Beyond the Family

Lori Thoemmes, LMFT


The impact of HIV on the family in its broadest sense is the topic of two books edited by Robert Bor and Jonathan Elford. The first, The Family and HIV, was published in 1994. The second book, The Family and HIV Today, is reviewed here and is an attempt to look at the more recent research related to issues that have emerged since the 1994 publication.

Illness as a Fundamental Part of Family

In this relatively slim edition, Bor and Elford cover a wide range of research that is valuable to practitioners. The overarching theme of the book is described in the forward by Darren Wolf: “The work outlined in this book helps us to understand illness not just in a social context, but illness and responses to it as a social context, as a fundamental part of relationships and family life.” The book goes on to consider the impact of a stigmatized and transmissible disease on relationships, the availability of support, partner choice, and the psychological well-being of family and friends. Bor and Elford classify the research they cover into four broad categories: disclosure, social support, partners, and parents and children. In the chapters they collect under these headings is research from locations ranging from rural Sub-Saharan Africa to El Paso, Texas.

It is important at the outset to note (and forgive) one problem with the book: of the 21 chapters, only two were written in 1996; all the others were written between 1993 and 1995. This means that the impact of change in treatment protocols is not reflected at all in this volume. Some version of this limitation will always be present when discussing HIV because new information about the virus, about the demographics of infected people, and about treatment is constantly being revealed. Despite this limitation, The Family and HIV Today contains research that is meaningful and pertinent for clinicians today.

If you are a person who loves to read statistics, this book will be a page-turner. For me, however, this aspect made it difficult at times to get through to the broader lessons of the book. Since this is a collection of research papers, most chapters include an introduction followed by methods, results, and discussion sections. While some of the more quantitative studies are challenging to read, there are some real jewels nestled in this book that make reading it worth the effort.

Disclosure and Social Support

One chapter in the disclosure category, by Therese Lie and Paul Biswalo, reveals the importance of really looking at your client population before making assumptions about what it means for an individual to disclose his or her HIV-positive status. Research from Tanzania showed that heterosexual clients most often shared their HIV-positive diagnoses first with a person of the same gender. This means that, in this context, married and co-habiting people usually did not choose their partners as their “significant others.” In a chapter entitled Culturally Sanctioned Secrets: Latino Men’s Nondisclosure of HIV Infection to Family, Friends and Lovers, Hyacinth Mason and others compare Latino men and White men at two Los Angeles HIV outpatient clinics. Researchers found that less acculturated Latino men were more likely than more acculturated...
men to withhold their diagnoses and their gay or bisexual orientation from others, especially family. Qualitative research conducted in Michigan and southwestern Ontario included extensive quotes from people after they tested seropositive that give a vital picture of the struggles people go through when negotiating sexual relationships.

In the chapters on social support, the authors review issues including how people with HIV disease and their caregivers utilize support services. One study, based in Los Angeles and San Francisco, is noteworthy in that even in these relatively well-funded urban areas, caregivers and HIV-positive people perceived a substantial unmet need for support services. Another interesting study in Queensland, Australia titled Carers’ Burden and Adjustment to HIV by Kenneth Pakenham, Mark Dadds, and Debra Terry showed that the more depression HIV-positive patients reported, the more depression caregivers were likely to report. This study also revealed that the HIV-positive person’s stage of illness did not significantly impact the caregiver’s adjustment, suggesting that the more burdensome aspects of being a caregiver are not necessarily the practical tasks of caregiving, but the psychological aspects of caring.

Partners, Parents, and Children

I found the section on partners to be one of the most interesting and useful. The research in this section includes a look at the family support of serodiscordant heterosexual couples. This research by Marianne Foley and others revealed that one-quarter of the HIV-positive partners and nearly half of the HIV-negative partners reported no family support.

However, once family members were informed of the HIV status, they were far more often perceived as supportive than non-supportive. Two different chapters explore the dynamics and impact of work with couples. One describes a couples counseling intervention for heterosexual partners, and another looks at intimacy and sexual risk behavior in serodiscordant male couples. Both of these chapters include information that could reduce HIV transmission.

