PALLIATIVE CARE
IMPROVING QUALITY OF LIFE

WHAT DOES PALLIATIVE CARE HAVE TO DO WITH HIV AND AIDS?



PAIN



AGEING



MENTAL HEALTH



ADHERENCE TO ART

WHAT IS PALLIATIVE CARE?

Everyone living with HIV and AIDS should receive palliative care as an essential part of their care and treatment. Delivered from the point of diagnosis, it is often given alongside curative treatment.

What does palliative care provide?

Palliative care is a comprehensive response to the care and support needs of people living with and affected by HIV.

It is ideally provided by a multidisciplinary team including medical and nursing professionals, people living with HIV, counsellors, professionals, community workers and volunteers. Appropriate referrals to other services are undertaken as required to achieve this.[2]

The comprehensive response involves:

- **physical care,** including the assessment and management of pain and other symptoms
- **psychological care,** including emotional support for the person and his/her carers, assessment and care for psychosocial needs including depression and anxiety, and bereavement
- **social support,** including identification of financial needs, poverty alleviation, food security and identification and planning for orphans and vulnerable children
- **legal support,** including identification of legal requirements and human rights issues
- **spiritual support,** including spiritual assessment and appropriate spiritual care.

Palliative care aims to provide the best quality of life for adults and children living with and affected by life-limiting illness. Palliative care improves quality of life through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[1]

Why do people living with and affected by HIV need palliative care?

- People living with HIV, including those on antiretroviral therapy (ART), experience pain and other symptoms that affect their quality of life through all stages of the disease.
- People living with HIV on ART report high levels of depression, fatigue, anxiety, pain and other symptoms.
- Physical symptoms, including pain, and depression contribute to significant reductions in ART adherence.
- An ageing population of people living with HIV requires increased care and support needs.
- Comorbidities such as cancer, hepatitis and cardiovascular disease contribute to symptom burden. People living with HIV are more likely to be diagnosed with cancer than the general population.
- Despite increased access to ART, people living with HIV continue to present late into care with a high symptom burden.
- Depression, anxiety, dementia and other mental health problems are prevalent in people living with HIV and highly under-diagnosed and treated.
- Despite increasing access to ART, many people still die from AIDS and comorbidities such as cancer.

How does palliative care help people living with and affected by HIV?

Palliative care:

- improves quality of life of adults and children living with and affected by HIV
- addresses physical, psychological, social, legal and spiritual issues
- supports ART adherence through identification and treatment of symptoms and mental health problems
- treats pain and other symptoms
- addresses and provides care for emotional and social suffering including depression and anxiety
- addresses the specific care and support needs of older people and children
- supports family members and carers
- provides end of life care
- provides bereavement support.

ADHERENCE TO ART AND PALLIATIVE CARE



People must adhere to ART for it to succeed. Some people fail to adhere to treatment due to several factors including physical symptoms, mental health problems and side-effects from the medication. Palliative care can address some of these factors.

What contributes to non-adherence?

There are many things that contribute to non-adherence to ART. These include:

- physical symptoms and side-effects, such as pain, vomiting and nausea[3]
- mental health problems, such as depression, anxiety and substance misuse
- limited social support
- poor relationships between the patient and the healthcare provider
- lack of community care and support services, including management of opportunistic infections, adherence counselling, support to family carers and nutritional support.[4]

What are the effects of non-adherence?

Non-adherence to ART can lead to a number of outcomes, which include treatment failure (resulting in increased morbidity and mortality) and an increase in the risk of viral mutations. This can result in cross-resistance to other medications[5] or transmission of multi-resistant virus strains. Non-adherence can also have a negative impact on quality of life, for example, in the development of mental health problems.

What is the extent of the problem?

The number and severity of symptoms and medicine related side-effects have also been associated with decreased rates of ART adherence[6, 7, 8]. A study in the United States found that patients reporting pain were less likely to be adherent than those without pain.[9]

A study examining data on 5,491 patients beginning antiretroviral therapy in 15 treatment programmes in Africa, South America and Asia found 21% of patients became lost within six months, including 4% who were not seen since receiving their first prescription of antiretrovirals.[10]

How can palliative care help?

