deviation is noted here for transparency and addressed further in the Discussion. Participant characteristics are summarized in Table 1.

Table 1
Participant characteristics (N = 11)

Participant ID	Health Center	Interview Date	Religion	CHW Designation	Years of CHW Experience
#100A	Butaro	22 Aug 2025	Christian (choir member; active in church leadership)	Maternal/child health & newborn care; retrained under the integrated model to cover all areas	~ 17 yrs (since 2008)
#101A	Butaro	22 Aug 2025	Catholic (baptized, prays at Runaba parish)	Prevention	~ 7 yrs (elected 2018)
#200B	Kirambo	13 Oct 2025	Catholic	Not captured	17 yrs (since 2008)
#201B	Kirambo	13 Oct 2025	Catholic	General population health, esp. children < 5; treats malaria, pneumonia, diarrhea	9 yrs (since 2011)
#202B	Kirambo	13 Oct 2025	Not captured	Illness identification; chronic disease/epidemic care	10 yrs
#300C	Rwerere	17 Oct 2025	Seventh-day Adventist	Binome	15 yrs
#301C	Rwerere	17 Oct 2025	Adventist	Binome	~ 17 yrs (since 2008)
#302C	Rwerere	6 Nov 2025	Catholic	Binôme	6 yrs
#400D	Rusasa	6 Nov 2025	Catholic	Prevention	5 yrs
#500 E	Ndogozi	14 Mar 2024	Christian	Binome	5 years
#501E	Ndogozi	14 Mar 2025	Catholic	Binome	~ 21 yrs (since 2004)

Three central themes emerged from the data: CHWs as embodied caregivers and cultural brokers whose work extends beyond death; CHWs' practice of hope-centered, spiritually grounded accompaniment; and CHWs as informal interpreters of the structural gaps that shape end-of-life care in their communities.

Theme 1 (Combined Themes 2 & 7): CHWs Perform Expansive, Morally Complex Labor as Embodied Caregivers, Cultural Brokers, and Community Educators Whose Work Extends Beyond Death

Although the formal CHW role in Rwanda is defined through maternal and newborn care, basic community case management, and health promotion, CHWs in Burera frequently take on responsibilities that extend far beyond these categories when caring for terminally ill patients. They provide hands-on caregiving in patients' homes, translate medical information between clinicians and families, and guide communities through illness, dying, and bereavement. In doing so, their work becomes not only clinical but also relational, social, and moral—requiring them to navigate cultural norms, family dynamics, and the emotional realities of end-of-life care.

Across interviews, CHWs described their work with terminally ill patients as expansive, embodied, and deeply relational, extending far beyond formal job descriptions or clinical expectations. Their care encompassed physical, emotional, social, ethical, and experiential labor that often occurred simultaneously. CHWs routinely assisted with hygiene, medication reminders, food preparation, and transportation to health facilities, frequently visiting patients' homes at night despite limited supplies, long travel distances, and personal safety risks.

This commitment to whole-person care was most evident in the ways CHWs described going beyond their official mandates out of a sense of moral obligation rather than institutional duty. As one CHW explained, the act of delivering medicine without first ensuring a patient had eaten felt incompatible with basic humanity:

"Cooking for them and looking after their daily needs is not part of my job. But, because of the compassion we have, it's hard to give someone medication without ensuring they have eaten first. Sometimes, I take food to them if it's available. This is not part of my job, but rather an act of humanity." (Participant #200 B)

The geographic proximity of some CHWs to their patients enabled a kind of continuous, informal caregiving that blurred the boundary between professional role and neighborly responsibility. One participant described checking in daily on a nearby family: "I was fortunate that the family lived nearby, so I could check if they needed anything like firewood or water, and I would bring it to them" (Participant #202 B). When patients lacked caregivers entirely, CHWs described assuming even the most intimate tasks. Asked directly whether they washed patients' clothing, one participant responded without hesitation:

"Yes, that should be done too, because there are patients who don't have caregivers. If they are your neighbors and live near you, would you really let them stay dirty and neglected? We should rather approach and help them." (Participant #400 D)

Two additional participants described a similarly expansive, improvised form of caregiving, extending into cooking, fetching water, and advocating on patients' behalf for basic housing needs:

"I would cook and find Irish potatoes for her and her family since they were poor and old. I would also fetch water for them. Their house was so old and let rain in, so I advocated to the government to build them a new house." (Participant #500 E)

CHWs also provided rudimentary wound care, drawing on observed practice and available materials. As one participant described, the rationale was both hygienic and deeply human: "We used clean water and a clean cloth to ensure hygiene and to keep the air fresh. You know, if a wound is not kept clean, it smells bad, and it makes the space unpleasant" (Participant #400 D). This practical, improvisational caregiving—performed without formal training or supplies—reflects the degree to which CHWs absorbed clinical functions in the absence of formal support.