The final section focuses on parents and children. The chapters include research on orphans and extended family in Zimbabwe, a review from the United States of primary caretakers of children born to HIV-infected mothers, and a discussion of childhood bereavement due to parental death from AIDS. The U.S. study showed that most children of HIV-infected mothers were being cared for by their mothers, challenging previous research that reported 40 percent of children whose mothers were infected by injecting drugs were in foster care. This is important data for providers working with women and children to consider in terms of assumptions they might make and the realities of client needs.

Conclusion

The Family and HIV Today is a wide-ranging and valuable review of research conducted between 1993 and 1996. Getting through some of the research methodology is trying at times, but it is worth the effort. The book adds to the reader’s understanding of how the data relate to specific populations of HIV-positive people; reading it will provide practitioners with material that will inform their thinking about HIV-related support systems.

Clearinghouse: HIV-Related Books


Injecting Drug Use: An International Overview
Greg Greenwood, PhD, MPH


Between October 1989 and March 1992, the World Health Organization (WHO) conducted a visionary and methodologically rigorous epidemiological investigation of the intersecting epidemics of injecting drug use and HIV in 12 cities throughout the world, ranging from Athens and Bangkok to New York and Rio de Janeiro. These data have “played an important role in informing national policies, and in placing drug injecting, HIV, and related health and policy issues on the international agenda.”

Drug Injecting and HIV Infection is a compilation and comprehensive overview of some of the key findings from this project. It was assembled and edited by three of the leading international scientists in drug injecting and HIV, with the assistance and expertise of an impressive roster of scholars from diverse disciplines. Written particularly for epidemiologists, medical professionals, and public health officials working in the fields of drug dependence, HIV, and health policy, the book is informally organized into chapters covering four domains. These include: the history and overview of the intersecting epidemics of injecting drug use and HIV; the factors that facilitate these epidemics, for example, the role of new injectors and diffusion of injecting practices; responses to reduce drug and sexual risk taking; and implications for future policies and interventions.

A Multi-Layered International Perspective

This book provides an international perspective of the epidemiological evidence regarding the emergence of HIV among drug injectors. In broad strokes, it identifies key individual and environmental determinants and maintenance factors that have fueled these intertwining epidemics. Part of the genius and elegance of this book is in the many ways the authors paint clear, comprehensive, and multi-layered pictures of injecting drug use and HIV. They adeptly synthesize the multiple levels on which injecting drug use and HIV operate.

Because injecting drug use and HIV are increasingly situated within communities marginalized by socioeconomic, racial and ethnic, and other social factors, the authors seek to present data that fairly represent the multiple micro- and macro-system factors at play and the various points of intervention and prevention. However, while the book cites universal factors and patterns across cities, it also explores differences: drug injecting and HIV are not only global epidemics, but also local manifestations.

While potentially cumbersome for readers who are not trained epidemiologists, the wealth of data and methodological review presented in Drug Injecting and HIV Infection is outstanding. One of the strengths of this book is the links it makes among research, prevention intervention, and policy. It is clear that researchers and communities in the study cities worked collaboratively to understand the relationship between the unfolding HIV epidemic and injecting drug use, and the needs for intervention and action. To illustrate these links, each chapter nicely balances the presentation of relevant data with summaries of findings. They also often discuss data in the context of analytic or methodological limitations, and sandwich data between an initial discussion and final summary of key points. This structure provides the interested reader with the details of the “trees,” as well as the larger view of the “forest.”

Conclusion

Drug Injecting and HIV Infection provides an excellent overview of the international epidemiology of injecting drug use and its links with HIV. However, because its strength is its broad focus, the book does not give a complete picture of the mechanisms underlying how and why these epidemics intertwine and reside primarily in marginalized communities. It would have been useful if the authors had offered hypotheses about how, for example, societal forces fuel the spread of injecting drug use and HIV. Another limitation, as the authors duly note, is the recent dynamic change in and spread of injecting drug use and HIV in other developing countries in places such as Africa and Eastern Europe.

