Inventing HIV/AIDS: Cultural and Political Contexts of an Epidemic

Brandeis University
Department of Sociology

Professor Ruth R. Linden SOC 197-B Tuesday 4:30 p.m.-7:30 p.m. Spring 1992

Whatever else it may be, AIDS is a story, or multiple stories, read to a surprising extent from a text that does not exist: the body of the male homosexual. It is a text people so want--need--to read that they have gone so far as to write it themselves. AIDS is a nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another.

Paula A. Treichler
"AIDS, Homophobia, and Biomedical Discourse"

Course Description

AIDS is a mirror of our times. It has summoned both the best and the worst in the American people. AIDS challenges each of us to confront the homophobia and racism at the heart of American society. The upward-spiraling incidence of HIV infection highlights our national health crisis, and reflects the dismal failure of Presidents Reagan and Bush to act in the face of global and domestic crises. HIV infection is also a reminder of the limitations of biomedical research and clinical practice, and the inherently political nature of science and medicine. But the HIV/AIDS pandemic (global epidemic) tells another story, as well.

Gay men living with HIV infection have taught us--all of us--how to practice safer sex. At the local level, thousands of People Living with AIDS (PLWAs or PWAs) and their allies have mobilized to demand equal access to drug trials, affordable health services, and protection from discrimination. Since 1987, ACT-UP (AIDS Coalition to Unleash Power), the most visible and outspoken direct action group, has built a movement that combines art and protest, community education and civil disobedience. Its tactics are a model for health and other issue-oriented movements in the 1990s.

How does an unlikely constellation of symptoms get constructed, alternately, as: "a strange virus of unknown origin," a sexually-transmitted disease, a chronic illness, a spectrum illness, a pandemic, and a public health megabureaucracy? A decade after its "official" start, how has the HIV/AIDS pandemic refigured North Americans' ideas about disease and death? How has AIDS transformed meanings of sexualities and sexual differences? These are some of the questions we'll be addressing this term in "Inventing HIV/AIDS."

Texts

Five books, one pamphlet and one recommended text are on order at the campus bookstore. In addition, I have prepared a xerox reader consisting of 12 articles. You may purchase a copy of the reader from me at cost or, if you prefer, read these articles on reserve in the library. Books will be on library reserve, as well.

Note: The third edition of *Searching for Women* will be published in about a month. At that time we will arrange to obtain copies directly from the Multicultural AIDS Coalition in Boston. This is our only text that is not available at the campus bookstore.

Note: James Jones' Bad Blood is on order at the campus bookstore but we will not be reading it after all. This book is not required for the course.

Our reading will proceed in the following order:

Required books:

Randy Shilts, And the Band Played On

Douglas Crimp, ed., AIDS: Cultural Analysis/Cultural Activism

Cindy Patton, Inventing AIDS

University of Massachusetts, Boston, Law Center and the Collaborative for Community Service and Development, and the Multicultural AIDS Coalition, *Searching for Women: A Literature Review on Women, HIV and AIDS in the United States*, 3rd edition, forthcoming winter 1992.

Cindy Patton and Janice Kelly, Making It: A Woman's Guide to Sex in the Age of AIDS

Douglas Crimp with Adam Rolston, AIDS Demo/graphics

Stephen Schecter, The AIDS Notebooks

Recommended book:

Nancy F. McKenzie, The AIDS Reader: Social, Political, Ethical Issues

Course Outline

Week 1

Jan. 21 Course Introduction

Weeks 2-3

Jan. 28- The First Four Years: Constructing and Reconstructing AIDS

Feb. 4

Week 4

Feb. 11 Sign/Signifier/Signified: Deconstructing AIDS Discourses

Douglas Crimp. AIDS: Cultural Analysis/Cultural Activism (Crimp, pp. 3-17)*.

Jan Zita Grover. "AIDS: Keywords" (Crimp, pp. 17-30).

Max Navarre. "Fighting the Victim Label" (Crimp, pp. 143-146).

Jan Zita Grover. "Constitutional Symptoms" (xerox).

Cindy Patton. "The AIDS Service Industry: The Construction of Victims, Volunteers, and Experts" (Patton, pp. 5-23).

Week 5

Feb. 18 Inventing HIV

Paula A. Treichler. "AIDS, Homophobia and Biomedical Discourse: An Epidemic of Signification" (Crimp, pp. 31-70). Cindy Patton. "What Science Knows about AIDS: Formations of AIDS Knowledge" (Patton, pp. 51-75).

