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Time to Deliver on Gender and HIV/AIDS

THIS SUMMER, more than 25,000 people from around the world gathered in Toronto to share new knowledge, experiences, and good practices in the worldwide battle against HIV/AIDS. The International AIDS Society chose “Time to Deliver” as the conference’s theme, arguing that we already have the evidence and tools necessary to deal with the pandemic: what we lack are “the resources and the collective will to translate that knowledge and experience into broadly available treatment and prevention programs.”

Part of what is also lacking in the “collective will” is a willingness to address gender. Despite a wealth of research on the role of gender in the pandemic, despite inspiring advocacy work by and for women living with HIV/AIDS, the needs of women and girls and gender considerations continue to be stunningly underrepresented in research, advocacy, and political agendas.

The International AIDS Conference itself is a case in point. During the 2002 conference in Barcelona, a mere 9.6 percent of posters, papers, or plenary presentations made mention of women and/or girls. Far fewer of these presentations focused on the needs of women and girls or on the gender dimensions of the pandemic. Two years later, at the International AIDS Conference in Bangkok, females appeared in just 8.3 percent of the program. Although women and girls were mentioned more frequently at the Toronto conference than in previous conferences, a preliminary analysis of the program suggests that gender analysis of the pandemic is still sadly lacking. Among sessions identified by conference organizers as having a gender component, more than one third did not mention either women or girls and many of those that did focused on sex differences rather than gender.

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BC Women's Hospital
and Health Centre
E311 – 4500 Oak Street
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Canada V6H 3N1
www.bccewh.bc.ca
Tel: (604) 875-2633
Fax: (604) 875-3716
bccewh@cw.bc.ca



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56 The Promenade
Winnipeg, MB
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pwhce@uwinnipeg.ca



National Network on
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Réseau pan-canadien sur la santé
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**National Network
on Environments
and Women's Health**
019 Health, Nursing and
Environmental Studies Bldg.
York University
4700 Keele Street
Suite 214 York Lanes
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www.yorku.ca/nnewh
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www.acewh.dal.ca
Tel.: (902) 494-7858
Toll-free: 1-888-658-1112
Fax: (902) 494-7852
acewh@dal.ca

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Centres of Excellence for Women's Health

Bureau of Women's Health
and Gender Analysis
2nd Floor
Richelieu Building
975 St-Joseph Blvd
Postal Locator 9002A
Gatineau, QC
Canada K1A 0K9
Tel: (613) 957-2991 Fax: (613) 934-8700
Toll Free: 1-866-225-0709
cewhp@hc-sc.gc.ca www.cewh-cesf.ca



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Production Manager	Susan White
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RECYCLED LOGO UNION BUG

(WPG SUN: PLS PLACE LOGOS)

■ It is long past “time to deliver” on gender and HIV/AIDS. We have recognized the problem; it is time to act.

c o n t ' d

This issue of the *Research Bulletin* aims to redress this lack of attention to issues of gender and HIV. Beginning with a backgrounder on the ways in which sex and gender function to make women and girls susceptible to HIV, this issue offers the reader material to both better understand the epidemic and to begin to think through our responses to it.

For example, media representations of the epidemic continue to emphasize HIV transmission through sexual activity and/or injection drug use, and the life-extending impact of anti-retroviral therapies. However, we are only beginning to talk about the complex issues involved in infant feeding that arise when a mother has HIV/AIDS and we are only now coming to understand the connections between childhood trauma (including sexual, emotional, and physical abuse) and subsequent isolation from one's family and community, substance use, and women's risk of contracting HIV. Given complex issues of trauma, we can now better understand the relationship between these experiences and other social inequalities that shape the lives of some of Canada's Aboriginal peoples—it is no wonder that Aboriginal women face a disproportionate risk of HIV infection in Canada.

Clearly, we need an array of responses to reduce the risk of HIV infection and/or ameliorate its effects. Moreover, these responses need to be developed with sex and gender in mind. Given, for example, the increased rate of HIV infection among women from heterosexual transmission, the historic

failure to tailor HIV/AIDS education and prevention messages and resources to young heterosexual men has had serious consequences—for both men and women.

We are learning that services originating in earlier phases of the epidemic are not necessarily appropriate for those who are currently infected. For example, are current counselling and other social support services meeting the needs of women with HIV? Are palliative care programs providing the kinds of education and support that caregivers for people with HIV/AIDS need? Are we using our program skills and resources to transform gender relations in ways that empower women and men, girls and boys to increase control over their health and their risks for HIV?

Given the evolving nature of the epidemic, both in Canada and worldwide, and our increasing understanding of how sex and gender are shaping this epidemic, it is long past “time to deliver” on gender and HIV/AIDS. We have recognized the problem; it is time to act.

Barbara Clow
*Executive Director
Atlantic Centre
of Excellence
for Women's Health*

Ann Pederson
*Manager, Research and Policy
British Columbia
Centre of Excellence
for Women's Health*

UNDERSTANDING THE EPIDEMIC

An Invisible Epidemic: The Implications of Gender Neutrality for Managing HIV/AIDS in Low-incidence Countries

Barbara Clow, Atlantic Centre of Excellence for Women's Health

As the HIV/AIDS epidemic has grown and changed in the past fifteen years, the international community has focused increasingly on regions hardest hit by the pandemic—sub-Saharan Africa in particular. International agencies, funders and researchers, corporations, national and local governments, and civil society are under pressure to devise responses to and solutions for the devastation wrought by HIV/AIDS. However, limited attention has been paid to the role of gender in the epidemic or the heightened vulnerability and suffering experienced by women and girls. While gender blindness is beginning to recede with respect to high-incidence regions, for many low-incidence countries—including Canada—it continues to confound the management of HIV/AIDS. Unless we recognize gender as a crucial factor in the spread of HIV, low-incidence countries may soon be transformed into high-incidence countries.

