A Guide to AIDS Research and Counseling  
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African American Ethnographics
Fred Allen Vanhoose, PhD


In Renee T. White's scholarly and compassionate book, Puting Risk in Perspective: Black Teenage Lives in the Era of AIDS, the author describes her ethnographic exploration of the lives of young Black women in urban America. It is an intimate perspective on how and why these women make decisions that put themselves at risk for pregnancy and sexually transmitted diseases.

White takes the reader on a journey through Black female adolescence in New Haven, Connecticut, a racially and economically segregated city in which the poverty of poor Black and Latino communities are juxtaposed with the privilege of the wealthy White communities in proximity to Yale University. In economically depressed New Haven, Blacks comprise 36 percent of the population, but Black adults and adolescents account for 63 percent of New Haven’s AIDS cases, and pregnancy and birth rates among Black teens are twice the rate for White teenagers. White discusses familial dynamics, peer influences, sexual experimentation, and the nature of Black teenage women's relationships with their parents, educators, and Black men.

Her literary style is frank and engaging, and she allows the voices of these women to emerge throughout the book. Her approach is comprehensive and methodologically sound enough for social scientists, yet accessible enough for a broader audience.

White’s meticulous review of the teen pregnancy and sexually transmitted disease (STD) literature uncovers strong biases among social scientists toward “racial encoding” when they compare data regarding various ethnic groups. For example, studies have attributed higher rates of sexual activity among Black teenagers to the “natural sexual tendencies of Blacks” without consideration of various cultural, socioeconomic, and gender-related risk factors. White convincingly argues that “ethnography is intended to shed light on populations that are simultaneously understudied and overstudied,” rendered invisible and silent through the interpretations of well-intentioned researchers who do not allow participants to tell their stories. Further, White asserts that ethnography, field research, oral narrative, and related qualitative data collection should highlight the perspectives of subjects, offering data in a human context unmatched by quantitative studies and unbiased by investigators.

The Lives of Black Teenage Women

In the early 1990s, White recruited 53 teenage women, 33 of whom were Black, for her two-and-one-half year field project. Through the women's words and White's observations, these young Black women depict a world fraught with violence, poverty, insularity, and a scarcity of critical community and familial resources. Their intimate relationships with Black men are often adversarial, characterized by mutual objectification and mistrust. Moreover, White found that the dearth of viable economic and other life-affirming opportunities for the disproportionate number of low-income Blacks in America, particularly adolescents, promoted a fatalism that ultimately contributed to risk taking.

In White's cohort, low-income Black teenage women (24 of the 33 with annual family incomes below $20,000) often chose motherhood as a way either to attain adulthood and the higher status of being considered a woman, or to obtain unconditional love from a child (if not from a man). These
women tended to avoid emotional intimacy with men and to use sex as a commodity to keep men engaged in relationships, an accommodation to the reality that marriage and conventional family life seemed remote. In this way, many of these women affirmed their desire for independence; at the same time, however, they often deferred to men, accepting infidelity and submitting to sex without condoms. In contrast, their middle class counterparts (four of the 33 with family incomes over $30,000) viewed their relationships as more egalitarian and perceived themselves as having viable opportunities for success and personal fulfillment; these women discussed sex openly with their partners, used condoms regularly, and deferred pregnancy.

The prevalence and inevitability of death among low-income Blacks in New Haven, and the pressing needs to find work, protect against violence, and raise children, served to desensitize many Black teenage women to planned parenthood and HIV prevention messages. Further, White found that condoms had become synonymous with STD prevention. Consequently, low-income Black women tended not to use condoms for contraception; more often, they used contraceptive sponges, diaphragms, intrauterine devices (IUDs), or the pill. White men and women more often used condoms for both contraception and STD protection. Given that contraception has traditionally been the female's responsibility, negotiating condom use brings up issues of emotional intimacy and dependency on male cooperation that few of the Black women in White's cohort chose to explore. Instead, they assessed personal risk based on their partner's physical health and appearance, knowledge of his past and present sexual practices, and his substance use history. Similar to repeat HIV testers among gay men, those women who engaged in unprotected vaginal sex and repeatedly tested negative surmised that their risk for HIV infection was minimal.

