

# Nurses at the Forefront of a Pandemic: HIV/AIDS Nurses

By Carl Kirton

Just over twenty-five years ago, young homosexual men in Los Angeles suddenly became ill with *pneumocystis pneumonia* (now called *pneumocystis jirovecii*) and started dying from this and other rare and opportunistic diseases. In 1981, two years later, it was discovered that a virus, eventually named the human immunodeficiency virus (HIV), was wreaking havoc on these young men's immune systems and leading to their deaths. As the virus progressed, its symptoms and infections advanced into acquired immunodeficiency syndrome (AIDS). Almost overnight, health care workers were

confronted with caring for individuals with a communicable disease that they knew very little about, and in a population with which they were generally unfamiliar. Many health care workers were conflicted by this new disease and the people who were affected by it. They struggled with their fears, their attitudes, their prejudices, and sometimes their own mortality. The epidemic that soon followed single-handedly reshaped the public health care system, organized health care institutions, standard medical and pharmaceutical research practices, and personal sexual behaviors.

Fast forward twenty-five years: much has been learned about how the AIDS virus is transmitted; what impacts transmission; and how people that are infected with this disease can live long and productive lives. However, despite these advances, HIV infection continues to be a worldwide health problem. Notable success has been made in controlling the number of new infections in some areas of the world and among some groups, including men who have sex with men (MSM). Yet troubling trends are occurring in others, high among them, adolescents and minority women.

Today, over 40 million people are infected with HIV worldwide. The number of infected individuals has grown annually since the start of the epidemic (see figure 1). According to United Nations AIDS Program (UNAIDS) it is estimated that during 2006 an estimated 4.3 million people were newly infected with HIV (UNAIDS, 2006). In the United States, each year, approximately 40,000 people are newly infected, a trend that does not change much year to year (CDC, 2004). What continues to fuel this epidemic? A major factor is that approximately 42 – 52% of the people living with HIV or AIDS are not regularly engaged in regular medical care, which is essential to their receipt of quality and effective HIV treatments, and ongoing prevention interventions. Furthermore it has been estimated that approximately 25% of the patients who are HIV-positive do not know and may unknowingly continue to spread the disease (Glynn, 2005; Marks, 2003).

Internationally, the impact the disease has had on individuals, communities and societies is devastating. Antiretroviral drugs, which are essential to HIV care and generally available in the US, offer little hope in the developing world where most people with HIV are desperately poor with little or no access to the health care needed to administer and monitor AIDS drugs. According to a recent report by UNAIDS, just 1 in 5 HIV

## International Nurse



Anne Sliney, DSc (hon),  
BSN, RN, ACRN

### Anne Sliney

is the Director of Nursing and Clinical Training for the William J. Clinton Foundation HIV/AIDS Initiative. She oversees the global nursing

and training programs supported by the Foundation.

Anne is an AIDS Certified Registered Nurse (ACRN). Before taking this position with the Clinton Foundation, Anne was an adherence specialist in the Brown University AIDS Program. She designed a program to provide community-based adherence assessment and intervention. She saw patients in their homes, homeless shelters, coffee shops, drug rehab, methadone clinics, assisted living facilities, and mental health centers. She served as a link and follow-up to the medical care received at local hospitals and clinics.

Anne has maintained a commitment to educating nursing students in the fascinating field of HIV nursing. She has mentored many students in community-based HIV nursing, along with frequent lecturing on global HIV nursing to undergraduate nursing students.

She is an adjunct faculty member in the Rhode Island College School of Nursing and was given an honorary Doctor of Science degree in May 2006.

The Clinton Foundation HIV/AIDS Initiative (CHAI) focuses on assisting governments to bring low-cost, high-quality care and treatment to people living with HIV/AIDS. By negotiating the price of ARVs with the generic drug companies, CHAI has enabled many countries to provide free or low cost treatment to its citizens. Similar negotiations with the manufacturers of laboratory equipment have resulted in increased access to the testing necessary to diagnose and treat HIV/AIDS.