Palliative care can improve adherence to treatment by addressing the barriers that prevent it. Palliative care:

- manages physical symptoms, including pain
- addresses psychological problems
- provides community care and support services and ensures that an individuals needs are being met
- supports the family members and community carers
- addresses mental health problems such as depression and anxiety, as well as tackling the root causes of mental health problems
- ensures effective and good communication at all times with the patient and their carers.

PAIN, HIV AND PALLIATIVE CARE



In the early stages of infection, around 30% of people with a CD4 count of more than 500 experience clinically significant pain, with up to 75% of people with AIDS suffering from pain.[11] Pain in people living with HIV can be from a diverse range of reasons, including HIV itself, opportunistic infections, medication side-effects, comorbidities and psychosocial causes.

Pain reduces the quality of life of adults and children living with HIV, whether they are on ART or not. It also causes their family and carers distress. Unfortunately, for people living with HIV, pain is underestimated and undertreated and there are many barriers that prevent access to pain treatment.

Palliative care can alleviate the pain of people living with HIV, which improves quality of life for them and their carers.

What factors prevent the treatment of pain in HIV patients?

There are numerous factors that prevent the treatment of pain in HIV patients. These include:

- the underestimation of the prevalence of pain and a lack of assessment by healthcare professionals
- a lack of training in pain management for community healthcare workers, healthcare professionals and a lack of support for primary carers
- a lack of access to opioids and pain-relieving medications because of government failure to put in place functioning drug supply systems, lack of policies on pain treatment, unnecessarily restrictive drug control regulations and the unnecessarily high cost of pain treatment.[12]

What is the impact of pain on people living with and affected by HIV?

If pain is untreated, quality of life is reduced, people suffer unnecessarily, adherence to treatment is reduced and people are unable to earn money.

Pain can also result in mental health problems, such as depression, for people living with HIV, as well as stress and anxiety for their family and carers.

What is the extent of the problem?

Several studies have found that between 29% and 74% of people who receive ART experience pain symptoms.[13]

Multiple studies report that 60% to 80% of patients in the last phases of HIV illness experience significant pain.[14]

It is estimated that one million end-stage HIV and AIDS patients live in countries with low or no access to controlled medications and have no or insufficient access to treatment for moderate to severe pain.[15]

How can palliative care help?

Palliative care can improve access to pain relief for adults and children living with HIV. Palliative care providers:

- evaluate, diagnose and treat pain from the point of diagnosis until the end of life
- support and teach family and community members how to manage pain
- train healthcare providers in different settings to treat pain
- develop safe and effective supply and distribution systems
- advocate for access to opioids and pain-relieving medication.

MENTAL HEALTH, HIV AND PALLIATIVE CARE



People living with HIV and AIDS have a higher incidence of mental health problems than non-HIV infected individuals, which has a negative impact on quality of life.[16] Mental health problems can include a desire for hastened death, existential distress, suicide and suicidal thoughts, stress, HIV related dementia and psychiatric disorders such as schizophrenia and bipolar disorder.

Palliative care can help prevent and treat the mental health problems of people living with and affected by HIV.

What factors contribute to mental health problems?

These are varied but include physical symptoms such as pain, psychological symptoms[17], access to employment, the burden of caring for family and community members[18, 19] and bereavement, including parental bereavement of children[20].

What impact do mental health problems have on people living with and affected by HIV?

As well as reducing quality of life, mental health problems can delay health seeking behaviour, decrease adherence to treatment, and increase the likelihood of dropping out of risk reduction programmes.[21] Mental health problems such as depression can also add to immune suppression.[22]

What is the extent of the problem?

Multiple studies have documented high burden of mental health problems among people living with HIV. From 38% to 63% present with symptoms of depression[23]. A representative sample of people living with HIV in the US, found that approximately 50% of people living with HIV had been diagnosed with psychiatric disorders[24]

In a study in the UK, 31% of a group living with HIV reported suicidal thoughts in the previous seven days.[25]

Depression also affects caregivers. Eighty-nine per cent of AIDS-related home-based care givers in the North West Province and Mpumalanga in South Africa were depressed or showed signs of depression.[26]

How can palliative care help?