The book also provides little information on small but important subcultures of injecting drug users, namely men who have sex with men and sex workers. Finally, while the book's chapters nicely build upon one another; and common threads are apparent in each, the lack of a clear, organizing framework hinders the flow of the text. Despite these limitations, Drug Injecting and HIV Infection provides a wealth of information for those interested in the epidemiology of these intertwining epidemics.
A Hands-On Exploration of HIV and Mental Health Practice
Marianne O’Connor, LCSW, PhD


Michael Shernoff, author, teacher, and clinician, has been involved in HIV work since he volunteered to work with AIDS patients for the newly formed Gay Men’s Health Crisis in 1982. In this book, he has assembled a collection of 28 cutting-edge articles written from the personal experience and expertise of practitioners currently working in the field. The chapters are carefully researched and written in a delightful “hands-on” style, making the collection both an ideal textbook for students and a valuable instruction manual for veterans of AIDS work. The authors consistently highlight problematic areas and make specific treatment suggestions based on their own and others’ work with people with AIDS. One of the book’s best features is the unique quality of the case histories, presented so vividly that they make the clients linger with the reader.

Dealing with Treatment

The first three chapters of the book address issues that arise from the seeming success of antiviral therapy. Shernoff and Darrell Wheeler point to the lack of exact science in this field. They note that the capacity to sustain long-term medication adherence has been correlated with other changes that affect quality of life, and ultimately, the belief that clients, themselves, will play a major role in determining their own health outcomes. The authors urge clinicians to support the self-empowerment of clients who cannot or who choose not to use combination therapy—even when this decision contradicts the clinician’s inclination.

Another chapter explores the conflicts and emotional distress that often accompany the decision of people whose health has improved to return to work. The third chapter on antiviral therapy looks at the impact of treatment on the content and process of support groups where, in addition to ongoing issues of illness, death, and grief, members are now dealing with the possibility of living longer, the fear of disappointment with treatment, and the actual experience of combination therapy, which often varies dramatically among group members.

Women and Children

A chapter on telephone support groups describes the successes of structured, “conference-call” bereavement groups for seropositive mothers who have lost children to HIV. The group leader, Lori Weiner, details the year’s 12 monthly sessions, as the women supported each other through the first holidays, birthdays and other meaningful anniversaries without their lost children.

“HIV, Women, and the Kitchen Sink Model” emphasizes the importance of training and utilizing members of the particular community targeted for interventions as front-line staff in prevention outreach work, surely one of the most difficult service tasks. Annette Hughes, creator of the models, states, “It simply is not enough to address HIV/AIDS exclusively when a woman cannot prevent poverty, read above the fifth-grade level, protect herself from an abusive partner, or refuse just one last hit off the pipe. Interventions that improve overall quality of life for women will likely be well-received and even welcomed into communities.”

A heart-wrenching chapter about dealing with the HIV-related death of a child in a group home, and a chapter about work on a pediatric AIDS ward emphasize the importance of consistent support from agency administrators of their staff. Such support is crucial; it gives workers an opportunity to process their own grief and “recharge” so that burnout does not affect quality of care.

Cultural Competency

Other chapters in the book describe support groups for HIV-negative gay men, a self-psychology group approach to working with seropositive slow and non-progressors, and work with serodiscordant couples. Diversity and cultural-competency issues are raised in chapters focusing on special issues to be considered in counseling homeless people with HIV, particular issues around spirituality in work with HIV-infected Hispanic clients, the difficulties African American males experience when HIV is identified with being gay in their communities, and the still “invisible African American woman.” Again, in each of these selections, authors raise well-considered questions about the quality of cultural understanding and service delivery for these populations, and offer specific suggestions to improve both.

The collection includes two extremely pertinent subjects that are rarely explored...
in mainstream publications: HIV medical and psycho-spiritual care for male-to-female pre-operative transsexuals, and rational suicide. In particular, James Grimaldi, who has created a case management model and support group for pre-operative transsexuals, describes this model and the roots of the intense trans-genderphobia that affects even the most well-intentioned professionals. In a chapter entitled “Dying Well,” Shernoff addresses concrete ways that health workers can serve the terminally ill, from providing them with someone with whom to discuss the darker side of dying to nitty-gritty details about choice of hospital, arrangements for children, wills and death services. In closing, he provides a set of crucial questions to ask a dying client and states, “The question for therapists working with dying clients is not whether we think suicide is okay, but rather have we done everything in our power to assure each of our clients that his/her life is precious and that considering assisted suicide is an understandable option.”

