

# Challenges and Opportunities in Expanding Palliative Care Access in Ethiopia

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## Abstract

Palliative care in Ethiopia is constrained, especially in rural areas where the majority of the population resides. Present efforts and research are urban-centric and reliant on external donors. This study explores the status of palliative care, the factors enabling or hindering it, in Ethiopia's rural and regional healthcare contexts. For this qualitative regional case study, healthcare professionals from diverse backgrounds, including health planners and practitioners, participated in focus groups with rural community members and individual interviews. The findings reveal a lack of integration of palliative care into the healthcare system and limited inclusion in educational programs. Challenges include low awareness, insufficient care for chronically ill patients beyond those with HIV, and a misconception that palliative care falls outside the scope of their services. Consequently, families and patients often resort to informal care options. To improve palliative care access, recommendations include better integration into national healthcare plans and academic curricula, along with the utilization of mobile technology. Policy makers are encouraged to consider a multifaceted approach, encompassing home, community, and facility-based models, for palliative care implementation in rural and regional settings.

**Keywords:** Palliative care; Ethiopia; Rural areas; Healthcare system; Holistic care

## Introduction

Access to palliative care is recognized as a fundamental international human right [1]. International forums and frameworks emphasize the obligation of nations to provide non-discriminatory access to care, essential medications, and necessary services to uphold these rights [2]. Globally, more than 56.8 million individuals require palliative care each year, comprising 31.1 million in need of early-stage care and 25.7 million nearing the end of life [3,4]. A significant majority of these individuals reside in low- and middle-income countries (LMICs), with the majority originating from low-income nations. However, in Africa, less than 5% of those requiring palliative care receive the necessary services, although there has been some progress in recent years [5,6]. This limited access may be attributed to factors such as morphine shortages, a severe scarcity of healthcare professionals, and the absence of palliative care within healthcare education and systems. Alarming, 45% of African countries lack identified hospice or palliative care facilities [7,8].

Ethiopia has initiated several palliative care projects, with integration into the national healthcare plan, policies, and guidelines. Healthcare providers have received training in this regard. However, palliative care in Ethiopia remains heavily reliant on donor support and primarily concentrated in urban areas, despite more than 78% of the population residing in rural regions. In this context, rural healthcare is provided in the countryside surrounding villages, often through health posts where health extension workers (HEW), also known as community health workers (CHW), deliver essential services. Regional healthcare, on the other hand, encompasses primary, secondary, and tertiary services within an administrative state or region of the country. Comprehensive palliative care encompasses the physical, social, psychological, cultural, and spiritual well-being of individuals. The limited availability of palliative care in Ethiopia can be attributed to the low awareness of comprehensive palliative care services among policymakers, healthcare professionals, and community members. Additionally, financial and human resource constraints, weak collaboration among stakeholders, and the absence of a holistic approach contribute to the challenges faced by palliative care in the country [9]. As a result, millions of Ethiopians

continue to experience limited or no access to essential palliative care services. In Ethiopia, there is a notable absence of comprehensive data regarding the provision of palliative care services and the corresponding needs. A handful of nonprofit non-governmental organizations, such as Hospice Ethiopia, Mary Joy Development Association (MJDA), and Beza for Generation (B4G), are actively involved in offering home-based support. Hospice Ethiopia, for instance, directs its clients to public referral hospitals, including Black Lion Hospital (Tikur Anbesa Specialized Tertiary Hospital), St. Paul Hospital, and Yekatit Hospital in Addis Ababa, where palliative care services are available. Although these hospitals provide limited inpatient care, none of them offer home-based palliative care programs. Furthermore, access to oral morphine is restricted, and the availability of specific palliative care education in the country is extremely limited, with only 1 to 2 trained staff members focusing on palliative care within these hospitals [10]. All of these services are centralized in the capital city, Addis Ababa, which necessitates rural patients to undertake arduous journeys, often exceeding 500 kilometers, to access vital resources such as oncologists, pathologists, radiation therapists, or palliative medication and care. Therefore, this study is designed to investigate the current state of palliative care, the factors facilitating or impeding its implementation, in Ethiopia's rural and regional healthcare settings.

