

# Stacked Against Us

## HIV/AIDS Statistics and

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*Cet article nous assure que les statistiques sur le VIH/sida ne sont pas fiables parce qu'elles ne reflètent pas la réalité des risques encourus par les femmes. L'évaluation des risques est basée sur des modèles masculins et ne saisit pas l'influence des relations de pouvoir quand il s'agit de mesurer les risques des femmes exposées au virus. D'autre part, les chercheurEs du sida n'ont pas encore exploré adéquatement les risques associés à la vulnérabilité sociale ou économique des femmes et des groupes minoritaires.*

According to Health Canada, at the end of 2000, women in Canada accounted for 13.8 per cent of cumulative positive HIV tests and 7.6 per cent of AIDS cases among adults (Health Canada). Statistics such as these, which describe the incidence and prevalence of HIV and AIDS among women in Canada, have been available for well over a decade. Unfortunately, these statistics do not always accurately or adequately describe the reality of women's experience; rather, they simply reflect the way we choose to conceptualize and subsequently measure risk in order to facilitate the categorization and labeling of certain individuals and groups (Gorna). Behind the epidemiology of HIV/AIDS is a story that women are "dying to tell." The story begins with two universal truths. The first is that women have been relegated to positions of social, political, and economic subordination that are mediated by race and class. The second is that these constraints inhibit women's capacity to protect themselves from exposure to

HIV (Doyal; Gorna; O'Hea Sytsman, Copeland, and Brantley; Rao Gupta).

Within most HIV/AIDS literature, high-risk behaviours are conceptualized within rather myopic social, historical, economic, cultural, and political contexts. The process by which this conceptualization occurs is particularly important because it often determines the extent to which we assign responsibility to individuals. Originating in the minds of researchers and policy makers, concepts of risk dictate the degree to which HIV/AIDS and women is given priority in society and the manner in which

related issues of power and patriarchy are understood, investigated, and ameliorated. Consequently, a discussion of women and HIV/AIDS cannot occur in isolation of their socio-economic and political position, which is characterized by diminished social and sexual autonomy (Arber and Cooper; Rao Gupta). During their lifetime, heterosexual women are at increased risk of exposure to HIV through gender and power relations relative to sexual decision making (Long and Ankras; Wojcicki and Malala). Women's sexuality is controlled through religion and legislation which dictate sexual activity, contraception, pregnancy, abortion, and birthing while silently sanctioning sexual assault (Lewis and Bernstein). Despite a 1948 Declaration enshrining women's rights to physical security, male violence remains a major threat to women's safety and a vector of HIV transmission (Gallagher; Champion, Shain, Piper, and Perdue; Doyal).

Concepts of risk often reflect their associated statistical measures—arbitrary, linear, and fragmented. "Who does the knitting" of conceptually fragmented experiences, determines the overall portrait of women's roles and risks relative to HIV/AIDS (Walby). Both the underlying and ensuing theory become a means of determining who gets left in and who gets left out; who is worth knowing about and who is not, thereby shaping what is recognized, what is recorded, and what is reported. As a consequence, theory is often devoid of context and subsequently limited in its ability to explain specific patterns of infection. A persistent focus on individual risk behaviour, therefore, might be interpreted as a subtle strategy for insulating policies, institutions, and practices that actually increase women's risk of exposure (Weiss and Rao Gupta).

HIV/AIDS research and policy agendas tend to follow a traditional top-down approach regarding the "who, what, why, and how" of risk. General discussions of HIV/AIDS take on a decidedly masculine tone, in the sense that risk models typically reflect male social and sexual behaviour, while portraying women as uncomplicated, viral vectors (Gorna; Long and Ankras). Unfortunately, these models are also used in determining the allocation of scarce research and intervention resources. What becomes clear in an assessment of these models is the relative value of men's health over women's (Catz, Merideth, and Mundy).

Decisions about which aspects of risk are valued direct both the methods and measures used in research, thereby indirectly influencing the subsequent findings. The World

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**Heterosexual women are at increased risk of exposure to HIV through gender and power relations relative to sexual decision making.**

