The realities of palliative care for cancer patients in Rwanda

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Rwanda faces a severe shortage of specialists: with only 10 clinical oncologists, one paediatric oncologist, and a few trained palliative care professionals. Many healthcare workers report low confidence in delivering palliative care due to insufficient training. Palliative care in Rwanda is often stigmatized. The author, a pioneer physician of the palliative care programme in public health, advocates for "decolonizing" palliative care by reframing it through African philosophies. His "Safari Concept" uses animal metaphors to explain suffering and promotes "Ubuntu" to foster community engagement.

Palliative care, as defined by the World Health Organization (WHO), is an holistic approach that improves quality of life for patients and families facing life-threatening illness through the prevention and relief of suffering. This includes early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychological, or spiritual *(1)*. Globally, palliative care is recognized as a human right essential to dignity.

In Rwanda, and many low- and middle-income countries, palliative care is often misunderstood as end-of-life care. This narrow framing limits access to timely interventions that could otherwise support patients from the point of diagnosis. This article critically explores Rwanda's palliative care landscape for cancer patients, reviewing historical development, research findings, patient and caregiver experiences, and key policy recommendations.

Historical and policy context

Early developments and national policy

Before 2011, Rwanda had minimal access to strong analgesics such as morphine. In 2009, the government initiated a home-based care programme for terminally ill patients, largely delivered by family members, aligning with cultural preferences for home death *(2)*.

In 2011, Rwanda launched a standalone National Palliative Care Policy (NPCP), among the first in Africa. This policy sought universal access by 2020 and included the following strategic goals: access to essential medications, integration into all health levels, healthcare worker training, and monitoring mechanisms *(3)*.

By 2012, Rwanda began domestic production of oral morphine, easing concerns about opioid misuse. Nurses were authorized to prescribe morphine, enhancing access at the community level *(4)*.

Integration into broader health strategies

Palliative care is embedded in Rwanda's Health Sector Strategic Plan III and the National Cancer Control Plan *(5)*. These frameworks emphasize holistic cancer care, including symptom relief and psychological support, ensuring systemic integration rather than isolation *(5)*.

Decentralization and home-based care

Home-based care remains a primary delivery model. It resonates with cultural values and facilitates care for patients in rural areas. Rwanda's model reflects the Ubuntu philosophy, community-driven support for vulnerable individuals, which bolsters sustainability and cultural acceptability *(6)*.

Mukasahaha et al. *(7)* conducted a needs assessment in nine Rwandan hospitals. They found that 25% of inpatients had life-limiting illnesses, yet 99.2% had unmet palliative care needs. Only 8.1% were seen by palliative care services, highlighting a systemic gap between policy and practice. Despite domestic morphine production, barriers persist. Opiophobia, fear of opioid misuse, continues to affect prescription rates. Legal reforms have improved supply, but cultural beliefs and insufficient provider training hinder effective pain control *(8)*.

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Twahirwa et al. *(10)* studied 120 home caregivers. Despite high exposure to pain education, 53.3% did not consistently apply pain management techniques. Patient satisfaction was low, and caregivers experienced significant emotional and financial burdens. Only 20% were educated on end-of-life signs.

The Safari Concept: Culture and metaphors in response to suffering

In Rwanda, there is a proverb that states: "When you are well, you belong to yourself, but when you are sick, you belong to your family". The "Safari Concept" employs animal metaphors to articulate experiences of suffering and promotes the principle of *Ubuntu* as a means of fostering community engagement *(6)*. This framework provides a novel lens for rethinking palliative care in Africa, rendering it more accessible, culturally relevant, and humane in alignment with the continent's values and lived realities. It exemplifies the importance of cultural sensitivity and innovative thinking in the development of care models that are truly centred on both patients and their families, thereby advancing the vision of palliative care as a universal right adapted to local contexts.

Within the Rwandan context, decision-making in healthcare is situated at the intersection of patient autonomy and community responsibility. This dual emphasis forms the foundation of clinical and ethical choices. The Safari Concept emerged as a response to four persistent challenges:

- The exclusion of family members from the decision-making process;
- Communication difficulties between healthcare professionals and families;
- Challenges in identifying the appropriate next of kin in hospital settings, given the broad cultural definitions of family; and
- The frequent neglect of the emotional and psychological needs of family members.

Experiences accumulated over the past decade, particularly through encounters with families, reveal profound suffering that has often gone unrecognized and unaddressed by healthcare professionals. The size of the family group involved in these discussions is determined by the family rather than by clinicians and may range from as few as five to as many as 60 individuals. Given the centrality of animal metaphors in Kinyarwanda, it became necessary to adapt medical discourse in ways that demystify and destigmatize palliative care.

From more than 800 family meetings, 12 distinct animal archetypes were identified, each representing a specific communication approach with families. These archetypes emerged through the questions posed by families and their expressed expectations of care. Each metaphor is rooted in pre-existing Rwandan cultural narratives used to describe circumstances or emphasize concepts requiring greater attention. During family meetings, the practitioner's role frequently entails identifying the most influential family figure, often metaphorically referred to as the "Lion" or "Lioness." This metaphor illustrates the dynamics of family hierarchy, enhances the effectiveness of communication, and informs subsequent communication strategies. Consequently, it is essential to observe how individuals introduce themselves, as this provides insight into the roles of family members in the decision-making process:

- Introductions proceeding from the eldest to the youngest suggest a traditional family hierarchy rooted in cultural values and strong traditions;
- Introductions beginning with the youngest and moving upward to the eldest indicate that hierarchy is determined by influence rather than tradition, and such meetings are likely to be more challenging to manage; and
- Introductions starting with females before males suggest that the meeting will proceed smoothly, although the decision-making process will likely involve extensive discussion.

