Those Born With HIV See Adulthood, Challenges

BY ERIK GOLDMAN
Contributing Writer

OLD GREENWICH, CONN. — A small cohort of young people who were born infected with HIV is alive and well and struggling to come to grips with an adulthood no one ever thought they'd live to reach.

"We first saw some of these kids when they were 4 or 5 years old, and it is so heartening to see them now as young adults. We never expected them to live this long," said Dr. Katlyne Lubin of the Albert Einstein College of Medicine's Rose F. Kennedy Center for Excellence in Developmental Disabilities, Bronx, N.Y. Since the early 1990s, the Kennedy Center has had a special program to help young children born with HIV, many of whom have significant HIV-related neurologic and developmental problems.

At a meeting of the Eastern Society for Pediatric Research, Dr. Lubin reported preliminary qualitative data gathered from the first-ever U.S. follow-up study of young adults born HIV positive. Her findings provide a window into the inspiring yet heartbreaking world of a unique generation.

"There was nobody like these kids before they were born, and because here in the United States we've been so successful in preventing maternal-fetal HIV transmission, there are hardly any others coming up behind them." Many of the survivors of the original Albert Einstein cohort are doing surprisingly well given the daunting difficulties posed by a chronic and life-threatening disease and cognitive impairment, all against a backdrop of inner city poverty.

Today, these young people face entirely new challenges as they enter an adulthood for which neither they nor the health care system are prepared.

Dr. Lubin's study is a follow-up to work originally begun by P. Papola, M. Alvarez, and H. J. Cohen at Einstein in 1994. The team assessed the neurocognitive status of 90 children, ranging in age from 5 to 14, who were born infected with HIV. All were residents of the Bronx, and nearly all were from poor African American or Hispanic/Caribbean communities (Pediatrics 1994;94:914-8).

The original study showed that 44% of these young people were below average in intelligence for their ages, and 56% were at borderline intelligence. Half had significant language impairments, and 74% required special education services.

As the youths have aged, nearly all of them have ceased coming to the Kennedy center, and have been essentially lost to follow-up.

"We began to wonder what had happened to all of these kids, so about 2 years ago we decided to try and do a follow-up study, and track down as many of them as we could. If you know anything about doing research in inner city communities like we have in the Bronx, you'll know this was a Herculean task," Dr. Lubin said at the meeting, cosponsored by the Children's Hospital of Philadelphia.

'We first saw some of these kids when they were 4 or 5 years old, and it is so heartening to see them now. ...We never expected them to live this long.'

Her team was able to find leads to 44 of the original 90 young people, who now range in age from 16 to 24 years, with a mean age of 19. Twenty of these were confirmed deceased, but the researchers were able to make contact with 24 of the former patients, some of whom they'd not seen in over a decade. "We sent them letters and called them asking if they would come in and fill out follow-up questionnaires."

Nine were living with adoptive families, and six were still living with a biologic parent, some of whom were HIV positive themselves. Three were living independently, and others were living with grandparents, siblings, or other relatives. Unfortunately, a significant number were in prison or detention centers.

The cognitive and neurologic problems present during their early childhoods have persisted to some degree into young adulthood. The mean total intelligence quotient in the group was 87, which is slightly lower than average (90-110). However, 17 of the young people were within the average range, and only 3 showed evidence of mild retardation. Fourteen still had language impairments, and 9 had learning disabilities.

Many of them were working very hard to overcome their disabilities. Nine of them were currently in school, four had already graduated from high school, two had obtained a general equivalency diploma, and two had actually graduated from college. "Given all the factors against them, these are major accomplishments," said Dr. Lubin.

Dr. Lubin attributed their survival in part to improvements in antiretroviral therapy over the last decade. She noted that 14 of the 24 patients reported taking their anti-HIV drugs every day; 9 reported poor compliance. One patient reported taking the drugs on at least 5 of every 7 days. The investigators observed an age-related trend toward noncompliance; the patients who were over 21 tended to be less compliant than those under 21.

Compliance also seemed to correlate with education; the youths who dropped out of high school were less likely to take their medications consistently. But Dr. Lubin cautioned that the sample size was not large enough to determine if these are truly meaningful observations.

Some of the young people were very actively engaged in self-management; 8 knew their T-cell counts, and 10 knew their current viral loads. Those who were most compliant with their medication regimens were less likely to abuse alcohol or street drugs, and less likely to have run afoul of the law than those who were noncompliant.

