

The success of Protocol 076 in reducing perinatal transmission of HIV from mother to infant has implications for training in health policy, health promotion, health protection and clinical intervention with HIV. The debate generated by the findings of Protocol 076 highlights important aspects of a metropolitan university's potential contribution to the public health of its population.

Women and Children with Aids:

A Public Health Challenge For Metropolitan Universities

The University of North Texas is about to implement a Master of Public Health (M.P.H.) program, offered jointly with the University's Health Science Center in Fort Worth. As Peebles has indicated elsewhere in this issue of *Metropolitan Universities*, the M.P.H. degree focuses importantly on "population medicine"—that is, "the health status and prospective remedies for large cohorts facing similar risks for and experience with morbidity, disability, and mortality." The population of the Dallas/Fort Worth Metroplex area is a ready laboratory for studying the many public health issues we now confront as a nation.

Most of the public health problems in the North Texas area are depressingly familiar: rising crime rates, high rates of infant mortality, substance abuse and addiction, homelessness, TB, increasing rates of sexually transmitted diseases, teen pregnancy, mental illness, violence, familial and spousal abuse, environmental hazards, and HIV/AIDS. Because they affect the population that a metropolitan university serves, these problems become an important focus for any metropolitan institution, especially one initiating an M.P.H. program.

I will outline below one such problem—the problem of women and children with AIDS. Because of my background in bioethics, I am most interested in the health policy dimensions of this issue, which raise, in sharp relief, the questions that metropolitan universities must assist in solving.

HIV Infection Trends in Women and Children

In August of 1988, there were 5,840 cases of AIDS reported in women in the United States. At that time, the U.S. Public Health Service projected that, by 1992, there would be between 29,000 and 36,000 women with AIDS. Data from the National Survey of Childbearing Women now indicate that in 1992, the estimated prevalence of HIV infection among childbearing women was 1.7 per 1,000. Yet, through June of 1994, the U.S. Centers for Disease Control and Prevention (CDC) had received reports of more than 53,000 AIDS cases among adult and adolescent women and more than 5,000 cases among children who acquired HIV infection perinatally. In 1994, 18 percent of the AIDS cases in the United States were female, almost three times the rate ten years ago. The 14,081 women reported with AIDS in 1994 represented nearly one-fourth of the total number of AIDS cases reported to date among women.

In 1987, Surgeon General Koop predicted that, by 1991, 3,000 children would be afflicted with AIDS. Yet, during the years 1989-1992, approximately 7,000 HIV-infected women gave birth each year, and an estimated 1,000 to 2,000 HIV-infected infants were born *annually* during those years in the United States.

The accumulating data indicate rapid increases in the numbers of women reported to have AIDS/HIV. In 1993, HIV infection was the fourth leading cause of death nationally among women 25 to 44 years of age, and the seventh leading cause of death among children one to four years of age in the United States.

Of great concern is the continued, steady rise of heterosexually transmitted cases of HIV. As the numbers of these cases have grown, heterosexual contact with an HIV-infected male has become the most rapidly increasing transmission mode among women. Nearly two-fifths of all cases among women have been attributed to heterosexual contact; slightly more are thought to occur through injecting drugs. Although black and Hispanic women constitute only 21 percent of all U.S. women, more than three-fourths of AIDS cases reported among women in 1994 occurred among blacks and Hispanics.

Almost 90 percent of cumulative AIDS cases reported in children, and virtually all new HIV infections among children are attributed to perinatal transmission of HIV.

HIV infection can be passed from a mother to her fetus or newborn in three ways: during pregnancy, to the fetus *in utero* through fetal-maternal circulation; to the infant during labor and delivery, and to the newborn during the postpartum period, through breastfeeding. From 15 to 40 percent of infants born to infected mothers become infected themselves. While researchers know that HIV can be transmitted to the fetus as early as 8 weeks, the preponderance of the evidence indicates that most transmission occurs late in pregnancy or during the time of labor and delivery.

Trends in women with AIDS are clearly ominous predictors of trends in pediatric

AIDS cases. These trends become especially important for Texas, including North Texas and the metroplex region, because the majority of cases of AIDS reported in 1994 were residents of only 5 states—including Texas. Moreover, 84 percent of reported cases were among residents of large metropolitan areas—those with 500,000 or more population.

Treatment of Pediatric Aids

While much of the AIDS/HIV research over the past decade has focused on biomedical and behavioral interventions to prevent HIV transmission and infection, advances in treatment options over the last several years have improved survival rates and the quality of life for HIV-infected persons. Despite these advances, however, pediatric HIV infection remains almost uniformly fatal. Reduction and/or prevention of pediatric HIV infection has consequently become a major focus of recent research and policy recommendations.

