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# Palliative Care in HIV/AIDS

*Habtamu Abera Areri*

## Abstract

In the era of HIV, palliative care is important to improve the quality of life of people living with HIV. The core activities of palliative care are control of symptoms and psychological, social, and spiritual problems. As a matter of fact, people living with HIV have a high burden of physical, psychological, and social difficulties which require palliative care that is holistic care. This implies palliative care for people living with HIV improves their emotion, physical symptoms, and psychosocial and spiritual functions. It can be provided by trained healthcare professionals, families, and community caregivers. HIV care and treatment guidelines should address the principles of palliative care, and policy should be in place to enforce its implementation for improving the quality of life of people living with HIV.

**Keywords:** palliative care, HIV, people living with HIV

## 1. Introduction

Palliative care refers to the active total care of patients whose disease is not responsive to curative treatment to improve their quality of life. The main goal of palliative care is achieving the best possible quality of life. In the process of palliative care, the core activities are control of symptoms and psychological, social, and spiritual problems [1]. This implies palliative care is a comprehensive care to solve physical, emotional, and spiritual impact of HIV/AIDS has on a person, no matter the stage of the illness [2, 3].

HIV is becoming a chronic condition that needs prolonged medical individual-centred care [4]. People living with HIV have a high burden of physical, psychological, and social difficulties which require palliative care that is holistic care and is recognised by the World Health Organization (WHO) as an essential element of HIV care, from diagnosis to end of life. According to Huang [4], in the management programme of HIV, palliative care should be integral to alleviate the distress and helps the people living with HIV to lead better quality of life. This means, in the continuum of HIV/AIDS, people living with this condition suffer from symptoms that are caused by opportunistic infections, the virus itself, or the side effects of antiretroviral drugs. Thus, to improve the individuals' quality of life requires to focus on palliative care, and enforcement of its implementation is critically important [3].

More importantly, people living with HIV need palliative care for many reasons such as pain, cough, nausea, weakness, fever, diarrhoea, breathing problems, other comorbidities, aging, and complex decision-making. Palliative care for these populations is a means of managing these challenging experiences and minimising burden on hospital resources [5]. Therefore, in the era of HIV, compressive package of care is critically important and should be in place in all HIV treatment guidelines.

## 2. Settings of palliative care

Palliative care includes a wide range of interventions to improve the quality of life of people living with HIV and their families. The delivery sites for providing palliative care include home, community, and facility based [6, 7]. However, it can be given based on patient preference.

**Home-based palliative care:** It is an affordable approach in resource-poor setting and plays a significant role for a large proportion of people living with HIV and their families. Most people living with HIV prefer home-based palliative care. It requires training and education for healthcare providers like nurses, medical doctors, and community care providers. The training should focus on:

- Clinical diagnosis and treatment
- Basic nursing care
- Procedure of referral for better facilities
- Communication skills

**Community-based palliative care:** These include clinics, day care centres, school-based clinics, health centres, and work place clinics.

**Facility-based palliative care:** These sites include hospitals which provide both outpatient and inpatient clinical care by trained healthcare providers in the form of follow-up and admission. The specific palliative care activities carried out in hospital (facility based) based are assessment, symptom management, and consultation; discharge planning for all palliative care patients; and education of healthcare providers throughout the hospital [6, 7].

## 3. Who provides palliative care?

Palliative care can be provided by several categories of trained healthcare workers like physicians, nurses, and palliative specialists and by trained family and community care providers. Each category of providers has a unique role and training needs [7]:

