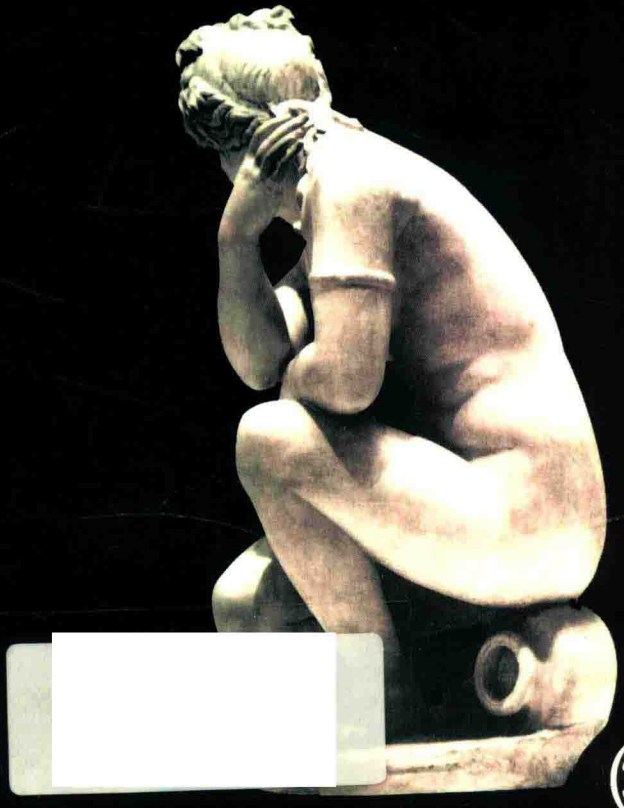
*En*Gendering AIDS

Deconstructing Sex, Text and Epidemic

TAMSIN WILTON



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*En*Gendering AIDS

For Lesley Doyal, teacher and friend

The most important work for saving lives must take place in the minefield of representation

Tessa Boffin

the language you speak is made up of words that are killing you

Monique Wittig *Les guérillères*

Acknowledgements

A book like this cannot be produced in isolation. Questions concerning the social aspects of AIDS, pornography, representation, gender and sexuality are (rightly) subject to lively debate, and my own ideas have developed in energetic discussion over many years with many people. I could not have written this book without that kind of interchange, and I am grateful to Diane Richardson, Lisa Adkins, Lesley Doyal, Dede Liss, Frankie Lynch, Jeffrey Weeks, Liz Frost, Norma Daykin, Sue O'Sullivan, Cécile Vélu, Ian Warwick and Cindy Patton as well as students on my 1994 Master's option, 'Representing Women', all of whom have influenced my thinking over the years. Thanks are due to Fiona Stewart of the Institute for the Study of Sexually Transmissible Diseases at La Trobe University, Melbourne, and to Nicola Gavey of the Department of Psychology at the University of Auckland, for being so generous in sharing their own important research with me. I am also very grateful to Professor Susan Kippax of Macquarie University, Sydney, for sharing her work with me and for making it possible for me to attend the third annual 'HIV, AIDS and Society' Conference and to Professor Doreen Rosenthal, Dr Anthony Smith and everyone at the Institute for the Study of Sexually Transmitted Diseases at La Trobe for their hospitality and their generosity in talking with me about their research. Special thanks to La Trobe's Marg Hay, to many students on my 'Social Aspects of HIV/AIDS' module at the University of the West of England, and to the Leicester Lesbian, Gay and Bisexual Community Resource Centre for adding to my collection of safer sex materials. Although every effort has been made to identify the copyright owners of images reproduced here, this has not always been possible. If copyright owners contact us, we will be glad to remedy our omissions.

My son, Tom Coveney, was forthright in his assessment of AIDS educational materials intended for young people, and Stuart Williams taught me much about the life-enhancing properties of gay porn before his death with AIDS. It saddens me that my thanks to Benny Henriksson of RFSL in Stockholm, whose work in organizing the first Scandinavian Conference on Safer Sex was an important early stimulus to my thinking in this area, must also be recorded posthumously, since Benny died with AIDS as I finished writing this.