Another participant described the physical intimacy this caregiving could require in a patient's final days:

"At this point, we had to physically open her mouth to feed her. The hospital gave me gloves to bathe the patient. It reached the point where her friends could not take care of her." (Participant #501 E)

Emotional labor was equally central to their role. CHWs provided comfort to patients experiencing fear, depression, and isolation while simultaneously managing their own grief in households marked by anticipatory loss. The tension between honest prognosis and sustaining hope was particularly acute. One CHW described accompanying a patient who had returned home from the hospital in despair, convinced he would not recover:

"I visited him as often as possible, comforting him in his illness. I would tell him, 'Stay strong, you will recover,' even though he was weak and would sometimes respond, 'No, I won't recover.' I reassured him, saying, 'You are in the hands of doctors, and they have given you medication—if you take it correctly, you will get better.' I also guided his caregivers at home, reminding them to administer his medication as prescribed and to maintain hygiene. I advised them to fulfill his requests and always speak kindly to him to prevent unnecessary distress, ensuring he lived his remaining days in peace." (Participant #200 B)

Social isolation compounded by illness could devastate patients' will to continue treatment. In one particularly striking case, a CHW described a patient whose wife had left him after a disfiguring illness—and who depended entirely on his CHW for emotional sustenance:

"Every morning, I go to check on him, see how he is doing, and encourage him to keep taking his medication. I show him the progress he has made from how he was before to how he is now to motivate him... When you provide comfort, the patient feels happier because he has no one else to support him besides community health workers. He is still alive and holding on." (Participant #200 B)

Social and relational labor also included identifying patients through community mapping, advocating for them within village and health system structures, and navigating strained or conflicted family dynamics. CHWs occupied an intermediary position between medical institutions and community life, acting as cultural brokers who translated clinical information into culturally meaningful explanations—particularly when illness was interpreted through frameworks of witchcraft or poisoning. One participant described the multiple pathways through which patients came to be known to CHWs:

"Sometimes a person from the community might trust you and come to tell you about their illness, even if they're not part of the households you're directly assigned to. In that case, you can still help or advise them.

So that's how we come to know the patients—through our reports, through community conversations, and during village meetings." (Participant #101 A)

The hospital-to-community handoff was equally relational. As one CHW noted, "We see ourselves as a bridge between patients and doctors" (Participant #200 B)—a description that captures not only the logistical function of care coordination, but the depth of trust required to sustain it. Clinicians often relied on CHWs to continue what began in the hospital:

"When the patient is struggling, the doctor or nurse tells them, 'Go find your community health worker. They'll be the one to help you get your medication.' Because of the household registration we've already done, the patient will then say, 'So-and-so is my CHW,' since that's the person assigned to their village." (Participant #100 A)

Ethical labor emerged in moments where CHWs had to decide whether to escalate care, how to balance compassion with institutional responsibility, and when to involve local authorities if families refused to provide care. These decisions were emotionally taxing and socially risky, exposing CHWs to potential community backlash. One participant described the painful position of being perceived as an adversary by the very families she sought to help:

"You need to find the right words, carefully choose how you speak to make your point. For example, when a family tells you, 'This patient is on the verge of dying, we won't take him back to the hospital,' you have to find a way to educate them... one of the biggest challenges is when families refuse to take care of the patient. In those cases, we sometimes have to involve local authorities. And when you do that, the family sees you as their enemy. They think you went to report them, but really you just want what's best for the patient." (Participant #100 A)

Another participant described attempting to mobilize official support for a patient who refused further hospital care, ultimately accepting the limits of her authority while maintaining her commitment to accompaniment:

"I kept urging her to seek medical help, but she wouldn't listen... I reported it to the sector's executive secretary. Then the executive secretary and I went to see her together, and we encouraged her again. She thanked us but said she had received enough treatment and didn't want to continue. So all we could do was continue to support and comfort her." (Participant #302 C)

Importantly, CHWs emphasized that their responsibilities did not end with a patient's death. Care extended into the post-mortem period through active participation in funerals, where CHWs often spoke publicly to clarify the medical cause of death and counter narratives attributing illness to witchcraft or poisoning. These moments of communal mourning became sites of narrative correction, education, and prevention advocacy, as CHWs linked individual loss to broader public health messages emphasizing early screening and timely care. One participant described how this played out at the funeral of a cancer patient:

"As community health workers, we usually take the opportunity to explain what caused the death, making it clear that it wasn't due to witchcraft, as people often claim. We also use the moment to sensitize the community on the importance of early screening and testing—when illness is detected early, it can be treated effectively." (Participant #300 C)

Another participant described speaking at a patient's funeral not in an official capacity alone, but as someone who had genuinely accompanied her through illness: "A family member was assigned to speak about her life, but as a community health worker who visited her every day, I also shared the conversations we used to have together during her illness" (Participant #302 C). The intimacy of this testimony—offered at the intersection of grief, community memory, and public health advocacy—encapsulates what CHW accompaniment ultimately looks like in practice.

Taken together, these forms of labor position CHWs not as peripheral health system agents, but as primary caregivers, cultural interpreters, and enduring stewards of community health whose work spans life, death, and collective memory.

Theme 2 (Combined Themes 3, 6 & 8): CHWs Practice Hope-Centered, Spiritually Grounded Accompaniment That Sustains Meaning, Dignity, and Professional Identity in the Face of Terminal Illness

While palliative care is often framed around direct discussions of prognosis and medical transparency, CHWs in Burera approach end-of-life care through a hope-centered and spiritually grounded framework. Rather than emphasizing the finality of illness, they sustain hope, dignity, and meaning for patients and families through prayer, encouragement, and consistent presence. This approach allows CHWs to accompany patients through dying in a way that aligns with community values while also helping CHWs themselves maintain a sense of purpose and professional identity in the face of frequent death.

Across interviews, CHWs consistently conceptualized their role as promoting life, dignity, and hope—even in the context of terminal illness. They described themselves as "life-promoters," emphasizing encouragement, reassurance, and presence rather than prognostic finality. Direct disclosure of terminal prognosis was widely rejected as culturally inappropriate and potentially harmful, with many CHWs expressing concern that explicitly telling patients they were dying could exacerbate suffering or precipitate despair. CHWs framed prognostic disclosure as the physician's responsibility, while positioning their own role as protecting patients' emotional and spiritual well-being. As one participant stated clearly:

"As a community health worker, that's not my role. It's the doctor who gives them that news. My role is to comfort and support them, so they don't lose hope—but the information about the diagnosis comes from the doctor... We, as community health workers, cannot tell a patient they have a terminal illness; that would only make them lose hope. Our job is to comfort them." (Participant #300 C)

This orientation was not passive avoidance but an active, ethically reasoned choice. Several participants noted that patients often came to understand the seriousness of their illness on their own as symptoms

progressed—and that the CHW's role was to remain present through that unfolding awareness without confirming or accelerating their fear:

"The patient comes to that realization on their own. As a healthcare provider, whether a doctor or a community health advisor, you don't tell them, 'You won't recover.' Instead, you always try to reassure them, saying, 'You will get better.' Even if they begin to feel their condition worsening, our role is to comfort them and offer hope, not to confirm their fears. Even in their final moments, we continue to provide encouragement and support." (Participant #201 B)

Two additional participants voiced this same protective stance toward disclosure in similarly direct terms:

"I never talked to her about death, and I don't think CHWs should ever talk about this stuff. I don't think anyone should tell them, because the patient would never take their medications if they knew they were not going to recover. It is encouraging if they don't know they are going to die." (Participant #500 E)

"Of course I didn't tell the patient she was dying. No one should tell them. Only comforting conversations should be initiated." (Participant #501 E)

This ethic of protective accompaniment extended to the language used even by hospital staff at discharge. As one CHW observed, the system as a whole tended away from explicit terminal disclosure: "They may say something like, 'We are discharging you, and the community health worker will continue to assist you with your medication.' But no one would tell them that they are dying" (Participant #200 B). Another participant articulated the underlying logic: "It's not good to tell them directly that the disease is deadly—rather you try to help them understand that they can be treated or that it may get easier, even though you know the disease is untreatable" (Participant #301 C).

