



Fueling the Epidemic: HIV-Related Stigma and Discrimination

Introduction

“Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.”

- U.N. Secretary-General, Ban Ki-moon¹

Thirty years into the HIV epidemic, HIV-related stigma and discrimination continue to be pervasive in the lives of people living with HIV. HIV-related stigma and discrimination occur throughout the world – however, they manifest differently and in varying degrees in different locations.²

Stigma associated with HIV and the resulting discrimination can be as devastating as the illness itself. Furthermore, the spread of HIV can be directed attributed to HIV-related stigma and discrimination. Despite the widespread recognition of the pervasiveness of stigma and discrimination and their harmful impact on HIV responses, appropriate levels of funding for programs aimed at reducing stigma and discrimination are still lacking.³

HIV-related stigma refers to the negative beliefs, feelings and attitudes towards people living with HIV and/or associated with HIV.

HIV-related discrimination refers to the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status.⁴

Canadian Attitudes Toward Those with HIV/AIDS

In a survey conducted in June 2011, Canadians expressed somewhat greater comfort interacting with those with HIV/AIDS, compared to survey results from 2006.⁶ However:

- 16% of survey respondents said that they “feel afraid” of people living with HIV/AIDS (up 3 points since 2006);
- 18% said that they would be somewhat or very uncomfortable working in an office with someone who developed HIV/AIDS. Fear of transmission, particularly through accidental transmission of blood, was the most likely reason for ongoing discomfort;
- 35% would be somewhat or very uncomfortable if their child was attending a school where one of the students was known to have HIV/AIDS;
- 54% would be somewhat or very uncomfortable with a close friend or family member dating someone with HIV/AIDS; and,
- 23% expressed discomfort shopping at a small neighborhood grocery store owned by someone with HIV/AIDS. The primary reason for discomfort was fear of “contracting it yourself.”

Those who describe themselves as “very knowledgeable” about HIV/AIDS were much more likely than others to report higher levels of comfort interacting with those with HIV/AIDS.⁷

Triggers of Stigma and Discrimination

A lack of understanding of modes of HIV transmission can bring about stigma and discrimination. Today, with the benefit of scientific advances, we know that HIV is not easy to transmit. However, fear of infection, including infection through casual contact, remains a leading trigger.⁵ The fact that HIV is sexually transmitted, and is predominantly found in already marginalized populations, also plays a key role. Morality and religious beliefs further contribute to stigma, as well as social judgments linking people with HIV to behaviours considered improper or immoral (such as sex work, drug use, men having sex with men, sexually active youth and so on).

Manifestations of Stigma and Discrimination

People living with HIV/AIDS can face stigma and discrimination daily, in just about every aspect of their lives. Discrimination in the workplace remains a key barrier to employment.⁸ Loss of employment because of HIV-status and exclusion in the workplace is widespread.⁹ Stigma can lead to a lack of access to educational opportunities or expulsion from school. It can result in abandonment by a spouse and/or family members, social ostracism and shunning. It may be expressed through stigmatizing language and behaviour, verbal harassment, or physical violence. Stigma can place limits on housing, restrict travel, and prevent participation in religious or cultural ceremonies.

Furthermore, stigma can reduce self-esteem, self-worth and can lead to increased depression, and suicidal thoughts. Many people living with HIV experience high levels of internalized stigma, manifesting as shame, guilt and self-loathing.¹⁰

Implications for HIV Prevention, Treatment, Care and Support

“It is stigma that makes those at risk of contracting HIV reluctant to be tested; it is stigma that makes it difficult, and often impossible, for them to speak about their infection; and it is stigma that continues to hinder access to the life-saving ARV therapies ...”¹²

Case Study

Kevin Toronto, Canada¹¹

It is hard to deal with HIV by myself. I really want to tell people, but I am afraid of losing more people in my life. And I’ve already lost a lot of people because of my drug use. I am afraid of how they are going to react or what they are going to say. People already look down at me because I’m Aboriginal on social assistance and a drug user. I already feel pretty alone in Toronto – I came here on my own and all my family members are on the reserve up North. The only person that I have told about my HIV is my brother – and he told me not to tell my parents and to stay away from the reserve. He doesn’t want my parents to have the shame of having a person in the family with HIV. Ever since I told him, he hasn’t written or phoned me. I feel rejected. Sometimes, I sit at home and just cry. I’m feeling down in the dumps a lot. When I get depressed, I forget to take my anti-retroviral medication.