There are many reasons why HIV/AIDS remains invisible in low-incidence countries such as Canada. First, we tend to ignore HIV precisely because the incidence is low; only a tiny proportion of our population—less than 0.3 percent—is living with HIV. Second, HIV/AIDS rates pale in comparison with many other chronic diseases. Because Canadians are more likely to live with and die from conditions other than HIV, policies and programs tend to focus on diseases such as cancer, cardiovascular disease, and diabetes. Third, we may ignore the epidemic because it seems to be confined to specific groups within our society—men who have sex with men (MSM) and injection drug users (IDUs) accounted for 70 percent of reported AIDS cases in Canada between 1999 and 2003. Canadians may assume that HIV/AIDS is a threat only to a small proportion of the population who engage in “risky behaviours” or, alternatively, they believe we have the means at hand to deal with the epidemic. As a result, we assume that HIV/AIDS will never pose the same challenges for us that it has for high-incidence countries. But changing patterns of HIV infection should sound an alarm for Canadians.

Between 1995 and 2001, transmission through heterosexual contact has risen alarmingly, from 7.5 percent to 30 percent. Similarly, AIDS diagnoses attributed to heterosexual contact in the same period have increased from 10.6 percent to 44.7 percent.¹ While these trends affect both men and women, they have had a deeper impact upon women. In 1998, approximately one-third of women diagnosed with HIV had contracted the virus through heterosexual contact. Five years later, in 2003, this proportion had risen to 65 percent. Thus, while people living with HIV and AIDS in Canada are still most likely to be MSM and/or IDUs, those newly infected with HIV are increasingly likely to be heterosexual women.

At the same time, infection rates among women of all ages are increasing. Among adults diagnosed with HIV between 1997 and 2001, the proportion who are female rose from 12 percent to nearly 25 percent, while the proportion of adult women living with AIDS rose from 6.1 percent in 1994 to 16.5 percent in 2002.¹ The biggest change has been seen among women between the ages of 15 and 29 years. Females accounted for 12 percent of all new infections in this age group in the early 1990s, but the proportion had risen to nearly 50 percent by 2004.

Not only are women experiencing greater vulnerability and new kinds of vulnerability to HIV, they also tend to “have a lower survival rate than men... [as a result of] late diagnosis and delay of treatment because of misdiagnosis of early symptoms; exclusion from drug trials and lack of access to antiviral treatment; lack of research into the natural history of HIV in women; higher rates of poverty among women and lack of access to adequate health care; and the tendency of many women to make self-care a lower priority than the care of children and family.”²

Vulnerable Populations in Low-incidence Countries

Some Canadians are more vulnerable to HIV infection than others. Rates of infection among white Canadians have been

dropping steadily in recent years, but Black Canadians and Aboriginal peoples have experienced disproportionate increases. Aboriginal people, for example, represent approximately 5 percent of the total population of Canada, but in 2004, 16 percent of all new HIV infections were found among Aboriginal people. Aboriginal women are likewise disproportionately affected by HIV compared with non-Aboriginal women. They are more likely to be infected through intravenous drug use—though heterosexual contact runs a close second—and they tend to be infected at earlier ages than non-Aboriginal women in Canada.

In part, these trends can be attributed to the fact that Aboriginal people are over-represented in high-risk groups, such as IDUs, sex trade workers, and prison inmates. For example, a female treaty Indian is 131 times more likely to be incarcerated than a non-Native woman.³ Similarly, in a study of IDUs in Regina in 2000, 90 percent self-identified as Aboriginal.⁴ More importantly, Aboriginal people *are* over-represented in at-risk groups because of the social, economic, and cultural conditions of their lives. Aboriginal women, in particular, are more likely to have inadequate or unstable housing or to be homeless; they are more likely to be unemployed or underemployed and living in poverty; they are more likely to have experienced sexual or physical abuse before the age of 12 or to be experiencing domestic violence currently; they are more likely to be isolated in a multitude of ways. All of these factors increase privation, dependence, and the risk of exposure to HIV infection.

Research, Policy, and Practice on HIV/AIDS

Despite the implications of these patterns of HIV infection for women, Canada's research, policies, and programs remain largely "gender neutral." Issues affecting women and girls are under-represented in research. For example, an analysis of recent annual meetings of the Canadian Association on HIV/AIDS

Research (CAHR) reveals that fewer than 10 percent of conference presentations dealt with women, girls, or gender.

In a country such as Canada, which enjoys publicly funded health care and a standard of living among the highest in the world, we seem to think that we have little to worry about when it comes to HIV/AIDS. We have active prevention and education campaigns and we can, in theory, offer care, treatment, and support to all those infected and affected by the pandemic. But we would do well to shed these assumptions and attend to the experiences of countries ravaged by HIV/AIDS, such as South Africa.

The first case of HIV in South Africa was diagnosed in 1982 and the disease was initially found mainly among men having sex with men. By the early 1990s, things began to change rapidly in South Africa: the number of infections attributed to heterosexual contact equalled those ascribed to homosexual contact, and the proportion of women infected with the virus began to soar. According to Dr. Olive Shisana, president of the Human Sciences Research Council in South Africa, the absence of gender mainstreaming in policies and programs has been responsible, in no small measure, for the plight of women and girls in sub-Saharan Africa.⁵

The history of the epidemic in Canada resembles that of South Africa. The first case of HIV was diagnosed in 1982 and for many years the disease was found mainly in men having sex with men. While the shift from homosexual to heterosexual exposure and mounting vulnerability for women and girls has been slower in Canada, the trends nonetheless mirror those of South Africa. It is time that we recognized the central role of gender in the HIV/AIDS pandemic and it is time to amend our responses to the needs and experiences of women and men, boys and girls.