Among children with perinatally acquired HIV infection, pneumocystis carinii pneumonia (PCP) remains the most common and devastating of the opportunistic infections. PCP in children under 12 months of age usually presents acutely and has a very poor prognosis. Unfortunately, ongoing AIDS surveillance has detected no substantial decrease in PCP incidence among HIV-infected infants; in fact, it remained relatively unchanged between the years 1989 and 1992. Of the 7,080 children born to HIV-positive mothers in 1992, 2.4 percent developed PCP. More significantly, from the perspective of those recommending public health policy, a total of 199 of the 300 children diagnosed with PCP between 1991 and 1993 had never received prophylaxis.

This study and others suggests that the above incidence is associated both with a failure to identify HIV-infected infants before they develop PCP and with limitation in the current guidelines for identification of children at risk for PCP. For many, the failure to identify infants at risk is arguably linked to the failure to identify and evaluate pregnant women with HIV infection.

The Public Health Challenge

Against these data are now juxtaposed the remarkable findings of the U.S. AIDS Clinical Trials Group (ACTG), a team of clinical researchers headed by Dr. Edward M. O'Connor of the New Jersey Medical School in Newark. In a multicenter randomized placebo-controlled study involving 477 women known to be infected with HIV, half were given zidovudine (AZT) during the study and the other half (and their newborn children) were given placebo. The test group received AZT orally five times a day during the latter stages of pregnancy and intravenously during delivery. Newborns in this group were also treated with AZT for approximately six weeks following delivery.

Forty infected infants were born to the women who received placebo, representing a 25.5 percent rate of infection. By contrast, among the women who received AZT only 13 infants (8.3 percent) were born infected—a stunning 67.5 percent reduction in the incidence of transmission. Reported side-effects in mother and child were similar in both groups except for lower hemoglobin concentrations in the treated infants. Hemoglobin levels returned to normal when AZT administration was terminated. The results were considered impressive enough to halt the study, and patients in the control group were offered AZT treatment. The results of that study were released in February 1994 in the *New England Journal of Medicine*.

The success of this trial, now known colloquially as Protocol 076, prompted researchers and clinicians to conclude that the use of antiretroviral therapy in the treatment of HIV-infected women and their newborns significantly reduces the risk of perinatal transmission of HIV.

News of the success of perinatal AZT treatment has generated mixed responses from health care providers and those in public health policy. On one hand, the potential of AZT therapy for preventing transmission from mother to child, as well as for preventing infection in newborns, underscores the importance of detecting HIV infection during pregnancy. All children identified as HIV-exposed, either prenatally or postpartum, are recommended for diagnostic testing, monitoring, and treatment. Because perinatally infected children develop PCP most commonly between the 3 and 6 months, effective treatment requires that children at risk for HIV infection because of maternal infection, be identified early, *preferably prenatally*, and that prophylaxis begin as early as the second month of life. If HIV infection risks can be determined prenatally, the results of Protocol 076 suggest that we can expect significant reductions in pediatric AIDS.

On the other hand, because perinatal identification of HIV for newborns includes identification of maternal HIV, some have recommended that testing should only occur in newborns. Studies suggest, however, that only 35 to 55 percent of children at risk for HIV infection are identified as newborns. Those infants not identified are, clearly, more likely to develop HIV infection and are more susceptible to potentially fatal PCP during their first few months of life.

These considerations have led to a variety of recommendations for stepped-up, even mandatory, HIV testing of pregnant women. Understandably, talk of mandatory testing generates considerable medical and public health controversy.

The Metropolitan University's Role

Although AIDS, particularly in pregnant women, presents some of the more sensitive health policy issues one might have to confront, the debate generated by Protocol 076 highlights important aspects of a metropolitan university's contribution to the public health of its population.

As Peeples points out in his article, M.P.H. training seeks to prepare public health practitioners in health policy, health promotion, health protection, and clinical prevention. The success of Protocol 076 has implications for each of these areas of public health training. The metropolitan university with an M.P.H. program will play a major role in addressing the dilemmas created by the successful treatment of pregnant women with antiretroviral therapy by:

- helping to frame the health policy debate;
- influencing the direction of research;
- seeking to develop appropriate HIV educational programs;
- ensuring that testing is accompanied by clear, thorough and adequate counseling;
- linking the several public health problems that confront women and children with HIV;
- ensuring proper case management and follow-up.

