Collateral Damage: HIV/AIDS Creates a Generation of Orphans and Vulnerable Children

BY KATHRYN UTAN

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With the AIDS pandemic advancing into its third decade and the virus already having claimed the lives of 22 million people and infected another 40 million worldwide, it is easy to forget that these intangible statistics represent real flesh-and-blood people. While images of the men, women, and children living with HIV/AIDS put a human face on this devastating illness, the number of individuals who are actually infected represents only a portion of those ravaged by the disease.

Nearly 15 million children under the age of 18 have already lost at least one parent to AIDS (see Fig. 1) and every minute of every day four more join their ranks. By 2010, UNICEF predicts that more than 25 million children orphaned by HIV/AIDS will find themselves alone, impoverished, and with little hope for the safe and healthy future that is every child’s birthright.1

The vast majority of children orphaned or made vulnerable by HIV/AIDS live in sub-Saharan Africa where the virus thus far has exacted the greatest toll. But, as the epidemic spreads, so too will the phenomenon of these children. The Caribbean—which is now home to the second highest HIV prevalence rate in the world—already has almost 250,000 children orphaned by AIDS and other regions, such as Eurasia, where the epidemic is on the rise are also reporting more young people made vulnerable by the disease.2

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Olga P. Zbrozhyk visits with some of the older children at Orphanage No. 3 during their mid-morning snack break. Thankfully, none in this group are HIV-positive.

As orphaned children grow older, they become increasingly aware that they do not have a family to call their own. Even with the most dedicated and loving care, it is difficult to overcome their feelings of loneliness and abandonment.
it is today’s levels of prevalence that foreshadow the number of children who will be orphaned by AIDS over the course of the next decade. Even in countries where HIV prevalence rates have stabilized or started to decline, the number of orphans will continue to increase or remain high for several years to come, says UNICEF (see Fig. 2).

In Eurasia and other parts of the world where skyrocketing rates of new HIV infections can be found, the unique needs of orphans and children made vulnerable by the disease must be taken into consideration as these countries develop long-term, comprehensive HIV/AIDS care and support strategies to cope with their burgeoning epidemics.

This article examines the growing crisis of children orphaned and made vulnerable by HIV/AIDS and explores the need for immediate action to address their plight in an effective, sustainable manner.

A Vicious Cycle of Poverty and Disease
Poverty and disease are like tinder and dry wood for the raging fire of the HIV/AIDS pandemic. When families are too poor to educate their children, those children will most likely live out their lives in poverty and give birth to a new generation condemned to the same fate. This poverty leaves individuals vulnerable to malnutrition, exploitation, and diseases—like HIV/AIDS—that are largely preventable if a person is armed with the knowledge necessary to avoid high-risk behaviors.
Contracting HIV or another debilitating disease strips away an individual’s capacity to work, thereby increasing one’s poverty, as well as contributing to the hardship of the family. When forced to choose between medication and food, potentially life-saving drugs are often passed over in favor of whatever meager sustenance can be eked out. Without access to life-saving medicine and support, people are easy prey for the relentless onslaught of destitution and disease. When people are not educated, empowered, or given the tools they need to protect their health and that of their families, they are condemned to an endless cycle of poverty and disease.

Acknowledging that HIV/AIDS wreaks havoc in particular on already economically hard-hit communities, further eroding the coping mechanisms of citizens and consigning many children to vulnerability, Chepkwony stresses that “Far greater effort is required to alleviate widespread suffering among these children,” including access to social services and educational opportunities.

As stated previously, HIV/AIDS is spreading so quickly that the family structure can no longer cope with the ensuing devastation. In the early stages of the epidemic, extended families and community networks are often strong enough to absorb most children orphaned by HIV/AIDS. But—as the experience of Africa clearly illustrates—as the virus claims first thousands then millions of individuals, traditional support systems become overburdened and unable to cope with the growing number of children in need of care and assistance (see Fig. 3). While extended families still assume responsibility for many orphans in sub-Saharan countries, recent studies indicate that roughly 50 percent of all street children there are orphans—the majority because of AIDS. Over the past decade, this region has witnessed a virtual explosion of these orphans with the number leaping from fewer than 1 million in 1990 to more than 12 million in 2004. Additionally, greater numbers of young people are living in households headed by single parents, grandparents, or even older siblings who are often still children themselves.