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UNDERSTANDING THE EPIDEMIC

Telling a New Story about Risk: Gender, Breastfeeding, and Broadening the Questions on Child Survival

Penny Van Esterik, Department of Anthropology, York University

Stephen Lewis called breastfeeding “the excruciating dimension of HIV transmission,”¹ and it was partly these words that inspired a conference at York University on “Gender, Child Survival, and HIV/AIDS: From Evidence to Policy” in May 2006. The issue of HIV transmission through breast milk is difficult politically, conceptually, practically, and scientifically, partly because there is no consensus about how to advise women who are HIV-positive to feed their infants. Although it is technically possible for breast milk to transmit HIV, the exact mechanisms of transmission through breastfeeding remain unclear. While the medical research on the transmission of HIV through breast milk is progressing,² interventions requiring exclusive replacement feeding to prevent HIV transmission have undermined child-feeding programs in many parts of the world.³ And unfortunately, the corresponding research on gender and AIDS is less developed, and less integrated into broader discussions of child survival.

The transmission of HIV through breast milk is only one small part of the problem facing women who are HIV positive.⁴ Women are often diagnosed later in the progress of their disease (which results in higher viral loads at diagnosis), and have poor access to care and medications. They are most often the caregivers for HIV-positive family members, and most likely to be exposed to abuse and violence. Because

gender inequity underlies the marginalization of women living with HIV, discussions of child survival and feeding must be undertaken within a context of poverty, poor access to treatment, drugs and medical care, and a focus to date on preventing HIV transmission to infants rather than one that aims to improve the health of mothers and their children.⁵

The research agenda has paid attention to women in only cursory ways. When research attention has focused on women, it has often studied sex workers, ignoring the fact that sex workers are also mothers. When research *has* looked at mothers, treatment was often directed to them only to prevent transmission to their infants. Women, mothers, and children were often ignored when “risk groups” such as gay men or intravenous drug users were studied, and when we shifted paradigms to talk about “risk behaviours,” breastfeeding mothers did not fit in well with paradigms that focused on sexuality rather than mothering.

Each shift in framework provided new ways to understand the disease, its transmission, and possible treatment options. When semen and blood were the focus of attention, we learned a great deal from gay men’s groups and support groups for people with hemophilia. When we look at breast milk as the carrier fluid, others issues come to the fore and

■ Women are still blamed for carrying out their expected gender roles as wives and mothers if fulfilling these roles means that a child becomes infected.

■ The storyline of AIDS is about other kinds of risky behaviour, not about mothers breastfeeding their children.

the questions change. For example, why was exclusive breastfeeding overlooked as an intervention, when it has long-term survival advantages for infants? What new processes can be understood when we look at mothers who breastfeed in the context of HIV/AIDS and at breastfeeding support groups? And how can groups working to support breastfeeding mothers further support the research and policy work of AIDS advocacy groups?

By focusing attention on mothers and children, and breast milk rather than semen or blood, it should be possible to move out of the discourse of blame and morality that often accompanies discussions of homosexuality, drug use, and sex work. It should be possible—except that women are still blamed for carrying out their expected gender roles as wives and mothers if fulfilling these roles means that a child becomes infected. How do we draw attention to women without defining mothers as a “risk group,” and treating mothering and breastfeeding as “risky behaviour”?

The subject is undertheorized because the storyline of AIDS is about other kinds of risky behaviour, not about mothers breastfeeding their children. We clearly need to develop some new storylines to help bridge the gaps between HIV/AIDS groups, women's groups, child survival groups, and breastfeeding advocacy groups to focus on the intersections between our various concerns, such as care, conflict of interest, gender inequality, and violence.

The conference examined these new stories. Details will be available in a report and CD prepared by conference co-sponsor, World Alliance for Breastfeeding Action (WABA). Following the conference, a joint statement was developed and circulated for endorsement and use at the International AIDS Conference in Toronto in August 2006. This statement is also available on the WABA and National Network on Environments and Women's Health (NNEWH) websites.⁶

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UNDERSTANDING THE EPIDEMIC

Sexual Violence and Dislocation in Women's Acquisition of HIV in Manitoba

Iris McKeown, J.A. Hildes Northern Medical Unit; Sharon Reid, Social Planning Council of Winnipeg; Pam Orr, Health Sciences Centre, Winnipeg; Shelley Turner, Winnipeg Regional Health Authority

Although the links between social inequality and HIV infection are well documented,¹ few prevention programs have attempted to create change on a societal level.² A recent study in Manitoba affirms, however, the need for policies and programs aimed at reducing social inequalities in order to reduce the incidence of HIV in women.

In Canada, the gap between knowledge and programs is particularly apparent in the increasing incidence of HIV infection among women within Aboriginal communities.³ The proportion of Aboriginal women reporting AIDS attributed to injection drug use has dramatically increased, from 2 percent prior to 1991, to almost 67 percent in 1998-2003.⁴

Our qualitative study documented the relationship between violence, engagement in risk behaviours, and HIV exposure, all of which are strongly correlated to economic conditions.⁵ ⁶ We interviewed 20 women between the ages of 22 and 48 who were living with HIV/AIDS in Manitoba.⁷ Eighteen were Aboriginal and had grown up on Manitoba reserves. The majority of the women reported that they likely became HIV positive through intravenous drug use, while a small number reported that they acquired the HIV virus from unprotected sex with a past partner.

The study found a striking similarity in the women's stories: social networks conducive to healthy coping strategies were essentially non-existent for the majority of participants who described experiences of social and emotional isolation both as children and as adults. All of the women indicated feeling isolated and unsafe as children in their homes due to sexual abuse, domestic violence, neglect, and emotional abuse. Their isolation and victimization continued in adulthood, with abusive partners and experiences of physical and sexual assault.