Spirituality emerged as both a personal resource and a carefully bounded professional tool within this model of care. Many CHWs described their faith as a source of motivation, resilience, and compassion that sustained them through emotionally demanding work. At the same time, they articulated clear professional boundaries, expressing respect for patients' diverse religious beliefs and avoiding the imposition of personal faith practices. One participant described how her Catholic community organized around a patient through structured mutual support:

"We have something called 'basic Christian communities'—we gather and reflect on people who are vulnerable or poor. So, there were times we selected her among those in need, visited her, took turns helping her. When we harvested, we also shared food with people who were struggling, not just with her but also other sick people in the community. We did that as part of our Catholic Church." (Participant #302 C)

When asked whether prayer would differ depending on a patient's religion, another CHW reflected that the offer of prayer transcended denominational boundaries: "I don't think a sick person would refuse to be prayed for, regardless of their religion. I would still say a prayer for them" (Participant #400 D). This expansive, non-coercive understanding of spiritual accompaniment—attentive to the individual while

drawing on communal religious resources—reinforced an ethic of care grounded in respect, relationality, and patient-centered support.

Despite material scarcity, emotional strain, and limited formal recognition, CHWs described this form of accompaniment as deeply meaningful and identity-shaping. Many expressed pride in being trusted by their communities and in remaining present with patients through the final stages of life, particularly when families had withdrawn or resources were exhausted. "Being there" until the end was repeatedly framed as both a moral responsibility and a source of professional fulfillment—helping to explain why hope-centered, spiritually attentive accompaniment persisted even in the absence of adequate structural support.

Theme 3 (Combined Themes 4, 5 & 9): CHWs Stand in Structural Gaps While Articulating Their Origins and Remedies

CHWs routinely step in where health systems and social supports fall short, providing care and coordination in the absence of adequate resources. Through this work, they develop a clear understanding of the structural causes of suffering—such as poverty, limited access to care, and health system constraints—and frequently articulate practical ideas for how these gaps could be addressed.

CHWs consistently described their work as sustaining an informal system of end-of-life care in contexts where formal support was limited or absent. In doing so, they were not only filling gaps, but acting as system interpreters—making visible how poverty, caregiving fatigue, and structural scarcity converge to produce breakdowns in care. From their perspective, family abandonment of terminally ill patients was not a failure of moral character but a consequence of cumulative strain. As one participant stated plainly: "Many of these serious diseases cause poverty in the families, yet people keep imagining that the patient is still in the same social class they were before. So, families often neglect them because they think the patient no longer brings anything of value into the home" (Participant #100 A).

Prolonged illness frequently exhausted household resources, forcing families to make painful trade-offs between food, transportation, school fees, and medical care. Medications often intensified hunger in already food-insecure households, compounding physical suffering. Seasonal agricultural labor demands further limited the time families could dedicate to caregiving—a tension one CHW captured with particular precision:

"The patient feels like they are spending money that won't help them recover, and they are using time on a patient with a disease which will never be cured. So they wonder why they should continue... Even in rural areas, you can't find someone just sitting idle, because it's planting season. Even if you have a patient, you must still work, and the remaining time after work dedicated to them no longer benefits them because you were focused on your work." (Participant #400 D)

Another participant tied this same financial calculus directly to her own definition of a good death:

"A good death is when the family is present and caring, when the patient is taken to a good hospital with good health centers and available medications, and when the cost of caretaking doesn't cause the patient's family to have to sell their land to pay for care." (Participant #500 E)

CHWs did not simply absorb these contradictions; they also advocated for patients against them. When family members expressed doubt about continuing to care for an elderly patient with no visible signs of improvement, one CHW pushed back:

"I tried to encourage her and show her that even though he was in pain, he could still recover. What mattered was that we kept caring for him and making sure he received his medication... I reminded them that sometimes people can pass away even when they are not sick. So, I showed them that even though they were caring for someone ill, their efforts were not in vain." (Participant #202 B)

