

## AIDS Doctors: Voices from the Epidemic

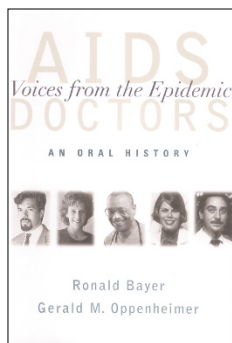
by Ronald Bayer and  
Gerald M. Oppenheimer  
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The AIDS epidemic has left a deep imprint on the social, cultural and medical landscape of the United States. Through ongoing research, AIDS has evolved over the past two decades from an untreatable, inexorably fatal disease to a chronic viral infection responsive to combination therapy. The trajectory of the US epidemic from the initial description of *Pneumocystis carinii* pneumonia in June 1981, to the status of AIDS as the leading cause of death in 25–44-year-olds by 1994/95, to the dramatic treatment-associated decline in mortality in recent years, is stunning and unprecedented. The culture surrounding AIDS has changed in many ways over its twenty years: from white gay men to minority IV drug users and their sexual partners; from caregivers offering comfort to an aggressive medical treatment model; from a crisis with uncertain boundaries to what the authors term, "the normalization of AIDS, the successful placement of HIV into a constellation of other medically serious disorders." The recent advertisements for one antiretroviral drug on New York City bus stops that display a smiling, muscular young man proclaiming, "I'm positive" demonstrate just how far HIV infection has moved

toward the medical and public mainstream.

Authors Ron Bayer and Gerald Oppenheimer, non-clinical academics with backgrounds in the public health and ethical issues of AIDS, chronicle the evolution of the epidemic from the perspective of American clinicians. The book is an oral history of the personal and professional impact of AIDS on doctors from the early 1980s to the present. Their chronicle was distilled from over 300 hours of interviews with 76 physicians from 1994 to 1999. The authors chose their subjects with the help of other doctors and experts in the field. Included were specialist and generalist physicians of national and local prominence, both office- and hospital-based, including some who were HIV-infected themselves. Of the 80 physicians asked to participate in the project, 76 agreed to be interviewed. The physicians speak with emotion and apparent candor about their experiences. The interviewees were given the opportunity to edit the transcript or sequester content from the book, but all quotes included in the book are attributed to those interviewed. An appendix contains brief biographical notes on each of the book's subjects.



Bayer and Oppenheimer use the "conversational narrative," to uncover the meaning of the events for each subject, and the work is skillfully annotated by the authors. Much of the book focuses on the era of "therapeutic impotence," a time when one physician saw herself as "a travel agent for death" in which she felt her role "... was to make the process as drawn out, as comfortable and as full of interesting things as it was possible to do. And I couldn't prevent the ultimate outcome, but I could manage it." Though those woeful sentiments have largely faded, it serves as an important reminder of how death defined those

years for everyone involved. The tremendous progress made in treating HIV infection has not stopped many experienced clinicians from looking over their shoulders for evidence of wider treatment failures from drug resistance, side effects or medication adherence problems.

The interviews elicit the intensity of commitment that drives these doctors to care for AIDS patients. Gay physicians and political activists, in particular, brought a passion to the work in a way that blurred personal and professional boundaries. Yet others recoil at what is termed "heroic doctoring." "It's a disease, not a way of life," says one physician who welcomes the end of AIDS exceptionalism.

The interviews and narratives capture the mix of wonder, despair and self-righteousness of physicians at the beginning of the epidemic. In 1999, many of the subjects are wistful for the earlier era, romanticized as one of unequalled camaraderie, personal discovery and career advancement in spite of the heavy toll on patients and themselves. For some, the powerful connection to patients and the self-identity as "AIDS people" is diluted as the disease is medicalized. For others, there is exhaustion and a desire for new challenges.

The emotional content of the interviews woven into a cogent chronology of the epidemic hits the mark as a "biography of the first generation of AIDS doctors." As the authors acknowledge, other caregivers, nurses, social workers, counselors and family members played vital roles in the response to the epidemic, and warrant separate accounts. Medical terms in the text are occasionally misspelled, but do not detract from an important story that is well told and highly readable. Bayer and Oppenheimer have preserved important memories of the short, dense history of AIDS in this country. Their book should appeal to both clinician and non-clinician as we move into the next decade of the epidemic.