A number of women described using alcohol and/or drugs at a young age to cope with their disruptive family situation.

The majority indicated they used alcohol and intravenous drugs to cope with past abuse issues, which was a contributing factor in becoming HIV positive.

A majority of the participants reported that as children they ran away from their families or foster homes to escape abuse. Running away from home at a young age (mean age = 12) meant the women's education was interrupted, and given their ages, their economic resources limited. As a result, many of these women entered the sex trade to secure an income, increasing their vulnerability to HIV exposure. One participant said:

I was broke all the time. I never had any money for food or cigarettes or anything and it came to a point where I would hitchhike to get drugs and somebody would say I'll give you so much money if you do this for me, and I did it. I walked away crying the first time.

Although all of the women reported that they had the ability and the power to insist on the use of a condom in their sex work, their condom use was sporadic. Their poor economic situation and substance use limited their ability to insist on the use of a condom. In other words, the women were engaging in risk behaviours but not entirely by choice.

The interviews confirmed that HIV-prevention messages were not reaching these women. As Waterston has argued, prevention strategies fail if they assume all women are *choosing* such risk behaviours.⁸ Current prevention efforts focus on education by public advertising campaigns and promoting the use of condoms as safer sex practice but have not addressed the social forces behind engaging in HIV-risk behaviours.⁸ Our study results suggest that recognition of the impact of violence, poverty, and isolation among women can help policy makers develop effective prevention strategies.

Policy Directions

A complex interplay of events and situations affected the decisions of the women interviewed in this study. We therefore know that prevention strategies aimed at such subpopulations will be ineffective without an understanding of women's position in society and recognizing the impact of experiences such as violence, poverty, and isolation on women throughout their lives.

Programs and prevention strategies must be culturally sensitive and relevant to the Aboriginal community. Using the experience and knowledge of HIV-positive women themselves in new and beneficial ways will go a long way in developing appropriate action plans. This research points not only to the importance of modifying HIV/AIDS prevention and intervention programs by taking into account the experiences of women but also to the need to address the fundamental determinants of some women's vulnerability to poverty, violence, and dislocation which puts them at greater risk for HIV infection in the first place.⁹

A full copy of the report, *Sexual Violence and Dislocation as Social Risk Factors Involved in the Acquisition of HIV among Women in Manitoba*, is available at:

www.pwhce.ca/publications_browse_subject.htm#violence



PRAIRIE WOMEN'S HEALTH
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Annotated Bibliography of Aboriginal Women's Health and Healing Research—2nd Edition

The Aboriginal Women's Health and Healing Research Group (AWHHRG) is releasing a second annotated bibliography of Aboriginal women's health research this fall. This edition extends the 2005 overview by including detailed quantitative information by region, group (First Nation, Inuit, Metis), and by Aboriginal authorship. Both volumes include information about HIV/AIDS, and important topics such as the social, educational, and economic determinants of health; Aboriginal perspectives on health and well-being; mental health; body image and diet; diabetes; self-determination and self-government; identity, culture, spirituality, and healing; and colonization, racism, and the unequal treatment of Aboriginal women.

For further information about the AWHHRG's work or for a copy of either of the bibliographies, please contact Linda Day, Executive Director, AWHHRG info@awhhrg.ca

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From Recognition to Action: Gender-based Analysis and Mainstreaming in HIV/AIDS

Erika Burger and Barbara Clow, Atlantic Centre of Excellence for Women's Health

Changing trends in the global HIV/AIDS pandemic underscore the vulnerability of women and girls to HIV infection, a vulnerability that is both biological and social. In other words, women and girls are at greater risk of exposure to HIV because their bodies are different than those of males *and* because their actions and attitudes are expected to be different than those of males. Once we acknowledge the role of gender in the pandemic, how do we understand it and how do we respond to it?

A Gendered Lens for Understanding Vulnerability to HIV/AIDS

Biologically, infected males are much more likely to transmit the virus to female sexual partners than vice versa because delicate tissues in the female reproductive tract make an ideal environment for infection from high concentrations of HIV in semen. Socially, women and girls are at greater risk of infection because they are more likely to be dependent on men—economically, culturally, politically—which means they may have limited ability to refuse sex or to negotiate safer sex. With less power and resources at their disposal, women and girls in many parts of the world are also more likely to suffer malnourishment, to live in poor housing, or to experience violence, all of which increase their chances of exposure to HIV and/or of developing AIDS-related illnesses.

Recognizing that gender is helping to drive the global epidemic of HIV/AIDS, we might expect that programs for HIV prevention, care, treatment, and support would incorporate the different needs of women and girls, men and boys. But all too often gender is dismissed as a “women's issue.” If we hope to win the battle against HIV/AIDS, we must acknowledge gender as a key social determinant of health and begin to address the gendered vulnerabilities experienced by women and girls as well as men and boys. Gender-based analysis and gender mainstreaming are techniques that enable us to incorporate our knowledge about gender's role in the pandemic and move from *recognition* to *action*.

Gender-based analysis or GBA is an *analytical tool* based on the conviction that differences of sex and gender matter in the world and that by understanding differences between women and men—as well as among different groups of women and men—we are better prepared to develop effective, appropriate, and sustainable policies and programs. Gender-based analysis involves comparing both the bodies and experiences of males and females—sex and gender—to understand *how and why* the pandemic has had different impacts and implications for women and men, girls and boys.

Gender mainstreaming is the *systematic application* of gender-based analysis throughout the course of research, policy and program development, and formulation and implementation of legislation.¹ Mainstreaming gender encourages us to probe the meaning of concepts and the language we use as well as to make explicit the assumptions and values that are driving research, policy development, and program delivery. It challenges the view that one policy or program can meet all needs, as well as the belief that everyone is affected in the same way by policies and programs.