Conclusion
White offers practical HIV and STD prevention interventions, including partnerships between educators, teen women, and parents, and the use of well-known hip-hop and rhythm and blues artists to educate the public. Strikingly absent from White's exploration, however, are the perspectives of Black men on how to effect meaningful behavior change; ironically, White focuses the responsibility of HIV and STD prevention mainly on women.

There are clear parallels between the issues faced by White's cohort and those of gay men, particularly Black gay men. The AIDS epidemic caused the untimely deaths of many and left survivors burdened by grief. Racism, poverty, injection drug use, and their psychological effects have resulted in a surge in HIV incidence among Black men who have sex with men. This has led to a fatalism regarding death, manifested through sexual risk taking. Further, similar to White's cohort, gay men have become habituated to HIV prevention messages, necessitating continuing innovation to sustain interventions.

Although White's research focused primarily on Black teenage women, her work offers important insights into the multifaceted nature of HIV prevention. It also challenges researchers and clinicians to use what can be learned from this cohort to inform their prevention efforts with other populations.

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Clearinghouse: HIV-Related Books


Documenting Asymptomatic Lives

George Harrison, MD


Mortal Men documents the transformations experienced by a group of men living with asymptomatic HIV. The book, based on a series of interviews that formed author Richard McIntyre’s doctoral nursing thesis, probes issues about gay life, sexuality, identity, and medical decision-making in case studies of the experiences of the author and 10 other men.

The Stories

Mortal Men begins with the author’s reflections on the epidemic and the community response to it, and focuses, in particular, on the difficulty of being HIV-positive without tangible signs of illness. After briefly reviewing the evolution of HIV treatment, MacIntyre writes about the basis for his study. He chose his subjects from among his friends or men he “had met at the gym, a bar, or a sex club.” The participants were between 25 and 45 years old. Although MacIntyre does not indicate the race, ethnicity, or other socioeconomic demographic characteristics, it is clear that the men represent a particular subpopulation of the gay community: highly educated, financially secure, and socially and sexually confident.

The first story is the author’s. MacIntyre writes about his process of separating from his family, becoming a nurse, and solidifying his identity as a gay man. In a manner that is forthcoming, at times chatty, and eventually wrenching, MacIntyre describes the two major loves of his life and their deaths from AIDS. Details of MacIntyre’s life are also woven into other stories in the book. Each story includes long quotations from these amazingly articulate men, supplemented by the author’s reflections and opinions. The focus of each story is on a participant’s decision to test for HIV, his reaction to his test results, his subsequent personal and social adjustments, and the way in which he determined the course of his HIV treatment.

Vivid Anthropology

Mortal Men contributes to the HIV literature in a variety of ways. As anthropology, the vivid, bracingly candid stories capture, in an immediate way, images of the times and the participants. These narratives bring to life a specific community of men at the convergence of gay liberation and HIV, and follow the experiences of these men over the course of the epidemic, detailing community expectations, mores, and practices.

Testimonies about the treatment decision-making process demonstrate the many factors that determine health care choices. While the participants were of a community, they had significantly different responses to the pressures regarding HIV testing and treatment. Some heeded only internal standards. Others looked to their community to define choices for them. McIntyre frequently chides physicians as the authority figures who failed to provide informed assistance to their patients, instead only mouthing the party line.

MacIntyre considers at length the effects HIV has had on sexual expression both on community and individual levels. Because sex played such a central role in identity for these men, changes in sexual behavior transformed identity, sometimes radically. The interviews document the struggle to rebalance an equation in which free sexuality suddenly became closely associated with illness, loss, and death.

A Very Active Witness

Two reservations about the book are worth noting. First, while the book is labeled as a study, it is one with a very active witness. While McIntyre advocates for narrative research as an important means of unearthing information, he goes beyond interpretation of data to introject his own personal beliefs. Second, MacIntyre’s selection criteria resulted in a group of subjects with homogeneous demographics but diverse individual psychologies. The book could have been enriched by including some control subjects, for instance, men of the same social group who were HIV-negative.