Palliative care addresses the factors that contribute to mental health problems and diagnoses and treats mental health problems when they occur.

Palliative care:

- evaluates, diagnoses and treats the mental health problems of people living with and affected by HIV
- addresses physical symptoms, including pain
- addresses psychological needs
- supports family and carers to provide quality care for their patients
- provides psychological and spiritual support for those facing the end of life
- supports the psychological, physical, spiritual and emotional needs of carers themselves, ensuring their own mental health
- makes sure that the full needs of an individual are met through effective referrals to appropriate services, eg income generation, employment
- provides bereavement support.

AGEING, HIV AND PALLIATIVE CARE



The success of ART has enabled many people living with HIV worldwide to live longer. However, as people living with HIV age, their palliative care needs grow. Palliative care can also support the many older people around the world who are principal care givers for people living with HIV.

What is the impact of ageing on people living with and affected by HIV?

Older people living with HIV often:

- face increased physical burden of symptoms
- experience a higher degree of psychological distress because of isolation and loneliness[27], a belief in reduced life expectancy and physical pain and symptoms[29]
- have comorbidities such as cancer, organ-degenerative diseases and other life-limiting illnesses
- have specific care and support needs as they approach the end of their lives.

Older people, particularly in developing countries, may also:

- carry the burden of caring for their family and members of the community, including vulnerable children
- experience the bereavement of their family members including their children, friends and community members.

What is the extent of the issue?

In 2006, UNAIDS estimated that 2.8 million people aged 50 and over were living with HIV.[30]

In the United Kingdom, one in 12 HIV diagnoses is of a person over the age of 50. While rates of late diagnosis are high in older adults, just under half of these diagnoses are thought to be of an infection that was acquired when the person was over the age of 50.[31]

Surveys in seven countries in sub-Saharan Africa[32] revealed that older people were caring for about 40% of people living with HIV, with each older carer supporting an average of two people living with HIV.

How can palliative care help?

Palliative care:

- makes sure that the comprehensive care needs of older people living with HIV are met, including managing physical, psychosocial and spiritual problems
- treats and manages the physical, psychosocial, spiritual and social needs that arise as a result of comorbidities such as cancer
- supports older carers in their caring role and makes sure they are cared for themselves
- provides older people affected by HIV with bereavement support
- provides end of life care.

RECOMMENDATIONS AND FURTHER INFORMATION

To improve the quality of life of people living with and affected by HIV:

- Palliative care should be available to all citizens, irrespective of age, in the setting of their choice including acute care hospitals, long-term care facilities (nursing homes), residential hospices, in the community and in the home.
- Palliative care should be included in national HIV and AIDS strategies and national health plans.
- Barriers preventing universal access to palliative care medications, including oral analgesics, need to be addressed.
- Multi-lateral and bi-lateral agencies should ensure palliative care is included in their policies and in the implementation of their HIV and AIDS programmes.
- Access to funding for community based organisations and services needs to be increased.
- Palliative care needs to be part of all undergraduate training for health professionals.
- Monitoring and evaluation of care and support services for people living with HIV needs to be improved at the global and national level.

For more information on palliative care around the world

International organisations

Foundation for Hospices in Sub-Saharan Africa
www.fhssa.org

International Association for Hospice & Palliative Care
www.hospicecare.com

International Children's Palliative Care Network
www.icpcn.org.uk

Worldwide Palliative Care Alliance
www.thewpca.org

Pan-national associations

African Palliative Care Association
www.apca.org.ug

Asia-Pacific Hospice Palliative Care Network
www.aphn.org

Asociación Latinoamericana de Cuidados Paliativos
www.cuidadospaliativos.org

Canadian Hospice Palliative Care Association
www.chpca.net

European Association for Palliative Care
www.eapcnet.org

U.S. National Hospice and Palliative Care Organization
www.nhpco.org

International palliative care funders

Open Society Institute – International Palliative Care Initiative
www.soros.org/initiatives/health/focus/ipci

The Diana, Princess of Wales Memorial Fund
www.theworkcontinues.org

True Colours Trust
www.truecolourstrust.org.uk

NOTES

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