Week 6

Feb. 25 Just So Stories: Green Monkeys, Africa and Patient Zero

Cindy Patton. "Inventing 'African AIDS" (Patton, pp. 77-97).

Simon Watney. "Missionary Positions: AIDS, 'Africa,' and Race" (xerox).

Margaret Cerullo and Evelynn Hammonds. "AIDS and Africa: The Western Imagination and the Dark Continent" (xerox).

Douglas Crimp. "How to Have Promiscuity in an Epidemic" (Crimp, pp. 237-271).

Jad Adams. "Origins" (xerox).

Week 7

March 3 Races/Racism

Evelynn Hammonds. "Race, Sex, AIDS: The Construction of 'Other" (xerox).

Ana Maria Alonso and Maria Teresa Koreck. "Silences: 'Hispanics,' AIDS and Sexual Practices" (xerox).

Beth Richie. "AIDS: In Living Color" (xerox).

Gloria Lockett. "Black Prostitutes and AIDS" (xerox).

Week 8

March 10 Spring Break I

Weeks 9-10

March 17 The Epidemic That Is Not One: Women and HIV Illness

Searching for Women: A Literature Review on Women, HIV and AIDS in the United States, 3rd edition.

Cindy Patton and Janice Kelly. Making It: A Woman's Guide to Sex in the Age of AIDS

March 24

Paula Treichler. "AIDS, Gender and Biomedical Discourse" (xerox).

Suki Ports. "Needed (For Women and Children)" (Crimp, pp. 169-176).

Carol Leigh. "Further Violations of Our Rights" (Crimp, pp. 177-181).

Nancy Stoller Shaw. "Preventing AIDS Among Women: The Role of Community Organizing" (xerox).

Weeks 11-13

March 31 Activism

Art activism:

Douglas Crimp with Adam Rolston. AIDS Demo/graphics

April 7 Treatment activism:

Paula Treichler. "How to Have Theory in an Epidemic: The Evolution of AIDS Treatment Activism" (xerox).

Vanessa Merton. "Community-Based AIDS Research" (xerox).

April 14 Guest speaker: tba

Week 14

April 21 Spring Break II

Week 15

April 28 "And Still These Words"

Stephen Schecter. The AIDS Notebooks

Week 16

May 5 Wrap-up/catch-up

Course Requirements

- (1) Regular attendance at class meetings, engaged participation in discussions and careful readings of all assigned material are expected. I heartily discourage unnecessary absences. It is everyone's loss when you miss a class.
- (2) Your experience working in an AIDS service organization (ASO), community project or public health agency, or as an AIDS activist, is the heart of this course. To be sure, being in the field is time consuming, but I believe it will deepen your learning in our course. I want you to have an experience dealing with HIV/AIDS on the ground, not merely as a set of cultural representations, texts and images.

Starting immediately, you should contact an organization or project whose work especially interests you. I'm told that there are 83 ASOs in Boston. As part of this syllabus, I have included an abbreviated list of organizations/ projects/agencies that need folks like you who can work for a few hours each week. I have contacted some of these agencies and projects myself, as indicated. Over the course of the semester, I want you to establish a routine of spending about three hours each week in the field.

- (3) Keeping a field journal is an essential part of doing fieldwork. Buy yourself a fresh notebook and get in the habit of writing about your experiences each time you return from the field, and whenever else it occurs to you. I cannot overemphasize the importance of recording fieldnotes. It will enable you to reflect on what you are learning and experiencing, inside and outside of class. It will also provide you with documentation of your changing consciousness about HIV/AIDS. What's more, your fieldnotes will prove to be essential when preparing your paper for this course. As the term progresses, we will discuss all of your questions about writing fieldnotes. Please remember always to bring your fieldnotes to class.
- (4) One paper, submitted twice--based on your experiences and reflections on your experiences--is required for this course. The first draft will be due in class on 3 March. The final draft will be due during finals week. Your paper should be approximately 15 double-spaced pages in length.
- (5) A one-page self-evaluation, including your self-grade for the course, will be due along with your paper or shortly thereafter.

Basis for Grade

Your final grade will be based on a combination of your class participation (20%), first draft of your paper (20%), field journal (25%), and final paper (35%).

Following is a list of ASOs, projects, groups and agencies that you can link up with and, potentially, work for a few hours each week. Those I have already contacted on your behalf are indicated with an asterisk.