The reality for these children is that they are much less likely to have access to food, shelter, education, healthcare services, and protection. In addition to this dearth of basic needs, children orphaned or made vulnerable by HIV/AIDS are generally burdened with the psychological trauma that accompanies the loss of one or both parents and the ensuing collapse of their family structure, not to mention the social isolation that often attaches itself to those whose lives are touched by the virus.

It is important to note that in nations with large populations of children orphaned by HIV/AIDS, the disease tends to have a negative impact on youth as a whole—even if a child’s own family structure remains largely intact—because it overburdens communities and erodes opportunities for education and growth.

A Growing Crisis in Eurasia

Because the HIV epidemic took root in the nations of the former Soviet Union a decade or more after it struck Africa and other regions of the world, the phenomenon of children orphaned by AIDS is just emerging Eurasia. The region’s epidemic differs from Africa’s in that it was initially spread through injecting drug use rather than heterosexual contact. In recent years, however, the epidemic has become more generalized—especially in the front-line countries such as Russia and Ukraine—and heterosexual contact now accounts for as much as 50 percent of all new HIV infections in some oblasts. Increased infection rates among women in their reproductive years are resulting in more and more infants being born to HIV-positive mothers and, consequently, more children orphaned or made vulnerable by the disease.

According to Chris Cavanaugh, co-director of the Assistance to Russian Orphans Program (ARO), the issue of children being born to—and abandoned by—HIV-infected mothers has increased exponentially. “The majority of HIV-positive women...
who abandon their children are injecting drug users or women who are physically or psychologically unable to cope with raising a child. These two groups are, in fact, very similar in that they generally do not seek any sort of counseling or prenatal support, often arriving at the maternity ward during the last stages of labor.”

Most maternity wards, however, are not equipped to meet the special needs of these women and their babies. “Currently, such facilities do not have psychologists or social workers who can meet with an HIV-positive pregnant woman to determine her mental state or social condition. There is no one to investigate whether there are family members who can care for her child or even to encourage the woman to remain in care long enough to conquer her addiction,” Cavanaugh explains, noting that hospital staff often report that many HIV-positive women abandon their infants and leave the hospital immediately after giving birth without providing any contact information or even their real name. These children then go through a legal process making them wards of the state and are transferred to a hospital if they have any medical complications or to a baby home—if one exists and is willing to accept a potentially HIV-positive child.

While the number of children orphaned or made vulnerable by HIV/AIDS is still relatively low in Russia—Cavanaugh estimates approximately 1,000 out of the nation’s 700,000 orphans have been born to HIV-positive mothers—the epidemic is clearly trending toward higher rates of infection among women of child-bearing age, which is almost certain to result in an increase in the total number of these children. And, because of the “medical-preventive” nature of hospitals and orphanages in Russia and other Eurasian countries, institutions are not mandated to provide child-development services even though lack of educational and emotional support during the first three years of life can severely hinder a child’s ability to thrive both mentally and physically.

“Children who remain in these environments for extended periods of time often acquire significant developmental delays that make them very difficult to place in family-based care, even if they are HIV-negative. They will most likely be shuffled from institution to institution until the age of 18, with very grim prospects of leading healthy, happy lives as productive members of society,” Cavanaugh admits.

A New Challenge for Orphanages

Olga P. Zbrozhyk, chief physician at Odessa Orphanage No. 3 in Ukraine, agrees that a lack of individualized care and attention is sorely missed by all but the youngest children. The orphanage—which houses 165 children under the age of four—was one of the first institutions in the city to accept potentially HIV-positive infants.