Stigma and discrimination have profound implications for HIV prevention, treatment, care and support. Stigma and discrimination prevent people from coming forward for HIV testing. The fear of stigma and discrimination also discourages people living with HIV from disclosing their status, even to family members and sexual partners. For instance, in an Ontario study, women described hiding their HIV status to help manage the fear of discrimination and the negative social attitudes, thereby reducing their ability to receive the support and help that they needed.¹³

HIV-related stigma and discrimination stand in the way of HIV prevention efforts – they lead people to be afraid to seek out information about how to reduce their exposure to HIV, and to adopt safer behaviour in case this raises suspicion about their HIV status.¹⁴

Already marginalized and stigmatized communities, including men who have sex with men, sex workers, and sexually active youth, are often excluded from targeted HIV-related programming and from school sexual health curricula. This results in limited access to essential HIV prevention information.

Much HIV-related stigma and discrimination is experienced in health care facilities, including prevention services, sexual and reproductive health services, and treatment, care and support services.¹⁶ As a result, those living with HIV often are reluctant to use the services needed to stay healthy. Health care workers can be unhelpful, demonstrate stigmatizing behaviours, or even refuse access to services. They are often ill-equipped to handle specific issues faced by different populations. Those living with HIV are often concerned about confidentiality of medical information and the very real possibility that health care providers will reveal their HIV status to others without their consent.¹⁷

It is estimated that the most effective stigma and discrimination reduction programs could potentially result in significantly more pregnant women using HIV services and adhering to treatment, potentially reducing mother-to-child transmission by as much as one third in settings where stigma is prevalent.¹⁸

HIV-Related Stigma and Discrimination and Marginalized Groups

Stigmatizing attitudes and discrimination do not apply to all people living with HIV equally. HIV-related stigma and discrimination intersect with other pre-existing stigmas including discrimination based on gender identity, sexual orientation, disability, race, ethnicity, immigration status, income, and stigmas associated with particular behaviours and activities (including drug use and sex work). Already marginalized groups tend to experience the most severe forms of stigma and discrimination.¹⁹

A recent Ontario study found that marginalized women living with HIV experienced overlapping forms of stigma and discrimination including racism, sexism and gender discrimination, homophobia and transphobia.²⁰

Case Study

Peter Kingston, Jamaica¹⁵

In Jamaica, I don't talk to anyone about my sexuality. People hate homosexuals where I live. I feel guilty about being attracted to other men and shame for being who I am. I dread the possibility of being alone and cut off from my family and friends. I don't know of any doctor or nurse who would accept me. Sometimes, when I feel really depressed and I have had a lot of alcohol, I have sex with other men. I usually don't use a condom since they are rarely available. Also, I cannot carry condoms with me since it would make my wife suspicious if she found them. I do not use a condom with my wife.

For instance, health providers may refuse to treat drug users for HIV or may make HIV treatment conditional upon starting treatment for drug use.²¹ Those living with HIV and a mental health disorder also face double stigma and discrimination. HIV stigma can exacerbate mental health issues, such as depression. In an Ethiopian study, patients with TB/HIV who perceived stigma had significantly greater risk of mental health disorders than individuals who did not perceive stigma.²²

Women may experience stigma differently than men – often the harshest and most damaging forms – and may have fewer resources for coping with it.²³ HIV-positive women also experience discrimination and rights violations in the context of their reproductive health choices. They may be denied family planning or sexual and reproductive health services, and are often advised by health providers to avoid pregnancy.²⁴ This discrimination that HIV-positive women experience may increase their risk of transmitting HIV to their partners or children or unintentionally conceiving. They are also sometimes coerced into being sterilized or into terminating a pregnancy.²⁵

Case Study

Njoki Nairobi, Kenya²⁶

My husband didn't tell me he had AIDS until right before he died, when I was pregnant with my second child. He left me with two small children. I didn't get antiretroviral treatment during the birth of my child and only sometimes have access to treatment myself. When I have medication, I hide it from everyone. Sometimes, when I am with others, I don't take my pills. I had to leave the small town that I am from and move to Nairobi. The nurse who treated me told my parents about my HIV, and then my parents pressured me to leave town. They were afraid that people would stop coming to their shop if people that knew their daughter had HIV. They gave me money to leave with my children. I was very sick when I arrived in the city. I am often sick and don't have enough money to feed my kids or myself. I have to beg. Sometimes, I have sex with men to get enough money to survive.