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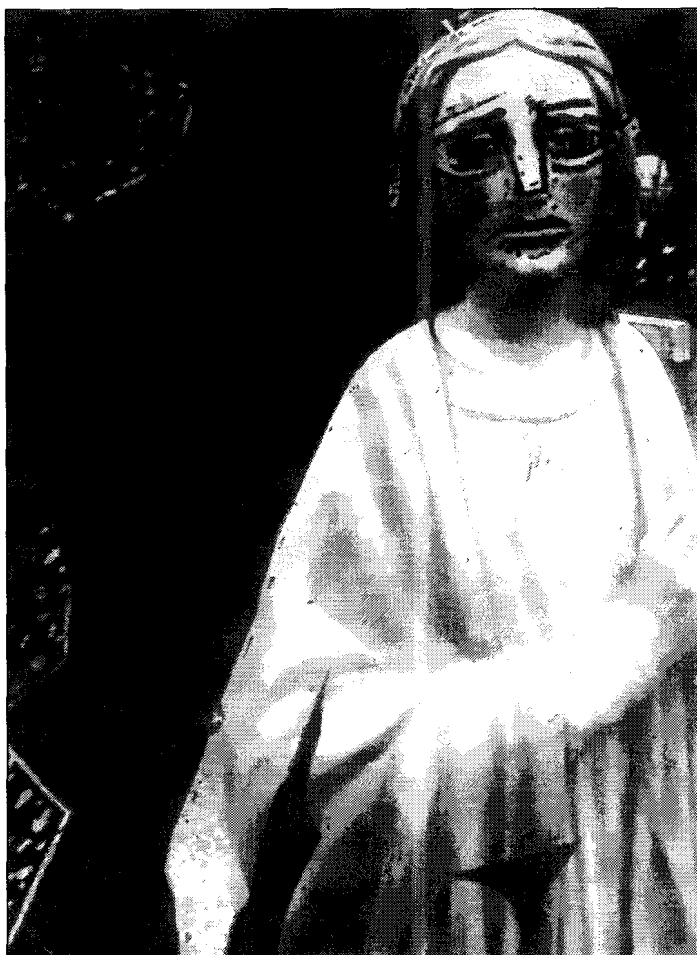
# Women

Health Organization (WHO) as well as various national health institutes have favored the use of Knowledge, Attitude, and Practice (KAP) as well as Knowledge, Attitude, Behaviour, and Practice (KABP) questionnaires to identify and measure risk factors for transmission, as well as individuals at high risk (Long and Ankrah). Unfortunately, these questionnaires are based on a widely accepted theory of behaviour change that ignores environmental determinants. They have the added limitation of cultural myopathy in their construction and, therefore, fail to capture the diverse experiences of women and populations who may be at risk (Long and Ankrah).

Despite the fact that, globally speaking, heterosexual contact is now the leading factor for transmission of HIV, women have not been permitted a voice in setting national or international research or policy agendas. The suppression of women's voices is reflected in the minimal funding allocated for women centered HIV/AIDS research as well as the cursory attention paid to women's issues at most AIDS conferences (Long and Ankrah). The under-representation of women in setting agendas as well as participating in and conducting HIV/AIDS research further perpetuates the absence of their experience in research that informs policy decisions (Walters, Lenton and McKeary).

A focus on AIDS mortality as the key indicator of disease prevalence, ignores the social context of the lives we are quantifying. In fact, the primary limitation of mortality is that it measures the dead. While both mortality and morbidity do give us an albeit limited and negative view of the distribution of "harm," they do nothing to elucidate the subjective meaning of this specific illness, particularly among women (Doyal). Similarly, measures that focus on morbidity often skew data in favour of women who have been identified as belonging to high risk groups and are therefore encouraged to come forward for testing (Long and Ankrah; Rao Gupta).

The study of HIV/AIDS and women is relatively new and international research efforts differ significantly (Illsley and Baker). Few countries, however, have employed social measures that explore the role of gender and power relations in women's risk of exposure to HIV (UNAIDS). Patriarchal models of sexual decision-making and inadequate operationalization of constructs such as power relative to issues such as condom use negate a meaningful analysis of gender (Long and Ankrah; Wojcicki, and Malala). An emphasis on behavioural risk, as measured by



Rochelle Rubinstein, "Brother's Keeper," Linocut on Photograph, 12" x 9." 2001

proxy A, B or C, essentially strips data of crucial contexts, thus drawing attention away from what may be the "root" determinants of women's exposure to HIV (Bassel, Witte, Wada, Gilbert, and Wallace). The difficulty begins with the use of highly structured, closed-ended questionnaires that pave the way for efficient, quantifiable results.

Although these indices may be useful in identifying variations in mortality and morbidity, they provide little in the way of useful information about socially constructed experiences that increase the risk of exposure to HIV. Similarly, they cannot be used to determine the range of risk. Nor can they be used to assume the same risk processes in men and women. In order to identify the most vulnerable groups of women, researchers must obtain qualitative information that may be compared at regional, national, and international levels. This will undoubtedly require widespread changes in the way we

collect data. Moreover, if international comparisons are to be made, national research must include context specific measures that facilitate these comparisons (Illsley and Baker). Unfortunately, a qualitative approach, essential in capturing the multiplicity of women's risk, is often neglected by researchers who remain sceptical about the seemingly circuitous route by which women encounter risk and the interventions most likely to effect change (UNAIDS).

