

ASSOCIATION OF NURSES IN AIDS CARE  
POSITION STATEMENT  
Palliative Care

Adopted by the ANAC Board of Directors, September 2005  
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Palliative care with its emphasis on symptom management, identifying hopes and concerns for the future, relief of physical and psychological suffering, and end-of-life care when needed, should be integrated into the comprehensive care of people living with HIV (PLHIV) from the time of diagnosis until death, including bereavement care for loved ones.

**Position**

It is the position of the Association of Nurses in AIDS Care that:

- Palliative care is part of the comprehensive care of all PLHIV and their loved ones.
- Consequently, palliative care should be considered the standard of care for PLHIV and their families from the initial diagnosis of HIV until death including the provision of bereavement care for families and friends.
- HIV clinicians should be able to provide primary palliative care while simultaneously providing antiretroviral treatment or refer patients for specialty palliative care.
- Palliative care should be integrated into education about HIV/AIDS for all clinicians.
- Insurance plans, including Medicaid, Medicare, and the Affordable Care Act, should provide payment for palliative care as part of routine care for PLHIV and their families.
- Research examining the impact of palliative care on PLHIV should be encouraged and supported.

### **Statement of Concern**

In the earlier decades of the HIV epidemic, the only treatments available were palliative, e.g., prophylaxis for infections; symptom management; relief of spiritual and psychological suffering; counseling about the need to identify a surrogate decision maker in the event of incapacity; weighing the benefits/burdens of cardiopulmonary resuscitation; and provision of end of life care.

With access to antiretroviral therapy (ART), HIV has been transformed into a manageable chronic disease with numerous choices for individualized therapeutic regimens, the ability to monitor immunologic and virologic response, and to adjust ART regimens based on resistance testing. As a result, the focus on end of life care has become less urgent. However, contrary to popular belief, the need for palliative care still exists. While thousands of Americans are living with HIV/AIDS, many are also living with burdensome symptoms, serious co-morbidities, and for long term survivors, the changes associated with aging (Simms, Higginson, & Hardy, 2012). Some of the more frequent multimorbidities include, but are not limited to, Hepatitis C/liver diseases, other end organ diseases (renal, cardiac, pulmonary), malignancies, diabetes, hypertension, lipid disorders, depression, PTSD, and substance use disorders.

### **Background**

The World Health Organization's (WHO) Global Health Sector Strategies for HIV, viral hepatitis and STIs, 2016-2021 notes that palliative care is a critical component of the comprehensive health sector response to HIV (p. 7). In addition, the National Clinical Practice Guidelines for Quality Palliative Care (2013), the Centers for Medicare and Medicaid Services, and the National Quality Forum have adopted the following definition of palliative care:

*Palliative care means patient-and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice (p. 9).*

As defined above, the principles of palliative care are central to improving the quality of life for PLHIVs and advancing HIV/AIDS nursing practice. The traditional medical model in the past separated palliative care from disease directed care. Only after a person's illness progressed to an advanced stage would clinicians explore the patient's hopes and concerns regarding their illness and their future, and turn their attention to ensuring adequate symptom management. Given the complex challenges faced by PLHIV, focusing solely on the disease and its treatments, is not only inadequate, but fails to recognize the human needs of PLHIV. The sequence of disease directed care, followed by palliative care, has been superseded by the model of care that integrates palliative care from the time of diagnosis throughout the course of chronic disease from the time of diagnosis.

Thus, palliative care should be included in the care of neonates to older adults with: chronic, progressive illnesses; chronic or life threatening injuries; life altering developmental delays; serious or terminal illnesses; dependence on life-sustaining treatment or long term care for support of activities of daily living; and even for those when cure is possible but whose treatment demands are excessive (NCP, pp. 8-9).

Primary palliative care includes: exploring a person's wishes and concerns about care needed when illness or injury progresses (e.g. advance care planning); assessing and managing

symptoms; acknowledging the spiritual and psychosocial aspects of illness; and recognizing when to refer to specialty palliative or hospice services (IOM, 2014).

The care of PLHIV at the start of the epidemic embraced palliative care. After ART became the standard of care, a false dichotomy emerged that failed to recognize the importance of simultaneously attending to viral suppression and to quality of life (Simms, Higginson, & Hardy, 2012.) While the provision of palliative care should never be used as a justification for denying access to ART, denying access to simultaneous palliative care may well increase the suffering of PLHIV and potentially affect adherence to ART (Simms, Higginson, & Hardy, 2012). It is no longer a question of either ART or palliative care but one of “both/and” to optimize the quality of care and living for PLHIV and their loved ones.

## References

- IOM (Institute of Medicine). 2015. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
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- Simms V., Higginson I.J. & Hardy R. (2012). Integration of palliative care throughout HIV disease. *Lancet Infectious Disease*, 12:571-75.
- World Health Organization (WHO). Draft Global Health Care Sector Strategy on HIV, viral hepatitis, STIs, 2016-2021. (draft 01.12.2015) [www.who.int/hiv/strategy2016-2021/en/](http://www.who.int/hiv/strategy2016-2021/en/)