CHAI has programs in 26 “core countries” and provides drug and lab procurement assistance in 62 countries. In these core countries, CHAI responds

to the requests of the government to fill gaps in comprehensive HIV care. When a partner government requests assistance with nursing or training, Anne assesses how CHAI can help and implement a plan to address the relevant issues.

Two of the largest nursing projects CHAI has taken on are in Kenya and India. In Kenya, the Ministry of Health identified their nursing shortage as a key barrier to scaling-up HIV/AIDS care and treatment. Anne and the CHAI Kenya team worked with the Chief Nursing Officer to establish a pilot project in which Kenyan nurses were hired and deployed to four high HIV prevalence districts. She believed that employing nurses would be the most effective way to bring treatment to rural areas. The goal was to prove the effectiveness of this model and attract other donors to significantly invest in nursing. The program started with 120 nurses over four districts. It now employs 1000 nurses and 100 clinical officers in 16 districts across Kenya. In January, 2007, the Danish government agreed to fund the project for the next three years. The Kenyan government has committed to absorbing these nurses after the initial three years.

In India, the Clinton Foundation was asked to create the national training program for HIV/AIDS nursing. In partnership with the Indian Nursing Council, CHAI gathered together a panel of nurse-educators to define the role of the nurse in HIV care and develop an appropriate curriculum. The curriculum will be approved by the National AIDS Control Organization of India as the official nursing curriculum.

Anne is also responsible for overseeing clinical mentoring programs requested by government partners. This involves sending HIV/AIDS experienced clinicians to work alongside their colleagues in developing countries. These mentors help the local doctors and nurses not only to provide care, but also to address problems within the facilities that create barriers to quality, comprehensive care.

## Nurse Scientist



Joachim Voss, PhD, RN

**Joachim Voss**, is an assistant professor at the University of Washington in Seattle in the department of Biobehavioral and Nursing Systems Department. He is a bed-to-bench-to bedside researcher. What does that mean? He currently researches the issue of fatigue in HIV/AIDS patients trying to identify biomarkers that can be used to measure fatigue quantitatively, which indicates mitochondrial and muscle dysfunction.

His current investigation focuses on genomic and proteomic methodologies to identify gene and protein patterns in muscle, fat and peripheral blood samples of HIV/AIDS patients with and without subjective complaints of fatigue. In order to do this, Dr. Voss did a fellowship at the National Institutes of Health, where he learned how to perform gene expression array studies, how to conduct statistical analysis of the large data sets that result from microarray experiments, and how to confirm the results with real-time PCR techniques and immunohistochemistry.

He also spent three years of additional training, taking classes in genetics, biology, chemistry and laboratory techniques all of which allowed him to perform these types of investigations.

As a doctoral student at the University of California in San Francisco, he worked with a quality of life/symptom management researcher and learned the foundation of research. Understanding and interpreting of theoretical models, methodology development and evaluation, and data management and analysis were only some of the aspects of his training.

Dr. Voss' began his nursing career in Berlin working in the acute care nephrology unit, the only nurse who was willing to work with HIV infected dialysis patients: two ladies in their late seventies who were infected by blood products they had received. He then worked in a large teaching hospital in Berlin that treated infectious disease patients suffering not only from HIV but also from hepatitis, tuberculosis, and malaria.

He later became the manager of a newly established 14 member specialized HIV/AIDS/Cancer Homecare Team in Hamburg. This team broke boundaries for current nursing practices, developed new standards of care, and initiated strategies with psychological supervision to protect themselves from emotional burnout and job frustration.

Dr. Voss came to the United States on a Fulbright Scholarship to study with nurse researchers at UCSF. It was after this experience that he was accepted into the doctoral program. It was here that he decided to focus his career on solving the problems of symptom-management in the HIV/AIDS population.

