

AIDS

Principles, Practices, and Politics

Inge B. Corless
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Reference Edition

AIDS

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Reference Edition

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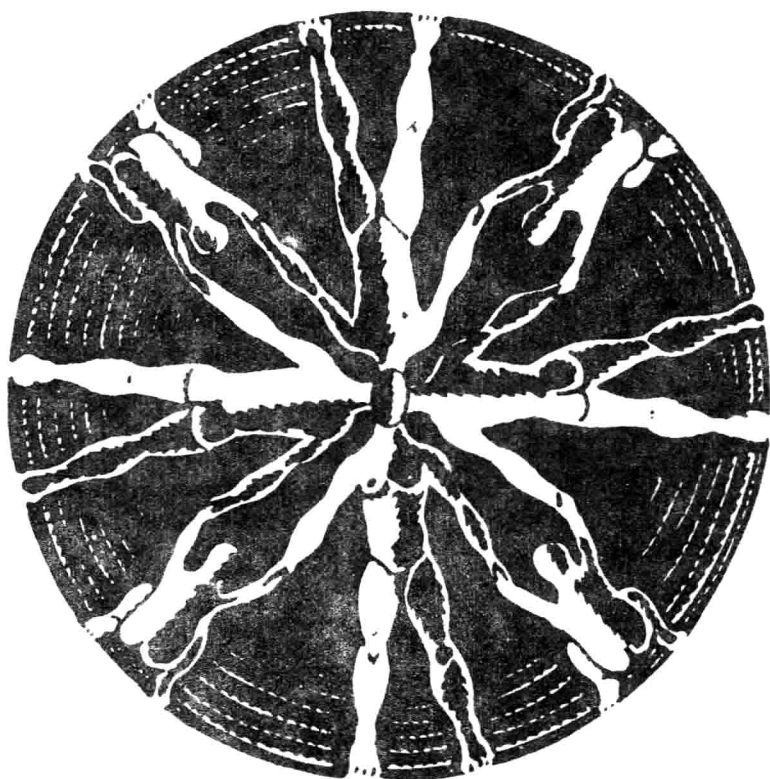
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AIDS: An Overview

This single-headed organism with different bodies represents the varied community afflicted with AIDS, men, women, and children and every race, color, and age. They are all caught in the whirling vortex of the epidemic.

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This book is dedicated to

ORI SHERMAN

August 30, 1934—August 28, 1988

who chose to see the glass of life as half full and in so doing engaged in an exceedingly productive period of artistic achievement. *AIDS: Principles, Practices, and Politics* is one beneficiary of the flourishing of Ori's artistic creativity. He will be remembered with much love, admiration, and great respect. His work in this book gives voice in another medium to the pain of loss, the fear, the challenge, and the eventual triumph of talent, dedication, inspiration, and the human spirit.

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Foreword

Throughout the world, there is a need for more dialogue and discussion about AIDS. Despite the extensive media coverage of AIDS during the past several years, despite the thousands of seminars and conferences for all professional groups, despite the thousands of publications for technical and general audiences, there is a need for more information and discussion about AIDS.

This need exists because the educational process is enormously complex and human attitudes and behavior clearly take time to evolve. At one level there is the wisdom of the Latin proverb *Repetitio est mater studiorum* [Repetition is the mother of learning]. Facts about AIDS must be repeated, discussed, and questioned. Only then can we expect that the answers may be incorporated fully into a person's understanding of AIDS. At another level AIDS is not a single issue that can be rapidly or even succinctly described. It has vital social, cultural, economic, and political dimensions. People think about AIDS and learn about AIDS in many different ways, and they enter the dialogue from widely varying entry points and perspectives.

In this regard two relevant generalizations have emerged from the worldwide experience with AIDS, particularly during the period 1986–1988. First, to the extent that populations and groups are informed and educated about AIDS, groundless fears recede and simplistic and illusory schemes for AIDS prevention and control are rejected. Second, policies on AIDS prevention and control that have been openly and widely discussed in public and in professional settings are generally more realistic and often more humane than some of the proposals that may have been advanced initially.

For these two reasons and because AIDS is now a part of our world, it is essential that energy and creativity continue to be directed into dialogue and discussion about AIDS. The wide range of authors in this book, *AIDS: Principles, Practices, and Politics* (reference edition), is to be applauded, for the perspectives are accordingly diverse. This book will stimulate thought and it may provoke controversies—both of which are to be hoped. For the danger is not controversy but silence, not open argument but complacency or isolation. This book is an exciting contribution to an ongoing dialogue of local, national, and international importance.