A Gender-based Framework for Action

A useful tool for evaluating our responses to the pandemic's gender dimensions is a framework developed by the World Health Organization and the International Centre for Research on Women.² The framework categorizes activities along a continuum to help us understand and evaluate our approach to gender mainstreaming.

1. Policies and programs that reinforce gender and sexual stereotypes

At one end of the continuum are policies and programs that might appear gender appropriate and effective, but which actually contribute to the pandemic by *reinforcing gender and sexual stereotypes*. One example might be condom-marketing strategies that rely on an image of a cool, macho, urban male and leave women entirely out of the picture.

2. Gender-sensitive interventions

The next step along the continuum involves *gender-sensitive interventions* that recognize differences between men's and women's needs and seek ways to meet those needs differentially. While these policies and programs attend to male and female differences, they may focus on specific dimensions of prevention, care, treatment, and support while ignoring the social and cultural context that determines gender norms and stereotypes. The female condom and microbicides would fall into this category—they are crucial methods for women to protect themselves against HIV, but often they cannot be used without the knowledge and consent of the male sexual partner.

3. Transformative interventions

The third category of work, *transformative interventions*, goes beyond simply acknowledging and responding to gender differences. These policies and programs urge women and men to examine the damaging aspects of gender roles and to experiment with new attitudes and behaviours that will contribute to more equitable roles and relationships. Peer education programs that challenge gender stereotypes, such as “Men as Partners” in South Africa, are excellent examples of this type of intervention.³ This program, designed and delivered by EngenderHealth, engages local men in an effort to deepen their understanding of the gender dimensions of the HIV pandemic. Many participants have experienced a profound shift in their personal beliefs about gender and some have gone on to train as peer educators, working with other men in their communities.

4. Structural interventions

The final point on the continuum involves *structural*

interventions which assess the broad societal factors that fuel gender inequality and strive to challenge and change the economic and social dynamics of gender roles and relationships. The VAMP program in India, an offshoot of a peer-education program called SANGRAM, is an inspiring example of change through structural intervention.⁴ In 1996, VAMP was established as a registered collective of people in prostitution and sex work (PPS). It has its own board of directors—staffed by women in prostitution—with a clear hierarchy of responsibilities and rates of pay as well as its own buildings and property in the town of Nippani. VAMP's mission is to create a common identity among PPS, thereby gathering strength to assert their rights—the organization has been enormously successful in requiring clients to use condoms. As human rights activist Joanne Csete concludes, “VAMP is a stunning AIDS success story.”⁵

Recommendation: Multiple Approaches to Action

A multi-method approach may serve us best as we strive to meet the immediate threat and long-term consequences of the HIV/AIDS pandemic. In the short term, gender-sensitive policies and programs are our best hope against HIV/AIDS because they can be implemented relatively quickly and because we can continually adapt policies and programs to meet women's and men's gender and age-specific needs within their current social and cultural context. In the longer term, however, our work should be both transformative and structural. We must strive to change minds and hearts as well as behaviour; we must address the gender inequalities across communities and around the world if we hope to halt the HIV/AIDS pandemic and prevent other health and human crises in the future.

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RESPONDING TO THE EPIDEMIC

Making Space for Young Heterosexual Males: Gender and HIV/AIDS Prevention Education

Jacqueline Gahagan, Laura Barbour, and Susan McWilliam, Dalhousie University

Healthy sexuality initiatives for young adults, including those aimed at HIV/AIDS and sexually transmitted infection (STI) prevention, have been in place for decades.¹ However, the majority of these initiatives were designed for and directed toward young heterosexual females and gay males.² In fact, most Canadian sexual health campaigns and interventions geared toward the prevention of HIV infection fail to include young heterosexual males.³⁻⁵ This is problematic since Health Canada statistics show an increase in HIV infection among females from unprotected sexual contact with HIV-infected male partners.⁶

Current research demonstrates that young Canadians are now less knowledgeable about HIV/AIDS and ways of protecting themselves against sexually transmitted infections than they were in the late 1980s.¹ It is therefore essential that we seek new and innovative ways of providing healthy sexuality education and resources for all youth, especially young heterosexual males.

The Buddy Study, a Nova Scotia-based two-year qualitative study funded by the Canadian Foundation for AIDS Research (CANFAR), was designed to explore and contextualize young heterosexual males' perceptions of sexual behaviours, roles, and responsibilities, and to determine obstacles and gaps in their sexual health decision-making. A series of 30 one-on-one interviews and 9 focus group discussions were held over a two-year period (2003-2004) with young males and females. Thirteen additional

in-depth interviews were held with sexual and reproductive health educators to draw from their experiences working with youth. Sessions were audio-taped, transcribed verbatim, then analyzed thematically to identify patterns in the data.

Analysis of the first-year interviews and focus groups with young males and sexual health service providers brought to light some of the complex, underlying constraints on some young males in talking about sex and sexuality. Interviews and focus groups with young females in the second year of the project brought a broader perspective to the relationship between sexual partners, social taboos, and barriers to healthy sexuality.

Gender was a key determinant of sexual health among study participants: (1) the nature and extent of risk-taking behaviours are linked to gender; (2) sex and sexuality are taboo, and socio-cultural comfort levels and restrictions around taboo topics differ according to gender; and (3) roles, responsibilities, and expectations (e.g., sexual behaviours in general, safer sex, contraception, and disease prevention) are often unequally divided between male and female partners within the context of a heterosexual relationship.

Here are some of our key findings:

- Young men were less likely than young women to talk openly about sex or to seek accurate sexual health information because of embarrassment or a fear of feeling foolish, stupid, or unmanly.

■ Young Canadians are now less knowledgeable about HIV/AIDS and ways of protecting themselves against sexually transmitted infections than they were in the late 1980s.