- **Medical providers:** The role of medical providers includes assessment, prevention, diagnosis, treatment, and management of pain and suffering experienced by PLWHA and their families. They can provide medical and psychological support including necessary drugs to control symptoms that occur because of HIV-related disease. Thus, palliative care should be an integral part of nursing and medical school courses. That helps medical providers to diagnose and treat people living with HIV and their families. For this purpose, training and education of medical providers is critical [7, 8].
- **Traditional healers:** These groups of healthcare providers are linked between medical providers and community care providers in many parts of the health system and critical in improving access to care. The traditional healers are familiar to the family and individual needs. It is simple for traditional healers to explain the meaning of illness and death for families. Therefore, it is vital to train and include traditional healers in palliative care [7].
- **Family and community caregivers:** Friends, relatives, and others in the community can be trained to ensure that the patient is comfortable. The use of

trained community caregivers such as volunteers, medical assistants, counselors, and family members could provide and create opportunity to expand the provision of palliative care in community setting. These trained community caregivers can provide basic care, support drug adherence, symptom management, referral, counselling on diet, and social support. Families and friends should be provided with support even after the death of the patient. Bereavement counselling is an opportunity to support the loss of the affected loved ones and to consider the future [7, 8].

- Palliative care should be included in the curriculum of medical, nursing, and other health professional students to ensure that healthcare workers are sufficiently prepared to care for PLWHA in all settings and are able to train family members and community volunteers [8].

#### 4. Principles of palliative care

People living with HIV need palliative care for symptom management, psychological support, spiritual support, and end-of-life support [8, 9]. Therefore, to fulfil these requirements, the guiding principles are to:

- ***Provide relief from distressing symptoms to enhance quality of life:*** There are many distressing symptoms occurring in people living with HIV which need serious effort to improve quality of life, regardless of the stage of illness.
- ***Integrate the psychological and spiritual aspects of patient care:*** Since palliative care is a holistic approach, services should consider the physical, emotional, spiritual, and social aspects equally. Therefore, interdisciplinary approach of services should be provided to better address the diverse needs of people living with HIV.
- Offer support to help patients live as actively as possible.
- Offer support to help families cope during illness and bereavement.
- Draw on experience and communication between the patient and healthcare provider to provide the best combination of interventions and medications.
- Affirm life and regard dying as a normal process.
- Strive neither to hasten nor postpone death [2, 3].

The crucial elements of palliative care in people living with HIV are the relief of pain related to physical, social, psychological, and spiritual aspects and enabling and supporting caregivers to work. The ranges of palliative care needed for people living with HIV are:

- Pain relief
- Treatment of other symptoms like nausea, fatigue, and weakness
- Supports (psychosocial, spiritual, for families and caregivers)
- Infection control [8, 9]

## 5. Palliative care for people living with HIV

Palliative care is critically important for people living with HIV to address multiple problems related to the diseases, its medication, and complications like pain, drug adverse effects, emotional distress, and physical symptoms [5]. These groups of patients experience a high degree of emotional problems like anxiety, depression, and mental health problems compared to general population [10]. Moreover, it is important for people living with HIV because of the following dimensions [8, 9]:

- **Complex disease process:** People living with HIV are suffering from ranges of several complications and opportunistic infections and related treatment side effects.
- **Complex treatments:** People living with HIV need lifetime treatment for viral suppression and treatment for comorbidities which will also create stress on the daily life of the patient.
- **Stigmatisation and discrimination:** In many parts of the world, people living with HIV are still suffering from stigmatisation and discrimination.
- **Complex family issues:** The disease has a great impact on the productivity of the family. The financial burden will increase as parents got infected and progress to advance illness.
- **The burden on healthcare workers:** The healthcare workers face stress related to lack of resources, symptom management, and management of related complications.

## 6. Ranges of treatment needed for people living with HIV

Palliative care needs for people living with HIV are multifaceted, depending on many factors such as the stage of the disease, the health infrastructure or system of each country, and the socio-economic status of patients. People living with HIV need palliative care for symptom and other related problem managements. Globally about 5.7% of adults living with HIV are needing palliative care at the end of life. The government should integrate palliative care policy in the national health delivery to improve the HIV care delivery system [11]. The service delivery should be patient centred which should be individualised, flexible, and collaborative. Communication should be open that will facilitate for shared decision-making during treatment planning [12, 13]. Therefore, people living with HIV need palliative care for symptom management, psychological support, family support, spiritual support, etc.

