INTRODUCTION: WOMEN AT RISK

From the beginning of the AIDS epidemic in the United States, cases of the disease in men have outnumbered cases in women, and this disparity has played a powerful role in constructing the epidemic's male profile. Early cases of acquired immunodeficiency syndrome (AIDS) among male homosexuals, injection drug users (IDUs), and hemophiliacs reinforced this profile. Table 1 in Chapter 1, which breaks down transmission categories by gender, demonstrates this male profile of the disease.

As a result of the male profile of AIDS, the impact of the epidemic on women in America has often been underemphasized and even overlooked. To understand the magnitude of this epidemic, there is a need to construct a female profile for it. The aim of this book is to create such a profile by describing the sociological impact of the epidemic on women, including women who are caregivers. The figures cited in this book will be for the United States only, unless otherwise stated.

Women's risk of infection from the human immunodeficiency virus (HIV) cannot be understood without closely examining gender roles and gender stratification. Toward this end, this book documents the relationship between poverty and HIV disease. In particular, this book will show that the concept of the "feminization of poverty" is vital to understanding the position of women in this epidemic.

Although the control and containment of the epidemic of AIDS among heterosexuals depends on male behavior, few studies have focused on the role of men in elevating women's risk patterns. Another aim of this book is, therefore, to thoroughly examine the behavior of heterosexual men as a determinant of women's elevated risk for HIV/AIDS.

Introduction

AIDS education and prevention efforts have often targeted women without considering their male partners or the role of men in sexual decision making. This book will examine women's risk vis-à-vis the behavior of their male partners, especially the vulnerability of female adolescents to HIV disease.

The first case of AIDS in a woman was reported in 1981, the same year in which AIDS was identified in homosexual men (CDC, 1981). The female case was hidden in a table listing cases of Kaposi's sarcoma (KS) and pneumocystis pneumonia (PCP) by gender and diagnosis (KS and/or PCP). Mortality rates were given for both KS and PCP and for the 108 total (107 male and 1 female) cases. The table also broke down the male cases by race and sexual identity. The only information given about the female case, however, was that the woman had PCP. The female case was not remarked on in the report itself, which simply stated that most cases of KS and PCP had occurred in white men. Two earlier issues of *Morbidity and Mortality Weekly Report* (*MMWR*), one of which documented the first five AIDS cases in the United States, had included only male cases. The issue that had in it the table listing the female case was about KS and PCP.

By the end of 1981, 6 cases of AIDS among women had been identified in surveillance figures, representing 3% of total number. Yet these cases were largely unrecognized in the scientific literature, an indication of how women would be treated in the years to come. By January 1983, 43 cases of AIDS among women had been reported (CDC, 1983a). In most of these the infected women were either drug users themselves or the sex partner of drug users. Many of the women who did not use drugs themselves had had no idea that their sex partners did. Thus, these women were unaware of the risk that they faced through heterosexual transmission. These early cases portended the epidemic of AIDS among heterosexuals in the United States.

The transmission categories of these early female AIDS cases were difficult to determine. It was thought that they had become infected through injection drug use. Moreover, the injection drug and heterosexual categories were not distinct. It soon became apparent, however, that some infected women who were sex partners of IDUs had been infected through heterosexual intercourse. The injection drug use and heterosexual transmission categories have remained intricately intertwined throughout the epidemic.

Introduction

As soon as cases of AIDS were identified among heterosexuals, attention focused on women for their role in infecting others. For example, in media accounts women were portrayed as "infectors" rather than as "infectees" (Wofsy, 1987). Research and policy agendas also reflected concern about women's role in infection (Patton, 1994). Women were seen as presenting a risk to others, and as a result, far more alarm was expressed about women's role in transmission than about the very real risk that women themselves faced. The media portrayed women as "vectors" or "reservoirs" of infection, either to their male partners or to their unborn children (Caravano, 1991; Patton, 1994; Treichler, 1988). Female prostitutes were targeted because of the risk they represented to their clients, and prenatal women, for the risk to their unborn children. Public concern about AIDS prevention had more to do with the health of men and children than with the health of women (Caravano, 1991).