Until very recently, the presuppositional basis of most epidemiological research in general, and HIV/AIDS research in particular, was that of a theoretical white male body. Within this ideological dominance of science, research agendas reflected basic hierarchies of oppression. Systemic gender discrimination continues to be reflected in decisions made about the relative value of those deviating from a white male norm. A gender bias within HIV/AIDS research is evidenced by the persistent emphasis on IV drug use and male sexuality as the primary index of risk (Long and Ankrah). Researchers seem unaware of how idealized social standards pertaining to women's sexuality may create risk conditions that compel them to conceal sexual behaviour that might be perceived as inappropriate or immoral (Wojkicki and Malala).

Within the medical care profession, diagnosis patterns are also shaped by gender stereotypes (Lewis and Bernstein). A biased interpretation of risk is evident in physicians' tendency to overlook heterosexual women's potential exposure to HIV (Blackburn). Similarly, little attention is paid to heterosexual women's direct risk through sexual oppression, past sexual abuse, and marital rape as well as indirect risk through diminished educational and occupational opportunities, all of which undermine their power (Champion *et al.*; Hader, Smith, Moore, and Holmberg; UNAIDS). The ensuing potential for under-representing heterosexual women clearly biases results that are used to inform further HIV/AIDS research and policies (Marmot *et al.*; Poland).

In addition to issues of gender, we must be equally cautious about interpreting reports of racial differences in HIV/AIDS rates, which often obscure the social, economic, and political determinants of risk among diverse ethno-cultural groups. For instance, the disparity in social, economic, and political power between white and non-white groups in North America makes it difficult to draw firm conclusions about ethno-racial differences related to high-risk behaviour (Amick, Levine, Tarlov, and Walsh; Beyrer).

According to recent Health Canada data, Black and Aboriginal women represent a higher relative proportion of those diagnosed with AIDS. These disproportionate disease trends in white and non-white populations have little meaning in isolation of a discussion about socio-economic and political determinants of risk among diverse groups. Care must be taken to avoid pathologizing Black and Aboriginal women's health, or rendering prob-

lematic their lives by emphasizing disparate rates of illness rather than the historical, economic, political and social contexts that facilitate risk. Likewise, aggregate racial data that do not specify whether Aboriginal people are Inuit, Metis, or First Nation, nor make any distinction between African, Caribbean, British, or Canadian born Black women, fail to acknowledge important cultural differences (Health Canada). Indeed, the use of racial categories becomes important only when it leads to a more thorough appreciation of the social structures that result in disparities in exposure to risk conditions, or to development of prevention and support programs that reflect these cultural differences, and the subsequent care and support needs of distinct groups (Schulman, Rubenstein, Chesley and Eisenberg).

The use of a "white infection rate" as the gold standard by which other groups' rates are judged to be excessive also exposes the racist underbelly of research. Aside from crude measures of mortality, there are myriad disparities between groups based on racial or cultural background; Though it seems that these determinants of risk somehow always manage to be shuffled to the bottom of the proverbial deck. As a consequence, virtually no attention is paid to reducing the enormous social disparities that may place women from disadvantaged groups at greater risk of exposure to HIV (UNAIDS). The over-representation of minority women in AIDS statistics might actually begin with a relative lack of power among poor women who do not always have the option of non-participation in remunerated research and are, therefore, not always in a position to give informed consent (Long and Ankrah; Rao Gupta).

Distributive justice begins with data that inform HIV/AIDS policies and programs in a way that ensures equitable prevention, treatment, and care. To do so, research must address situational issues (e.g., access to resources, gender roles and responsibilities, socio-economic and political constraints) that structure behaviour. HIV/AIDS statistics permit us to glimpse the ill effects of high-risk behaviour yet, tell us nothing about how social, economic, and political structures create high-risk conditions. Indeed, statistics often obscure more than they reveal. Regrettably, these data often represent the sole source of information used in the development of HIV/AIDS policies and programs. Although qualitative research findings are becoming increasingly available, they are frequently ignored in favour of large-scale epidemiological evidence. In failing to acknowledge the limitations of our reliance on the spurious neutrality of epidemiological inquiry, we have adopted what Mills refers to as "an epistemology of ignorance."

HIV/AIDS policy and research is often conceived in an environment that is subtly and perniciously structured around race, gender, and class. Yet, many researchers, policy makers, and program planners choose to disregard certain truths about their privileged perspective, thereby

failing to notice the disturbing implications for those with little economic or political power (Mills). HIV/AIDS policies and interventions aimed at reducing risk must, by necessity, be broad. Broad enough, in fact, that they do not isolate women on an ethno-cultural or international scale (Boehm; UNAIDS). The process must begin by addressing social and economic conditions that play a key role in creating disparities in women's risk of exposure. This will not be accomplished, however, by present trends that focus on women as vectors of infection rather than as individuals in their own right, deserving of equal consideration in all aspects of HIV/AIDS research, prevention, treatment, and care.

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