These dynamics were intensified by profound gaps in pain management and symptom control outside hospital settings. CHWs expressed significant distress at witnessing unmanaged pain in the home alongside frustration with the limits of what they could offer beyond comfort and presence. Hospitals were widely perceived as spaces where pain relief was more reliably available, motivating repeated efforts to encourage referral. As one participant explained:

"When someone goes to the hospital, the doctors can offer comfort and pain relief. Even if a person won't recover, at least their pain is managed. People in the community had learned that it's better to be treated at the hospital rather than suffer at home. Hospitals can offer support that we don't have in the community." (Participant #302 C)

Unmanaged pain and its visible effects could also isolate patients from their own communities, as one participant described of a patient nearing death from cancer:

"There is no good death. Cancer is the worst one... If the patient dies quicker, before their family gets tired of them [that would be better]. Clementine's death cannot be classified as a good death. People started disliking her; they hated the way she smelled, and no one from the community wanted to visit her. Even the Kirambo doctors were so sad for her." (Participant #501 E)

CHWs also articulated concrete strategies for addressing structural gaps—reflecting not a desire to medicalize their role, but to strengthen their capacity to accompany patients with competence, dignity, and compassion. Regarding clinical skills, one participant noted the limits of improvised wound care: "If I had known how to properly treat the wound, I could have done it, but I didn't have the resources or knowledge at the time. I think getting more knowledge on how to treat wounds for patients would help" (Participant #400 D). Others identified the need for disease-specific training: "We have not received any training specifically for caring for cancer patients. So, I think that kind of training is necessary" (Participant #400 D).

Nutritional support emerged as one of the most consistently identified gaps. CHWs described witnessing patients who were simultaneously receiving medication and experiencing severe hunger—a

combination that undermined treatment adherence and accelerated decline. One participant made a pointed critique of how food aid was allocated:

"Here at the hospital, some patients are given porridge, but it's clear they base it on criteria like appearance or perceived wealth when deciding who gets food. What I would suggest is that support shouldn't be based on those things—they should assess the severity of the illness instead." (Participant #101 A)

The inadequacy of transportation support was equally well-documented. While Partners In Health provided some travel assistance for patients with certain diagnoses, CHWs noted the absence of equivalent support for food or nutritional supplementation: "I feel that Partners In Health doesn't provide adequate nutritional assistance, which is crucial for the patients" (Participant #300 C). One participant extended this argument to include caregiver welfare, noting that the husband of a seriously ill patient was himself at risk:

"Since the husband is the one taking care of the patient, he also needs daily support. For instance, if they had mutual health insurance, it would be a great help, or even some financial assistance to use for things like transportation when needed. He would also benefit from food with proper nutritional value to help maintain his strength as he takes care of her." (Participant #201 B)

CHWs also described the personal costs of their work—costs that were rarely acknowledged or compensated. They identified rain boots, umbrellas, flashlights, and soap as essential tools for maintaining professional standards in difficult terrain: "In cases of heavy rain, we also need umbrellas and boots to help us reach the patients and provide quick assistance" (Participant #201 B). One CHW described forgoing nighttime visits due to inadequate lighting: "If I had a bigger flashlight, I could go earlier to assist the patient and provide comfort" (Participant #201 B). Another noted the economic sacrifice embedded in their unpaid labor:

"Sometimes we must stop our own work to go support a patient, even if it means missing out on daily earnings. If there was a form of compensation for time used to care for the patient, that would improve our ability to support both the patients and our own families. It would make our responsibilities more manageable." (Participant #202 B)

Taken together, these reflections reveal CHWs not simply as gap-fillers, but as astute analysts of the systems in which they operate. Their articulations of what is missing—in training, equipment, nutrition, transportation, and financial compensation—constitute a form of structural critique rooted in daily practice. They are not asking to be medicalized; they are asking to be equipped. And in the space between those two demands lies the full complexity of what it means to accompany the dying in rural Rwanda.

Discussion

This qualitative study offers an in-depth account of how Community Health Workers (CHWs) in rural Rwanda navigate the care of dying cancer patients in the absence of formal palliative care training, dedicated equipment, or financial compensation. Three intersecting patterns emerged: CHWs perform wide-ranging, often physically and emotionally intimate caregiving labor that extends well past their official job description and continues after a patient's death; they practice a hope-centered, spiritually attuned form of accompaniment that deliberately defers prognostic disclosure to physicians while still supporting patients through their own gradual recognition of decline; and they act as informal interpreters of the structural gaps — in nutrition, transportation, equipment, training, and compensation — that shape end-of-life experiences in their communities.