The intertwined transmission categories used in surveillance reports through 1983 also obscured female cases. As already mentioned, heterosexual transmission did not exist as a separate category; significantly the next highest transmission category for women after "injection drug use" was "none/unknown." At the end of 1983, 36% of female cases – compared to 4% of male cases – were in this category (CDC, 1983b). However, the nearly 200 female cases remained overshadowed by the male cases, which were more than 10 times that number.

The potential magnitude of the female epidemic continued largely unremarked. The small number of reported female cases were especially deceiving because of the long latency of the disease from the time of infection to the onset of symptoms. Women who were just beginning to exhibit symptoms had been infected years earlier. But many more women were infected with the virus and would be identified as having AIDS in the years to come.

Early in the epidemic, seropositivity for the AIDS virus could not be determined because the antibody test did not become available until 1985. Even when the test did become available, however, infected women continued to be overlooked. Many women did not recognize their own risk and did not ask to be tested. Likewise, physicians often did not think to test women because of the disease's powerful male profile.

Physicians were slow to recognize the symptoms of HIV disease in women. In many women, the disease was detected only after a long

process of exclusion of other diseases. AIDS-defining conditions had a male profile, and women were experiencing different symptoms compared to men. Physicians often failed to connect recurrent vaginal candidiasis, or yeast infections, an early symptom in women, to HIV disease. As a result, many women were in the advanced stages of the illness before receiving an AIDS diagnosis, and some women died before receiving such a diagnosis. Because of late detection and diagnosis, female cases were seriously undercounted.

Today, female cases comprise 16% of the total AIDS cases (CDC, 1997a). The incidence of AIDS cases is increasing more rapidly among women than men (CDC, 1995). The injection drug transmission category, the largest category for women, represents almost half of the female cases. The second largest category for women, heterosexual transmission, represents over one-third of female cases. Heterosexual transmission has continued to increase for women and is currently the fastest growing transmission category (CDC, 1995).

These figures raise perplexing issues: How did female cases in the United States grow over 2,000 times in 14 years, from 43 in 1983 to 98,468 at the end of 1987? And, what factors in particularly have influenced the course of the epidemic for women? This book will offer a sociological explanation.

Although the epidemiologic impact of AIDS has been evident for some time, the sociological impact has not yet been fully described. We need to address the gap between the advances made in biomedicine and the lingering sociological issues. An examination of the sociocultural context of the AIDS epidemic among women is long overdue and is the focus of this book.

Chapter 1 reviews the epidemiology, risk/transmission, and natural history of HIV disease in women and children. A profile of female cases will show that HIV disease affects women differently, depending on their age, race, geographic location, and sexual orientation. This profile will also show that transmission and disease presentation and diagnosis are different for women and for men. The chapter includes a discussion of HIV disease in children and adolescents.

Chapter 2 discusses the complex sociological issues that HIV disease creates for women's reproductive health. Reproductive rights and sexual discrimination are critical issues facing many infected women. The chapter covers approaches to perinatal risk reduction and examines

women's reproductive choices and sexual decision making. Adolescent sexuality is given special attention in this chapter.

Chapter 3 deals with two special populations of women – drug users and prostitutes – and examines the roles of gender and culture in drug use and sexual behavior. The important influence of male behavior on female drug use and sexual behavior will be shown. The chapter investigates the intricate tie between drug use and prostitution and reveals the problems created for women by a legal system that criminalizes both of these behaviors.

As soon as AIDS cases were identified among heterosexuals, concern was expressed about prostitutes, who were seen as vectors for heterosexual transmission. Chapter 3 examines this attention to prostitutes and especially to the behavior of their partners, both paying and nonpaying, and reviews policies on the mandatory testing of prostitutes.

An understanding of women's risk for HIV disease cannot be achieved without examining gender and cultural roles. Development of effective HIV prevention strategies requires a close examination of these roles. Chapter 4 covers the intersection of gender, culture, race, and class in the epidemic. It will show that women's position in the epidemic, compared with that of men, has been one of both unequal access to care and unequal quality of care. The male profile of the epidemic has resulted in education and prevention programs based on the needs of men. This chapter reveals how the media and social institutions involved with health care have created barriers for women by failing to take account of differences between men and women in social roles, social status, and power. Particular attention is given to adolescent socialization in shaping power relations based upon gender.

