

ASSOCIATION OF NURSES IN AIDS CARE

POSITION STATEMENT

Palliative Care

Adopted by the ANAC Board of Directors, September 2005
Reviewed and Revised by the ANAC Board: September 2006, August 2008

Position:

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

- *Palliative care should be part of the comprehensive care of all patients with HIV/AIDS.*
- *Palliative care should be integrated into the standard of care for patients with HIV/AIDS and their families from the first diagnosis of HIV until death.*
- *Every provider should be able to provide or refer patients for palliative care, while simultaneously providing therapeutic treatment.*
- *Palliative care should be integrated into education about HIV/AIDS for all providers.*
- *Insurance plans, including Medicaid and Medicare, should eliminate any barriers to obtaining palliative care.*
- *Research in this area is lacking and should be supported and encouraged.*

Statement of Concern:

With the availability of HAART in the industrialized countries, HIV/AIDS has been transformed from a uniformly fatal disease with no treatment to a manageable chronic disease. In the early years of the HIV epidemic, the only treatment providers could offer was palliative. This included some prophylaxis for infections, symptom management, relief of physical and psychological suffering, and end of life care. With the introduction of HAART, treatment changed to a more therapeutic focus. This includes expanded options for prophylaxis, monitoring of CD4 and viral load, resistance testing and design of individualized therapeutic regimens with numerous possible options. The focus on palliation has become less important and in many cases has been lost completely. However, the need for palliative care still exists. Palliative care should be integrated into the comprehensive care of people with HIV/AIDS from the time of diagnosis until death.

Background:

The Health Resources and Services Administration (HRSA)'s HIV/AIDS Bureau Working Group on Palliative Care in HIV has defined palliative care as follows:

Palliative care is patient-and family-centered care. It optimizes quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

The traditional medical model of care separates palliative care from curative care. Given the complexities of challenges faced by people with HIV/AIDS, focusing solely on the disease and its treatments is inadequate care.

Since people are living much longer with HIV/AIDS, there are increasing numbers of patients with many serious co-morbidities including but not limited to Hepatitis C, end stage renal disease, diabetes, hypertension, cardiac disease and lipodystrophy. Symptoms of prevalence in persons living with HIV/AIDS in the post-HAART era include fatigue, trouble sleeping, anxiety, and pain (Hughes, 2004). In addition, many patients also have a diagnosis of substance abuse and all the medical, psychological, social and spiritual problems that encompass this diagnosis. The new paradigm of palliative care calls for the integration of palliative care throughout the course of chronic disease. The need for end of life care still exists as well. There should not be a sequential offering of first curative and then palliative care. From the first knowledge of the diagnosis until death, patients and their families can benefit from the focus on alleviation of suffering as stated above. This type of care should be integrated into all HIV care.

"Palliative care is not a luxury; it is an integral component of providing the highest quality of care possible. Attention to symptom control, comfort and quality of life issues are in fact characteristics of the best standard of care possible, and attention to ...palliative care issues...will ensure that patients receive the full benefit of antiretroviral therapy." (Working Group on Palliative and end of Life Care, p8)

References:

- Hughes, Anne. Symptoms Management of HIV-Infected Patients. *Journal of the Association of Nurses in AIDS Care* 2004; 15(5):7S-13S.
- Kutzen, Harlee. Integration of Palliative Care into Primary Care for Human Immunodeficiency Virus Infected Patients. *Am J Med Sci* 2004;328(1):37-47.
- O' Neill, J., Selwyn, P. & Schietinger, H. (2003). *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. HRSA.
- Workgroup on Palliative and End of Life Care in HIV/AIDS. *Integrating Palliative Care into the Continuum of HIV Care: An Agenda for Change 2004: RWJ Promoting Excellence in End of Life Care program*.