Framing the Debate

Virtually every metropolitan university with public health offerings, whether they be through traditional public health degree programs or other academic units, will have ties with local departments of public health. Through these natural links with public health practitioners, metropolitan university faculty have opportunities to be involved in regional and state health policy development, particularly as it affects AIDS policy. Many university researchers are already involved in dimensions of AIDS policy research; it is an obvious extension of their research efforts to suggest community involvement in policy discussions.

For example, the CDC now place greater emphasis on HIV planning and service delivery that responds more explicitly to local community needs. Accordingly, they have created regional planning councils throughout most states that have been charged with developing educational programs, interventions, and service delivery strategies/programs that respond to the particular communities of persons affected by HIV in that region. In the North Texas area, such a regional planning council has involved faculty from the University of North Texas Colleges of Arts and Sciences and Education. Through these faculty, the university has had a significant voice in shaping the policy dimension of the regional response to AIDS. These faculty members have helped the regional planning council to make contact with local agencies, including student health services at other area institutions, in order to identify populations at need as well as to help determine the level and kind of services needed.

As one might expect, needs for AIDS/HIV services and education differ from region to region, even within a single state. Where areas of the state are heavily urban, the needs of minority or drug-using populations are likely to be greatest.

Metropolitan universities can also help respond to the need for epidemiological and demographic data specific to the locale, through survey research centers and other data-gathering entities on campuses. Public health researchers at these universities quite naturally have an interest in studying populations that might be underserved or forgotten in the larger national thrust to provide services.

Influencing the Direction of Research

Women and children have always been among those who have AIDS. Nonetheless, there was little focus on women in earlier years of the epidemic, and CDC defining criteria for the diagnosis of AIDS did not even include conditions unique to women until January of 1993. In fact, a news report on National Public Radio on November 30, 1990, proclaimed that over half the women who died of AIDS had never been diagnosed.

Historically, medical research has paid scant attention to women's health issues, except as they affect child health, and women have routinely been evaluated for health care intervention and treatment based on extrapolations from results obtained from studies conducted exclusively on men. In fact, numerical projections and statistics on AIDS/HIV were based, for many years, on data pertaining to transmission between males.

Although women are now included in clinical trials, they were eclipsed in much of the early HIV research, leading many to suggest that there are still fundamental questions about disease progression in women that remain unanswered. Indeed, there are still fundamental questions about the long-term risks associated with AZT intervention, such as that used in Protocol 076.

In heralding the results of the ACTG 076 study, for example, little attention has been given to the clinical questions that remain unanswered—all questions of enormous importance to women. What are the long-term effects of this level of AZT exposure/treatment on mother and child? Could administration of lower levels be equally beneficial? If AZT were only administered late in pregnancy, could we expect the same results? Will treated infants develop AZT resistance, precluding its use later in the course of their illness? Is the effect of AZT sustained in infants? Is it in the best interest of mother or child to proceed on the basis of the results of a relatively small trial that has not been fully peer-reviewed?

Metropolitan universities with ties to health science centers can respond to the need for additional research in special areas such as the above by providing internal research incentives for exploring clinical and other questions that remain unresolved. Often their clinics provide a ready laboratory for studying both medical and psychosocial implications of treatment options for a disease like HIV. Their patients often represent the very populations most at risk. In addition, coursework and fieldwork in M.P.H. and other health-related programs must pay special attention to address-

ing the psychosocial, behavioral, and racial dimensions of HIV.

The disparities in the risk of HIV among blacks and Hispanics must be examined in the context of the social fabric in which the infection occurs, and at the core of that fabric one finds the problems of poverty, drug abuse, teen pregnancy, lack of education, inadequate health care and social support services, prostitution, and child and spouse abuse.

Frequently, the university health science center setting provides the opportunity for practitioners from various disciplines—for example, social work, pediatrics, mental health—to work together in studying the needs of patients. Coursework and fieldwork in an M.P.H. program must pay special attention to addressing the psychosocial, behavioral, and racial dimensions of HIV. This collaborative research will yield the kind of data currently missing from studies on women and AIDS.

Understanding the Public Health Educational Mission

Universities that have adopted public health as one way to serve the populations of their metropolitan areas will have a major impact on the development of public health educational programs, both within local public health departments and in their schools.

Clearly, one's view of public health education rests on assumptions one has about what prevention measures in general, or HIV interventions in particular, should accomplish. These assumptions obviously shape recommendations for new educational programs, as well as public health educational policy. It is important to ask, therefore, what should count as a measure of any successful educational program.

It seems clear from the history of public health that for many in health education the bottom line—the public health goal—is elimination of disease. For many in HIV/AIDS education and prevention the goal has been zero transmission, 100 percent risk reduction. Short of that, public health education and intervention are said to have failed.