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Care) at the University of the West of England, Bristol, for buying me out of my teaching obligations for fifteen days to enable me to finish work on this book, and for supporting my travels in search of knowledge!

Introduction: A Note on Terminology

The central argument of this book is that representational and discursive practices are important in the context of the epidemic of HIV infection because they shape our response to this new health threat very directly, and in ways which are not always easy to recognize or amenable to change. It behoves me then to be punctilious about my own practices as a writer, to make explicit the political nature of the choices that I make about language, and to write reflexively and self-critically. I hope I have done this, and would hope that critical readers will alert me to instances of language use in this book which they find problematic or offensive. Some of my key decisions warrant explanation here.

In referring to the epidemic I use varied terminology, 'the epidemic of HIV infection', 'HIV/AIDS' or 'AIDS epidemic', all with specific meanings. HIV (Human Immunodeficiency Virus) is the virus which damages the immune system to such an extent that infected individuals eventually go on to develop AIDS (Acquired Immune Deficiency Syndrome). AIDS itself is not a disease, nor can it be transmitted from person to person. Rather, it describes a condition of chronic immune system depletion which leaves the body vulnerable to a host of opportunistic infections, including cancers, fungal infections, viruses, protozoa, etc. The clinical diagnosis of AIDS is subject to continual redefinition (for example, the Centers for Disease Control definition of AIDS was expanded in response to complaints that the original definition excluded several conditions specific to women with HIV infection), and many clinicians tend to speak of 'HIV disease' or 'HIV-related diseases/conditions' rather than of AIDS.

Additionally, infection with HIV can cause clinical problems quite apart from damage to the immune system. In some individuals it may give rise to drenching night sweats or a brief 'flu'-like episode (generally around the time of infection). The virus may cross the blood–brain barrier and cause encephalitises (brain inflammations) leading to disturbances of emotion/mood or dementia. It may cause neurological damage, with difficulty in coordination, balance, etc. It is preventing infection with HIV which represents the initial health emergency, and has become the focus of health education campaigns worldwide. The second health emergency is to prevent the development of severe immune system deterioration in people with HIV infection, and the third is to develop therapies to prevent, control or eradicate the many opportunistic infections in immune-compromised individuals.

AIDS may be a relatively incoherent clinical term, but its *cultural* significance is enormous. The word 'AIDS' is overburdened with proliferating and always contingent meanings, encompassing notions of clinical disease, social dis/ease, contamination, exclusion, discrimination, hostility, economic/material inequalities, religious doctrine, political expediency, moralism/morality, sexuality, deviance, criminality, risk, blame, disfigurement and death. This is a far from exhaustive list because the full list could fill a book by itself, and it is this complex of social, cultural, political and clinical meanings which I take to be encompassed in the word 'AIDS'. The *social construction* of the epidemic, in other words. In this book, I use 'HIV infection/disease' to refer to the clinical entity, 'AIDS' to refer to the epidemic as socially constructed, and 'HIV/AIDS' when I want to refer to both.

Sexual identity is a protean, shifting set of meanings and is always contingent on social, cultural, material and geographic location. When I refer to 'lesbians' or to 'gay men' I am referring only to those groups of people who have access to a self-consciously lesbian or gay identity and choose to adopt/perform such an identity. Even within this group there are profound dissimilarities, and I have tried to be as specific as possible, differentiating between, for example, men on the urban gay scene in Western industrial nations and isolated gay men who, because of age, disability, poverty, geographical, ethnic or class location, do not partake in that scene. 'Homosexual' is a term coined by the (pseudo)science of sexology and, as such, is deeply implicated in the pathologization of lesbian and gay people. I generally avoid using it, except where context specifies its use. 'Homosex' and 'heterosex', on the other hand seem to me to be unambiguous and useful shorthand ways of denoting 'sexual activity between persons of the same sex' or 'sexual activity between persons of different sexes' respectively, and I use them accordingly.