“For infants and very young children, being institutionalized is not such a heavy burden provided that their basic needs are being met. When they are three or four, however, they are acutely aware that they do not have a real family to call their own. They constantly ask ‘where is my mother … when will I be able to see my mother?’ We have a wonderful, dedicated staff and they try to be mothers to every one of the children here, but there are 20 or more in a group and only two or three care-providers, so it is very difficult to fulfill each child’s need for love and maternal attention,” Zbrozhyk says.

She estimates that more than 100 children with HIV have lived at Orphanage No. 3 during the course of the past seven years. Often, these children were abandoned at local maternity hospitals, in market places, or even in garbage cans. Roughly 30 children in residence in December 2003 were born to HIV-positive mothers. Of that number, nine were confirmed as HIV-positive themselves and three had developed AIDS.

“At first we were a bit apprehensive about finding the best way to care for these children while at the same time protecting the health of the others and ourselves, but we all conducted our own research
and attended several training workshops sponsored by the local health administration and other groups to obtain the information we needed to implement adequate precautions and care guidelines,” Zbrozhyk explains. Initially, they kept the high-risk group separated from the other children. As they became more knowledgeable and experienced, their comfort level grew and they began to integrate the HIV-positive—or potentially infected—into groups with other children according to their age and development levels.

“Of course, they are very young children so they all must be watched closely by their teachers and care providers to ensure they don’t bite, scratch, or otherwise engage in behavior that might result in the spread of the virus. Also, universal precautions are always observed when we provide care or medical treatment,” she stresses, pointing out that in all the years they’ve been working with HIV-infected children, no cases of cross-contamination have occurred.

When HIV-positive children at Orphanage No. 3 reach the age of four, if they are relatively healthy, they are generally sent to Orphanage No. 9 on the outskirts of Odessa where they will stay until they turn eight years old. If they are not healthy, they are sent to institutions that specialize in their particular condition. According to Tatiana A. Groza, who has served as the director of Odessa Orphanage No. 9 for the past seven years, in December 2003, 13 of the 61 children living there were HIV-positive.

“In recent years, we’ve seen an overall decrease in the number of children coming into our facility. This can be attributed to an overall decline in Ukraine’s birth rate, primarily because of socioeconomic conditions here; when people feel insecure about their future they tend to put off having children,” Groza observes. Unfortunately, this trend does not apply to HIV-infected children. Their numbers continue to increase, she laments.

“But the first HIV-positive child came to us in 2001, we really didn’t have the proper conditions to keep children with an infectious, incurable disease. In part, this was because for almost 30 years there were no repairs whatsoever made to our facility. And, in my opinion, even the healthiest children need proper conditions in which to thrive. For sick children who have special needs, this is even more critical,” Groza explains. So, she started to look for sponsors who would finance a reconstruction and renovation project to ensure all the children benefit from a good environment and conditions appropriate to their development and recovery. Some projects have been completed while others—the construction of an on-site pre-school and elementary education facility, for example—are currently under way.

As with Orphanage No. 3, employees at Orphanage No. 9 didn’t know how to deal with HIV-positive charges early on. Staff from the Odessa AIDS Center and volunteers from Médecins Sans Frontières (MSF) came to teach them about the many different aspects of caring for HIV-infected children. “First of all, they taught us about universal precautions and how to take care of these children and prevent the spread of the virus. We also learned about the various kinds of treatment that can be offered to children with HIV, and how to deal effectively with many other aspects of their care,” Groza explains.

“There are several groups of children here and each group is, by and large, treated as separate entities with their own teachers, care-givers, and units. Each group has its own facility or area and its own equipment, bedding, and other necessities. So, this cluster of HIV-infected children formed its own group, not so much because of their status rather because that is the principal manner in which this orphanage works,” Groza continues, stressing that they are not kept isolated from the other groups. They’re taken care of as if they were normal, healthy children.
Although the children are too young to fully comprehend their diagnosis and its implications, Groza and her staff are careful to teach them how to keep themselves healthy and others safe. Even so, they do tend to get sick more frequently than the other children. “Respiratory infections, indigestion, and diarrhea are the main problems, although the digestive disorders are not really related to the HIV infection. Inflammation of the lymphatic nodes is also common and almost all of them have hepatitis B,” she admits.