## 7. Symptom management

The treatment of people living with HIV requires the balance between acute and control of symptoms. Many people living with the disease suffer from different symptoms including pain. The common symptoms that require treatment are pain, nausea, vomiting, diarrhoea, weight loss, sleep disturbance, depression, mouth sore, sadness, fever, cough, skin problem, and respiratory problems [14, 15].

The central focus of palliative care is symptom management. For symptom management, opioids are essential for pain management. It is vitally important to consider the WHO pain management ladder. However, the plan for pain management

depends on the individual preference. Managing symptoms enables people living with HIV to function fully. The need for palliative care for people living with HIV arises from the disease and its associated complications like varieties of symptoms and side effects of the drug management [8].

*Pain* is the most common symptom patients are suffering from and for which they should be treated if they complain of it. It can be managed both medically and psychologically. Spiritual and emotional support and counselling should always include the medical management of pain of people living with HIV. Deep breathing techniques, relaxation, and distracting attention of patients will also help as relieving methods for pain symptoms [8, 16].

*Nausea and vomiting* are another common distressing symptom the patients need to get advice on foods and feeding habits. The patients need to drink water, tea, ginger, etc. to get rid of the symptoms. The person with these problems should identify and avoid aggravating factors.

*Diarrhoea* is also a common problem which needs management. It may be a side effect of antiretroviral regimens; other causes include Cytomegalovirus colitis, cryptosporidiosis, microsporidiosis, giardiasis, Kaposi sarcoma, and other infective agents. Oral rehydrating solutions should be given to prevent dehydration. Use oral rehydration solution if there is a large volume of diarrhoea. *Encourage the patient to drink plenty of fluids to replace lost water.* If it is not possible to get oral rehydrating solutions, local remedies could be considered. To prevent and control diarrhoeal symptoms, it is advisable to avoid eating raw foods. In general, for diarrhoeal disease management, it is recommended to increase frequency of food intake, such as rice soup, porridge, ORS, bananas, and other soups [16].

*Mouth sore* is perhaps more than any other symptoms that could affect communication as well as comfort of people living with HIV. A sore mouth is very common in palliative care and may be severe in people living with HIV. It causes painful swallowing which may be caused by Cytomegalovirus ulcers of the mouth or oesophagus, virus, or fungal infection. In most cases it can be prevented by keeping the mouth clean and moist and treating any infections promptly. Nystatin oral drops after food and at night hold dose in the mouth to allow it to act topically. For fluconazole 50 mg daily for 5 days, use higher doses (200 mg daily for 2 weeks) if patient has difficulty swallowing and you suspect oesophageal candidiasis. Rinsing the mouth with diluted salt water after eating and at bedtime is the recommended care for patients with mouth sore [16, 17].

*Fever* in people living with HIV infection usually suggests an infectious complication. It may be a side effect of antiretroviral regimens; if suspected, assess and treat cause with paracetamol or acetylsalicylic acid, and encourage the patient to drink water, diluted tea, or fruit juice frequently. Fever, cough, weight loss, and night sweats in an HIV-infected person may indicate a heightened suspicion of tuberculosis (TB). At all stages of HIV, TB must be diagnosed, treated, and controlled. If fever is persisting, palliative care team must agree to do all that could minimise suffering [16].

*Weight loss* is also another challenge in the management of HIV conditions despite the use of antiretroviral therapy. Resting energy expenditure is high, and, therefore, food intake should be increased to prevent detectable risk of death. There are different related factors with weight loss in people living with HIV. These include mouth sore, disease of the upper gastrointestinal tract, anorexia, side effects of drugs, food insecurity, malabsorption due to diarrhoeal disease, and poorly controlled infections [16, 17].