- Most participants did not regularly use condoms.
- Young women were more likely than their male partners to take responsibility for safer sex because they felt they would face greater personal consequences from pregnancy or sexually transmitted infections.
- Most participants believed that “society” puts more pressure on young women than on young men to be responsible and practise safer sex.
- The greatest sexual health priority for the participants was preventing pregnancy.
- Most of the participants believed they were not at risk of coming into contact with HIV through unprotected sex, even when the sexual partner is not well known to them.

These findings indicate a relationship between gender-based normative sexual behaviours, pervasive socio-cultural paradigms that regulate and normalize sexual beliefs, and attitudes and understandings of responsibility among participants. All the participants in this study provided scenarios in which gender imbalances related to responsibility for safer sex, contraception, disease prevention, and sexual behaviours played a significant role in sexual health decision-making processes.

Recommendations

For practitioners:

- Develop accessible, youth-friendly, gender-appropriate, sexual and reproductive health facilities;
- Ensure that adequate, detailed information about HIV and other STIs is provided to both young males and females in a gender-sensitive manner; and

- Provide condoms in locations that are easily accessed by all youth, including youth in more rural or remote areas.

For policy makers:

- Focus on primary health care for all Nova Scotians as a means of improving overall health and wellness and reducing HIV infection among youth;
- Focus on gender-based sexual norms in developing HIV prevention messages and intervention strategies by conducting gender-based analyses; and
- Create a forum for youth to discuss gender differences in sexual decision-making and sexual health education needs in an effort to increase open dialogue.

Gender continues to play a central role in shaping sexual behaviours, roles, and responsibilities among young adults. In order to address the sexual health needs and concerns, including HIV prevention, of young heterosexual males, educators and service providers must first address the close connection between gender norms and sexual behaviours. Building capacity across the sexual and reproductive health spectrum, including enhancing the involvement of young heterosexual males, will ultimately improve HIV/AIDS prevention education programming and services for all young Canadians.

For a copy of the full report, visit:

www.acewh.dal.ca/eng/reports/Buddy_Study_Report.pdf



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RESPONDING TO THE EPIDEMIC

Give It to Me Now: Sexual Health Information and Services for Older Youth in British Columbia

Emily Falk, former Fulbright Fellow, BC Centre of Excellence for Women's Health, Ann Pederson, BCCEWH, and Elizabeth Stanger, Language Services, Cross Cultural Care and Diversity, Vancouver Coastal Health

Sexual health is a state of physical, emotional, mental and social well-being related to sexuality... Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.

~ World Health Organization¹

The period from 19 to 30 years of age is an important transition period characterized by the end of formal education, living independently from one's family of origin, securing employment, and establishing intimate relationships. In this time of exploration, young adults may put themselves at risk for sexually transmitted infections (STIs) and pregnancy by having sex with multiple partners, having sex without consistently using protection, or engaging in serially monogamous sexual relationships.² Data for British Columbia show that young adults between the ages of 19 and 30 shoulder a disproportionate burden of STIs, and about half of the births in the province annually are to mothers between 19 and 30.³ Moreover, a woman is sexually assaulted every six minutes in Canada and "in BC 59 percent of women over the age of 16 have experienced at least one incident of physical or sexual violence. This is the highest rate among the provinces in Canada."⁴ Given this reality, it seems clear that young adults in BC need information about their sexual health and services that would support their forming healthy relationships.

There is little literature about the sexual health information and service needs of young adults beyond adolescence, and there are few services targeted at this age group. This study was designed to help bridge this gap as well as to help in designing sexual health services using the WHO sexual

health framework instead of one focused on STIs such as HIV or gonorrhea.

Using self-administered questionnaires (paper and on-line), we collected data from 357 women and men aged 19 to 30 in BC about their experiences accessing sexual health information and services; the characteristics of the people and places from which they like to receive information and services; any concerns they had in seeking information or help; and potential challenges they anticipated in seeking appropriate information and care.

The majority of respondents had spoken with a health care provider about sexual health in the past year. Pregnancy and sexually transmitted infection prevention and testing were their most common concerns. Fewer than half of respondents reported being offered any kind of barrier protection and almost no one reported that they'd discussed talking with a partner about sex (i.e., negotiation skills) or sexual violence.

Men and women obtained information through different channels. Women reported obtaining information from friends/family, followed by brochures/pamphlets/books/the *BC Health Guidel* magazines, followed by GP/family doctor and local sexual health clinics. Men listed the same two first sources, but named "sexual partner" as their third choice most often. This may suggest that men believe that they can obtain the information they need without the input of a health care professional.

Regarding the characteristics of services, respondents preferred sites where no appointment was needed and "The provider is the same sex as I am." In open-ended responses, respondents valued providers and services that were friendly,

■ Although young adults ... want convenient, confidential, and accurate information from health care providers, they obtain most of their information from friends and family.

safe, and non-judgmental; maintained privacy and confidentiality; had current, accurate information; normalized their health concerns; were easy to access; and affordable. Respondents were open to receiving sexual health information in various established medical locations, such as doctors' offices or clinics, but were less open to non-medical locations such as grocery stores.

The cost of oral contraceptives was the most commonly reported challenge and it was identified significantly more often by women than men. A low level of education was related to many challenges in accessing sexual health information and services. Also, most people were not aware that medications to treat STIs are free in BC, although the majority believed that they should be.

Based on these study findings, health care providers should screen young adults for sexual activity and risk factors, and should discuss a wide range of sexual health topics, including how to discuss safer sex with a partner, relationship violence, and where to get more information. In addition to other forms of contraception, samples of barrier protection (male

condoms, female condoms, dental dams, latex gloves) should be given to clients. Peer- or volunteer-based sexual education/counselling programs could be more widespread, both in the context of medical settings and through informal networks. Sexual health services should consider lay-referral networks, given that young men in particular rely on informal sources of information to manage their sexual health.

