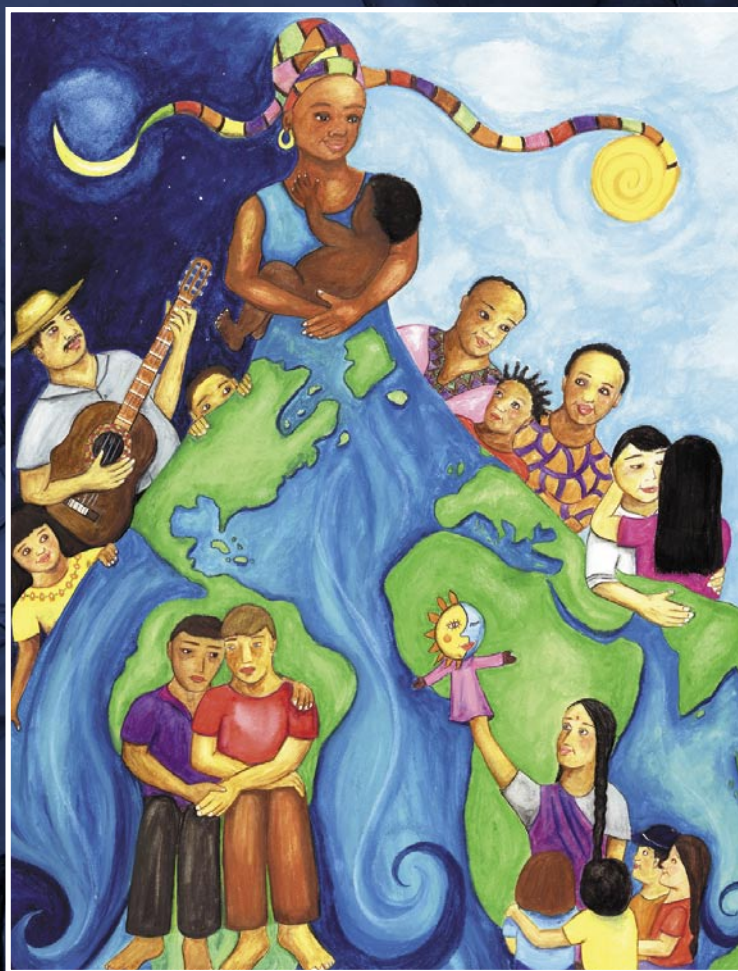


updated treatment info includes ART

HIV, Health, & Your Community

A Guide for Action



Reuben Granich, M.D., M.P.H. · Jonathan Mermin, M.D., M.P.H.

HIV, Health, and Your Community

A Guide for Action

*This book is dedicated to the many people
throughout the world who face the challenge of
working and living with HIV every day.*





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R.G. • J.M.

Introduction

The idea for this book grew out of our experiences working to help growing numbers of people with HIV (human immunodeficiency virus). In Rwanda, one of us met a doctor who struggled to care for a hospital ward overflowing with women with HIV and tuberculosis. Families were camped outside, cooking and caring for their sick relatives; patients without families suffered because food and other supplies were scarce, but often other people shared what they had. Working long days under tough conditions, the members of the health care team had to make difficult decisions about treatment. They watched as a few patients died each day despite their best efforts.

Health workers, social workers, and educators joined together to lessen the suffering caused by HIV. When asked where they had learned to do their jobs, they shrugged their shoulders and pointed to each other. They had learned from experience and word of mouth. Why was there no guide that addressed some of the basic issues regarding HIV disease in areas where most of the people with HIV live? There were thousands of scientific articles about HIV, but the language in them was often obscure and the topics not relevant. In addition, these articles were often unavailable to health care workers in the less industrialized world. What was missing was a comprehensive reference book covering basic topics related to the HIV epidemic.

We have tried to write a book that is both readable and practical. We describe some of the experiences of people we have known, many of whom have died from HIV or in the civil disturbances that frequently accompany the epidemic. Bearing in mind our readers—local health and community workers who have a desire to learn more about HIV—we have tried to keep the language and format simple.