Mortal Men will be useful reading for a variety of audiences. The general public will find in it the human face of HIV. Providers will be reminded of the challenges of reaching out to people with HIV in a manner that delivers services and support while facilitating health decisions. Asymptomatic people with HIV may find in this book a mirror of their lives. MacIntyre’s story, scattered throughout the book, is the most satisfying of all, benefitting from his ability to describe his experience as a lover, a widow, a nurse, and an asymptomatic man. The best of his work documents the overlay of competing memories, the intersection of love and loss, and the difficult process of living in the middle of the epidemic.
HIV Burnout in Context
Michelle Cataldo, LCSW


Providing HIV-related care is stressful—involving work with disabled and dying clients, and with stigmatized and impoverished populations, in a context of inadequate resources. While none of these stressful working conditions is new, the AIDS pandemic has brought them together, perhaps as never before.

In Dying to Care?, David Miller reminds us that while organizational and contextual variables are instrumental in creating burnout, interventions tend to be directed at individuals. In this highly academic volume, Miller advocates for preventive, “context management” of employee burnout.

An Exhaustive Guide
To this end, Miller provides the reader with an exhaustive (and often exhausting) review of the work stress and burnout literature. The result is a useful guide to the research on burnout, with a special emphasis on work stress and burnout among HIV health care providers. Unfortunately, Miller overwhelms the reader with so many studies that some focus is lost.

Only Part Two of the book specifically relates to AIDS burnout. Part One offers a more general overview, including reviews of occupational stress literature, and the symptoms and correlates of burnout. Part Two discusses HIV-related burnout, including methodological limitations of prior studies, two studies on staff burnout in the United Kingdom, a look at volunteers and burnout, and the management of occupational stress.

In Chapter 5, “Burnout in HIV/AIDS,” Miller offers a compelling discussion of the institutional experience of burnout, exploring the circumstances of a peer-led community service organization that ultimately closed. He notes that community-based organizations had sprung up “to tackle the acute needs of people at risk . . . [and] when the shape of the pandemic changes and responses to needs change with them, problems may arise that may eventually cripple the organization.” Indeed, many of the individual factors correlated with burnout—lack of experience, lack of clear limits around role, and rapid role expansion—have plagued AIDS agencies as well.

This speaks to the special dilemma of burnout in HIV work: constant functioning in a crisis mode leads to burnout, yet it is the acuity of the AIDS crisis that determines funding and public support.

Despite these challenges, at the heart of stress and coping theory is the importance of the meaning we attribute to our circumstances and stressors. Miller’s point that HIV staff, more than other health care workers, may derive satisfaction from difficult client encounters, is a salient one. He also refers to protective effects—including social support, perceptions of autonomy and control, and a sense of personal accomplishment—that mitigate the experience of HIV-related work stress. Deeper exploration of these factors, and quotes from Miller’s subjects on the meaning they ascribe to their work, would have been welcome, adding to the accessibility and richness of his findings.

The Internal/External Divide
Miller clearly has a command of both the breadth and depth of his subject, but is less successful in communicating this understanding to me. Dying to Care? serves as a fine academic resource for researchers interested in work stress and burnout, but readers who are looking for a more personal reflection of their experience may be disappointed. Additionally, I found Miller’s writing style exceptionally difficult to follow.

Miller does provide a valuable critique of current practice in burnout management, defining key “lessons and paradoxes from the burnout literature.” While causes of burnout are chronic and complex, he notes, proposed solutions are acute and simplistic. Further, the staff they are meant to assist are rarely consulted about their needs.

When staff are interviewed, they cite problems, including understaffing, too many patients, or the need for better management—all of which are systems problems. Managers interviewed, however, proposed internal, individually-focused solutions. It is this perceptual divide that must be bridged to achieve effective management of HIV-related work stress and sustain the energy of AIDS service providers.

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Impact of the New HIV Treatments
Dan Karasic, MD


Psychosocial and Public Health Impacts of New HIV Therapies is a snapshot of the HIV epidemic at the end of the 20th century. This collection of short chapters covers the spectrum of challenges facing clinicians and researchers in treatment and prevention in the era after the introduction of combination antiviral treatment.

In recognition of the rapidly changing information on HIV, the editors focus on general principles that they hope will remain relevant as the details change. The book includes chapters describing the new antiviral drugs, their potential interactions with psychiatric medications, adherence issues, mental health implications, prevention issues, economic considerations, ethical issues, post-exposure prophylaxis, and new challenges in behavioral research. With a glossary that defines even basic medical terms, the book is accessible to students new to HIV; the chapters by leaders in the field are useful to more experienced clinicians.