The book closes with a section on public policy. This section examines racism in AIDS service organizations, the quality of professional education, suicide and hastened death, and HIV prevention for youth.

**Conclusion**

The only disappointment in this book was an omission: it does not explore the significant advances made in HIV prevention among infants born to seropositive mothers who receive medically competent and emotionally supportive prenatal, birth, and post-partum care. In light of the enormous scope and high quality of this fine book, however, these oversights can be easily forgiven.

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**Social Work and HIV in the New Millenium**

Marta Friedman, LCSW and Maureen O’Neil, LCSW


**A Biopsychosocial Perspective**

The book is divided into 18 chapters and three parts, allowing the reader to focus on specific areas of interest. The first part addresses HIV from a biopsychosocial perspective. Chapter 1, for example, provides a medical description of HIV and an accessible account of the HIV disease process. Dawn Everitt, an HIV-positive woman and AIDS treatment advocate, writes a chapter that describes what a virus is, what HIV is in particular, and how different medications impede the replication of the virus at different stages of its life cycle. She discusses a variety of treatment considerations and complications, aiding readers in understanding just how complex the notion of adherence is, as well as highlighting why some people either cannot, or choose not to, partake of the medications that have been introduced in recent years.

In Chapter 3, Brian Giddens, Lana Ka’opua, and Evelyn Tomaaszewski look at the need to develop culturally competent skills in supporting clients as they face treatment decisions. They pose Ka’opua’s DIVERSE Model as a way to guide social workers through ethical decision making with clients who are culturally different and who may have different belief systems, values, and preferences.

**The Shape of the Epidemic**

The second (and largest) part of the book identifies the individuals and groups affected by HIV in the United States today. For instance, in Chapter 4, Patricia Stewart
discusses the impact of HIV within many African American communities. She presents staggering statistics that remind us of the magnitude and breadth of HIV in these communities. She presents a vivid discourse covering issues including racism—on a personal and institutional level—the fear of genocide, and the “historic disregard for the sanctity of Black people’s lives,” and she discusses the role of Black family life in terms of parenting practices and partner relationships. She provides the reader with suggestions for effective and respectful interventions and with the impetus to better understand personal biases and limitations.

In Chapter 5, Susan Taylor-Brown and Lori Weiner identify many of the key issues for parents with HIV, including making plans for their minor children, accepting that a child is HIV-infected, dealing with disclosure, and handling issues of legacy. Part 2 is effective in acknowledging the spectrum of issues that interplay with the experience of HIV across the life span. For example, in Chapter 10, Cynthia Cannon Poindexter and Nathan Linsk address the impact of HIV on older people. Indeed people are living longer with HIV and therefore moving from young adulthood to middle age. Older people themselves have been infected through the same avenues as many younger people. This chapter reminds us of this fact as well as of the roles that older people have played as caregivers.

The Social Worker’s Role

The third part of the book identifies many of the diverse roles for social workers in HIV care and includes chapters on prevention, advocacy and social policy, adherence, mental health issues, bereavement, and spirituality. In Chapter 15, Larry Gant describes the links between effective advocacy and the advancement of social policymaking in HIV prevention, care, and treatment. Among the issues he discusses are advances in treatment and increased longevity, changes in behavior, changes in rates of transmission, differential treatment based on provider education and bias, and the overall lack of understanding about HIV transmission across many populations. As Gant points out, social workers will have an ever-expanding role as advocates and educators for individuals as well as communities, and will need to focus efforts on primary prevention as well as secondary prevention. Gant also addresses advocacy in terms of the general social response to the current trends in HIV. He identifies the “Lazarus Effect” as the most significant factor affecting HIV policy. He defines the Lazarus Effect as an “expression for the declining AIDS death rates and increasing life spans of people living with AIDS” that is due largely to the success of current medical treatment. While such treatment has meant, for some, a substantial improvement in quality of life, it has also posed challenges in terms of sustained sobriety, sustained adherence, and access to care and benefits.

