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978-0-521-56679-7 - Women, Families, and HIV/AIDS: A Sociological Perspective
on the Epidemic in America

Carole A. Campbell

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WOMEN, FAMILIES, AND HIV/AIDS

A Sociological Perspective on the
Epidemic in America

CAROLE A. CAMPBELL



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PREFACE

Using data from epidemiological and other biomedical sources, *Women, Families, and HIV/AIDS* describes women at risk for AIDS. This book, which is based on a conceptual framework combining descriptive epidemiological methods and sociological theory, offers a sociological analysis of how women's social and economic positions in relation to men affect their sexual decisions as well as their health practices. In addition, the book analyzes how the generally stronger position men have in society and the behaviors of men place women at elevated risk for AIDS. Finally, this book explores the emotional and social consequences of an AIDS illness on children and other family members.

This book is the culmination of my work in the field of women and AIDS for the last 12 years. My first formal research in this field was as a collaborator in a multicenter study of female prostitutes (Project 72) conducted by the Center for Disease Control and Prevention in 1985. Working with Rick Reich of the Clark County (Nevada) Health Department, I collected data at a legal brothel outside of Las Vegas. I am grateful to Rick for his encouragement and support in that research endeavor as well as in my subsequent work on AIDS.

In 1987 I developed the course "AIDS and Society" for the Sociology Department at California State University, Long Beach (CSULB), where I teach. I am indebted to my students in that course who have continuously challenged and inspired me. Teaching a course on AIDS is among the most difficult, yet inspiring, ventures of my professional career. My hope is that this book will be useful to other faculty and students in AIDS courses.

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In the early years of the AIDS epidemic, most research attention was directed toward gay men. Women's issues related to HIV were being overlooked. In particular, the role that gender played in determining women's risk for HIV and their access to care was not being addressed. In 1990 I published "Women and AIDS" in *Social Science and Medicine*. In that work, I examined the implications of gender roles and gender stratification for women's HIV/AIDS risk and prevention. That publication was followed, in 1991, by "Prostitution, AIDS, and Preventive Health Behavior," also in *Social Science and Medicine*, which dealt with the work lives of prostitutes in relation to their risk for HIV. In writing that article I also drew upon data collected in the 1985 multicenter study.

After focusing for several years on women's vulnerability to HIV, I realized that the role of heterosexual men in determining this vulnerability was not being given sufficient attention. Gender role socialization and gender power relations needed to be studied more closely. This line of thinking led me to write "Male Gender Roles and Sexuality: Implications for Women's AIDS Risk and Prevention," published in *Social Science and Medicine* in 1995. This article emphasized the gender role socialization and sexuality of heterosexual men in determining women's risk for HIV and examined the conflict between masculine identity and HIV/AIDS prevention goals.

By now it is well recognized that women do not have control over condom use (e.g., Wermuth, 1992; Worth, 1989). Acknowledging women's vulnerability, however, is not enough. Men's behavior, particularly that behavior that is formed during adolescence and increases women's risk for AIDS, should be closely scrutinized in the context of gender power relations. That is one of my goals in this book.

I have had the fortunate opportunity to present some of the ideas from my work on heterosexual men and AIDS at several professional conferences. These meetings of practitioners in AIDS prevention and service delivery have included HIV/AIDS Epidemiology and Prevention Information Exchange, sponsored by the State Office of AIDS in 1994 and held in Fresno, California; Women and HIV: A Call to Action, sponsored by the University of California, Santa Cruz, in 1995; and the 1997 conference, Safer Communities: Rethinking HIV Intervention Strategies, sponsored by the HIV Epidemiology Program of Los Angeles.

My thoughts on the need to further examine the role played by men in prevention and service delivery were well received and reinforced at

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those meetings. Several health service providers commented that my perspective was refreshing and long overdue. It is gratifying to know that my ideas are relevant to those working in the trenches of AIDS prevention and service delivery. I appreciate their comments, insights, and support, and their enthusiastic response has encouraged me to continue in this line of advocacy. I also want to express my admiration for their tireless dedication to AIDS prevention and service delivery.

From a focus on heterosexual men, my work has expanded to include research on families with HIV/AIDS. Interviews with infected caregivers showed me the extent to which entire families were affected by the disease. Another goal of this book, therefore, is to examine the impact of HIV disease on all family members.

I am extremely indebted to Project AHEAD and the CARE Program, both of which are community-based organizations in Long Beach, California. For the last few years I have been involved with these agencies as a collaborator and consultant, which has taught me a great deal about the realities of AIDS service delivery to families dealing with HIV disease. I wish to thank these programs for facilitating the interviews for this book.

As part of my teaching at CSULB, I serve as field placement coordinator for the Sociology Internship Program. In this role, I work with a number of other community-based AIDS organizations in addition to Project AHEAD and the CARE Program. My ongoing contact with service providers at these agencies has sensitized me to the tremendous barriers to AIDS service delivery, some of which are described in the last two chapters of this book. I hope that what I have gained from my involvement with the community is reciprocal, that is, that this book will contribute to better AIDS prevention and service delivery and that service providers will benefit from reading it.

I am greatly indebted to the individuals who willingly shared with me their personal accounts of living with HIV disease. Their descriptions of how the disease has changed their lives are indeed sobering. I am deeply grateful for their enthusiastic response to and interest in this book. Their contribution is immeasurable.

Many persons helped make this book possible. Dr. Raymond M. Berger helped revise several chapters. Two CSULB students, Lourdes Vidal and Gail Libbee, provided painstaking assistance with the interviews.

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I am grateful to my colleagues in the Sociology Department at CSULB for their support of this project. Professor Douglas A. Parker deserves special acknowledgment for his guidance and support. The Sociology Department's secretary, Lily Monji, performed numerous tasks in the production of the manuscript.

Research support to conduct and transcribe the interviews was provided by CSULB. I am most grateful to Joy Thomas, librarian, who compiled the index for the book. Her careful work and attention to detail are appreciated. The CSULB library, particularly the Interlibrary Loan Department, assisted by obtaining many books and articles.

I also wish to acknowledge the anonymous reviewers of this manuscript and its earlier prospectus. Their comments and suggestions were most helpful. In addition, I am grateful to Elizabeth Neal and Mary Child, social sciences editors at Cambridge University Press, for their guidance and support. Their editorial comments were especially useful.

I also wish to recognize William F. Wagner, my undergraduate mentor at the University of Albuquerque and now on the faculty of Mankato State University, for his support during the early years of my academic career in sociology. My graduate school mentors, Professor Richard H. Ogles and Professor Edward L. Rose, at the University of Colorado (Denver and Boulder, respectively), also deserve recognition for their support throughout my academic career. Both have contributed much to my growth as a professional sociologist and to them I express my deepest gratitude.

Family members also provided much help. My mother, Dorothy Baumgardner, and sister, Marie Rosales, sent numerous helpful articles. And my three-year-old grandson, Malik Jameel Campbell, helped by taking naps while under my care, which allowed me to work on this book. I am grateful to all those persons who gave me encouragement and a sense that I could make a contribution to (and possibly a difference in) people's lives.

Portions of some chapters in the book appeared in the three articles in *Social Science and Medicine*: "Women and AIDS," vol. 30, pp. 407–415, 1990; "Prostitution, AIDS, and Preventive Health Behavior," vol. 32, pp. 1367–1378, 1991; and, "Male Gender Roles and Sexuality: Implications for Women's AIDS Risk and Prevention," vol. 41, pp. 197–210, 1995. Some content also derived from two coauthored publications: with M. D. Peck, "Issues in HIV/AIDS Service Delivery to High Risk

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