These findings complicate a purely biomedical model of palliative care organized around prognostic transparency and individual autonomy. As described above, a "good death" in high-income, Western contexts is often characterized by direct disclosure and advance planning (Institute of Medicine, 2015), yet the CHWs in this study consistently and intentionally withheld terminal prognoses, framing this omission not as deception but as an act of protection and care consistent with a communal, spiritually embedded understanding of death. This suggests that palliative care programs developed for the BCCOE catchment area should be built around, rather than against, CHWs' existing hope-centered communication practices, reserving direct prognostic disclosure for physicians while equipping CHWs with structured language and training for the accompaniment role they already occupy.

The structural findings in Theme 3 point to concrete, actionable gaps for program design: disease-specific training (particularly in wound care and basic symptom management), reliable transportation and weather-appropriate equipment (rain boots, flashlights), nutritional support for patients and caregivers, and some form of compensation or protection for the income CHWs forgo when they prioritize home visits.

This study has several limitations. It was conducted in a single district served by a single referral hospital, with a small purposive sample of eleven CHWs, which may limit generalizability to other regions of Rwanda or to CHW systems structured differently. Interviews were translated in real time and later transcribed and translated by data officers, introducing the possibility that some nuance in participants' language was altered in translation. Demographic data were incomplete for some participants (age was recorded for only four of eleven, and additional-employment questions were asked systematically of only two), which limits the precision of the sample description. Finally, this analysis centered CHWs' own accounts of their practice; it did not include the perspectives of patients, family caregivers, or supervising clinicians, whose views may complicate or extend the themes identified here, nor did it include participant observation, which had been proposed in the original protocol but was not carried out. One participant (#501 E) described a caregiving experience from approximately ten years before the interview, outside the two-year eligibility window specified in the protocol; this participant's account is retained in the thematic analysis below but represents a deviation from the stated inclusion criteria that should be weighed when interpreting the findings.

Future work should incorporate patient and family caregiver perspectives directly, examine whether CHWs' hope-centered communication approach aligns with what patients and families in this setting actually want to hear, and evaluate the impact of targeted CHW training and resourcing (as identified by participants themselves) on patient and caregiver outcomes as the BCCOE palliative care program is developed.

Conclusion

CHWs in Burera District function as the true accompagnateurs of the dying, absorbing physical, emotional, social, and ethical labor that extends well beyond their formal mandate and persists beyond a patient's death. Rather than direct prognostic disclosure, they practice a hope-centered, spiritually grounded form of accompaniment shaped by local understandings of a dignified death, while also serving as clear-eyed analysts of the structural gaps — in training, equipment, nutrition, transportation, and compensation — that constrain the care they can provide. As the BCCOE palliative care program is developed, these findings suggest that CHWs should be equipped and resourced to sustain the accompaniment role they already perform, rather than retrained into a purely biomedical disclosure-centered model.

Declarations

Ethics approval and consent to participate

This study ("Community-Based Palliative Care: A Look into the Current State of Community Health Workers and End-of-Life Care in the Burera District") was reviewed by the University of Global Health Equity (UGHE) Institutional Review Board (Kigali Heights Building, 5th Floor, Kacyiru, Kigali, Rwanda). Creighton University School of Medicine IRB Committee also reviewed and approved this study to be conducted. Written informed consent, including specific consent for audio recording, was obtained from all participants prior to enrollment using a UGHE IRB-approved consent form. Participants received 5,000 RWF as compensation for their time. The study was performed in accordance with the Declaration of Helsinki.

Consent for publication

No individually identifiable information is included in this manuscript. All participant excerpts are de-identified and presented under generic study IDs.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

CR and AF conceived and designed the study as co-principal investigators. CR led data collection, with contributions from FA and GIN. CR and AF developed the codebook and conducted data analysis; KF provided qualitative methods expertise. AP and SS contributed to data analysis, results interpretation, and manuscript writing. JB and SB contributed to study conception and design and to manuscript writing. FA and GIN contributed to study coordination and data collection and critically reviewed the manuscript. All authors contributed to interpretation of results, manuscript writing, and dissemination of findings, and read and approved the final manuscript.

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