Jonathan M. Mann
Director, Global Programme on AIDS
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Preface

Few diseases in modern times have received the media attention given to Acquired Immune Deficiency Syndrome (AIDS). Whether examined in print or via visual media, a particular slant or "take" on the subject is employed as reporters attempt to present a story. The approach taken in this book is that AIDS is complex and multifaceted. Consequently this volume brings together a broad range of perspectives and incorporates the expertise needed to address the multiple problems inherent in the AIDS epidemic. Although experts in any given field have lengthy and fruitful dialogues with their peers, both in person and in publication, less attention has been given to an exchange of views and expertise that extends beyond disciplinary and geographic boundaries.

This book is also distinctive for its inclusion of visual images that symbolize issues discussed in the text. The editors felt it was important to include the drawings because all of the complexities and nuances associated with HIV infection have not yet been articulated. Art enhances our awareness and gives expression where words may be inadequate. Together, the artist, clinicians, scientists, and public officials present a more complete picture of the different aspects of the AIDS pandemic than would otherwise be possible.

The fundamental questions addressed in these papers apply to a range of issues critical to every society. These include protection of the health of the members of a society, provision of health care, education of health care workers and citizens, and attendant costs. Although the focus of this book is on AIDS, the approaches and solutions suggested are of broader interest and application. Indeed the AIDS pandemic necessitates our confrontation and resolution of many unresolved problems, such as the accessibility and financing of health care.

Our intent is to enhance the knowledge of the reader in a number of fields relevant to AIDS in order to facilitate a more profound appreciation of the problems associated with pandemic. Both microscopic and macroscopic views are necessary to comprehend what is at stake as countries respond to the challenges posed by AIDS.

AIDS: Principles, Practices, and Politics may be helpful to both the educated citizen and the scientist in exploring the scope of the problems associated with AIDS. Moreover, as schools and universities develop courses on AIDS, the present volume may be of use as either a reference or a course text. Indeed, the Table of Contents may serve as a guide for structuring a course. This book will also be useful to any individual who would like a resource on the multiple dimensions of the AIDS pandemic. Although the question of how quickly this material becomes dated is of concern, the papers included in this book address fundamental issues. While statistics change, the problems discussed in this book

are rooted in the social structure and will take longer to resolve. *AIDS: Principles, Practices, and Politics* explores these problems and lays a foundation for solutions.

Our lives have been enriched by our work on this project and the friendship and support we have found in each other and those around us. We thank Inge's daughters, Theresa and Patricia, and Mary's husband David, for their loving support throughout the development of this project. Additional organizational support was provided by Maureen Ryan and Rebecca Hughes. We thank both of these special colleagues.

Sandra Tamburrino and Carolyn Ormes, our production editors, truly made it all happen and we thank them. Last, but not least, Kate Roach, our unflappable editor on this project, has earned our respect and friendship. Her belief in this book transformed it from dream to reality. Our work was also enhanced by Ron Wilder, who assumed the editorial task when the book was in production, and we acknowledge his support with much appreciation.

Our thanks as well to all of our colleagues who provided helpful suggestions during the formation of this volume. Finally, we acknowledge our contributors whose insights and wisdom are reflected in these pages. We thank you for sharing our vision and the ardors and delights involved in its development.

Inge B. Corless
Mary Pittman-Lindeman

Introduction

AIDS, the acquired immune deficiency syndrome, is a complex and far reaching phenomenon that encompasses multidisciplinary principles, practices, and politics. The papers included in *AIDS: Principles, Practices, and Politics* address some of the most common, difficult, and distressing issues confronting professionals and the general public. These problems are analyzed by experts and specialists in each area.

To understand AIDS, the book first explores the AIDS retrovirus, originally termed LAV, lymphadenopathy virus, by Luc Montagnier and his co-workers at the Pasteur Institute in France; HTLV-III by Robert Gallo and his colleagues at the National Institutes of Health in Washington, D.C.; and ARV, AIDS-related virus, by Jay Levy and his associates at the University of California, San Francisco. Standardizing the virus name to human immunodeficiency virus (HIV) has been complicated further by discoveries of new viruses or sets of viruses, such as LAV-II/HIV-II. Given the concern for the immense devastation in terms of human lives that has occurred as a result of the rapid spread of HIV infection, the international research community has set aside the debate over terminology and scientific primacy in favor of international cooperation and a global effort to combat AIDS.

Efforts at the development of a cure have resulted in the identification of drugs that delay progression of some of the manifestations of the disease but do not eliminate the virus or resolve the underlying immune deficiency. Thus efforts to contain HIV infection have emphasized preventive measures. These efforts at prevention have taken two major approaches that are addressed in this text: developing a vaccine and educating the public about the disease.

