

Flashbacks to the Beginning of the Epidemic

Richard Gettings, a registered nurse and regional supervisor for AIDS Healthcare Foundation/Positive Healthcare Florida, has been providing care to people living with HIV/AIDS for 13 years. As part of a joint capacity-building effort co-sponsored by AIHA and AIDS Healthcare Foundation, Gettings traveled to Odessa, Ukraine, in December 2003, where he served as a trainer at the first antiretroviral therapy (ART) workshop held at the Southern Ukraine AIDS Education Center. This workshop focused on training practitioners to select appropriate candidates for ART, effectively plan a course of treatment for them, and manage their subsequent care. He returned to Ukraine in March 2004 to assist in developing the curriculum to be used by the Kiev-based Regional Knowledge Hub for the Care and Treatment of in Eurasia for training multi-disciplinary HIV/AIDS care teams. Here, he talks about how his experiences in Ukraine remind him of the many challenges of providing care to HIV-positive people during the early days of the epidemic in the United States.

When I was first asked to provide training to Ukrainian healthcare practitioners at a session in Odessa in December 2003, I was flattered and a little surprised to have been chosen to help in this endeavor. Then I realized that my experience treating people living with HIV/AIDS (PLWHA) spans more than

a decade and that I was, in fact, well-suited to the task of teaching others what the past 13 years had taught me.

Since then, the time I've spent in Ukraine helping train care providers has served as a reminder for me of what HIV/AIDS care was like in the United States during the early stages of our epidemic and why I embarked on a career that allows me to provide care and comfort to people living with the virus.

I decided to become a nurse in 1991, largely because many of my friends were infected with HIV and some had already died. I wanted to be able to help somehow and nursing proved to be the right answer for me. At that time in the United States, people didn't know where to get tested and, even when they did, it was very costly. Education regarding the progression of HIV disease was in its infancy and people simply didn't know what the signs and symptoms of AIDS were. There were no real treatment options, so alternative medicines—such as laetrile therapy, which became popular in the 1970s as a cancer treatment—were being smuggled into the country by underground organizations. These drugs could not be imported as medicine, but individuals could bring the substances in as herbal remedies.

One patient in particular sticks in my mind. His health had been declining for several years and one day he arrived at the hospital unable to breathe properly. Once admitted, he was diagnosed with Kaposi Sarcoma of the lung and died three days later. From that point on, my goal was to care for PLWHA and keep abreast of advances in treatment. I became an AIDS

Certified Registered Nurse and attended every conference on the subject that I could find. The area of fatigue and the use of disease management in the care of patients with HIV were of particular interest to me, so I conducted my own research and even had some articles published.

Over the years, I have worked in both in- and out-patient settings, including an ambulatory clinic where a team of two doctors and two nurses oversaw the care of 1,500 patients. Currently, with the collaboration of 24 nurses and three outreach workers, I supervise the cases of approximately 3,000 patients enrolled in a disease management program in South Florida—a region with the second-highest HIV/AIDS incidence and prevalence rates in the nation. These patients receive benefits from the state-supported Medicaid program.

Preparing for that first trip to Odessa, I was excited and ready to share my experience with colleagues there. I was told that the situation in Ukraine today is similar to what it was like here in the United States during the early 1990s and that there are vast differences in the resources available in the two countries. A colleague of mine who started practicing in 2000 was dismayed when I told him that some diagnostic tests might not be available. He was concerned about treating HIV without the use of frequent CD4 counts and viral loads. I reminded him that when I started working in an outpatient setting in 1993, we had CD4 counts, but no viral load tests and the only medication available was AZT, yet we still made progress.

Eager to find out what could and couldn't be done in Ukraine, I set off from Miami

during the first week of December 2003. My colleague—Dr. Michele Babaia, a physician at AHF/Whittier Healthcare Center in California—and I found a talented group of physicians, nurses, and social workers who had for years been treating PLWHA in Ukraine.

We learned rather quickly that there are many differences between the medical community in the United States and that of Ukraine. For example, our first assumption was that nurses in Ukraine receive the same type of education for diagnosing, caring for, and treating PLWHA proved incorrect, and we learned that nurses there are responsible for the basics of life while a patient is in their care; they have not been trained to take an active role in diagnostics or the planning of treatment.

We also learned that the Soviet model of care was vertical in nature and that the individual disciplines we rely on to provide components of HIV-related care—physicians, nurses, and social workers, for example—each operate independently of the others. This new-found knowledge forced to rethink my approach to teaching our model of care, which integrates all off these disciplines into one comprehensive team.

Everyone at the workshop was very enthusiastic to learn how care is provided to PLWHA in America. The team model was a novel idea for the Ukrainians, but I explained how our own experiences with the epidemic resulted in an understanding that a multidisciplinary, horizontal approach works best with this disease. They learned that all members of the care

team keep each other informed of patient progress and status, which makes everyone able to perform more efficiently and effectively.

It was encouraging to see so many professionals eager to learn from our experiences. Workshop participants would propose a particular situation and we would describe how we would approach care and treatment given the specific conditions they outlined. We spoke openly about both our successes and those responses that needed to be reworked after less than optimal outcomes.

One of the things that seemed to surprise the Ukrainians the most was the fact that even though my patients are being given antiretroviral medications free of charge, many are still non-compliant with their treatment plan. I remember finding that same fact hard to believe during the 1990s when we discovered our patients being less than adherent.

Over the years, my colleagues and I have found that reasons for non-adherence vary greatly from person to person. Many times substance abuse prevents a patient from taking his medication or perhaps the side effects of the drugs prove to be a problem. Sometimes it's a control issue—with so many aspects of their lives spinning out of control, some patients feel a need to determine if and when they take their medications. At the workshop, we looked at ourselves to try to truly understand non-adherence, asking how many of us had actually finished a regimen of antibiotics without ever missing a

dose. We realized that if we couldn't do it for 10 days how difficult it must be to cope with the idea of taking medications for the rest of your life. We also discussed different ways to improve adherence, including education and behavior modification, which seem to be the best tools available. We also concluded that in limited-resource settings it is important to assess the probability of adherence before starting patients on an antiretroviral regimen.

It was gratifying—but also extremely frustrating—to see these health professionals providing care to so many people despite grossly inadequate equipment, supplies, and pharmaceuticals. International donor funding will have a great impact on the care available to PLWHA in the region and I hope to remain part of these efforts. We can save so much time and have such a positive effect on so many patients if we are willing to share the experiences we have had with our fellow practitioners. We all learn from our mistakes, but it is a wise man who avoids those mistakes by learning from others. ■



Photo: Kathryn Ujan.

Richard Gettings discusses HIV/AIDS treatment options at the Odessa ART training held in December 2003.