The transmission of HIV related to drug use is, again, not as straightforward as some would have us believe. It is only the sharing of uncleaned injecting equipment between already-infected and uninfected user which poses a risk, and this takes place in highly specific circumstances. Many recreational drugs are not illegal (alcohol, nicotine, caffeine), and many illegal drugs are not commonly injected (marijuana, ecstasy, LSD), whilst many substances which are injected are legitimate medical treatments (insulin, Factor 8). It is vital to distinguish between the drug user who is at risk of HIV and the drug user who isn't. Additionally, the phrase 'intravenous drug (ab)user' is problematic, both because the notion of 'abuse' carries pejorative moralistic overtones and because it refers so specifically to the practice of injecting into a vein. Much drug injecting, whether clinical or recreational, is intramuscular or into the subcutaneous tissue ('skin-popping'), activities which, in the appropriate circumstances, are as risky for HIV transmission as injecting into a vein. In order to be as clear as possible I use the phrase 'injecting street drug user' to describe those users whose drug use may expose them to HIV infection.

The question of how to describe the so-called 'Third World' and 'First World' countries, always problematic, has become more so with the disintegration of the Soviet bloc. Phrases which adhere to a progress-narrative paradigm, such as 'developed' and 'underdeveloped' or 'developing' imply that the 'underdeveloped' nations should hurry up and catch up with the 'developed' nations, and fail to recognize that the 'developed' nations are only as wealthy and technologically advanced as they are *because* they have pillaged and continue to pillage the resources of countries exploited during colonialism. Such language also fails to question the costs of technological development, costs which include pollution, smoking and obesity and possible global environmental catastrophe and which suggest that industrialization may not unproblematically be held up as worthy of international emulation. It is also increasingly the case that the so-called 'industrialized' nations may more fittingly be thought of as 'post-industrial', since the growth of international capitalism, with its global markets and multinational corporations, has resulted in mass unemployment and the development of post-Fordist labour conditions in the West and the so-called 'greening of labour', the dispersal by multi-national manufacturers of manufacturing processes to poorer countries where wage bills, health and safety legislation and pollution controls are below the standards achieved in the West.

I have found this probably the most difficult problem to resolve, partly due to the dramatic shifts taking place as I write in the status of many central European countries, the former Soviet Union, etc. I have (somewhat arbitrarily) chosen to refer to 'the West' as shorthand for the former colonial powers and other advanced European countries plus those massive former colonies where white colonists succeeded in all but exterminating the indigent people (the United States, Canada, New Zealand and Australia) and whose economic and political power is considerable. Where so-called Third World countries are mentioned, I usually refer to them geographically (sub-Saharan Africa, the Far East, etc.), since lumping them together erases important economic, demographic, geographical, cultural and religious differences which are generally significant in the context of HIV/AIDS.

Finally, I do not use the term 'risk group'. This is because categorizing certain groups of people as 'at risk' implies that those outside such groups are somehow *not* at risk. It is also because the accepted taxonomic conventions whereby individuals are assigned to such 'risk groups' are misleading. Injecting street drug users, for example, will be presumed 'at risk' from their drug use, rather than from sexual transmission, and, if HIV positive, will go on record as infected through drug use *not* through sex. Similarly, HIV positive gay men will be assumed to have acquired HIV from male partners, even if they have had sex with female partners as well.