Orphaned or abandoned children of HIV-positive mothers also experience specific forms of HIV-related stigma and discrimination. They may be segregated and placed in specialized orphanages. Schools may refuse to accept a child who is HIV-positive or who has parents who are HIV-positive.²⁷ Lack of access to education further fuels the epidemic – research demonstrates that education is a powerful protective factor against HIV infection.

Racism experienced, for instance, by Aboriginal and Black populations, also drives the transmission of HIV. Racial prejudice can limit access to medical and support services. In Canada, Aboriginal people report that they are “not treated like people” by health providers, and experience longer waits at emergency departments because they are Aboriginal.²⁸ In the United States,

higher rates of HIV infection among African Americans in comparison with the general population has been attributed to racism (for example, reduced access to sexual health care clinics and disproportionate incarceration rates among African Americans).²⁹

Stigma often leads immigrants to deal with HIV in silence and secrecy. Social support is often limited and immigrants may fear becoming isolated from their social community if their HIV status is revealed. As a result, they may not make use of social support groups.³⁰

Some men who have sex with men report that stigma and discrimination is more strongly related to their sexuality than with being HIV-positive. Men living in Toronto from the Caribbean community reported strong homophobia in their community and stigma on the basis of presumed homosexuality, regardless of whether or not their HIV status is known.³¹ Homophobia and transphobia can reduce access to HIV prevention services and contribute to sexual violence – both of which increase HIV infection risk for sexual minorities and transgender people.³²

The People Living with HIV Stigma Index was developed by and for people living with HIV to measure and build evidence about the stigma experienced by people living with HIV in their communities. It was developed through a partnership between the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. For more information, see: www.stigmaindex.org.

Stigma and the Criminalization of HIV Non-Disclosure

The overly broad use of the criminal law in the case of non-disclosure of HIV status perpetuates stigma and discrimination and further marginalizes populations that are affected by HIV. Sensationalistic media stories, headlines and photos fuel stigma and present those living with HIV as criminals. Stigma and a lack of understanding of the science of HIV infection and transmission lie behind the drive to criminalize HIV non-disclosure.³³

Furthermore, criminalization undermines public health efforts to address HIV – it discourages HIV testing, and encourages denial and unsafe behaviors. Those with HIV may not want to get tested or disclose their status because of fear that this information might be used against them in the future (for example, in the form of threats or false allegations).³⁴ Criminalization also leads to a reduced willingness to access HIV services – trust between the individual and the health care worker is eroded and those with HIV may be reluctant to honestly communicate with health care providers.³⁵

Conclusion and Recommendations

HIV-related stigma and discrimination are pervasive and fuel the spread of HIV/AIDS. There is a need for increased levels of funding dedicated to strategic, coordinated and comprehensive programs for stigma and discrimination reduction. Emphasis should be placed on:

- Involving people living with HIV/AIDS and key affected populations in the design, implementation and monitoring of programs;
- Strengthening networks of people living with HIV/AIDS and other stigmatized groups as key actors in effective stigma and discrimination reduction efforts;
- Educating and raising general public awareness and knowledge levels of HIV/AIDS, including effective education on transmission risk, and dealing with fears and misconceptions about HIV/AIDS. This would include the engagement of mass media and media campaigns;
- Including activities that foster interaction among people living with HIV/AIDS, those most at risk of infection and key audiences to dispel myths about people living with HIV/AIDS;
- Mobilizing community and religious leaders and celebrities to foster respect and compassion for people living with HIV and to encourage greater openness around sexuality;

- Recognizing that HIV-related stigma and discrimination intersect with other forms of stigma, discrimination and disadvantage;
- Ensuring that staff members within health care settings provide care that is non-discriminatory, maintains confidentiality, meets the needs of key populations, and is respectful of human rights; and,
- Addressing harmful criminal laws that fuel stigma and discrimination against marginalized groups and people living with HIV/AIDS, including the overly broad use of criminal law with respect to the non-disclosure of HIV status.

Case Study

Beatrice Montreal, Quebec, Canada³⁶

I called my friend and I said, “I just found out I am HIV positive.” Within a week, the whole community knew. Everything changed. No one talks to me anymore. I go through the back entrance of the apartment building so nobody sees me. I feel like a criminal. People bother me, say bad things, and treat me like I’m evil. I feel more stigmatized as a woman because people think I am promiscuous. The lady at the hair salon won’t do my hair anymore because she thinks she’ll get AIDS from me. I stay away from people, including doctors who look down at me. On the news, they had a photo of another HIV-positive person who got charged for having sex with someone without telling them about their HIV. I don’t want to see my face in the newspaper.

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