*Sleep disturbance* like insomnias, which is a subjective complaint of inadequate nocturnal sleep, is manifested as difficulty of initiating or maintaining sleep, early-morning awakening, non-restful sleep, or a combination of all of these. In many cases insomnia is a symptom of another mental or physical disorder which includes pain,

anxiety, depression, drug withdrawal, and side effects of certain ARV regimens, especially those with efavirenz [17]. A general care for sleep disturbance includes:

- Assessing and managing the cause
- Reducing the intake of stimulants and avoiding alcohol near bedtime
- Exercising regularly in the earlier part of the day
- Providing benzodiazepines

*Respiratory symptoms* are also common problems people living with HIV are suffering from. For instance, cough or difficulty breathing may be due to common opportunistic infections seen in people living with HIV. Difficulty in breathing is a frightening experience due to fear of death. Therefore, as a general care:

- *Position the patient to sitting to maximise ventilation.*
- *Ensure good ventilation by opening windows, using a fan.*
- *Adjust activity to help slow and deep breathing [17].*

## 8. Psychological support

People living with HIV face different aspects of psychological problems that require different forms of support [9, 14, 15]. These include:

- Counselling and testing
- Psychological and spiritual support
- Preparing for death

## 9. Psychosocial and spiritual support

People living with HIV need psychological and spiritual support critically important for coping with the overwhelming feelings and the threat of death. Psychological support helps people living with HIV to adapt to the disease and its complications. People living with HIV should disclose and involve in networking to get support from family, peers, and support groups. A multidisciplinary team is needed to address various concerns of people living with HIV. Psychosocial support for people living with HIV should also address finances, housing, and assistance with daily living. Spiritual support helps them to understand the meaning of life and improves belief and their faith. Spiritual support is also considered as resources for self-managing for these category populations [15, 16].

## 10. Support for the caregivers

Caregivers are frequently feeling anxious or have problems with sleeping, as the person they care for comes closer to the end of life. Mild psychological

distress is usually relieved by emotional support from health workers by explaining the physical and psychological symptoms and challenging beliefs about death and dying. Through palliative care application, healthcare providers can reassure the caregivers and that you can give them more information and support [9, 14, 15].

## **11. Preparing for death**

Preparing for death starts with effective communication with the family. Starting to talk on distressing concern helps both the families and the patients regard will, care of families, and related costs. Discussing sensitively about dying and grief reaction is an important aspect of care for people living with HIV and their caregivers [9, 15].

## **12. Benefits of palliative care**

The benefits of palliative care are numerous which include the impact of palliative care on physical, emotional, social, and spiritual well-being. Managing symptoms affects overall functioning and plays a role in supporting ART adherence along with engagement and retention in HIV care. Palliative care as a complement to other care may contribute to a comprehensive HIV treatment. It is also a cost-effective approach that helps to reduce disease burden. Routine implementation of palliative care could contribute to manage complications and, thereby, enhance overall HIV care [18, 19]. It improves the outcome for patients with HIV and may complement antiretroviral treatment by increasing adherence through better management of side effects from the treatment, providing holistic and end-of-life care when necessary. Overall, palliative care will provide the following benefits:

- It improves quality of life of patient and families.
- It promotes better health outcomes, adherence, and retention and prolongs survival.
- It causes patients to spend more time at home and reduces the number of hospital inpatient days.
- It provides patient, family, and caretakers satisfaction.
- It reduces overall cost of disease [15].

## **13. Establishing palliative care programme**

The World Health Organization recommends three important programmes for effective national palliative care programme such as policies, education, and availability of drugs. Government policies must be placed to support palliative care. For the healthcare providers and other concerned palliative care, education must be available. Finally, for the management of pain and other symptoms, appropriate medications must be available. These three programmes are essential for establishing palliative care programmes [9, 15].