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Sex, Texts, Power

Those of us involved in the struggle against HIV/AIDS are an odd lot. Inclined to respond with enthusiasm to the sight of a used condom, carefully knotted, lying on the ground (a much-prized indicator that someone, somewhere, is practising safer sex) and to spend our leisure time encouraging our friends to talk about sex and drugs, we view the world from a peculiar (in both senses of the word) perspective. I spend much of my time wondering, not why the advent of AIDS gave rise to panic, but why there is so *little* panic. In my more pessimistic moments I am inclined to entertain friends and colleagues with scenarios of global economic catastrophe, the collapse of health care infrastructures – the problem of AIDS is, according to Dr Donald McDonald, 'bigger than the Public Health Service' (Brandt, 1985: 188) – and unimaginable consequences for human rights, civil liberties and women's rights (in particular women's reproductive rights).[1]

The single aspect of AIDS which I find most disturbing is that the overdeveloped nations of the West have managed to develop a colossal and expensive AIDS industry, comprising governmental and non-governmental agencies, academics, health educators, scientists, social scientists, medical professionals, writers, publishers, journals, newsletters, conferences and symposia, which has almost entirely failed to intervene effectively in the social, economic and political infrastructures which we know to be instrumental in the continuing rapid growth of the pandemic. 'AIDS', as Allan Brandt puts it, 'makes explicit, as few diseases could, the complex interaction of social, cultural and biological forces' and 'demonstrates how economics and politics cannot be separated from disease' (Brandt, 1985: 199–204). Yet, rather than developing appropriate and wide-ranging interventions informed by this awareness, Western governments have tended to cling obdurately to health policies which stress individual (rather than collective) responsibility for health, and to kowtow to self-appointed guardians of public morality such as fundamentalists of various religions. The reactionary and outmoded emphasis on individual responsibility for health is expedient as a cost-cutting exercise in the face of ever-increasing health care costs,[2] but also appeases (and is ultimately rooted in) a moralistic and victim-blaming model of disease:

> There remain those who believe fear of disease will lead to a higher morality . . . To those who subscribe to this belief, the message is clear: the way to control sexually transmitted disease is not through medical means but rather through moral rectitude. A disease such as AIDS is controlled by controlling individual conduct . . . The current trend in health policy is to accept this model of disease

> and to apply it to a myriad of other diseases, to reduce the emphasis on social or external determinants of disease and health, and to stress individual responsibility. (Brandt, 1985: 203)

Although at first sight the notion of making changes in sexual and street drug injecting behaviours appears exemplary of the model of individual responsibility, this assumes a naively asocial model of individual psychology. Rather, both the *initial adoption* and the *continued practice* of safer sexual and injecting behaviours is intimately bound up with social factors such as gender, 'race', socio-economic class, geographical location and kin/peer relations, and with related socio-psychological factors such as self-esteem and sexual identity, and it is with some of these factors that this book is concerned.

Who are the women in AIDS?

It is becoming common to read that women's needs are not being properly identified or met in the context of HIV/AIDS (Berer with Ray, 1993; Squire, 1993; Richardson, 1989; Panos Institute, 1990a; Patton, 1994). This assertion of failure to meet women's health care needs is present more generally in feminist literature on health (Miles, 1991; Graham, 1993; Doyal, 1995). It is, of course, the very existence of feminist writers, and of a specifically oppositional feminist discourse which prioritizes women, that makes such assertions possible, just as it is the existence of gay liberation movements and of a queer discourse in resistance to homophobia that makes it possible to identify the widespread failure to meet the needs of gay men (King, 1993; Kayal, 1993).

It is undoubtedly the case that the HIV/AIDS-related needs of women are marginalized, ignored and denied, and that women's subjugation to men is both reflected in and reinforced by the ways in which the pandemic has been gendered. In this, however, women are not unique. The social group whose HIV/AIDS-related needs *are* adequately met *does not exist*. Whether in the field of health education, health promotion, health care, social care or the provision of resources, questions of morality, political expediency, religious dogma or ideological hegemony are generally given precedence over preventing the transmission of HIV or improving the survival time and well-being of people living with HIV or AIDS.