The book is meant for people who are searching for answers to questions about HIV prevention, epidemiology, diagnosis, and treatment. Each chapter begins with a fictional story; where useful, boxes with text or illustrations have been added to highlight key points. At the end of each chapter we answer questions raised by the story, hoping at the same time to answer some of the reader's questions. The appendix discusses common diseases suffered by peo-

ple with HIV and treatments for them. It is intended for the doctor or nurse who is involved in caring for people with HIV disease, and unlike the other chapters requires some basic medical knowledge. HIV health care is always changing, and some of the recommendations in the chapter may be outdated. Adaptations to individual situations are encouraged. Finally, we have included a glossary of words often used in discussions about HIV.

In Chapter 1 we meet Shoba, a student from Pakistan. We learn about the basics of HIV biology and how HIV affects a person's immune system, the nature of a virus, why viruses are difficult to treat, and the difference between HIV-1 and HIV-2. We explain the basic elements of the immune system, focusing on the cells most affected by HIV. We end the chapter with a short discussion of medicines against HIV.

In Chapter 2 we meet Saleema from Morocco. Saleema has a brother she thinks has signs of HIV infection. We explain some of the symptoms that someone with HIV may experience.

In Chapters 3 and 4 we meet Min-Soo from South Korea and Lon Chin from China. Min-Soo asks questions about where AIDS (acquired immune deficiency syndrome) was first found, how we know HIV is not spread by mosquitoes, and how to figure out how many people have HIV. We present a short history of the HIV epidemic and discuss how HIV has spread worldwide and how it interacts with other diseases. Lon Chin's parents are afraid to let her move to the United States because they think she will get AIDS. Lon Chin wants to know about how much HIV and AIDS there is in the world so that she can help her parents understand why she will not get HIV by studying in the United States. We discuss HIV and present the latest information on the number of people with HIV and AIDS.

In Chapters 5 and 6 we meet Olga from Uzbekistan and Clarence from Ghana, who are concerned about how HIV is spread from one person to another. They want to know what kinds of sex put them at risk and what other ways there are of getting HIV. We explain how HIV is spread and how it is not spread. We talk about the role of other sexually transmitted diseases in the spread of HIV and about how drugs and alcohol can increase a person's chance of getting HIV.

In Chapters 7 and 8 we meet Jean-Patrice from French Guiana and José from Mexico. Jean-Patrice wants to know how well the HIV test works. We discuss the test, the difference between confidential and anonymous testing, and the accuracy of test results. We also discuss mandatory testing, how testing relates to family planning, and how it may encourage or discourage behavior change. José is worried about how much blood is needed for the test and what

he should do after he gets the results. We explain common testing procedures and pre- and post-test counseling.

In Chapter 9 we meet Odette from Gabon. Her situation is complicated. Her social standing in the community and in her family influence her chances of getting HIV. We discuss how economics, ethnicity, health care beliefs, education, drug and alcohol use, prejudice, and age can all affect a person's risk of getting HIV.

In Chapter 10 we meet Angela from Brazil. Angela is pregnant and finds out she has HIV. She is worried about telling her boyfriend and says she is thinking about killing herself. We discuss how health care workers, family members, and friends can support people who have HIV. We describe some of the challenges of coping with HIV, some basic interventions that can help people with HIV stay healthy, and the benefits of support groups, community support, and home care. We give some tips on how to avoid burning out as a caregiver.

In Chapters 11, 12, and 13 we meet Phan from Vietnam, Carlos from the United States, and María from Peru. Carlos needs help teaching others to avoid the virus. He wants to know how to approach high school students and teenagers who do not go to school. We describe places for HIV outreach and give him the tools to either start his own prevention project or help an existing project in his community. Phan needs help and how to encourage everyone to participate. We also provide a sample lesson plan for a day-long training session. María needs help finding more funding for the project she runs for women with HIV and AIDS. We discuss ways to look for funding both in her community and outside it.

We would like to add a word of caution. HIV, AIDS, and sex are sensitive topics. Parts of our book may be offensive to you. We do not intend to shock readers, but we use explicit language throughout the book in order to bring you the most accurate information possible. You may have to change some of this language to work with your community.

We hope you find this book useful. We know it can be improved with your suggestions. We are always interested in hearing about HIV projects and people's personal experiences working in the field, and we welcome thoughts from people with HIV, their families, and caregivers. Please send your comments to us in care of the Hesperian Foundation, 1919 Addison Street # 304, Berkeley, California 94704, USA, or visit the Hesperian website at www.hesperian.org.