## Methods

### Study design

To investigate the enabling factors and implementation challenges

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of palliative care in rural and regional healthcare settings, a qualitative case study approach was employed, guided by a pragmatist worldview methodology, which offers flexibility in data collection and analysis. In-depth interviews were conducted with a total of 42 participants hailing from one of Ethiopia's eleven administrative regions. Ethiopia's healthcare system operates on a three-tier model, encompassing primary healthcare units (PHCU), secondary care (general hospitals), and tertiary care (comprehensive specialized hospitals). The specifics of the study settings are discussed in detail elsewhere. The national palliative care guideline provides comprehensive instructions on how and where palliative care should be integrated into each level of the healthcare system.

**Study participants and recruitment:** The study focused on professionals working in selected healthcare units within the healthcare settings, regional health representatives, tertiary health school heads, and rural community members residing in the chosen villages for a minimum of six months. A total of 42 participants were purposefully selected from units and settings within the region. This included two policymakers from the Regional Health Bureau, seven pharmacists, five doctors, four health officers (clinical officers), and 17 nursing leaders, including chief nursing officers, who held leadership roles in various healthcare institutions. Additionally, three academic leaders from nursing, medicine, and pharmacy schools at universities and one regional health college, as well as three Health Extension Workers (HEWs) deployed in rural health posts, were part of the participant pool. Detailed participant information is available elsewhere. An interview framework was consistently used for all participants, tailored to their respective specialties. For instance, questions posed to academic leaders placed greater emphasis on palliative care education, while pharmacists focused on medication availability, and nurses and doctors concentrated on service implementation. Most interviews were conducted in the local language, with exceptions for three school leaders and two hospital leaders who preferred English [11,12]. Two focus groups, each consisting of eight rural adult community members, including farmers of both genders and community and religious leaders, were conducted. The focus group discussions revolved around strategies employed for caring for individuals with life-limiting illnesses and the challenges associated with rural caregiving. Topics encompassed the state of palliative care services, sustainable public health approaches to palliative care provision, and challenges at all healthcare levels. These focus groups, conducted in the local language, lasted 45 to 50 minutes and were facilitated by the author (AA).

**Data collection:** The study took place in late 2018, with interview guides developed based on the four key components of public health strategy: policy, education, medication availability, and implementation. For the focus groups, questions were adapted from existing literature and aimed to capture the experiences of community members in caring for individuals with life-limiting illnesses. The majority of interviews and focus groups were conducted in the local language, facilitated by the author (AA) and recorded using an audio recorder, ensuring confidentiality. To maintain anonymity, the original recordings, as well as their translations and transcriptions, were de-identified. The data were translated from the local language to English and back-translated into the local language, although some words may not have exact English equivalents. The translation and transcription were performed by the author (AA), potentially introducing some researcher bias. To mitigate this bias, the research team systematically reviewed the data and questioned the researcher regarding the concepts during the results development stage.

**Qualitative data analysis:** The analysis of qualitative data followed a thematic analysis approach, guided by established methodologies. The thematic analysis involved six key steps:

- Familiarization with the data: The process commenced with a thorough immersion in the data, gaining a deep understanding of the content.
- Systematic coding of core features: Core features and patterns in the data were systematically identified and coded.
- Searching and gathering relevant data: Data relevant to the research objectives were collected, and potential themes were developed based on this information.
- Checking themes for relevance with codes: The emerging themes were cross-checked for consistency and relevance with the underlying codes that defined them.
- Scholarly Report Writing: The final analysis was documented in a scholarly report, detailing the identified themes and their implications.
- In the final step, the developed themes were synthesized to offer a comprehensive depiction of palliative care practices and to pinpoint the obstacles and facilitators in delivering palliative care in rural and regional healthcare settings. Verbatim transcription of the audio files from interviews, conducted in the interviewees' language, was carried out by the author (AA). The data analysis was facilitated by the use of NVivo 12, a software package designed for qualitative analysis [13].
- Rigor: The rigor of the qualitative research was maintained through four distinct criteria, which encompassed credibility, dependability, confirmability, and transferability. Detailed information regarding the rigor criteria can be found elsewhere.

## Results

Within this theme, the status of palliative care in rural and regional healthcare settings is described through three sub-themes: palliative care for chronically ill patients, disease-specific palliative care (with a focus on HIV patients), and holistic palliative care.