Beyond the Myths

In a chapter on the mental health implications of combination antiviral treatment, Seth Kalichman and Bineetha Ramachandran diagram the potential trajectory of HIV disease as a chronic disease, treatable but not curable, and contrast it with cancer. The authors describe how this changing disease trajectory complicates treatment decision making, and they briefly touch on how individual coping styles may affect the decision-making process. They also discuss the potential effects of combination antiviral treatment on career, relationships, identity and community, as well as mental health effects of treatment success and failure and potential effects on sexual behavior. Finally, they recommend mental health interventions to improve coping skills for living with HIV as well as for reducing transmission risk behavior.

Since protease inhibitors and many psychiatric medications are metabolized by the cytochrome P450 system, one chapter provides an excellent review of the literature on drug interactions. Given the paucity of data on interactions actually established in people with HIV, a description of the principles for predicting drug interactions is particularly helpful. It would have been useful for the chapter to have included a discussion of potential interactions of non-nucleoside reverse transcriptase inhibitors (NNRTIs), which are also cytochrome P450 mediated.

The efficacy of combination antiretroviral therapies is highly dependent on close adherence to rigorous regimens. Poor adherence leads not only to treatment failure, but also to possible failure of future regimens. Judith Rabkin and Margaret Chesney’s chapter on treatment adherence provides an excellent review of factors affecting adherence, including patient beliefs and knowledge, social environment, psychiatric illness and substance abuse, complexity of treatment regimen, and the doctor-patient relationship. Rabkin and Chesney also summarize data from adherence intervention trials to suggest how adherence may be improved.

In a chapter on HIV prevention in the era of combination therapies, David Ostrow describes five “myths” of HIV prevention. Two are of particular note: behavioral interventions to prevent transmission do not work, and combination antiviral treatment—in reducing sexual transmission risk and through the use of post-exposure prophylaxis—is the ultimate prevention solution. Ostrow is especially concerned that the focus on post-exposure antiviral treatment may diminish interest in and resources for implementing effective behavioral prevention strategies. Ostrow also fears that myths which overstate the efficacy of antiviral regimens to treat HIV and to prevent transmission may lead to increased risk behavior. He states that behavioral and medical prevention strategies should be implemented together.

Conclusion

The final chapter lists areas for future research in “AIDS as a chronic illness.” It is a measure of the changing nature of the epidemic—with problems regarding access to antiviral treatment, treatment failure, and treatment toxicity—that one would be more hesitant in 2000 than in 1998 (when this chapter was written) to describe AIDS as a chronic illness. Despite this ever-changing nature, and whether the reader uses the book for an overview of the issues or as a starting point to a more detailed review of the literature, the strong views of the authors in this book will not fail to provide the reader with a sense of the challenges ahead.
Global Prevention Challenges
Marshall Feldman, LCSW


Families and Communities Responding to AIDS is another anthology in the fine Social Aspects of AIDS series edited by Peter Aggleton. This is an updated collection of essays on studies conducted in the United Kingdom, Australia, and Africa, and originally presented at the 1997 conference on Social Aspects of AIDS. Although the overall collection is a valuable contribution to the field, the title is somewhat misleading; these essays focus on specific topics rather than on a broad overview of the challenges faced by families and communities. Conversely, because the book covers a variety of topics, readers have the opportunity to be introduced to areas outside their particular field of practice.

From the Brilliant to the Basic

The book is informally divided into two sections. The first focuses on the issues of biological families coping with HIV and AIDS. The second explores HIV prevention primarily among gay and bisexual men in the United Kingdom and Australia.

The first chapter, “Getting on with Life: The Experience of Families of Children with HIV Infection,” provides an excellent overview of the particular concerns of families with children infected with HIV. Employing a clear and accessible writing style, the authors balance theory and personal narrative to illustrate the range of issues confronting these families. They combine general concerns about child care with the specifics of HIV-related child care.

The three chapters that follow examine the perspectives of Africans, who live either in Africa or in the United Kingdom. These essays serve as an introduction, and a particularly relevant one in light of the recent International AIDS Conference in Durban, South Africa. But the specifics of the studies covered in these chapters are of limited use to those not working with people born in Africa, and it is difficult to imagine how the projects discussed in these chapters might be replicated with other populations.