Patients should have the option of a gender-matched provider. This is especially important for women. Clinics may also want to consider recruiting more male volunteers to communicate with men about the benefits of sexual health services.

Clinics and services should consider access issues such as location, hours of operation, waiting times, and clinic atmosphere. Although young adults in this age group want convenient, confidential, and accurate information from health care providers, they obtain most of their information from friends and family. The challenge is therefore to ensure that accurate, high-quality information is widely available.⁵

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RESPONDING TO THE EPIDEMIC

Gender Matters: Understanding the Emotional and Social Support Needs of Women with HIV/AIDS

Julie Maggi, Department of Psychiatry, University of Toronto & St. Michael's Hospital Mental Health Service and Tamara Daly, School of Health Policy and Management, York University, and the National Network on Environments and Women's Health

Researchers at the University of Toronto and York University, in partnership with the National Network on Environments and Women's Health (NNEWH), are currently interviewing women with HIV/AIDS in Toronto in the first phase of a study to understand more about women's emotional and social support needs, and when and under what circumstances women use formal and informal health care and social services. Examining these issues is important for three key reasons. First, the social, political, and economic context of women's lives makes some women more vulnerable to HIV/AIDS. For example, in Canada, women in prison, Aboriginal women, and black women are disproportionately infected, but we have little data on how these women, once infected, are differentially affected. Hough and colleagues report that women with the disease are also often coping with single parenthood, poverty, and racism as well as HIV/AIDS.¹ Our study is examining some of these issues, including what potential barriers women immigrating to Toronto from HIV/AIDS-endemic areas may face.

Second, social support is important for people with HIV/AIDS, but to date we have little understanding of the

social networks that women are turning to for support. The majority of studies show that in people with HIV, friends, rather than family provide social support.²⁻⁴ In sharp contrast, however, one study specifically looking at HIV-positive women in an urban setting showed that they have few friends involved in their lives and a paucity of formal caregivers; in fact, children form the core of women's social networks.¹ With the changing face of the HIV epidemic in Canada, we need to know more about what unique social and emotional supports women with HIV/AIDS need, given their gendered life experiences, their multiple roles (e.g., mother, partner, caregiver, worker, community participant), and what resources they are able to access, given their life circumstances.

Third, with changes to the disease's epidemiology, there has been a shift in the site of care. Since the introduction of Highly Active Antiretroviral Therapy (HAART), HIV disease has become a chronic and manageable illness for those with access to HAART. As a result, the formal provision of care has shifted from in-patient hospital care to the ambulatory setting and to the community. Given this

■ It is unclear how well existing resources are tailored to the emotional and social support needs of women.

transition, we need community and ambulatory resources that are appropriate for women with HIV.

To date, investigation of these needs is limited, particularly in Canada, but preliminary examination reveals a disconnect between hospital and community-based supports. For instance, referral patterns for formal mental health services in one downtown inner-city hospital in Canada are out of proportion with the number of women with HIV/AIDS. At this hospital, women make up a very small proportion of referrals to its specialized HIV psychiatry service, which provides ambulatory care in a mental health setting and within an HIV medical clinic. Of the 73 new patients in the program in 2002, only 5 percent were women. By 2004, the number rose to just 6 percent. In addition, health care staff have expressed concern that women seen in medical clinics are reluctant to follow up recommendations for community social and emotional support resources. This finding is consistent with another Ontario-based study of both men and women, which showed that men and women who use community-based AIDS service organizations are less likely to use mainstream health promotion and support services.⁵

Interestingly, that study included a disproportionate number of women, yet it did not address in what ways women's service needs differ from those of men, pointing to the need for research that is gender-based.

As the HIV/AIDS epidemic evolves, it is unclear how well existing resources are tailored to the emotional and social support needs of women. By the study's conclusion, we hope to understand more about where women with HIV/AIDS go for care, whom they rely on for social and emotional support, and when and under what circumstances they choose to use the formal health care system and community agencies for care. This information will assist women with HIV/AIDS, as well as policy makers, health care administrators, and practitioners in meeting the service needs of women with HIV/AIDS.



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RESPONDING TO THE EPIDEMIC

Gender and the Costs of Palliative Caregiving for People with HIV/AIDS

Ann Pederson and Lorraine Greaves, British Columbia Centre of Excellence for Women's Health

According to a 1994 Angus Reid report, 84 percent of all Canadians surveyed indicated a preference to spend their final days at home with their family.¹ This demand, coupled with demographic changes and progressive movements concerned with holistic care for patients, has necessitated the growth of palliative home-based services.² However, a key concern for both caregivers and patients is costs—who pays and for what? While palliative home care may be cost effective for governments, and may be welcomed by patients, its costs have been understudied. In addition, health care costs are usually perceived to be solely economic, whereas many other “costs” and indeed, some benefits, may be associated with providing palliative home care.

Health Canada's Bureau of Women's Health and Gender Analysis funded a multi-site study in 2002 of the gendered caregiving costs for those offering palliative care to people with HIV/AIDS or cancer. This synopsis is derived from two reports from that research¹ and focuses specifically on the issues confronting palliative caregivers of people with AIDS.

Costs of Providing Palliative Care for a Person with AIDS

The study measured the social, economic, emotional, psychological, and spiritual costs and benefits for both female and male informal and formal caregivers providing palliative home care for a person with cancer or AIDS.¹ The study demonstrated that informal caregivers (unpaid family and friends) spent much more time on caregiving tasks and were more likely to report physical effects arising from the experience of caregiving than formal caregivers. They also incurred greater out-of-pocket expenses than formal caregivers: on average, informal caregivers performed approximately \$6,000 worth of caregiving labour in the final four weeks of the patient's life. Informal caregivers also reported that they and other people close to the dying person

interrupted their work in order to provide care, typically by reducing their work hours.