In Chapter 13, Cynthia Cannon Poindexter aptly summarizes the social and psychological issues of people with HIV as well as the challenge to the social work profession. She says: “The losses are extreme and multiple, the crises are intense and serial, the disease is infectious and life threatening, and the stigma is pervasive and debilitating. We are stretching our profession, bringing old knowledge and techniques to bear on a new and often overwhelming issue.”

Conclusion

Vincent Lynch and the book’s expert contributors have achieved the goal of providing a clear and concise guide, a tool that is relevant to our practice as social workers, and to our existence in a professional and personal world that has known HIV far too long and far too intimately. We would like to thank Lynch not only for his efforts to bring this body of work to life, but also for his many years of dedication to social work and HIV. He has been, and remains, a grand force among our colleagues.

New Book on Bereavement

The AIDS Health Project announces the third volume in its monograph series: "Working with AIDS Bereavement: A Comprehensive Approach for Mental Health Providers". The book reviews psychodynamic and cognitive theories of bereavement and proposes a treatment model that integrates a variety of approaches. The book costs $10.95 plus shipping and handling ($2.00) and tax for California purchasers (8.5%). For multiple, rush, or international orders, call 415-502-4930, or send payment and address to UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
A Review of HIV Prevention
Michael Discepola, MFTI


As a dedicated HIV prevention professional and an active participant in the San Francisco HIV Prevention Community Planning Process, I developed expectations for this book from the moment I read its title: Preventing AIDS: A Sourcebook for Behavioral Interventions. Although skeptical at first, I was surprised by Seth Kalichman's ability to offer the reader so much content and depth in so few pages. I found the book accessible and thorough. It addresses the lack of common language among researchers, program developers, practitioners, and community planning groups. In addition, it examines the common goals and strengths inherent in contemporary prevention technology while offering readers a fresh lens through which to view the issues pertinent to the development of new and viable behavioral interventions.

Behavioral, Not Medical, Interventions
I was pleased with Kalichman's choice to focus on behavioral interventions as opposed to medical interventions or medical research. Despite medical advances in the treatment and prevention of HIV disease—such as those achieved in reducing transmission during pregnancy and childbirth—individual decisions to change risk-related behaviors remain the most viable means of preventing new HIV infections.

Kalichman's sourcebook reviews what is known about HIV risk behaviors with the sensitivity and insight one might expect from a front-line practitioner. In doing so, it explicitly acknowledges the complex and interrelated psychosocial and sociocultural factors that influence risk behavior, including substance abuse or psychopathology in either or both of the partners. It also discusses characteristics of relationships, including love, affection, sexuality, self-esteem, survival, intimacy, coercion, and trust to HIV transmission risk. Further, it acknowledges two additional dimensions: biological factors and the prevalence of HIV in a population. Kalichman concisely reviews the behavioral change theories he suggests have most influenced the advancement of HIV prevention, including the Health Belief Model, the Theory of Reasoned Action, Social Cognitive Theory, and the Transtheoretical Model. In addition, he cites an impressive body of scientific evidence, research, and field data. He looks closely at the strengths and weaknesses of systems and interventions designed for individuals, small groups, and communities, and surveys the relationships among HIV prevention sciences and the process of the transfer of prevention technology to everyday practice.

Kalichman's book offers a critical resource useful for the novice as well as the experienced prevention practitioner. Although particularly valuable reading for public health, research, and mental health students, it should be read by all outpatient practitioners who provide services in mental health, substance abuse, and targeted HIV prevention. Every outpatient provider must consider the context of HIV risk behavior as it relates to his or her clients' abilities to communicate assertively and effectively with their partners. Counselors who understand the complexities of these behavioral issues will remain a powerful resource in preventing new infections and transmissions of HIV; those who do not will hinder the dissemination of new and responsive interventions.

Conclusion
Despite some deficits, including the omission of a useful epidemiology of HIV, inadequate chapter conclusions, and the omission of the word “unprotected” in several sections describing vaginal and anal sexual risks, Kalichman's sourcebook leaves the reader with insights, questions, and plausible solutions to a myriad of issues pertinent to effective HIV prevention.