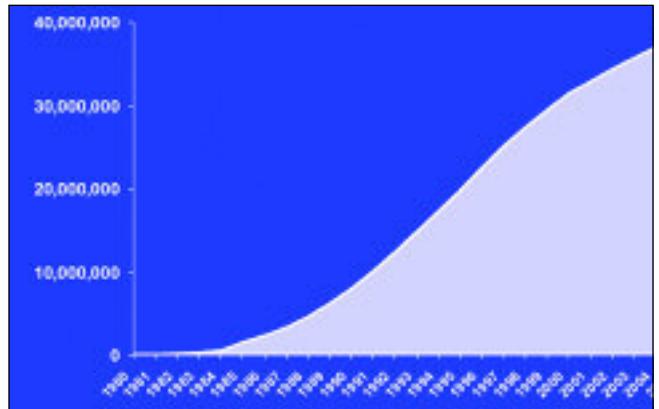


Figure 1. Timeline of the worldwide incidence of HIV infection

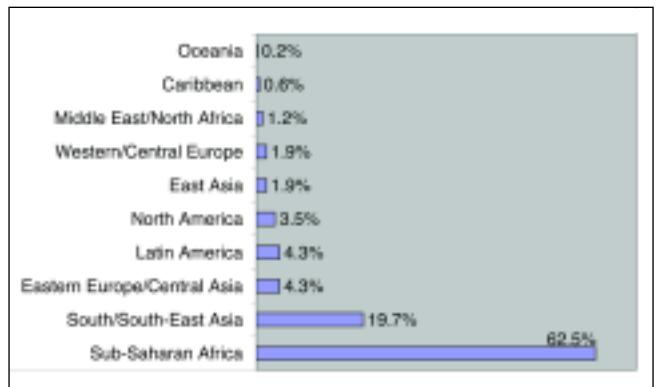


Figure 2. People Living with HIV/AIDS by Region, as Percent of Global Total, 2006

patients in developing countries get the drugs they need. Figure 2 demonstrates that the greatest impact has been and continues to be in Sub-Saharan Africa where two-thirds of the people in that region are living with HIV/AIDS. This disease has devastated the adult population and has left behind some 12 million orphaned African children. It has also negatively impacted the health care workforce, especially nurses. In some communities caregivers themselves may be infected with HIV and must balance caring for themselves while caring for others. It is often the case that there are just not enough health care workers to care for the HIV-infected population or there simply is not enough expertise.

The Association of Nurses in AIDS Care (ANAC), the professional organization for the community of HIV/AIDS nurses, and its individual members are working to affect change in the pandemic. Anne Sliney is an AIDS Certified Registered Nurse (ACRN) and a member of ANAC. Anne has a long history of working with patients who have HIV/AIDS and is currently the Director of Nursing and Clinical Training for the Clinton Health Foundation. Through her work Anne is ensuring that developing countries have a talented and sustainable nursing workforce to care for the growing HIV infected population in countries that have been impacted by a shrinking nurse workforce (see sidebar 1). She works

## HIV/AIDS Nurse Specialist

with government and nursing leaders providing hands-on support and mentorship so that quality HIV care is given to even the hardest to reach individuals. You can read more about her work and the Clinton Health Foundation by visiting their website at [www.clintonfoundation.org](http://www.clintonfoundation.org).

Training and education of others is just one of the ways in which nurses contribute to the field of HIV/AIDS. Many scientists, including nurses, continue to work towards understanding how the virus works in the body, how HIV drugs impact viral and cellular dynamics, and how individuals respond to and cope with having a long-term chronic disease. ANAC member, Dr. Joachim Voss, is a “bed-to-bench” researcher studying symptoms in HIV/AIDS. Dr. Voss works in his laboratory at the University of Washington and is currently studying whether there are markers in the tissue of HIV/AIDS patients with symptoms of fatigue that indicate mitochondrial intoxication (see sidebar). He hopes to discover this marker so that clinicians will be able to quantitatively measure fatigue someday. Nurse scientists such as Dr. Voss make important contributions to our understanding of this disease and someday nurses like Akosua Abankwah may use Dr. Voss’ findings to determine how their nursing interventions work.