PROJECT CONTACT PERSON TELEPHONE

Fenway Community Jim Goshen 267-0900 Health Center Volunteers Coorindator ex. 210

7 Haviland Avenue

Boston

Fenway has a primary commitment to providing health services to the lesbian and gay community, including the HIV community. It is the only clinic of its kind in Boston. If you want to work primarily with and for lesbians and gay men, this would be a good agency to contact. They need assistance with diverse tasks, including: data entry, childcare, translation, public relations/media, writing, and office work. Jim will arrange a one-hour orientation session for interested folks from our class. (See materials I've brought to class.)

*AIDS Office, Dept. of Jim McLaughlin 727-0368 Public Health

Public Health 150 Tremont Street

Boston

The AIDS Program needs short-term telephone coverage for the counseling and testing hotline until the beginning of March, when this service will be phased out. They would like to interview folks from our class as a group. Judy Gorbach might want an intern to work with her. If you're interested, call her. There may be other opportunities at the Department of Health, as well. Call Jim or Mindy Mazur for more information.

*AIDS Action Committee Eileen Pollack 437-6200

of Massachusetts, Inc. ex. 283

131 Clarendon Street

Boston

AAC has more than 3,000 volunteers who work in a range of administrative and direct-service capacities. They especially need assistance with basic client services, data entry (evenings), special events fundraising, and the Citizen's Response Network. To volunteer, you must attend extensive AIDS Awareness Training as follows: Friday, 7 February (6:30 - 9:30 PM); Saturday, 8 February (9:45 AM - 5:45 PM); and a follow-up session on Thursday, 13 February (6:30 - 9:00 PM). See information packet I've brought to class. Interview required.

*Hospice at Mission Hill Betsy Simmons 566-7800

20 Parker Hill Avenue ex. 283

Boston

Mission Hill is Boston's 18-bed hospice for people with end-stage HIV illness. Usually requires a minimum five hour/week commitment for six months, but would consider decreasing both required number of hours and duration for an especially serious and sincere person. There

will be a volunteers training during the fourth week of February or the first week of March. See information packet I've brought to class. Interview required.

*The Names Project Dan Miranda (h) 739-1306

Volunteers Coordinator (o) 451-9003

The Names Project organizes and displays the AIDS Memorial Quilt. The Quilt (1,000 panels) is probably coming to Boston in May. There are many logistical tasks to be done in preparation for displaying the Quilt, as well as ongoing administrative work. The Names Project also sponsors 40 outreach events yearly.

*Boston Women's AIDS Marcelyn Dallis 859-8689

Information Project 464 Massachusetts Avenue

Boston

This project trains hair stylists and small-business owners as community health advocates. Then, community health advocates provide their clients and customers with information on preventing HIV infection. Project targets women of color. Women volunteers needed. No white men, please.

ACT-UP/BOSTON 492-2887

Meetings are on Tuesdays, 7:00 PM, at the Boston Living Center, which is located at 140 Clarendon Street, 7th Floor, Boston.

THE FOLLOWING INFORMATION WAS PREPARED BY HENIA HANDLER AT THE FENWAY COMMUNITY HEALTH CENTER

Community Servings Ernia Hughes 287-1605

Volunteer Coordinator

Delivers meals daily to PLWAs and their care givers. Located at Dorchester House.

Haitian AIDS Project Ceregine Eusebe 825-9307

420 Washington Street

Dorchester

Provides services for the Haitian AIDS community. Projects include case management, education and research.

VINFEN Corporation Respite Coordinator 522-0996

Amory Street Family Respite Program provides respite services to PWAs and their caregivers.

RUAH Dorie Searie 641-4128

Volunteers Coordinator

Jill Ruge

Project Development Director

RUAH is a housing project for homeless women with AIDS and their children. This sounds to me like an especially exciting and crucial project.

Lemuel Shattuck Hospital Shelter Unit 522-8110 Jamaica Plain Suzanne Gunston ex. 223

Provides AIDS prevention services for homeless folks. Various opportunities available.

AIDS Unit in Hospital Patrick Riggs 522-8110

Volunteer Coordinator ex. 460

Various opportunities, such as visiting with patients and providing physical therapy to patients. Interview required.

Community Research Evelyn Colon 424-1524

Initiative of New England 338 Newbury Street

Roston

Mostly needs clerical and data entry support, filing out forms, etc., to support clinical drug trials and the drug reimbursement program. Could use two people.

Arlington Street Church

Drop-in center for street youth, 7:00 PM - 12:00 AM three nights/week. Program also does street outreach. Contact: Judy Gorbach, 727-0368 for name and telephone number of contact person.