Rwanda is a landlocked country characterized by both urban and rural settings, with the majority of the population residing in rural areas. In the context of palliative care, it is also critical to recognize the diversity of educational backgrounds, environments, and perceptions of care. These differences manifest as follows:

- **Urban families** often regard extensive medical evaluations and treatments as expressions of care, even when outcomes may be unfavourable. They also tend to believe that society evaluates them based on the location of their loved one's death; and
- R**ural families,** on the other hand, generally prefer their loved ones to die at home, surrounded by family and the broader community. While this preference may be shaped by cultural values, financial limitations, and logistical considerations, such as transportation and home care resources, it should not be misinterpreted as a reflection of poverty or lack of sophistication. In fact, rural families may be more educated than initially assumed.

After gathering this information, we categorized the observed behaviours emerging from discussions – including emotions and perceptions of medical facts – through the use of animal archetypes. These archetypes are employed not to depict the individual but to symbolize the type of suffering experienced. While multiple archetypes may emerge, it is generally the predominant one that reflects the principal form of suffering and its associated representation Selected examples include:

- **Giraffe suffering: Distance**
  - Behaviour: Families hold unrealistic expectations, disregarding available local resources.
  - Interpretation: This reflects scepticism about the

competence and expertise of the local healthcare team.
  - Management: Engage in confident yet humble dialogue without undermining the family's sense of dignity.
- **Hyena suffering: Conflict**
  - Behaviour: Unresolved intra-family conflicts manifest in the hospital setting, impeding decision-making.
  - Interpretation: The dual role of individuals as both patients and social connections produces inevitable tension.
  - Management: Collaborate with the family's leading figure to safeguard the patient's interests.
- **Tortoise suffering: Armour**
  - Behaviour: Families demonstrate a strong reliance on various potential cures, including religious beliefs, traditional healing practices, and philosophies.
  - Interpretation: This orientation reflects a desire for redemption or the fulfilment of unfinished responsibilities.
  - Management: Employ carefully chosen language to ensure respectful and effective communication.
- **Porcupine suffering: Haunting**
  - Behaviour: Families continually redirect present illness discussions towards past traumatic experiences.
  - Interpretation: This reveals a deep entanglement of past and present that complicates meaningful dialogue.
  - Management: Provide healthcare teams with education, training, and wellness support to strengthen resilience in the face of emotionally taxing interactions.

Lessons learnt

Traditional palliative care existed before modern palliative existed. The current model of palliative care comes from a different culture and understanding, which may harm patients' and families' choices. It is important to create a model that focuses on a community-centred approach beyond disease outcomes.

Context matters. The adaptation of existing tools or metrics should follow an adoption process based on the perceptions of care, instead of being transposed from a model to another context. For example, translating the five stages of Elisabeth Kubler-Ross into Kinyarwanda would be difficult to do, and mostly impossible to teach because of cultural differences. But using the Safari Concept tool, even for someone not familiar with palliative care, it resonates for the majority of Rwandans.

Terminology is crucial. The experiences with Rwandan patients revealed that the terminology "end-of-life care" has no meaning in the Rwandan philosophy of life. The appropriate term is "Life until the end", which reflects a deep connection with the person to the last breath, and that has to be done together with family members, not alone.

The way people die reflects how society lives. As Rwandan society is based on community, good death and bad death are not related to the disease outcomes or active treatments. Understanding suffering through the lens of African culture and community reveals a complex, interconnected web where the individual's experience is inextricably linked to their social, spiritual, and moral environment. For any intervention or care, particularly in fields like palliative care, a deep appreciation of these cultural nuances is not just beneficial but essential for providing truly person-centred and effective support. Ignoring these dimensions risks alienating individuals and communities from care that could otherwise be profoundly impactful.

Innovations and collaborations

Educational partnerships

Transnational collaborations have accelerated progress. The Human Resources for Health Program and Dana-Farber's Global Cancer Medicine Center have supported training, policy development, and the establishment of palliative teams at Butaro Cancer Center *(4)*.

Advance care planning (ACP)

Advance care planning is emerging as a key focus. Despite the NPCP, ACP is rarely practiced due to low awareness and training deficits. Efforts are underway to embed ACP into routine cancer care at both hospital and community levels *(9)*.

Research gaps and monitoring

While epidemiological data exist, research into context-specific models of care remains limited. The African Palliative Care Association calls for more implementation science to develop culturally adapted frameworks suitable for low- and middle-income countries like Rwanda *(11)*.

Conclusion and recommendations

Summary of achievements

Rwanda's pioneering NPCP, integration into national health plans, and domestic morphine production mark significant strides. Cultural alignment through *Ubuntu* and decentralized care enhances sustainability. However, challenges persist: unmet needs, opioid misconceptions, human resource deficits, and caregiver burdens.

Policy recommendations

- Strengthen legal frameworks to ease opioid access while ensuring safety.
- Systematically integrate palliative care into all health programmes and insurance schemes.
- Fund and expand community-based models aligned with cultural preferences.

Practice recommendations

- Scale up training across all health worker cadres.
- Establish ongoing mentorship and support for caregivers.
- Embed psycho-social services and ACP in standard care.

Research recommendations

- Invest in context-specific implementation science.
- Develop robust monitoring systems.
- Sustain mutually beneficial international partnerships.

By reinforcing these pillars, Rwanda can move beyond isolated success stories to a national framework that ensures dignity, alleviates suffering, and supports both patients and caregivers across the cancer journey. ■

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