Ms. Abankwah is a staff nurse at North General Hospital’s Department of HIV/AIDS and she treats a gamut of symptoms, including fatigue (see sidebar). North General Hospital (NGH) is located in the East Harlem section of Manhattan in New York City. Many of its residents are predominately African-Americans and Hispanics and 38% its residents live below the poverty level. HIV care providers in this community continue to be challenged by the fact that many of the new HIV cases are diagnosed late in the disease, when HIV has already progressed to AIDS. Death from HIV in the community is still relatively high compared to the



Akosua Abankwah, BSN, RN

Working with clients who have HIV/AIDS brings me joy and fulfillment because I know that in my role as clinician, educator, and advocate, I make a difference in the lives of my patients. Every day I have the opportunity to teach patients how to engage in safer sex practices, be adherent to medications, and manage their symptoms associated with HIV infection. I work extensively with an interdisciplinary health team which includes physicians, nurse practitioners, physician assistants, social workers and case managers. I am challenged by the

rest of Manhattan. In 2003-2004 the average annual HIV-related death in East Harlem (68/100,000) was still more than three times the Manhattan (22/100,000) and NYC rates (18/100,000) (Olson, 2006).

On a typical day Ms. Abankwah makes routine assessments of patients in the clinic and by telephone, and in collaboration with primary care providers helps to resolve actual or potential problems. She educates patient about their medications, makes assessments of adherence to the medicine, and teaches patients about their disease and safer sexual practices. Ms. Abankwah found support for her practice by joining the Association of Nurses in AIDS care. ANAC is composed of a dedicated group of nurses, healthcare professionals and others who are committed to advancing HIV/AIDS nursing. ANAC has members around the world and while most of ANAC’s members are nurses, many other people who care about HIV nursing are also

constant changes in the field of HIV/AIDS and attend many seminars and courses to make sure I stay current and knowledgeable. I am currently enrolled in graduate school, studying to be an adult Nurse Practitioner specializing in HIV/AIDS.

I have to incorporate holistic transcultural nursing concepts into my day to day practice as many of my patients come from a variety of cultures and ethnic backgrounds. Many of my patients have substance use and mental health problems and as such mental health assessments and interventions are an important part of my practice.

As a nurse and a member of ANAC, the concepts of caring and presence are the driving forces that enable me to be who I am for my clients. Presence is “a mode of being available or open in a situation with wholeness of one’s unique .....” (Paterson, 1988). Offering my self as presence is a great tool that connects me to my patients.

members. These affiliate members are social workers, pharmacists, physician assistants, lawyers, doctors and any variety of people who simply care about the nurses who treat people with HIV and/or AIDS. Many nursing students are affiliate members of this 2500 member organization.

By joining ANAC, Ms. Abankwah connects with a network of professional nurses on the front lines of HIV work. Her membership in ANAC keeps her up to date with the latest developments in the field through the Journal of Association of Nurse in AIDS Care (JANAC) a highly regarded peer-reviewed journal, opportunities to attend ANAC’s annual scientific and educational conferences, and the opportunity to access patient related documents, prepared by nurse experts, which she uses in her practice.

By becoming an AIDS Certified Registered Nurse (ACRN), a certification she is studying for, she knows that she will join thousands of expert

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nurses who work to improve the quality of HIV/AIDS nursing care and prevention. You can learn more about ANAC by visiting [www.anacnet.org](http://www.anacnet.org). ©

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## Selected important issues in HIV/AIDS nursing

- Implementing strategies to keep HIV patients engaged in routine HIV medical and nursing care.
- Implementing prevention research findings to help reduce HIV transmission here in the United States and around the world.
- Implementing routine HIV testing in all health care settings.
- Ensuring access to antiretroviral drug here and in the developing world.
- Prepare for emerging issues in HIV care such as diabetes, liver disease, obesity and elder care.

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