

Caring for the Innocent Victims of Ukraine's HIV/AIDS Epidemic

In 1996 when Kiev pediatric infectious disease specialist Svetlana Komar encountered her first cases of children with AIDS, the country's HIV epidemic was still in its infancy. There were no AIDS Centers, virtually no national research or statistics about the virus, and no programs to train clinicians in the intricacies of providing care and treatment to adults living with HIV/AIDS, let alone children. The challenges she encountered when diagnosing and treating her young patients and her inexhaustible desire to fight for the lives of these innocent victims of Ukraine's growing epidemic drove Komar to learn everything she could about HIV/AIDS and how to best manage the disease in infants and children. Her ongoing quest to educate herself on the topic has earned her the reputation as one of the country's leading specialists in pediatric HIV/AIDS. Her dedication to preventing mother-to-child transmission of HIV and easing the suffering of those children who are already infected has earned her the undying gratitude of her young patients and the people who love them. *CommonHealth* recently spoke with Komar at Kiev Children's Hospital No. 1, where she has served as director of the Department of Infectious Diseases since 1999.

CommonHealth: *You are one of the few doctors in Ukraine who has a significant amount of expertise treating children who*

have been diagnosed with HIV/AIDS. Can you describe how you first became involved with treating these children?

Svetlana Komar: After I graduated from Kiev Medical Institute's Pediatrics Department in 1987, I accepted a position in the Infectious Diseases Department of Kiev Children's Hospital No. 1. Adult patients who were suffering from HIV/AIDS were relatively rare and pediatric cases were even more so. In addition, we had no real experience diagnosing or treating HIV infection and no protocols for screening pregnant women. All in all, making any sort of objective assessment of the situation was a challenging job. We often learned that a woman was HIV-positive only after noticing an unusual progression of pneumonia, persistent yeast infections, swollen lymph nodes, and other tell-tale signs in her child. It wasn't until August of 1996 that I confronted my first pediatric AIDS patient. He was 4 years old at the time and his name was Arnold. His mother was a commercial sex worker and his father was a student from Africa. He came to the Children's Hospital because there were no specialized AIDS Centers as there are today. There was no other place for him to go and he died two years ago, about 18 months after his mother passed away. So, through this boy, I witnessed the sad drama of HIV/AIDS.

CH: *What do you remember about Arnold's case?*

SK: I remember that it was his grandmother who took care of him for the most part, although his mother did come to visit him from time to time. She was quite young, but looked older. She appeared old and looked ill and very tired of life. She was also very aggressive and argumentative, always

mistrustful of the doctors and unwilling to accept our advice about diagnostic tests or treatment for herself and her child. It took a long time for her to open up, but she finally told me her story and I came to understand her feelings of hostility toward the medical establishment. As it happened, she was aware of her HIV-positive status when she arrived at the maternity hospital to deliver Arnold. The humiliation and lack of sympathy she suffered there were at the root of her rejection of medical assistance. The pain and anger she felt as a result of the way she was treated was compounded a month after she delivered Arnold. She took the boy to a nearby shop where she ran into the obstetrician who helped her during labor and delivery. The doctor screamed for all the customers to hear that this woman—a prostitute who had AIDS—must be banned from public places, particularly those that sell food, so as not to spread the disease to others. The doctor went on to shout that no AIDS patients should be allowed to visit shops because they present a danger to the public at large. I later learned that this is called stigma and that it is an evil that is as horrible, if not more so, than the infection itself. Society's alienation of people living with HIV/AIDS destroys their lives and spirits much the same way the virus destroys their bodies.

CH: *Can you pinpoint a time after you encountered these first few HIV/AIDS cases when you began thinking in earnest that Ukraine was facing a true epidemic—that the disease was spreading from the high-risk groups to the population at large?*

SK: Looking back, I think there was one particular case that I had in 1998 that made me start thinking along those lines. We admitted an 18-month-old boy who had been

gravely ill with hepatitis for the previous six months. He lived in a Central Ukrainian village with his parents and grandmother—it was a good, happy, caring family. The little boy had stopped walking, lost a considerable amount of weight, and was plagued with recurrent bouts of pneumonia, jaundice, diarrhea, and anemia. As we were piecing together the child's medical history, we learned that his mother had undergone surgery and received subsequent blood transfusions at a clinic in Kiev approximately six months before she became pregnant. This set off an alarm bell for us and we tested both mother and child for HIV. The tests came back positive and soon after that the father was diagnosed with HIV as well. This family had no real chance of surviving because treatment was not yet available at that time. The mother was the first to die and, despite our best efforts, the child died, too. I don't know what happened to the father; he stopped coming to the Hospital. I do know that the grandmother left the village. I think it was this sad story that made me realize that HIV/AIDS was not only a serious matter, but that it was here to stay.