These goals seem to reflect an impoverished notion of education. Serious public health and social consequences can flow from a failure to appreciate how unlikely it is in a democratic society that we will ever bring about 100 percent risk reduction or complete behavior change. Equally serious consequences can flow from an expectation that they could.

Even if we were to agree that completely eliminating risky behaviors is desirable in combating HIV, our commitment to the kind of education we champion in a democratic society will not allow us to realize that end. A democratic society places a high value on pluralism; hence, the principle of respect for people has important moral force. Respecting people requires a presumption in favor of individual responsibility, just as it leads us to embrace certain values, such as mutual respect among people. Placing a high value on individual responsibility requires not only

that we accept all people as possessing equal moral status, but also that we treat them with such respect. As June Osborn stated in a recent article in the *New England Journal of Medicine*:

Advocacy of voluntary approaches stems not from ideology but from the facts of the case; since private behavior is at issue, the most effective policies will be those that enlist the cooperation of those at greatest risk, thus optimizing both human rights and the health of the public [381:444-447].

The criteria for successful public health education in such a context will be vastly different from the criteria implicit in policies that *mandate* certain behaviors or outcomes. Under voluntarist public health policy strategies for reducing transmission of HIV must rely heavily on moral persuasion, rational deliberation, individual respect and concern for others, and hence, on the availability of current and accurate information on HIV transmission and prevention.

Under such a conception of education and public health policy, success is achieved if individuals can be participants in their own learning and if they can differentiate and accept responsibility for moral choices. Such a conception of education carries with it certain risks, however—namely, that some people will learn and understand but will not change their behaviors, that they will forget, that they will make mistakes, that HIV will not be entirely eliminated. In fact, a voluntarist approach to HIV prevention strategies may make some people more willing to take risks with themselves and others than they were before. And, not surprisingly, those are risks that many in public health are unwilling to accept.

The issues involved in developing a successful program of HIV prevention should not be conflated with issues involved in effecting behavior change. Only if we think that successful prevention programs must eventuate in specific behaviors (or the absences of those behaviors) are we pushed to think that prevention is equivalent to coercion. So, for example, while we might agree that HIV/AIDS prevention requires telling people what their responsibilities are to others (including their offspring), it is a very different enterprise to force them to do so or to determine what will happen to those who fail to do so.

It is in the development and promulgation of appropriate programs for education and prevention that the metropolitan university can have the greatest impact on the public health of its metropolitan community.

Seeking to Develop Appropriate HIV Educational Programs

As the debate continues over what kinds of HIV education programs are appropriate for various targeted audiences, metropolitan universities have an opportunity to fill a special niche. For many, the university offers an arena for discussion of topics that are not comfortably addressed in many other public settings. Metropoli-

tan universities can serve as conveners of parties to the debate, and can provide the kind of neutral forum essential to dialogue on some of these important issues.

The Emory AIDS Training Network is an example of one such important educational effort undertaken early in the growth of the epidemic. Through links established with other universities, and in building a list of qualified faculty, the Emory AIDS Training Network has been successful in providing appropriate HIV education to groups as diverse as the National Foodservice Administrators, mental health and mental retardation care providers, corrections/penal officers, teachers' associations, church youth groups, and industry human resources personnel.

By celebrating AIDS Day each year, or sponsoring an AIDS Awareness Week each year, the metropolitan university begins to develop in its students an awareness of the issues and the people affected by AIDS that will ensure responsible and thoughtful future leaders, educators, and policymakers. Often students who participate in these campus discussions take the message further—to their parents, their churches, their own communities, their friends. Equally important, many of these students become volunteers in community-based AIDS/HIV service organizations. The university setting also allows for the development of special educational materials, through research efforts of faculty, that are age-appropriate and relevant to the community's needs.

The University of South Carolina, in 1985, developed the first academic course on AIDS/HIV in the country. Rather than focusing on AIDS prevention, the course sought to teach undergraduate honors students the clinical, legal, psychosocial, and scientific dimensions of the disease. The course was co-taught by a philosopher and a physician, and utilized guest speakers from the public health community, people with AIDS, legislators, and religious leaders. This course was so successful that many students who were involved in it through the years stayed in AIDS policy, health law, and AIDS service delivery, or moved into careers better understanding how to respond to the disease and those suffering from it.

Acknowledged nationally as at the forefront of helping business respond to AIDS, the National Leadership Coalition on AIDS, through its connections with business leaders and faculty in colleges of business, has developed special materials appropriate to responding to the disease in workplace settings. Many who were involved in developing this educational material were able to call on the faculty resources of metropolitan universities. In developing its *AIDS in the Workplace* educational materials, Levi Strauss used faculty from metropolitan universities whose research interests offered insight into the appropriate kinds of educational workplace materials.