The gender role and sexuality of men also must be understood if successful AIDS prevention and control strategies are to be developed. Toward this goal, Chapter 5 closely examines male sexuality in the heterosexual context and male-female gender dynamics. The socialization of adolescent males and the importance of altering male behavior as factors in controlling the heterosexual epidemic are stressed.

It has been evident for some time that HIV disease is a family-based disease. Women, as mothers, grandmothers, sisters, and aunts, have assumed informal, caregiving roles in the family for both adult members with HIV and the children of infected women. The impact of the disease on family life and the caregiving role of kin are discussed in

Chapter 6. The women who have had to become caregivers have many unmet needs themselves. This chapter also examines the barriers to service delivery to families with HIV disease and stresses the need for family-based services.

Women have played an important and heartening role in AIDS service delivery throughout the AIDS epidemic. Chapter 7 looks at women's other roles in the epidemic, including those they have taken as either professional or volunteer caregivers, and underscores the importance of informal caregiving. This final chapter presents a critical evaluation of the policies affecting families dealing with HIV disease, particularly those policies that affect children and youth.

Each chapter opens with excerpts from either the interview transcripts or diaries of the women and men (eleven in all) who kindly provided accounts of their experiences living with HIV disease. These vignettes give an important human dimension to the book, one not always achievable in a scholarly treatment; their direct accounts document daily realities and enable readers to understand the challenges for and constraints upon persons living with HIV disease. Biographies of these individuals as well as a description of how the interviews and diaries were obtained are found in the appendices.

Women, Families, and HIV/AIDS is organized around the theme of gender. The material presented here will show how gender dynamics permeate the AIDS epidemic and how gender roles and expectations affect AIDS transmission, prevention, and care.

1

EPIDEMIOLOGY, RISK/TRANSMISSION, AND NATURAL HISTORY OF HIV DISEASE IN WOMEN AND CHILDREN

When I first found out I had HIV, I was living on the streets of downtown L.A. I was addicted to heroin, cocaine, and alcohol. I had careless sex, shared needles, and ignored all precautions. I got it from sharing needles.

I'm still alive, living with HIV and dealing with it in the most positive way I possibly can. HIV is not death but a situation that I got myself into by my own actions.

– Loretta

I have an 11-year-old son who has AIDS. He was infected through a blood transfusion in 1986 when he was 14 months old. I didn't find out his diagnosis until 2 ½ years ago. He is really doing good right now. He has regular colds and ear infections like regular kids. He's never been hospitalized.

It's rough. It's really hard but we just take one day at a time. I don't know if it would be any easier if it were an adult you were dealing with. I guess it hurts to everyone in their own little way. But it's real hard when it's a kid. It's real hard but I just cope with it day to day.

– Mariana

The doctors that diagnosed me told me that my daughter wasn't born infected. Because I breastfed her for 8 months, that's what harmed her.

And up to this point we haven't had problems which have required hospitalization, thank God. I thank God that in the six years of her life, my daughter has remained stable, so her doctors say. I ask God that he always keeps us this way.

– Juana

> I started turning tricks. I kept on doing it 'cause the money was good and I was so strung out. I didn't care – didn't never bleach no needle.
>
> – Eunice

> I'm from Central America – Guatemala. My husband, Bobby, was from Puerto Rico. He was recovering from drug addition in a rehabilitation place in New Hampshire. He was admitted in the hospital and because of his drug history was found HIV positive. I was told I should go and get tested for HIV. I got the diagnosis of HIV in 1988. Our son, Marvin, passed away in 1993, and Bobby passed away three years later in 1996.
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> – Leticia

EPIDEMIOLOGY

Experts consider HIV seroprevalence estimates of childbearing women to be a good measure of the rate of infection in women because most women with HIV disease are in their childbearing years. One way seroprevalence of HIV infection in childbearing women has been estimated is through anonymous HIV antibody testing of blood specimens routinely collected from newborns for metabolic screening. A seroprevalance study of childbearing women conducted by the Centers for Disease Control and Prevention (CDC) since 1988 has used data from anonymous newborn serosurveys. This nationwide blind serosurvey, the Survey of Childbearing Women, has found that 7,000 HIV-infected women have given birth each year since 1990 (Rogers, 1997a).

