Book Review


In AIDS Doctors: Voices from the Epidemic, the authors have written an engaging, important, but ultimately frustrating account of the lives of physicians working in the early years of the AIDS epidemic. The scientists profiled in this book were among those responsible for charting the parameters of the unknown disease first colloquially labeled gay cancer, then GRID (Gay Related Immune Deficiency), and finally AIDS (Acquired Immune Deficiency Syndrome). The clinicians interviewed were among those willing to face unknown risks to care for patients cast out from society and ignored by the medical establishment. Through their work with the social, biological, and political issues of this new disease, these physicians developed a discrete professional and personal community into which the reader is introduced through the course of the book.

The greatest strength of Bayer and Oppenheimer’s work is the lens they provide the reader into this discrete community of early AIDS doctors. Using oral history, the authors attempt (with variable success) to allow the subjects to speak directly to the reader, without the mediating presence of an interpreter. As a result, one is able to hear prominent researchers and clinicians discuss the problems they faced as they began to establish their careers and to address this frighteningly incomprehensible illness. Issues frequently approached throughout the book include rationalizing the risks of routine exposure to blood products from infected patients (both before and after a viral etiology of AIDS was identified), negotiating institutional politics and bureaucracy as a junior clinician while working with socially marginalized communities and an underemphasized illness, and maintaining boundaries between one’s personal life and the overwhelming professional burden of caring for people with AIDS. The personal motivations cited for establishing a career as an AIDS doctor are often based on several interwoven factors, ranging from pre-existing involvement with affected communities to opportunistic identification of an area with the potential for major research and subsequent career advancement. What might appear to be the most obvious reason for acting as a pioneer in the field of AIDS work, a selfless devotion to help people in need regardless of the personal cost, is oddly left unmentioned - possibly because it is a topic which can not be openly discussed. The perspectives of these community elders are invaluable for future physicians/scientists who may be currently wrestling with similar issues or seeking a deeper understanding of the foundations of the field which they one day will enter.

AIDS Doctors: Voices from the Epidemic also provides a reminder of the messy early disputes surrounding important events that have since been homogenized in superficial, standardized retellings. The early termination of AIDS Clinical Trial Group Protocol 019 (ACTG 019) studying the use of AZT in treating asymptomatic people with Human Immuno-deficiency Virus (HIV) is a perfect example of this excavation of conflicts that have been papered over by the passage of time. While AZT is routinely accepted as an important component of current combination therapy for AIDS, the drug was initially perceived as everything from a life-saving miracle cure to a government-sponsored poison. Bayer and Oppenheimer identify the combination of hope and fear which greeted the termination of ACTG 019. Preliminary results demonstrated slower progression to symptomatic AIDS among HIV-positive patients who were given AZT, and ethical concerns called for the study’s early termination. However, significant professional criticism was directed at the flaws in the design of the study, casting the clinical importance of AZT into doubt. The physicians interviewed then go on to describe the mix of frustration and despair that they felt upon the later publication of the European Concorde study which demonstrated that while AZT slowed the rate of progression to AIDS, it had no effect on lifespan or mortality rates.

The reader also hears the perspective of researchers like Jerome Groopman and Martin Hirsch who were personally targeted by AIDS activists for their work with AZT. During one of ACT UP’s more notable demonstrations, or “zaps,” activists interrupted a professional conference presentation by Groopman and Hirsch to denounce them as “murderers.”

In spite of these individual accounts, the personal perspectives offered by Bayer and Oppenheimer are significantly lacking in several respects. The central problem lies in their approach to the early years of the AIDS epidemic as an isolated period rather than as a fragment of an ongoing era into which the past, present, and future are all interwoven. There is scant attention paid in the book to those who became AIDS doctors after the definition of HIV as the etiologic agent of AIDS, and even less discussion of mentoring future AIDS doctors by the physicians interviewed.

As a result, the relationship between the issues faced by the first AIDS doctors and the struggles of their successors are ignored. The replication of early research problems in current clinical difficulties, the personal and political motivations held by those entering an area of research with a frightening disease and an unidentified pathogen as opposed to a fully established, virally-linked field of study, and the link between the foundational
work described in the book and future progress in the fight against AIDS are all subjects left untouched.

Diversity is also lacking in other areas of cohort selection, leading to a gross underrepresentation of issues of race, urban versus rural practice settings, and community relationships. Token recognition of the work of occasional African-American and Latino physicians is provided in the course of the book, but serves as more of an addendum to the core issues rather than a fully integrated analysis of race in the social and medical construction of AIDS in clinical practice. Similarly, while a few physicians who do not practice in major metropolitan areas and/or centers of academic medicine are interviewed, the intriguing questions surrounding the treatment of AIDS in rural America during the dark years of the epidemic remain unanswered. The question of extra-institutional work on social and political issues of AIDS care is also unmentioned, leaving the reader with the perspectives of scientists targeted by AIDS activists, but not of those who worked in conjunction with groups like ACT UP.

The basis for these omissions is articulated in the Appendix on Methodology. Bayer and Oppenheimer state, “We began by asking three AIDS doctors to prepare lists of 50 others who had been involved in the care of patients since the epidemic’s earliest years. On reviewing their initial rosters—which had a remarkable consistency—we came to believe that there were important gaps.” (p. 275) The authors then go on to explain their efforts to expand their initial list by including more community-based physicians and HIV-positive physicians. However, the problems inherent in the book appear to stem from the fact that the subjects chosen for interviews were derived from a pre-existing, closed circle of colleagues. With few exceptions, Bayer and Oppenheimer merely replicated common perceptions of what constituted an early “AIDS doctor” in their choice of subjects, and therefore missed the opportunity to challenge current views of what constitutes an AIDS doctor, what role these physicians serve in their communities and/or institutions, and how they balance their personal and professional lives. This liability is significant in that Bayer and Oppenheimer’s book is the first major contribution to the history of the medical community’s response to AIDS and therefore serves as the foundation for later studies. The limited framework which they have adopted here will define the paradigm for future historical analysis of physicians and AIDS.

Despite the central flaws of their work, Bayer and Oppenheimer’s AIDS Doctors approaches an untouched area, and therefore serves as an essential resource to students of history, public health, science, and medicine interested in exploring the social, personal, and professional development of AIDS treatment. The publication of these personal perspectives on the development of what are now seen as historical “facts” is vital to any understanding of how the current clinical response to AIDS was shaped and consequently central to any future work in the field of AIDS research and care.

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