## **14. Palliative care policies**

The World Health Organization recommends that all countries should adopt a national palliative care policy, ensure the training and education of health professionals, ensure the availability of morphine in all healthcare settings, and ensure standards for pain relief and palliative care are progressively adopted at all levels of care [6, 7]. Therefore, palliative care programme should be an integral part of the national healthcare system [HIV care and treatment]. The presence of appropriate policy helps to solve existing obstacle, access drugs, and facilitate for resource and funding. Public health approach is a key approach of national plan that can be established through home care and community support [3, 9].

Policies can be generated from various levels of government and public and private institutions, such as medical and nursing schools, public and private healthcare facilities, and community-based organisations [6, 7]. Key actions for policy development include:

- Identifying the role of healthcare providers.
- Training and developing capacity of healthcare providers.
- Offering access to a wide range of medications for symptom and opportunistic infections.
- Establishing evidence-based programmes.
- Working with other stakeholders especially key governmental officials to promote policies and programmes to enhance access to pain and symptom control medications. Availability and prescribing opioids require strong policy support.

## **15. Palliative care training and education**

Palliative care training and education should be an integral part of nursing and medical schools. Educated healthcare providers can provide better palliative care. There should be also continuous professional development on the area of palliative care for caregivers. Its effectiveness for people living with HIV depends on the providers' skills and is only as good as the skills of its providers. Therefore, palliative care training and education helps its implementation in an effective way [9, 14]. The training programme of palliative care should address three areas: [1] attitudes, beliefs, and values, [2] knowledge base, and [3] skills [15].

The best training includes hands-on clinical experience under the supervision of a skilled professional who serves as a mentor and guides colleagues in every aspect of palliative care ranging from symptom management, especially pain control, to the art of listening. Healthcare professionals should get interdisciplinary training which also provides them an opportunity for establishing a team that helps them understand and respect each other. Training and education will avoid misconception about palliative care especially regarding pain management [9].

## **16. Presence of drugs for palliative care**

Drugs used for HIV pain and other symptom managements should be available and regulated by government policies. The drug list for palliative care in HIV is

basic and short, and it can be found on any country's essential drug list. However, availability of these drugs for palliative care may be hindered by government policies regulating controlled substances such as opioids for distributing and dispensing the drugs. Palliative care professional should also advocate for legislative or regulatory changes at all level to make appropriate drugs because some of the drugs may not be legal in some countries, for instance, opioids. Procedural barriers may also need to be overcome for drugs to people living with HIV. However, drug availability is not only dependent on appropriate policy and efficient procedures, but also there should be policy for efficient way of utilisation, and the drugs should be available all the time to patients suffering from pain [9, 14].

Symptom control medications in palliative care that include essential medications for opportunistic infections in each health facility are as follows: [1] for pain management paracetamol, aspirin, ibuprofen, tramadol, morphine liquid, and dexamethasone and [2] for other symptom managements amitriptyline, diazepam, phenobarbitone, metoclopramide, chlorpromazine, ORS, co-trimoxazole, flucloxacillin, fluconazole, acyclovir, clotrimazole 1% cream, and nystatin suspension and pessaries [20].

## 17. Conclusion

Palliative care is critically important for people living with HIV to lead better quality of life. It helps them manage pain and other symptoms, the complex drug treatments, and psychosocial impacts and helps the patients self-manage. Therefore, care providers need to be educated on palliative care and have favouring attitude to implement it. HIV is becoming a long-term health effect with many concerns. Therefore, people living with this condition need compressive palliative care to address psychosocial and spiritual concerns and improve quality of life. The courses designed for healthcare providers should consist of palliative care related to HIV, and training should be given for families and friends of people living with HIV for better support. There should be in place policy to enforce the implementation of palliative care for people living with HIV.

### Author details

Habtamu Abera Areri  
School of Nursing and Midwifery, College of Health Sciences, Addis Ababa  
University, Ethiopia

\*Address all correspondence to: [habtamu.abera64@gmail.com](mailto:habtamu.abera64@gmail.com)

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