Currently, there are 633,000 adult and adolescent (> 13 years) AIDS cases in the United States. Males comprise 534,532 and females, 98,468 of total cases (Table 1). From the beginning of the AIDS epidemic, the number of male cases has exceeded the number of female cases. However, the number of female cases continued to increase at a rapid rate. In 1981, the year in which HIV disease was first identified in women, women comprised 3% of total adult AIDS cases. Today, women comprise 16% of total cases (CDC, 1997a).

A majority (68%) of female AIDS cases have been reported in the four years between 1993 and 1997 (Stine, 1998). In 1997 women comprised 22% of new cases. Table 2 shows how the percentage of female cases has increased yearly since 1981. The increase has been especially

Table 1. *U.S. adult/adolescent*[a] *AIDS cases by exposure category and gender*

	Gender					
	Males		Females		Total	
Exposure Category	No.	(%)	No.	(%)	No.	(%)
Men who have sex w/men	309,247	(58)	–	–	309,247	(49)
Injection drug use	118,658	(22)	43,214	(44)	161,872	(26)
Men who have sex w/men & inject drugs	40,534	(8)	–	–	40,534	(6)
Hemophililia/coagulation	4,483	(1)	206	(0)	4,689	(1)
Heterosexual contact	20,493	(4)	38,391	(39)	58,884	(9)
Transfusion	4,705	(1)	3,509	(4)	8,214	(1)
Other/undetermined	36,412	(7)	13,148	(13)	49,560	(8)
Total (% of cases)	534,532	(100)	98,468	(100)	633,000	(100)

[a] >13 years.

Source: HIV/AIDS Surveillance Report, cases through December 1997, Centers for Disease Control and Prevention.

significant since 1985 when women accounted for about 7% of total AIDS cases.

Age. A large majority (74%) of women with AIDS are between 25 and 44 years old, and their median age is 35 years old (CDC, 1997a). The mean age at diagnosis with AIDS for women is 36 (Sabo & Carwein, 1994). Women who are IDUs and sexual partners of IDUs make up the largest number of HIV-infected women of childbearing age. Although most of the women with AIDS are between 25 and 44, 13% are between 45 and 59 (CDC, 1997a). In recent years, for both men and women aged 50 and over, cases attributed to injection drug use and heterosexual transmission increased whereas cases caused by transfusion declined (CDC, 1998).

Female cases are similar to male cases in that a majority of the infected women and men, 74% and 76%, respectively, are in the 25–44-year-old age category. The modal age category for each is 30–39 years old (CDC, 1997a). Female cases differ from male cases in that the women are slightly younger: Although the average age of women at diagnosis is 36, the average age for men is 38 (Sabo & Carwein, 1994). Male cases outnumber female cases in every age category.

Table 2. *Adult and adolescent female AIDS cases, United States, 1981–1997*

Year	Female Percentage of Total Cases
1981[a]	3.0
1982	6.9
1983	6.8
1984	6.4
1985	6.6
1986	7.4
1987	8.0
1988	10.4
1989	10.5
1990	11.5
1991	12.8
1992	13.5
1993	15.9
1994	17.7
1995	18.8
1996	20.2
1997	21.8

[a] Reporting began in late spring.
Source: HIV/AIDS Surveillance Reports, year-end figures, 1981–1997, Centers for Disease Control and Prevention.

In 1993 when the surveillance definition of AIDS was expanded, the largest increases in cases were among persons 13–19 and 20–24 years old. In these age groups, a greater proportion of cases was reported among women (35% and 28%, respectively), and was due to heterosexual transmission (CDC, 1994). Overall, the expanded definition resulted in a greater proportional rise in cases for women than for men (128% vs. 113%, respectively) (Ibid.). This disproportionate increase was predominantly due to the inclusion of individuals with CD4 T-cell counts below 200 or with pulmonary tuberculosis. Further implications of the expanded definition are dealt with later in this chapter.

Today, one in four new infections occurs among youth under the age of 22 (Rotheram-Borus, 1997a). Adolescents are at increasing risk for HIV infection from sexual transmission. HIV infection is growing at an alarming rate among young women particularly, and the highest rate of increase is found among those 15–19 years old (Stine, 1998).