The chapters in the second section, focusing primarily on HIV prevention issues with gay and bisexual men, range from the brilliant to the mundane. The best of these encourage the reader to look beyond the bioeducational models of prevention and to examine the meaning of sexual practices, intimacy, community, and family. The least compelling of these chapters present information on gay men’s lives that is too basic for professionals working in the field at this time in the epidemic.

In an excellent chapter, entitled “Narratives of Care, Love and Commitment: AIDS/HIV and Non-Heterosexual Family Formations,” the authors propose a broader definition of family. They suggest that family members included in this expanded definition, employed by gay men and lesbians, are as important, if not more important, than people included in families of origin. The authors explain how the concept of family affects the provision of services to this population. In no way diminishing the value of this chapter, it is notable that there are no chapters in this section that examine the interactions of gay and bisexual men with their families of origin.

In “Young Gay Men and HIV Risk,” which presents the results of an Australian study of 254 men under age 25, the authors report that young gay men are not more likely than older gay men to engage in high-risk sexual behaviors. The study demonstrates that age itself is less of a variable than cultural, economic, and social factors in predicting and assessing sexual choices for this group. It will be important to see if future studies confirm or contradict these groundbreaking findings.

Conclusion

Overall, this collection of essays, though limited in focus, provides good solid information, thought-provoking essays, interesting studies, and an opportunity to consider a broad range of topics within this area.

Brooker Book Benefits AHP

Barbara Rose Brooker is donating the proceeds from God Doesn't Make Trash, her new book about HIV and homophobia, to the UCSF AIDS Health Project. The book covers two generations in the evolution of the HIV epidemic. The first half of the book takes place in San Francisco in 1983 as the first men and women with AIDS lose their jobs, homes, insurance, and families. The second half emerges 15 years later with interviews of men and women in San Francisco who are living with HIV. The book is available for $16.00 on amazon.com (ISBN: 0738828270).
HIV Prevention for Families at Risk
Susan W. Haikalis, LCSW


The editors of Working with Families in the Era of HIV/AIDS have pulled together detailed descriptions of prevention programs across the country, focusing predominantly on African American heterosexual families. The focus is on interventions that encourage empowerment, improve communication between parents and adolescents, and foster effective sexual negotiation, skills that will be critical to reverse the trend toward increasing seroconversion in this population.

The book is divided into three sections: an overview; a section on direct prevention programs; and a section on adapting to HIV that, while ostensibly focused on people with HIV, emphasizes the ways in which HIV-positive parents can work with HIV-negative children to help these teens develop more healthy, intimate relationships and reduce their HIV risk. Each of the 11 chapters describes a program funded during the 1990s by the National Institute of Mental Health (NIMH), all of which were collaborations between social service agencies or medical centers and major universities. The programs developed group interventions and used facilitators recruited from the community. Each program developed a curriculum and follow-up for interventions. Program facilitators were trained on HIV, effective communication skills, and how to conduct group sessions. Several of the programs were evaluated and demonstrated significant growth for the participants.

Program Content

Interventions ranged in length from four to seven group sessions, usually between two and four hours long, and included eight to ten participants. Some of the sessions were for both parents (predominantly mothers) and adolescents (ages 12 to 14); other sessions separated these groups. Facilitators frequently assigned homework, which was then discussed at the next session. Common topics covered in the majority of the programs were: HIV 101, values and peer pressure, listening and communication skills, talking about sex, sexual decision making, consequences of early sexual activity, condom training, disclosure of HIV status, and custody planning. Most of the programs focused on strengthening problem-solving skills and mobilizing social service systems to provide support and care. The families were taught to work together to define a problem, find solutions, carry them out, and review the results.

For example, the “Keeping it R.E.A.L.! (Responsible, Empowerment, Aware, Living)” program in Atlanta taught mothers how to support their adolescents’ efforts in reducing risk. In this collaboration between the Boys and Girls Clubs and Emory University, mothers and adolescents participated in seven highly interactive sessions held for two hours every two weeks. Topics included HIV 101, sexual decision making, adolescent parenting challenges, and listening and communication skills. Mothers and adolescents who attended regularly developed more effective communication skills. Training and the use of peer facilitators increased the effectiveness of the program.