All of the HIV-infected children get a check-up, including blood work, at the AIDS Center every three months. After the results of their blood tests are back, a physician comes to the orphanage to examine them and make any necessary adjustments to their care and treatment, Groza explains. “In addition, doctors from MSF come here quite often to evaluate the children and are proactively involved with their care. Currently, four of the children have been receiving antiretroviral therapy for more than a year through an MSF program and we’ve noticed a real difference in them. One girl actually grew taller and the others have gained some weight. They’ve been doing well at their check-ups, so we’re very pleased with the outcome.”

So far, none of the children at Orphanage No. 9 have developed AIDS. “We are not a healthcare institution, rather an educational and residential one, so we are really not qualified to house children who are so very sick—whether with AIDS or another disease,” Groza reports.

A sad fact of life at Orphanage No. 9 is that once the children are old enough to live there—HIV-positive or not—they are likely to remain institutionalized until they reach the age of 18, she acknowledges. “Not many get adopted. Usually families want young children or infants.”

Providing a Network of Support
Regardless of their family situation, all children have certain needs that must be met if they are to grow and thrive. A safe, nurturing environment and access to food, water, basic healthcare, and education are all critical elements of a child’s development. For young people who have lost one or both parents to HIV/AIDS, however, assistance in the form of psychological support, legal advice, and even job training may also be crucial.

Over the past several years, a number of community-based programs designed to provide care and assistance to these children have been established. By organizing services and support, many of these grassroots programs provide a much-needed safety net for HIV-affected children and their families.

For example, Save the Children—a Connecticut-based non-profit with child-assistance programs in more than 40 developing countries—has programs targeting children affected by HIV/AIDS in four African countries. According to HIV/AIDS Program Director Stacy Rhodes, in addition to working to prevent new infections, these programs focus on mobilizing communities to provide care and support for these children and their families.

“One of the challenges is the stigma surrounding AIDS,” she explains. “While people are often hesitant to talk about it, there’s a need to educate the community and children about the disease. Providing education about HIV/AIDS is one of the most important things we do, and it helps to reduce the stigma and discrimination.”

For example, Save the Children works with local schools to teach children about HIV/AIDS and encourage open discussions. They also provide support and counseling to children and families affected by the disease.

“Women in our programs in Malawi grow and harvest vegetables for families affected by HIV/AIDS in their village and older children are given vocational training to prepare them for future jobs,” Rhodes explains, noting that even the simple act of providing food and support can make a big difference in the lives of these children and their families.
of having community members visit affected households on a regular basis helps ensure that families are getting the emotional support they need.

World Vision, a Christian nonprofit based in the state of Washington and dedicated to helping children and communities in more than 100 countries, also assists orphans and families made vulnerable by HIV/AIDS in Africa. In the Rakai region of Uganda, one out of every three children has lost one or both parents to AIDS. Established in 1990, World Vision’s Rakai Orphans Project has helped stricken communities develop the resources they need to address the social, emotional, spiritual, and economic ramifications of the epidemic by providing clothing, tuition, and school supplies to primary-school children. Additionally, the program helped create some of the region’s first peer counseling and support groups for people living with—or affected by—HIV/AIDS. Other project components include agricultural support, vocational training, and the construction of primary schools and health centers.