In the context of HIV/AIDS (very much a *heterosexually* transmitted condition), deconstructing the gendering of the pandemic is important for two reasons. Firstly, because large numbers of women have been and continue to be needlessly infected with HIV, become ill with HIV-related conditions faster than comparable men, and die more quickly than men once diagnosed with AIDS (Califia, 1995; Bury, 1994; ACT UP/NY Women and AIDS Book Group, 1990). Secondly, because the gendering of AIDS has profound implications for the ability of *all* people – men as well as women, straight as well as gay – to protect themselves from infection

and to live well with HIV or AIDS if already infected. The discursive construction of AIDS intersects with and nuances a range of pre-existing discursive 'packages' of gender and the erotic, as well as of 'race', class and disease. In so doing, it is instrumental in the socio-cultural constitution of 'women', but also of 'men', 'heterosexual' and 'homosexual'.

> Discourse on AIDS – medical and social policy writing, political rhetoric, media representations and public talk about HIV and AIDS – tends to ignore, sideline or pathologize women. The discourse is both under- and over-gendered. The categories of 'women' often seem like screens onto which other social conflicts – around for instance 'race', sexuality and poverty – are being projected in disguised forms. (Squire, 1993: 5)

It is important to deconstruct not only the 'woman' of gendered AIDS discourse, but the co-constitution of 'not-woman' so produced. It is also important to identify the manipulation of gender polarity in the constitution of other presumptive polarities – 'race', class, sexuality, etc. For example, some commentators have suggested that the discursive gendering of AIDS incorporates into the textual/ideological 'feminine' any and every 'other' according to an internal logic whereby the *subject* of AIDS discursive production – the producer of discourse, the owner of the discursive 'gaze' – is masculinized and the *object* feminized. Thus not only are gay men, lesbians, people of colour, poor people, haemophiliacs and 'junkies' all feminized, so too are those living with HIV and AIDS (Juhasz, 1993).

Cindy Patton suggests that AIDS discourse is organized within and has given rise to what she terms the 'queer paradigm' (Patton, 1985; 1994: 19), whereby people living with HIV/AIDS or *vulnerable* to HIV infection ('risk groups', in the invidious and unhelpful parlance of establishment statisticians) are constituted as queer. Although there is, as Treichler (1988a: 261) comments, 'evidence that in some respects [gay men] do fill the role (of contaminated other) that women, especially prostitutes, have played in the past', it is clear from what we know of the history of the sexually transmitted diseases (STDs) (Llewellyn-Jones, 1985; Brandt, 1985) that the queering of the other identified by Patton derives from (and clearly intersects with) the feminizing of the other which is so marked a feature both of the project of imperial colonialism (McClintock, 1995) and of the social construction of STDs. I suggest that it is more helpful to interrogate the 'queer paradigm' as a specific manifestation of a more general gendered paradigm and to identify the probable consequences of that gendering.

One glaringly obvious characteristic of AIDS discourse is its erasure of heterosexual men from the discursive field. This is inevitable within the intellectual matrix of a model of 'gender' organized quite precisely around the invisible and unproblematized *norm* of heteromasculinity (see below pp. 95–100), but has very negative consequences for health promotion. In particular, the negative consequences of masculine socialization and of the imperative to demonstrate competence in a restrictively narrow range of male-performativity behaviours, go largely unrecognized. Swedish sex

educator Erik Centerwall has warned that boys and young men experience emotional isolation and that the process of developing a heterosexual male identity is a problematic one:

> The message has often been that male sexuality is wicked and that men are dirty and inconsiderate. This message may also be a male self-experience. It is a negative sexuality which makes me a man in the eyes of other men. The wicked urge becomes something that creates identity. (in Berer with Ray, 1993: 203)

In the context of gendered relations of power, a gender/sexual identity which achieves coherence around a 'wicked urge' is clearly troubling; in the context of preventing the further spread of an invariably fatal sexually transmitted disease it becomes profoundly disturbing.

Is HIV a sexually transmitted disease?

This book focuses on the sexual transmission of HIV and draws comparisons between the social construction of AIDS and historical shifts in the social construction of syphilis and gonorrhoea. But to what extent is it accurate to present HIV as an STD? While HIV is capable of being transmitted through specific kinds of sexual contact, it may also be transmitted 'vertically' (from HIV positive mother to infant during pregnancy or delivery), or by direct blood/blood contact (by receiving infected blood or blood products during medical procedures or by the sharing of street drug injecting equipment between HIV-infected and HIV-uninfected users without proper cleaning procedures).

