WOMEN:
THE MISSING AND NEGLECTED PERSONS IN THE AIDS PANDEMIC

CORA L.E. CHRISTIAN, M.D., MPH
CARIBBEAN STUDIES ASSOCIATION
XXTH ANNUAL CONFERENCE
CURACAO
MAY 22-27, 1995

Abstract

WOMEN: THE MISSING AND NEGLECTED PERSONS IN THE AIDS PANDEMIC

CORA L.E. CHRISTIAN, M.D., MPH

The proportion of U.S. female AIDS cases due to injection drug use has stabilized; the proportion due to heterosexual transmission, on the other hand, has more than doubled since 1983. Initially, AIDS cases were the addicts, the alcoholics, the prostitutes, the homeless; but now they are the noncompliant, the unsuspecting, the ones who don't believe or suspect that they are at risk. Across the Caribbean a similar phenomenon exists. If we focus internationally, we will see that AIDS is the most effective apartheid weapon. This article reminds us who they are, how they feel, how they live, what they do, what they get, and where they should go.

WOMEN: THE MISSING AND NEGLECTED PERSONS

IN THE AIDS PANDEMIC

I am clear that I cannot tell you anything new and revealing about HIV/AIDS. You know the alarming statistics. You know women are the fastest-growing population to be infected by HIV, and AIDS is now the leading cause of death in women aged 25 to 44 (CDC, 1995). You know that while the proportion of U.S. female AIDS cases due to injection drug use has stabilized, the proportion due to heterosexual transmission has more than doubled since 1983 (Tross, 1994). In nearly 60% of all U.S. female cases due to heterosexual transmission, the infected man is a substance user and for New York City, considered to be the trend setter in this epidemic, the percentage is closer to 89% (Tross, 1994). Initially, they were the addicts, the alcoholics, the prostitutes, the homeless; but now they are the noncompliant, the unsuspecting, the ones who don't believe or suspect that they are at risk. I can tell you that across the Caribbean a similar phenomenon is occurring, initially more prevalent in the female sex worker who bartered sex for drugs and/or money. But now the increasing numbers are like those in the U.S.A. And if we focus internationally we will see that AIDS is the most effective apartheid weapon. In 1990, UNICEF forecasted

that between 3.1 and 5.5 million children would shortly be orphaned in ten East and Central African countries alone (**World Health No.6,** Dec., 1993). Right in my home, the USVI, we read as late as March 25, 1994, that one third of the one out of every eight persons who are infected are native born Virgin Islanders; one third is from the United States; and one third is from the other islands in the Caribbean. (St. Croix Avis, March 25, 1994 p.1). I would consider that a great equalizer. And of the women who are infected, bisexuality and male prostitution are the silent culprits. In fact, the surveillance director, Jameel Muhammed, is quoted as stating our V.I. statistics are showing that women are getting closer and closer to equalling men in having this virus. He states that bi-sexuals rarely come out the closet and could be infecting their wives or girlfriends. He speaks to the issue of anal sex and its dangers. In Puerto Rico, noted as number two per capita for HIV/AIDS cases, Jose Toro, AIDS foundation director for Puerto Rico, states that some 92% of the children with AIDS in Puerto Rico contracted the virus from their parents.

"The world does not require so much to be informed as to be reminded" (Hannah More). I need to remind you who they were, who they are, how they live, how they feel, what they do, what they get, and where they should go.

But before I do so, I want to tell you a short story to set the right mood for this discussion. While she was enjoying a cruise to the U.S. Virgin Islands, Kim Bassinger, the famous actress, noticed that another female passenger at the next table was suffering from a bad cold. "Are you uncomfortable?" she asked sympathetically. The woman nodded. Ms. Bassinger continued. "I'll tell you just what to do for it," she offered. "Go back to your stateroom and drink lots of orange juice. Take two aspirins. Cover yourself with all the blankets you can find. Sweat the cold out. I know just what I'm talking about. I'm Kim Bassinger from Hollywood." The woman smiled warmly and introduced herself in return. "Thanks," she said, "I'm Dr. Jocelyn Elders, Surgeon General of the United States."

Although the above is not a true story, it re-emphasizes that my role is only to remind you of the scourge of the disease.

Who were they?

They were gay, homosexual; then they were IV drug users, alcoholics, prostitutes. They were persons who in the opinion of some were on the fringes of society; they were not really people of importance; they were people who got what they deserved from the misguided behavior they had.

Who are they now?