### Palliative care for chronically ill patients

Participants acknowledged that certain aspects of palliative care, such as physical care, pain management, and psychosocial support, were available to chronically ill patients. However, these services were often insufficient and fragmented. A medical doctor from a comprehensive specialized hospital pointed out that they primarily focused on pain management and disease pathology, rather than offering comprehensive palliative care. Another doctor noted that physicians mainly concentrated on treatment, while nurses provided psychosocial support. However, the provision of holistic palliative care was not the responsibility of the oncology unit, as noted by a clinical nurse leader in that unit. Likewise, clinical ward nurses in the comprehensive specialized hospital primarily focused on physical care, such as feeding and preventing bedsores, rather than offering holistic palliative care. Some nurses also provided psychological and economic support to patients and their families. However, bereavement care for families was often lacking. Palliative care was noted to be primarily limited to HIV patients. International non-governmental organizations provided funding for this care, which was often administered at home. Participants highlighted the strong support for the HIV program, with funding and attention from governmental and non-governmental

organizations. However, the sustainability of palliative care, even for HIV patients, was questioned due to its heavy reliance on donor funds.

**Holistic palliative care:** Participants observed a lack of holistic palliative care, regardless of the disease or hospital setting. While some medical professionals provided medication, measured vital signs, and offered advice to patients, the care provided was not considered holistic palliative care. Some participants felt that palliative care was not systematically or thoroughly implemented in the healthcare system. Patients diagnosed with incurable illnesses often received inadequate information about their care options upon discharge from the hospital. Within this theme, four sub-themes emerged as barriers to palliative care provision: awareness, leadership, and policy-related challenges; education-related challenges; costs of palliative care; and socio-cultural attitudes, norms, and other constraints.

**Awareness, leadership, and policy-related challenges:** Participants noted that palliative care received insufficient attention in healthcare policies and that it should be a concern for both national and regional governments. The absence of clear government leadership and direction on palliative care was highlighted, and participants emphasized the need for leadership, budget allocation, and policy support from the federal and regional health authorities. Limited awareness of national health policies and guidelines related to palliative care among educational leaders and healthcare workers at all levels was identified as a key challenge. Some participants were unaware of the National Palliative Care policy and felt that the documents were not well distributed. Overall, there was a lack of awareness among healthcare professionals, including nurses, doctors, and health workers.

**Education-related challenges:** Participants pointed out that medical education curricula did not adequately cover palliative care. While some nursing programs included palliative care in diploma and specialty programs, the teaching and assessment of palliative care depended on individual lecturers' interests. Gaps in the formal curriculum were not effectively addressed through in-service training, leading to a lack of trained staff and high staff turnover. Furthermore, healthcare professionals faced challenges in applying theoretical knowledge to their practice due to a lack of necessary resources.

**Costs of palliative care:** The cost of palliative care services, particularly the expense of medications, had a significant impact on the provision of care. The scarcity of hard currency in the country made it challenging to provide continuous palliative care. Some patients and their families preferred for the patient to die at home, mainly due to the high costs associated with hospital care. Private for-profit options existed but were often unaffordable for many patients.

**Socio-cultural attitudes, norms, and other constraints:** Socio-cultural attitudes and community preferences influenced where and how patients received care. Families often sought to have their loved ones die at home, even when the cost was not a concern. These community attitudes also affected healthcare professionals' perspectives and attitudes. In some cases, traditional and alternative healing practices were pursued by patients and their families, in addition to seeking medical care.

## Discussion

This study sought to investigate the status of palliative care, the factors enabling or hindering its implementation, and the associated challenges in rural and regional healthcare settings in Ethiopia. The findings highlight significant systemic barriers and enabling factors in delivering palliative care in these settings. This discussion will delve

into the implications of the study's findings and how they align with previous research while suggesting potential solutions and strategies to improve palliative care access [14].

**Focusing on preventable and curable diseases:** The study reveals a concerning trend where healthcare facilities in Ethiopia prioritize the treatment of preventable and curable diseases, often sidelining palliative care. As a result, palliative care provided to chronically ill patients is limited to physical care, pain management, and psychosocial support. The absence of comprehensive or holistic palliative care leaves patients and their families seeking alternative care options through private clinics, charitable organizations, religious entities, or traditional healers.

**Barriers to palliative care implementation:** The study identifies several critical systemic barriers to implementing palliative care in Ethiopia:

**Limited national leadership and focus:** Palliative care is not receiving the attention it deserves in national and regional healthcare policy frameworks [15]. There is a lack of clear government leadership and direction regarding palliative care. Participants stress the importance of government involvement and financial support.