While the informal caregivers reported many similar experiences regardless of whether they provided care to a person with cancer or AIDS, a number of issues specific to palliative caregiving for people with AIDS were identified. For example, it was more likely that friends served as informal caregivers for people with AIDS, while people with cancer were usually cared for by family members or spouses. Caregivers of AIDS patients were more likely to purchase specific items to assist in caregiving, and more often reported economic hardship in their patient's family as a result of the caregiving effort. Caregivers for people with cancer were more likely to request additional, skilled nursing services than AIDS caregivers.

Caregivers for people with HIV/AIDS are often younger than the caregivers of others with terminal illnesses, and, in Canada, they have frequently been homosexual males and often the patient's partner. As a result of the social stigma of AIDS, these caregivers often have less access to support services and resources, and patients' partners sometimes make extraordinary financial sacrifices.³ They therefore tend to be less economically secure than the caregivers of people with cancer, in part because of their relative youth. In addition, these young men were not necessarily socialized to be caregivers and becoming a caregiver may result in the caregiver unintentionally disclosing his sexual orientation.⁴

Benefits of Providing Palliative Care for a Person with AIDS

Despite these challenges, 94 percent of all caregivers in the study, including those providing care to a person with AIDS, reported that their experience gave meaning to their lives. Caregivers consistently stated that such meaning came from

making a difference in the life of another person by being there for them and by helping them to die at home. This was particularly the case with informal caregivers, one of whom described the experience like this: "When you love someone, you want to do what you can and as much as you can for them. They need love, companionship, and understanding." Further, a number of the informal caregivers of persons with AIDS reported that the experience gave them the strength to help others and become more involved in AIDS volunteer work. As two such caregivers indicated: "That's why I'm a volunteer for AIDS organizations," and "It led me to start working in the field of care and community aid."

Recommendations

The caregivers in this study called for more resources and planning to be devoted to palliative care to ensure that services were available across regions and income groups. They called for some compensation for unpaid caregivers through employment insurance or the tax system to recognize and facilitate their involvement in palliative caregiving for their family and friends.⁵ Both formal and informal caregivers asked for more training and education regarding palliative care issues, including the process of dying, the trajectory of illnesses, and pain management and other interventions. Caregivers also called for a more streamlined team of caregivers, mixing formal and informal, and different kinds of services to provide seamlessness and better communications among all concerned.

Among those provided palliative care for a person with AIDS, caregivers were most concerned about the need for training about the illness's trajectory. Specifically they said:

- "An AIDS caregiver (paid or unpaid) should know what to expect. They need to know about the disease, its symptoms and to know what happens over the course of the disease."
- "Home care workers should be more educated about working with people with AIDS."

As the face of the HIV/AIDS epidemic changes in Canada, it can be expected that the caregiving issues will also shift, reflecting more female patients and different caregiving patterns. Ongoing monitoring of the issues facing caregivers of people with AIDS, particularly with respect to palliative home-based care, is required.

For the full report or the policy brief, contact the British Columbia Centre of Excellence for Women's Health at bccewh@cw.bc.ca.



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RESPONDING TO THE EPIDEMIC

Viruses of Inequality: Women's Health and Human Rights

Marilou McPhedran and Susan Bazilli, University of Victoria, International Women's Rights Project (IWRP)

The University of Victoria International Women's Rights Project (IWRP) has recently completed an analysis of HIV/AIDS as the "virus of inequality" in Southern Africa. We found that this virus is directly linked to issues of democratic reform and post-conflict renewal. The British Columbia Centre of Excellence for Women's Health advised on the project, and together the IWRP and the BCCEWH intend to continue this analysis.

The social determinants of health inequity include social, political, and economic sources of ill health at national and community levels. Addressing the human rights dimensions of health inequities could therefore have the potential to prevent deaths and chronic illness through mechanisms such as treaties and legal agreements. Gender inequalities have a profound influence on patterns of health and illness. Systemic barriers to women's health are impediments to women's lived rights (that is, the nexus between women's health and their realization of their human rights). Such issues have been identified in numerous international human rights treaties.

For example, the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) specifically addresses many of these systemic barriers, including violence against women and limits on women's political participation. Such limitations reflect the premise that health care policy is an important but limited component of the necessary multi-sectoral response to the HIV/AIDS pandemic, which needs to be examined in the context of women's legal rights (through national and international laws, including constitutions and international treaties).

New laws identifying women's legal rights, and providing remedies to the differences in power and access to resources

between women and men in power in southern Africa are examples of material markers that need to be tracked and changed. We also require a fuller understanding of how gender shapes the impact of HIV/AIDS on political and social access by women and girls, day-by-day, as they strive for their lived rights.

This perspective highlights a number of connections between legal rights, lived rights, and health, including how:

- Women are excluded from much of the decision making related to HIV/AIDS and from development of health, social, and economic policies needed to be able to live their rights;
- Women's vulnerability to HIV/AIDS is exacerbated by their limited opportunities to live their rights to human security, food security, and political participation;
- Structural conditions limiting health opportunities for women and girls are influenced by the extent that women and girls are prevented from exercising their rights as articulated through the international treaty system;
- Civil society organizations, as crucial front-line mechanisms for increasing health opportunities for women and girls, are vulnerable to the effects of HIV/AIDS on their operational abilities; and
- Attitudes and practices of governmental leadership have an impact on women's health and access to resources, including prevention and treatment of HIV/AIDS.

These, and a range of other factors, illustrate the wide range of determinants and barriers to women's health related to HIV/AIDS in Southern Africa and their connections and possible solutions lodged in the international legal and treaty systems.