They are still the homosexual, the IV drug user, the alcoholic, the prostitute, but now they are also the terminally ill who utilize many of our health care resources; the bankrupted who utilized all their resources to survive just one more day; the mentally ill who have psychoses as the virus rearranges their thinking processes and puts them into a living hell; the homeless who live in the streets for they have no more resources, they have been discarded; the undereducated who just knew it could never happen to them; the wife who knew she was safe, for her husband is her only partner; the housewife who now and then had a fling; or the secretary who goes to an office party, has always admired her boss who is now a little tipsy, and neither could say no; the child who happened to be born to an infected mother. Given the universal scenario, it could be you or me. No one is excluded; no one is safe unless we take special precautions.

How do they feel?

They feel worthless, ashamed, guilty, alone, tired, desperate, detached, depressed, isolated, helpless, stressed, angry, anxious, disoriented, delirious, tense, burdened, weary, uneasy, afraid, apprehensive, impatient, useless, unimportant, quarantined, separated, segregated, secluded, suicidal, homicidal. Apply all

these, sometimes at the same time, and you'll understand how they feel.

How do they live?

They live with a lack of health care or poor health care; they live with a lack of proper housing or no housing; they lack nutrition, clothing, transportation, insurance, support.

What do they do?

They escape. Sometimes they escape the helplessness and hopelessness with drugs, alcohol, sex, and crime. Sometimes they escape by just giving up. Sometimes they escape by suicide.

What do they get?

They often get barriers. They get the barriers of money, politics, lack of resources, prejudice, lack of education, judgment, or religion.

Where They should go:

Professor Rebecca J. Cook of the University of Toronto states that some governments are failing to acknowledge and assure the health

rights of women by denying them access to a basic standard of health care. Women are being overwhelmed with having to provide care for chronically ill husbands, and brothers. When women fall ill, now at an increasing rate, who will care for them? Because of their low social status in many societies and lack of economic independence, they are limited. Even after adjusting for income, race, insurance and geographic differences, Dr. Hellinger of the Agency for Health Care Policy and Research states that females with AIDS receive fewer health services than males with AIDS. A female with AIDS is 20% less likely than a male injection drug user to be hospitalized for AIDS-related conditions (Research Activities No.171 December, 1993).

Yet the little data on female sexual partners of intravenous drug users point to the lack of risk reduction behaviors, or even intent to reduce risk. In one sample of approximately 1900 non-IDU, 70% had not taken any safer sexual precautions during their last sexual encounter with their main partner when they knew other partners existed. Reluctance to initiate, or even consider, methods of sexual protection that might have the potential to seriously disrupt their primary sexual relationship, their family home and their primary source of income is probably a common barrier to HIV risk reduction (Tross, 1994).

In 1993, at the Caribbean Studies Association Conference in Jamaica, Claudia Chambers of the University of the West Indies and Professor Claudia Mitchell of the University of California reported on the sexual behavior and its related attitudes and practices of men and women inside and out of relationships in one Caribbean country. This behavior can be applied to many other countries both in and outside the Caribbean. Because women find themselves in subordinate positions, it is sometimes difficult for them to negotiate the terms, including the use of condoms. Some use sex as the unit of exchange, and offer or withhold based on receipt of money or goods. In common law relationships, the bargaining aspects and the risks seem to be great because the MAN both "buys" and "binds". The price of confrontation with the man may result in withdrawal of support money for the woman and her children, a violent response, a withdrawal of "love", a loss of acceptance. "Me give enough loving..... him must pay for it.... pay". This is not prostitution, where materialism has fuelled the wants. This is transactional sex, a response to the inequalities of wealth and power, where women's needs to care for child and self, are pitted against men's allegedly stronger sexual urges. (Mitchell, 1993).

Further, use of cocaine, particularly crack, also operates as a powerful obstacle to HIV risk reduction--largely because intense drug hunger often drives women to indiscriminately exchange sex for drugs or money with dually addicted men in crack houses (Tross,

1994). These women seldom perceive themselves to be at risk for HIV infection.

Despite all that is out there in the media, the impact of the HIV epidemic on women in 1994 highlights the absence of perceived risk, intention to protect themselves, and consequently attempts to initiate safer sexual behavior change. When women are instructed to use condoms consistently or to abstain from sex, the focus is on behavior. However there are cultural and psychological precursors that must be in place before we see a change in behavior. The psychological precursors are the perceived need to change and the intent to change (Tross, 1994). The cultural precursors are even more complex, for race, ethnicity, language, the messenger and the model all affect the outcome. We, in the health care field, are trained in biomedicine and are accustomed to predict the outcome of a given experiment. If substance A is combined with Substance B, we can expect Outcome C with X percent of confidence. The situation with HIV, and I suspect with many other health issues, highlights that this approach will not work.