CH: *As you began to see more and more children infected with HIV, what were the main challenges you faced trying to provide them with adequate treatment, care, and support?*

SK: Initially, our problems stemmed from the things we lacked. We were plagued by a near total absence of necessary supplies, including diagnostic equipment, antiretroviral medicines, and drugs to treat opportunistic infections. We also had no basic infrastructure for diagnosing and treating HIV-infected children and no clinical protocols to guide us in the provision of therapy. Finally, we lacked healthcare providers with the

knowledge and skills needed to diagnose and treat HIV infection in infants and children. Some of these problems persist even today—especially the shortages of diagnostic supplies, medicines for treating opportunistic infections, and trained specialists. There are a number of reasons for this. First and foremost, the government is not properly engaged in addressing issues related to HIV/AIDS treatment. As a result, we have no solid framework for providing necessary services, no core of well-trained clinicians capable of providing care, and no facility dedicated specifically to the care of pediatric HIV/AIDS cases. This, in turn, has limited our access to antiretroviral medications. And, when even the most basic necessities are absent, those healthcare specialists who are trying to provide care to people living with HIV/AIDS soon lose their enthusiasm and often give up. Another problem we face is consistency of care across the country's various regions. In some oblasts the situation is better, in some it's worse. Overall, though, it is less than optimal throughout.

CH: *Your department is not specifically an HIV/AIDS unit, but an infectious disease ward located in a children's hospital. What are the strengths in this approach?*

SK: Because the hospital is a multidisciplinary healthcare institution for infants and children with all sorts of conditions and ailments, patients with HIV/AIDS receive treatment in the same department as children with other diseases. Everyone involved—from patients and their families to physicians and other care-providers—can witness first-hand that this is not a problem provided certain precautions are adhered to. This is an important factor in helping erase the fear and stigma that is attached to the virus. Also, the

pathology of HIV is very complex and can manifest itself in many ways; treating HIV-positive children in a general hospital helps ensure they get adequate care for the broad range of opportunistic infections and other conditions brought on by the virus. Finally, admission to the hospital can optimize the effectiveness of therapy by giving them access to the same specialists and improving continuity of care.

CH: *How many HIV-positive children have been diagnosed and treated at Children's Hospital No. 1?*

SK: That's difficult to say, although I'd estimate that there have been hundreds. Most of these children come to us after they have been sick with a variety of illnesses—or maybe one or two recurring conditions—over the course of several months. Diagnosing HIV infection in children has its limits. For example, we can only definitively say that a child is HIV-positive when he or she is 18 months old. Before then, the test may return a positive result because the baby's blood contains the mother's antibodies; this doesn't mean that the child has HIV. There is a DNA test that can diagnose HIV in children as young as three months, but it is not available in Ukraine. Instead we've learned to rely on other diagnostic criteria—particularly clinical indicators—to determine the need for further testing. The Hospital doesn't have the laboratory capacity for on-site HIV testing, so we send our samples to the Kiev AIDS Center for screening. All in all, diagnosis of HIV in children remains very difficult and often comes too late, which means that treatment is also started later than it should be under optimal circumstances.

CH: *When did antiretroviral medications*

become available to your patients and how are these provided to the Hospital?

SK: The Ukrainian government first provided antiretrovirals for 10 of our patients in July 2002. These children are alive today because of this medication. And, after fighting for so long to save their lives, the possibility of providing them with the treatment they needed was a tremendous gift to me, as a doctor, and certainly to the children themselves and their families. This is how we came by our sound track record of providing care to HIV-infected children. In 2003, we became involved in a program sponsored by Bristol-Myers Squibb that enabled us to provide antiretroviral therapy to another 15 children. Throughout Ukraine today, more than 100 children are receiving antiretroviral therapy—many because of assistance provided through the Global Fund to Fight AIDS, Tuberculosis, and Malaria. So, treatment is becoming a reality here in Ukraine and our children will have the opportunity to live and grow. I can't even begin to express my delight with this because I know all too well what it is like to lose a patient for lack of medicine. I have also seen the positive effects of antiretroviral drugs and can fully measure their impact on hundreds of families throughout Ukraine.



Photo: Vira Illiash

Svetlana Komar

CH: *You mentioned earlier that some regions of the country have greater capacity to provide care to HIV-infected children than others. Do some parents bring their children here to you for treatment because of this?*

SK: Yes, this does happen. I understand that many doctors practicing in the provinces are overburdened and may not have experience treating patients with HIV/AIDS. Because I do have this experience, I cannot refuse to see a child when doing so can be tantamount to a death sentence—nor do I want to. Sometimes I encounter problems with the Hospital's administrative offices, but I have no intention of turning away children who need my

help. And the sad fact is that the number of HIV-infected children will continue to grow unless there are effective programs to prevent mother-to-child transmission of the disease. The HIV/AIDS epidemic is a cruel reality and children are the only victims who are completely innocent. Looking back over the years since I first treated young Arnold makes me think of a private AIDS institute I visited last year in Berlin. They have a memorial plaque there commemorating each and every person they have lost to the epidemic. The plaque has photos of these people with their smiling faces looking down on us. And even though they are no longer with us, they seem to instruct us—the living—from wherever they are in eternity, charging us to take care, to be prudent, and to cherish life. We do not have such a memorial at the Hospital, but I remember every one of my patients. The images of their faces are imprinted on my soul and their histories make an archive of my own personal experiences. ■