While these efforts are moving forward, there are a number of questions that confront professionals, researchers, the public, and persons with HIV disease that are discussed in this text. First, to what extent is HIV infection spreading? Discussions of the epidemiology are presented for various risk categories. The danger from AIDS is not limited to gays and intravenous drug users, as is apparent from the development of seropositivity in transfusion recipients and in the partners of virus-exposed individuals. In addition, in Africa, AIDS appears to be largely heterosexually transmitted. It is difficult to estimate the true extent of the problem in Africa due to malnutrition, the effects of which are similar to AIDS, and to the lack of appropriate laboratory facilities to test for infection. The repeated use of needles without intermittent disinfection in some public health clinics in Africa may also serve as a source of disease transmission. Transfusions, frequently given for malaria and during child birth, may have abetted disease transmission. The Surgeon General of the United States has taken the position,

based on the findings of AIDS investigators, that children and adolescents must be alerted to the danger of infection with HIV as a result of sexual intercourse or intravenous drug use. The potential for the virtual elimination of a generation of young people is a real and present danger in the United States, Africa, and other high prevalence locations.

Second, why do some people who test positive for exposure to the virus develop AIDS rapidly while others do not? The extent to which cofactors are necessary for the development of the disease in an individual is not clear at this time. The obverse of this question is why is it that some who test positive do not develop AIDS? The other possibility, of course, and one almost too dreadful to contemplate, is that everyone who tests positive will eventually develop AIDS. Many feel that it is only a matter of time.

Third, what social and health care resources are necessary to deal with the epidemic? The resources required to care for those with AIDS, particularly as the number of patients increases, will have profound economic, social, and personal impact. The illness and death of so many persons in the prime of their working lives will have vast demographic implications not only for the current economy but also for the support of the aging population.

The observation that the AIDS epidemic highlights all the weaknesses and gaps in the health care system of the United States is well taken. If there is one silver lining to the gray cloud of AIDS is may be a rationalization of the health care system with guarantees of access to all individuals. If, however, the demands for care are greater than available resources, some painful choices will be necessary. How and for whom should limited resources be utilized? And who will make such determinations? In a related issue, will national health insurance be enacted if private companies refuse to enroll clients?

The needs of the person with AIDS and his or her care givers are not uniform. The medical and social needs will vary, depending not only on whether the person with AIDS is a pregnant woman, a child, an intravenous drug user, a hemophiliac, a gay man, a transfusion recipient, or the partner of a seropositive individual, but also on the contextual and situational factors pertaining to that individual. The availability of health care and other support services as well as the political milieu and the presence of informed care givers all affect care giving. The presence of professional care givers cannot be assumed. Decreases in the number of students electing to enter the nursing profession combined with a fear of disease transmission, pressures by family, friends, and colleagues, and a concern with career may decrease the availability of professional care givers at the very time when the need is greatest.

Hospice programs face a more difficult challenge in providing care for persons with AIDS than for people with other terminal illnesses. The capacity of hospice programs to respond to the AIDS epidemic will depend in large measure on the availability of other needed resources such as housing. Unfortunately, the current Medicare reimbursement mechanism for hospice care (which emphasizes home care) may prove inadequate to the needs of persons with AIDS who lose their homes when their landlords learn of their illness; who become impoverished by their health care needs before Medicaid covers their costs; or who may or may not have family members, friends, or lovers willing to act as care givers. This situation is not dissimilar to the Medicare recipient living alone or with a partner in frail health who has housing but no one who can assume the role of continuous care giver.

One resource that has been developed as a result of the AIDS epidemic is a volunteer "buddy" and support program, which provides emotional and practical support for persons with AIDS. This type of resource will also need financial support to maintain the organization, even though the major portion of care giving is provided by volunteers.

Fourth, do we have an adequate approach to dealing with the ethical dilemmas posed by AIDS? Concerns exist regarding the ethics and decision-making process that will be used to establish public policy in the area of HIV testing and reporting. Many serious concerns are raised by the specter of a society that searches out and isolates those who are infected with the HIV virus and restricts their civil liberties. On the other hand, the call for the safety of the public's health poses a challenge that requires careful balancing between the needs of the community and the civil liberties of the individual. Thus, far, the balance has been leaning toward the protection of civil liberties, but federal proposals for mandatory testing may be indicative of a change in emphasis.

With the exponential growth in research information, new programs, and public policies related to this epidemic, it would be impossible to adequately cover all topics of interest. Topics not addressed include the legal implications of the pandemic, certain aspects of public policy, information on HIV-II, and other issues. The ramifications of infection including HIV dementia, the Belle Glade phenomena, the role of corporate leaders in educating their employees, as well as other subjects, will be included in the next volume. The topics included in this book represent the breadth of the issues that must be considered when contemplating the meaning of the AIDS pandemic.

Where it has been difficult to achieve an international accord on the use of nuclear arms, the emergence of a retrovirus may foster setting aside political differences to develop the concerted efforts necessary to control the pandemic and preserve life. It is our hope that by examining some of the principles, practices, and politics associated with AIDS this book makes a contribution to those efforts.

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