It is probably more useful and accurate to think of it primarily as a blood-borne infection, similar in transmission routes to hepatitis. 'To include in the category [of STD] those diseases which "can be [sexually] transmitted" makes the category so large as to be meaningless' (Wellings, 1983). Moreover, to present HIV as an STD is to disregard other potential transmission scenarios, with possibly fatal consequences, and to locate HIV in an already stigmatized category of diseases. Since HIV/AIDS is in any case profoundly stigmatized and stigmatizing, to inflexibly categorize it as an STD would compound an already grave problem. Nevertheless, although HIV should not be presented simply as a sexually transmitted disease, the principal mode of transmission remains (hetero)sexual (WHO, cited in Panos Institute, 1990a). Indeed, with increasing use of procedures to protect the blood supply, with wider use of needle exchange schemes for injecting street drug users and better dissemination of information on cleaning injection equipment, other modes of transmission can be expected to decrease. Inevitably the proportion of cases of infection due to sexual transmission is growing and will continue to do so. The only category other than sexual transmission which can confidently be expected to increase is vertical transmission to infants, since increasing numbers of infected women will inevitably result in increasing numbers of infected infants (Panos Institute, 1989; 1992; WHO, 1994).

In order to understand the nature of the pandemic, and to get an accurate idea of the extent and rate of growth, AIDS must be seen at a *global* level. However, local social and economic factors have a sharp impact on the *initial* epidemiology of HIV infection over quite small geographical areas. Thus, for many reasons, it was possible for heterosexuals in the West to believe, for a few years at least, that HIV was in some way associated with sexual contact between men, or with the urban gay male lifestyle (Davies et al., 1993; Panos Institute, 1990b). A lethal combination of denial, racism and homophobia ensured that this foolish misunderstanding became widespread and long-lived, *even though* it was very soon clear that, in most countries around the world, heterosex was overwhelmingly the commonest means of transmission. The white racist imaginary simply (and familiarly) constituted the epidemiological trend in the United States (where the majority infected with HIV were and still are gay men) as the global norm and declared that the (putatively *abnormal*) high rate of heterosexual transmission in the so-called Third World – especially sub-Saharan Africa – was due to pre-existing abnormalities, failures or pathologies among the (black) indigenous populations. Thus it was suggested that black African men refused to admit to homosexual practices, engaged in abnormally violent heterosex, were uncontrollably promiscuous, frequently used prostitutes and had multiple wives (Wilton 1992a; Panos Institute, 1990a). Thus, just as heterosexual scientists had argued that it was something about *being gay* which resulted in large numbers of gay men becoming infected, white scientists argued that it was something about *being black* which resulted in the high rate of heterosexual transmission in some African countries.

Current estimates suggest that over 75 per cent of HIV infections occur through heterosex, with the sharing of street drug equipment, vertical transmission, sex between men and receipt of infected blood/blood products *together* accounting for another 25 per cent (WHO, cited in Panos Institute, 1990b).

The extremely long asymptomatic period of HIV infection means that its epidemiology is very slow to reflect change. In the industrialized West, therefore, it remains the case that the groups hardest hit by HIV/AIDS are gay communities, and that the socio-political ramifications of homophobia continue to deny those communities the resources they need, especially in terms of health education (King, 1993). Nor should it be supposed that AIDS-associated homophobia is a problem solely for lesbians and gay men. The ideological intersections of gender and sexuality which are so directly expressed in homophobic discourse impact on the lives of *all* members of societies organized around the heterosexual imperative.

It would be both arrogant and foolish of me to write about the intersections of sex and gender as though they were universal or even directly comparable across cultures. Such intersections, and the meanings which accrue to them, are culturally and historically specific to a fine degree. For example I know, from my own experience, that there is not one 'lesbian