Not surprisingly, given the age range of the subjects, use of alcohol and cannabis was common, with 18 reporting use of the former, and 13 reporting use of the latter. Only 4 of the 24 reported using "hard" drugs such as heroin or cocaine.

Although most were doing fairly well, seven had major problems with the law (arrests, detention, or prison), and six had already done jail time.

For Dr. Lubin and her colleagues, as well as for the patients themselves, the reunions were extremely moving and often bittersweet.

"It was so amazing to see them as big kids. We knew them as little children and now, here they were, fully grown. Many of them looked absolutely wonderful. They have a sense that they're doing well, and that they're going to be around for a while. But at the same time, it is very sad because their futures are very uncertain. And they're reaching an age where they are becoming sexually active and having relationships. And no matter how open-minded you are, HIV carries a huge stigma. They're struggling with the question of to whom they should disclose their status."

Eleven of the former patients reported disclosing their HIV status to close friends, but an equal number had not disclosed it to anyone. And 16 were sexually active, but only 7 reported that they always disclosed their serostatus to sexual partners. Another 7 of the 16 said they'd never disclosed to a sexual partner, and 2 said their willingness to disclose was variable. Ten of the 16 said they used condoms all the time, and 4 said they used them on most occasions. Two said they had never used condoms.

Some of the youths, particularly the older ones, expressed the wish to become parents but feared having an HIV-positive child. Dr. Lubin noted that two of the girls in the cohort had already had their first babies, both of whom were HIV negative.

These youths were also struggling with the larger question of what to do with their lives—adult lives no one expected them to have. As a group, they have a lower educational level than the average, which limits their employment prospects. "A lot of them are really pretty lost. They're having difficulty transitioning to independence. They do not know how to deal with money or pay rent or anything like that. We've identified the need for programs that help them deal with basic life skills, and teach them how to deal with the various medical and social services for which they qualify." ■

Acute Hepatitis C Outbreak Emerging in HIV-Positive Patients

BY ROBERT FINN
San Francisco Bureau

SAN FRANCISCO — Acute hepatitis C infections among individuals who are HIV positive have been documented in four countries, and treatment of this coinfection remains controversial, Dr. Marion G. Peters said at a meeting on HIV management sponsored by the University of California, San Francisco.

The largest outbreak was documented in the United Kingdom, where 210 people from London and surrounding cities were found to be infected. Cases also have been reported in Germany, France, and the United States.

Dr. Peters of the University of California, San Francisco, and her colleagues documented 11 cases of acute HCV infection in the San Francisco Bay Area among men who have sex with men. Presentations varied greatly, ranging from incidental elevations of aspartate aminotransferase and alanine aminotransferase levels to severe liver dysfunction. Ten of the 11 patients had adequate CD4 counts. Five of them had recently had a sexually transmitted disease.

Five patients were treated with interferon and ribavirin, and four of them achieved sustained virologic responses. Six patients were untreated; three of them developed chronic hepatitis C and three seroconverted spontaneously, losing their hepatitis C RNA.

Among the 210 patients with acute hepatitis C documented in London, 64% were on antiretroviral therapy, and their mean CD4 count was 552 cells/mm^3, which Dr. Peters described as "perfectly adequate."

Subtyping identified five clusters of patients. The patients in each of the clusters apparently acquired the virus from a single individual or small set of individuals. One of the clusters contained 43 patients. Genotype 1a was found in 78% of the cases overall. A total of 30% of the patients had had syphilis within the previous year.

A case-control study involving 60 of the 210 patients documented significant levels of high-risk behavior. Patients with acute hepatitis C were more likely than were controls to be users of intravenous drugs. They reported a larger median number of sexual partners and higher levels of Internet dating, one-night stands, group sex, and use of party drugs.

Studies of monogamous couples in which both partners have hepatitis C show that their viruses are rarely identical and that sexual transmission occurs in only 1 case in 500. This suggests that blood-to-blood transmission, perhaps due to traumatic sexual practices, is likely to account for the transmission of hepatitis C in patients who are HIV positive.

Most authorities recommend treating these coinfected patients with interferon and ribavirin, but controversy remains over when to begin treatment after the pinpointed infection event. "We know that if you wait too long the patient will become chronic and then [his or her] chances of responding are very low. So we are fairly aggressive, and if we have a pinpoint of when they acquired [the infection], I would wait 12 weeks. ■

Pages 30a—30f〉