The recognition of the rich diversity is critical. It is apparent that in homogeneous societies, ethnicity is invisible and language is not an issue. But in diverse societies, ethnicity is very visible and language is an emerging problem. The definition of ethnicity varies by country. For example, in the United States,

attention is on skin color, blood quantum and language. Hispanic America and the Caribbean focus on language and culture. The United Kingdom, of which some still exist in the Caribbean, focuses on membership in the British Commonwealth. People who originally are descendants from India partially, or in totality, focus on religion, language and caste. If we refocus on the United States, race is viewed as holding equal or even greater meaning than ethnicity for nonwhites than whites because race is the defining symbol of their unequal power relationship with whites. Although the United States of America represents at least three types of populations: the native or aboriginal settlers, the dominant settlers and the emerging settlers, the issue of race is the defining factor. On one hand, whites are viewed as ethnic groups--the Irish, the Polish, the Jews, the Italians, the Scottish--and allowed to have ethnic pride, while for nonwhites talk of ethnicity is viewed not as pride but politics. The case of the American Indian tribes or the case of African Americans or Mexican Americans versus Puerto Rican Americans (Tross, 1994).

I don't believe there is anyone who is unaware that 75% or more of the women who are infected with the virus are women of color--Blacks, African Americans, Hispanics, Puerto Ricans. In New York City, the race of the mother of the Pediatric cases as late as December, 1993, was 53% Black, 37% Hispanic for a total of 90% of all cases (Tross, 1994). And still ethnicity is fluid, for it

changes over the life cycle of the individual as well as for the group. We can further complicate that with the known fact that it is necessary to speak to a client or patient in his or her native language when we speak of issues of sex, HIV, STDs and the ability to communicate health messages and to successfully give health services. This aspect of cultural competency is not solved by interpreters but by providers who are fluent in the language and culture. Realistic strategies to fight HIV/AIDS must be based on cultural competency. Hence the cry of varying minorities to see their own have opportunities to become physicians, dentists, nurses, physical therapists, social workers, EMTs, etc.

And what about those health care providers? Even if culturally oriented and competent, are they emotionally ready? In a survey of health care providers in the Virgin Islands in 1993, 50% of dentists stated they were not willing to care for HIV/AIDS patients. Twenty-six percent of physicians and 10% of nurses stated they too were not willing to care for HIV/AIDS patients. When asked if they were interested in training in HIV/AIDS care, 33% of dentists said yes. 76% of physicians and 91% of nurses responded that they were interested in training in HIV/AIDS care. There was consistency for the nurses and physicians in that those who were willing to treat wanted more training, yet in the dental category less wanted training than those who were willing to treat (Christian, 1993).

By the turn of the century, AIDS will be the third most common cause of death in the United States. It already is on our Virgin Islands top ten list. The increasing presence of HIV in every community necessitates that primary care providers become involved in and knowledgeable about caring for patients with HIV. The growing population of individuals with HIV and their families also need guidance in seeking and accessing appropriate care.

What about the women? Fortunately, in the U.S.A., the Agency for Health Care Policy and Research (AHCPR) requires all applicants for research grants to include minority populations and women in study populations so that research findings can be of benefit to all persons in the population under study. Special emphasis must be placed on including minorities and women in studies of conditions that disproportionately affect them and especially if they are the majority. The Clinical Practice Guidelines, which act as a quick reference guide for clinicians managing early HIV infection, have several areas that speak to the issues related to women and children-pregnancy, pap smears, management of infected infants and children. AHCPR should be congratulated for inclusion of these groups despite the limited control trials of these populations. It must be remembered that guidelines are precisely that- guidelines.

If you recall the lady with the cold in the beginning of my presentation, you would know that this lady speaks of "dancing with

the bears". Dr. Elders states " When you're out dancing with the bears, you have to make sure you don't get tired and sit down. You have to wait 'til the bear gets tired, and then you can sit down." (American Association for World Health Vol. 7, Nos. 3-4 p.9) Dr. Elders may not have been talking about HIV/AIDS, but she was certainly talking about the need for us to educate our society on how to be healthy. She was certainly talking about teaching responsibility. She was certainly talking to not only Health providers but Education providers. She was saying that there are budgets for drug prevention, sex education, AIDS prevention, anti-smoking campaigns. Yet we do not have one single, comprehensive health program. "We have lots of little pieces, but we've got to put them together and make a quilt."

AIDS is a family disease. For all of us, the most significant relationships and fundamental experiences of life occur within the family. The family setting is therefore the natural framework for matters concerning health and, specifically, HIV/AIDS. If the family's role is important in keeping its members healthy and protecting them from disease, that role becomes essential when it comes to treating, rehabilitating and assisting them during illness.

From the dawn of human history, the family has been at the heart of human development. The family is the first emotional and social

support mechanism we experience. It is our first teacher, our first health care provider. And it is usually the women in the family who assume responsibility for each of these essential functions. Whether the extended family of several generations living in the same household, as exists still in the Caribbean, or the nuclear family of mother, father and their children or the single parent family, what unites them all is love partnership, a set of common values and a vision of the future. But when HIV enters that family, instead of love, we see fear, shame, helplessness, economic chaos, educational neglect, hate and hopelessness. And if the family member who is ill is the mother, then the caregiver, it is as if the very body of the family is just a shadow of death and disease. Those most vulnerable to the death of the family are the children, our messengers from the future.