At the XII International AIDS Conference held in July 2000 in Durban, South Africa, the need for a framework that can guide the development of programs for orphans and children made vulnerable by HIV/AIDS was stressed. According to Naisiadet Mason of the Society for Women and AIDS in Africa—a regional organization dedicated to helping women and their families in the fight against HIV/AIDS—representatives of governments, non-governmental organizations, international agencies, the private sector, community groups, and young people themselves have since held both formal and informal meetings to determine certain key elements that underpin effective programs for these children (see “Supporting Communities, Families, and Children” sidebar, page 64). By keeping them in mind, groups looking to provide support for orphans and vulnerable children can help ensure that their needs are being met to the greatest possible extent.

As countries in Eurasia begin to create programs targeting their growing population of children orphaned or made vulnerable by HIV/AIDS, learning more about multidisciplinary models that adopt this holistic approach—and have been proven effective in other parts of the world—can save time and eliminate wasteful duplication of effort. One example of an organization that has considerable experience is the Hope for African Children Initiative (HACI), which partners seven international organizations targeting the needs of orphans and vulnerable children. “The activities of our member organizations are child-focused, community-based, and committed to ensuring program integration into a broader network of support,” HACI’s Grace Chepkwony explains, stressing that HIV/AIDS-related problems cannot be adequately tackled by any single intervention.

This broad approach to care and support encompasses a wide range of activities geared toward preventing new infections, including transmission from mother-to-child; reducing HIV-related stigma and discrimination; enhancing access to education, healthcare, and basic necessities; providing psychosocial support; preparing families for transition; and supporting income-generating activities, according to Chepkwony.

“As front-line caregivers, families and communities are critical to addressing the enormous challenges confronting orphans and children made vulnerable by HIV/AIDS,” Chepkwony concludes. “Creating strong alliances and networks of local non-governmental and community-based organizations, mobilizing additional resources from the international donor community, and scaling up successful programs and interventions can help ensure a brighter, better future for these children.”

Trying to Beat the Odds
According to a study commissioned by ARO and conducted this year by Transatlantic Partners Against AIDS, the consequences of children being orphaned or abandoned is a heavy burden to society and state alike. Outcomes for children growing up in
institutional settings are grim indeed, with only 30 percent adequately adapting to life on their own. Another 30 percent wind up unemployed and homeless, 30 percent are drawn into a life of crime, and the remaining 10 percent commit suicide. The study concludes that social adaptation of children born to HIV-positive women may fall even lower due to unnecessarily long hospital stays early in life. According to Cavanaugh, ARO programs are working to change these dire odds for orphans and vulnerable children by stimulating, supporting, and developing community-based services targeting families at risk. “We are currently implementing a new program component that includes abandonment prevention services and family-based care solutions for children born to HIV-positive women by providing funding and technical assistance to grassroots organizations that have come to us with innovative projects targeted to the specific needs of their communities,” he explains.

The problems faced by children orphaned by HIV/AIDS usually start long before their parents die, according to Sandra L. Thurman, president of the International AIDS Trust, a Washington, DC-based non-profit that earlier this year released a report on this topic. By stripping away the productive (adult) generation, the HIV/AIDS pandemic forces children to assume the role of care-giver and often provider. Left to fend for themselves and possibly their siblings, these children are vulnerable, malnourished, and devoid of opportunities that would allow them to grow and flourish. The social and economic ramifications of this vast, young army of disenfranchised children coming of age with virtually no support or preparation to become active, productive adults can be difficult to fully appreciate. “We talk a lot now about getting treatment to people living with AIDS, but we also have to look at the social impact this epidemic is having on families and communities, particularly in the hardest hit regions,” Thurman points out.

“We need to move beyond feeling beleaguered to feeling outraged by the unacceptable suffering of children. We must keep parents alive and ensure that orphans and other vulnerable children stay in school and are protected from exploitation and abuse.”

Society at large may not be able to truly grasp the long-term effects watching their parents grow sick and die, being forced to leave school, and compelled to seek work to support their families will have on millions of the world’s children, but ignoring the growing problem is certain to result in at least some of these orphans coming back to haunt the world as unproductive, rebellious adults unless something is done to address their plight.

References
4. Ibid.
6. Ibid.