In conclusion, I am left with a concise text to use in educating peers and in debating and formulating prevention strategy. I came to respect Kalichman's scholarly, dry yet accessible review of HIV prevention theory, practice, and research. I am grateful for his reminders to all prevention practitioners to communicate with each other and remain sensitive to those at greatest risk for HIV infection. I particularly appreciate his assertion to all practitioners: "Interpersonal style, humor, rapport, sensitivity, empathy, and genuineness account for much of the success in behavior change interventions."

Perhaps Kalichman will offer stronger conclusive thoughts and recommendations for practice in his next book. Even if he does not, I, for one, will read it anyway. Until then, I accept his challenge to consider what has been done and what remains undone to prevent HIV, and I salute his optimism for the future of prevention technology.
**Internet Update**

For people involved in the rapidly changing field of HIV work, the Internet can be a useful tool for obtaining the latest news and information. Although there are many HIV-related web sites, finding the right one for a particular purpose can be time consuming and sometimes frustrating. Most of the following web sites focus on specific issues and provide links to other relevant sites.

AIDS Educational Global Information System (AEGIS) (http://www.aegis.com) claims to be “the largest HIV/AIDS web site in the world” and offers access to news, legal information, and clinical research from numerous sources. Operated by the Sisters of St. Elizabeth of Hungary in San Juan Capistrano, California, the site receives support from pharmaceutical companies and other corporate sponsors. The AEGIS site covers a comprehensive range of topics and access to articles from national and international newspapers, wire services, and HIV newsletters. Featured topics include prevention, issues related to living with HIV, and the science of HIV. The site also provides links to publications concerning advocacy, issues affecting service providers, and government research.

AIDS Clinical Trials Information Service (ACTIS) (http://actis.org) offers access to the National Library of Medicine’s AIDS trials and AIDS drugs databases. The AIDS trials databases provide up-to-date information about clinical trials performed by private and federal sponsors. Information on drug pharmacology, side effects, and interactions is available in the AIDS drugs database.

Johns Hopkins AIDS Service (http://www.hopkins-aids.edu) contains information on the latest advances in HIV disease research. An expert question-and-answer forum offers clinicians and clients direct access to medical researchers. Unique to this site is a science forum on HIV disease in Portuguese.

HIV/AIDS Treatment Information Service (http://www.hivatis.org) provides information about federally approved guidelines for HIV and AIDS treatment. The site is a Department of Health and Human Services (DHHS) project co-sponsored by the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

The Henry J. Kaiser Family Foundation (http://www.kff.org) focuses on major health care issues. The “HIV/AIDS” section of the site features information on a variety of topics, including prevention, education, policy, and research. The “Daily HIV/AIDS Report” is updated each weekday. Visitors to the site also can register to receive customized daily and weekly news updates by e-mail. The foundation’s Health Policy program provides analysis and explanations of health policy.

Avert: AIDS Education and Research Trust (http://www.avert.org), a British web site, provides information on numerous topics, including issues affecting women, children, and gay men, and strategies for educating youth about HIV. A section offers various HIV and AIDS statistics based on age, gender, sexual orientation, and ethnicity.

HIV InfoWeb (http://www.infoweb.org) is an on-line library containing HIV-related topics ranging from treatments to travel. Special attention is devoted to housing, law and policy, and alternative medicine. A photography section provides visual representations of people affected by HIV.

Gay Men’s Health Crisis (GMHC) (http://www.gmhc.org), an agency based in New York, provides information in English and Spanish about medical care, nutrition, support groups, substance abuse, and emergency services for people with HIV.

Galen II (http://galen.ucsf.edu), the University of California San Francisco (UCSF) library’s home page, offers access to MEDLINE, AIDSLINE, and many other databases and journals.

**Next Month**

Discussions of perinatal HIV infection have often focused on the issues of small children. But, young people infected with HIV at birth in the 1980s are now entering adolescence. In the January issue of FOCUS, Tracy Bush-Parker, LCSW of Children’s Hospital in Los Angeles suggests that these young people are dealing not only with a stage of life that is difficult for any person, but also with issues such as living with a chronic illness, discovering dating and sexuality, and facing the illness and death of peers with HIV.

Also in the January issue, Sue Ellen Abdalian, MD of Tulane University and Karen Lingard Wright, MEd, an adolescent case manager in New Orleans, consider the parenting and developmental issues affecting young mothers with HIV.
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The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.