Times of great social upheaval have always resulted in major changes in family life. Very often it is the young who represent the most radical break with traditional values. It is said that children are the mirror of society; young people are quicker than older generations to perceive and respond to the trends of the times. Young activists of the past, with their outpouring of youthful energy, their indomitable and devoted spirit, proudly express in the full-voiced singing " We shall overcome", their eyes aglow with idealism, have virtually disappeared from the main stage of world history (Ikeda). With the realization that, far from

being a utopia, a paradise at the end of the rainbow, their "promised land" was in fact a wasteland filled with oppression, servitude, violence and disease. The world's youth have been drawn into a whirlpool of confused values. The misconduct of youth and the rise of crime are symbolic expressions of an underlying malaise. Although there is no end to the list of people who lament our future and sound the alarm, President John Silber of Boston University makes an insightful observation when he says, "The greatest threat lies within our own borders and within each of us".

A typical example can be found in Greek mythology in the "Trials of Heracles". The story is that when Heracles was on the verge of manhood, he came upon a fork in the road and did not know which to take, at which point two women appeared before him. The one was fair to see and of high bearing; her limbs were adorned with purity, her eyes with modesty; sober was her figure and her robe was white. The other was plump and soft, with high feeding. Her face was made up to heighten its natural white and pink, her figure to exaggerate her height. Of course, the former lady was there to lead Heracles toward virtue and the latter to entice him toward vice. I will omit what the advocate of evil said, because it is identical to the surest way to make a child miserable. Here are the words of the advocate of virtue. "But I will not deceive you by a pleasant prelude: I will rather tell you truly the things that are, as the gods have ordained them. For of all things good and fair,

the gods give nothing to man without toil and effort. If you want the favor of the gods, you must worship the gods: if you desire the love of friends, you must do good to your friends: if you covet honor from a city, you must aid that city: if you fain to win the admiration of all Hellas for virtue, you must strive to do good to Hellas: if you want land to yield you fruits in abundance, you must cultivate the land" (Ikeda, 1994. And I would add "if you treat a man as he is, he will remain as he is; if you treat him as he ought to be and could be, he will become as he ought to be and could be." (Goethe)

We cannot expect youth to espouse values that we ourselves do not practice. Regardless of the times, there lies unchanging in the depths of the young human soul an earnestness that responds to earnestness, a seriousness that reacts to seriousness; this is the true character and prerogative of youth.

One day I was struggling with my unending number of responsibilities and projects and wondering as a mother whether I was neglecting my children, neglecting giving them the quality time they deserve to grow into responsible, virtuous, honorable, caring adults. I had tormented myself and anguished over the problem for several months without a true solution. I went to my father, an honorable, fair, law-abiding, faithful, responsible man and posed the question to him. Knowing that he would have much advice for me

after raising six responsible children with very different personalities and interests, I sat myself down to listen. He simply replied, "Children learn by example". That is all he said, and no more.

Let us by our example treat the roots of our family, the women and the branches and flowers, our children as we ought to; let us as individuals, families, communities and nations by our example teach the concept of cause and effect, of responsibility for our actions, of nothing gained without effort; of the oneness of humankind with its environment. Let us by our example care for people who HIV positive and have AIDS without judgment and give hope when there is despair.

If we treat each other as we ought to be and should be, we will be as we ought to be and could be.

BIBLIOGRAPHY

Simopoulos, A. "New Surgeon General Dancing with the Bears" American Association for World Health, Vol. 7, Nos. 3-4 p.9.

Centers for Disease Control, The Nation's Health, April 1995 p.10.

Christian, C., V.I. Needs Assessment November 1992 and January, 1995. Unpublished

Dempsey, B. "One out of Every Eight in V.I. is HIV Positive" St. Croix Avis, March 25, 1994 p.1

Hellinger A. " Research Priority Areas"., Research Activities, No. 171, December, 1993, p.4.

Ikeda, D. "Live with Wisdom and an Indomitable Spirit", Seikyo Times, January, 1994 p. 10

Kalibala, S. & Anderson, S. " AIDS in Africa: A Family Disease". The Magazine of the World Health Organization, No.6, December, 1993, p.8

Mitchell, C & Chambers, C. "Women and AIDS", (Verbal Presentation at CSA May 1993)

Tross, S. "Randomized trial of Stage of Behavior change Oriented Intervention for Inner City Heterosexual Women", HIV Center Columbia Presbyterian, Cicatelli Associates Proposal of Feasibility to Vaccine Trial NYC Blood Center. p.1