Linking Programs

Universities offer additional opportunities for addressing a pandemic like AIDS that other institutions and organizations cannot offer. At the University of North

Texas, for example, a researcher in domestic violence is studying inner city women and their familial relationships. As a part of that study, the researcher has been able to identify special needs that women with AIDS and their children confront. Because of her position in a major research university, and because of the collaborative environment in which she finds herself, this researcher is able to share information learned through research with others working on AIDS service delivery, clinical services for people with AIDS, psychological interventions that straddle abuse and AIDS, and so on.

In the larger world outside a university setting, this kind of collaboration is often more difficult, in part because of distance limitations and agency limitations that artificially separate persons working on different aspects of the same disease. The university setting also provides the opportunity for considerable collaboration on strategies and goal-setting. In a single metropolitan university, like the University of North Texas, one will find faculty in areas such as social work, health and behavioral medicine, public health, psychology, and education collaborating on research that addresses similar problems. The University of North Texas has formed an AIDS research group that meets periodically to discuss each member's current research initiatives and to develop ways to coordinate research efforts on AIDS/HIV.

The university setting is also a natural one in which to look specifically at issues affecting women in the epidemic, and most, including metropolitan universities have active and engaged Women's Studies programs.

As Kathy Anastos and Carola Marte point out in their article, "Women: The Missing Persons in the AIDS Epidemic," in *Health/PAC Bulletin*, (p. 6), the problem of the "missing women" in the AIDS epidemic goes well beyond the epidemiology and case definition of AIDS or HIV. Societal attitudes toward women led to a pervasive inclination early in the epidemic to view women as "vectors" of HIV transmission to men and infants, rather than to focus on women's own risk of becoming infected and sick. Women were not educated about their own risk factors, much less about the possible risks to a developing fetus. Women were, and still are, largely ignored by mainstream media in their (now dwindling) coverage of HIV/AIDS.

Faculty involved in Women's Studies programs are often an especially valuable resource for those interested in women's health, women in science, and literature on general issues affecting women.

Ensuring Proper Case Management and Follow-up

Many metropolitan universities have programs that are heavily engaged in community service and outreach, often as a part of their training in programs like social work, clinical psychology, health and behavioral medicine, psychiatry, and preventive medicine. When those universities develop intern or practicum programs, they have the opportunity—as some social service agencies may not—to structure the

case management and follow-up more thoroughly to ensure the appropriate outcome of treatment.

When a metropolitan university is also affiliated with a health science center, there are even greater opportunities for interdisciplinary and multidisciplinary approaches to care and follow-up than are available in most public health agencies. The multidisciplinary team approach to caring for women and children with HIV will be more likely to address the social and cultural effects of the disease—a particularly critical problem for women with HIV. Combined with instruction on self-care, assertiveness, parenting, and nutrition, clinical treatment of a woman and/or her infected child is more likely to be successful.

As the above discussion indicates, metropolitan universities will clearly play a central role in addressing this serious public health challenge.

Suggested Readings

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Note: Documentation in support of the positions described in this paper is extensive. The author would be pleased to provide references and documentation upon request. Address requests to: Dr. Nora Kizer Bell, Dean, College of Arts and Sciences, University of North Texas, Denton, TX 76203.

Declaration of Metropolitan Universities

We, the leaders of metropolitan universities and colleges . . .

- reaffirm that the creation, interpretation, dissemination, and application of knowledge are the fundamental functions of our institutions;
- accept a broad responsibility to bring these functions to bear on our metropolitan regions;
- commit our institutions to be responsive to the needs of our communities by seeking new ways of using resources to provide leadership in addressing metropolitan problems through teaching, research, and service.

Our teaching must:

- educate students to be informed and effective citizens, as well as capable practitioners of professions and occupations;
- be adapted to the diverse needs of metropolitan students, including minorities and underserved groups, adults of all ages, and the place-bound;
- combine research-based knowledge with practical application and experience, using the best current technology and pedagogical techniques.

Our research must:

- seek and exploit opportunities for linking basic investigation with practical application, and for creating interdisciplinary partnerships for attacking complex metropolitan problems, while meeting the highest standards of the academic community.

Our professional service must:

- develop creative partnerships with public and private enterprises that ensure the intellectual resources of our institutions are fully engaged in mutually beneficial ways;
- include close working relationships with elementary and secondary schools aimed at maximizing the effectiveness of the entire metropolitan education system;
- make the fullest possible contribution to the cultural life and general quality of life of our metropolitan regions.