**Lack of awareness:** The lack of awareness of palliative care among political leaders, healthcare professionals, and community members is a significant challenge. Professionals and even leaders of academic institutions in the healthcare field lack awareness of palliative care. This lack of awareness is a barrier to providing adequate palliative care, as patients and caregivers cannot access services they are unaware of.

**Cultural norms and attitudes:** Socio-cultural attitudes and norms in Ethiopian communities significantly influence patients' and families' preferences for home-based care, even when hospital care is available and affordable. Traditional and alternative healing practices are commonly pursued alongside medical care.

**Education-related challenges:** Medical education curricula in Ethiopia do not sufficiently cover palliative care. In-service training opportunities for palliative care are limited, and these training initiatives are not consistently integrated into healthcare facilities. This lack of training results in a shortage of trained palliative care staff.

**Cost of palliative care:** The cost of palliative care, particularly the expense of medications, has a substantial impact on the provision of services. Patients and their families often prefer home-based care to hospital care for cost reasons, even when it is not the best option for the patient's condition.

**Enabling factors:** On the positive side, the study identifies several enabling factors that could improve palliative care access in rural and regional areas:

**Integrated referral system and service delivery model:** Integrating palliative care into existing healthcare service delivery models and establishing a well-structured referral system can improve access to palliative care in these settings.

**Utilizing a reserve health workforce:** Utilizing unemployed and retired nurses and other healthcare specialists can help address the shortage of trained palliative care professionals.

**Palliative care education:** Improving the availability and consistency of palliative care education in universities and colleges is vital to building a healthcare workforce knowledgeable in palliative care.

**Community resources:** Private clinics, charities, religious organizations, and volunteer caregivers can serve as valuable resources for community-based palliative care.

**Technology and health insurance initiatives:** Leveraging mobile phone technology, ongoing health insurance programs, and existing healthcare worker programs, such as Health Extension Workers (HEWs) and the Health Development Army, can improve palliative care access in rural and regional settings.

**Palliative care for HIV patients and sustainability concerns:** The study highlights the contrast between palliative care for HIV patients and other chronic illnesses. While there is some home and facility-based palliative care for HIV patients, concerns about the sustainability of these services due to donor dependence are raised.

**Similarities with Previous Research:** The findings of this study align with previous research conducted in Ethiopia. For example, a study by Kaba et al. reported that the actual practice of palliative care was limited to physical care and financial support. Additionally, Mamo et al. indicated that the existing care model primarily focused on pain management rather than holistic palliative care.

There are several initiatives within the region and at the national level that can improve palliative care access. For instance, palliative care is well integrated into Ethiopia's five-year healthcare plans and guidelines. Integrating basic palliative care into primary healthcare and training community health workers could enhance community access to and home-based palliative care. Community-based self-help groups, such as 'iddir,' traditionally associated with funeral support, have already started to provide basic home-based care and support to HIV patients and families. Pre-service and in-service training opportunities could be organized by universities and regional health science colleges. Health Extension Workers (HEWs) could serve as a bridge between community volunteers and healthcare staff providing palliative care services at different healthcare levels.

**Limitations:** The study has a few limitations. Firstly, the findings may not be fully generalizable to other regions in Ethiopia, as the study's participants and educational institutions were purposefully recruited from a single region. Additionally, the ongoing COVID-19 pandemic and the recent civil conflict in Ethiopia may have influenced the focus and priorities of the national health policy. In conclusion, this study highlights the challenges and enabling factors for palliative care in rural and regional healthcare settings in Ethiopia. The barriers to palliative care implementation are significant and complex, but there are also promising opportunities to improve access to palliative care through better education, leveraging community resources, and establishing structured referral systems. Further research and collaborative efforts are needed to address these challenges and ensure that palliative care becomes an integral part of healthcare in Ethiopia.

## Conclusion

Palliative care in Ethiopia is severely limited, especially in rural regions where over 78% of the population resides. Existing efforts and research predominantly target urban areas and heavily rely on donor support. The study highlights a significant absence of holistic care, revealing multiple obstacles. These obstacles include a lack of

awareness about palliative care, fragmented interventions for patients (excluding those with HIV), and the failure to integrate palliative care into both the healthcare system and educational curricula. However, the study also identifies factors that enhance access to comprehensive palliative care, emphasizing a blend of home, community, and facility-based approaches.

## Acknowledgement

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## Conflict of Interest

Author declares no conflict of interest.

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