Although the 11 program designs were basically similar, each one adapted to its specific community and culture. Many described the process of programmatic change in response to newly identified client needs as they worked with the participants—a basic tenet of social work. The use of case vignettes in the majority of chapters was helpful in demonstrating the effectiveness of the programs.

Conclusion

This book is an effective guide for agencies serving HIV-positive people of color, particularly African Americans, who are raising children. All of the programs recognize that HIV is often the least of their clients’ problems, given histories of poverty, substance use, community and domestic violence, homelessness, and mental illness. However, a common thread among programs was that clients wanted to find ways to be more effective parents. For instance, while many had never, personally, been effective negotiators for safer sexual behaviors, they wanted their children to learn these skills. Further, the group experience improved their own negotiation skills.

Each chapter is annotated with an extensive bibliography and information on how to contact the program developers. With the significant increase of HIV in the adolescent age group in urban areas in the United States, every community should consider replicating these successful programs to help reduce this threat to our youth.
Brief Reviews


Signification is about the cultural meanings attached to words or acronyms such as "AIDS," "HIV," and "epidemic" and the process of creating new concepts such as "safe-sex" to replace the moralistic, value-laden proscription against promiscuity. [How to Have Theory in an Epidemic] is about stigmatization and how the medical epidemic can be placed within a cultural context with structural arrangements tolerating and promoting worldism, and homophobia. For the author, the failure of Centers for Disease Control and Prevention (CDC) researchers to listen to their own data, which suggested women were being infected and dying, is not surprising given the lower-status history of women's health issues. The negative media portrayal of Africans living with AIDS is consistent with a historical context of colonialism and postcolonial relationships. This book is also about social activism and how doctor-patient, government bureaucrat-citizen, and drug company executive-consumer relationships have been transformed away from an unequal balance of power. . . .

Treichler's book is a long series of essays about specific moments in time and thus chronicles the evolution of cultural meanings particular to AIDS. Media depiction, both print and broadcast, is discussed in several chapters, which include photographs of magazine covers and examples of other print materials to illustrate important points. As our knowledge of AIDS and HIV has evolved, so too have the language and meanings attached to this epidemic. . . . To the extent that this author demonstrates that medicine is a legitimate and practical topic in cultural studies, the influence of this work will be long-standing.


Smearing the Queer: Medical Bias in the Health Care of Gay Men, by Michael Scarce, is a fascinating read. . . . The author provides eye-opening revelations about heterosexist attitudes: gay men are somehow depraved, pleasure-seeking, and infected and they might spread their diseases (such as HIV infection) to a "general population virtuously going about its business." That Scarce does this through citing recently published articles by prominent health care professionals is, quite simply, embarrassing to the medical field. His conclusion, late in the book, that gay men should become engaged allies with women's health movements because of their many and closely intertwined health issues (Reality female condom used for anal sex, anal Pap smears analyzed in gynecological centers, etc.) is a creative and efficient approach to tackling some of the health care issues facing homosexual men.

However, this book, for all its thought-provoking ideas, suffers from a lack of focus . . . [and] while chock-full of interesting details such as behind-the-scenes politics of putting the Reality female condom on the market, [it] may ultimately be alienating to many. Its use of vulgar language, ribald poetry, and the author's personal sexual details might cause health care professionals making an initial foray into gay men's health care issues to cringe. . . .

Even with its weaknesses, Smearing the Queer remains an innovative, in-depth look at the issues facing homosexual men and, consequently, their health care providers. Its sensitive and thorough approach to the scientific, political, and social issues involved in this provocative topic, as well as its useful suggestions for work to be done in the future, are enough to overcome its shortcomings.

Next Month

It seems that each week new data suggest a shift in the epidemic: one subpopulation of people or another is the "fastest growing segment of the epidemic." In the January 2001 issue of FOCUS, David G. Ostrow, MD, PhD, Professor of Psychiatry and Behavioral Neurosciences at Loyola University Medical School, reviews the overall HIV incidence data for the United States and focuses on the urban gay male epidemic, particularly in light of recent data suggesting a rebound in the number of new cases.

Also in the January issue, Janet M. Blair, PhD, MPH, an Epidemiologist at the Centers for Disease Control and Prevention, reviews incidence data to describe the epidemic among women.
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