Working from Within Endemic HIV Stigma

Developing Canadian Social Workers’ Understanding of the Challenges Faced by Newcomers Managing HIV

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Abstract

HIV stigma is central to this article’s discussion and analysis because of the widely documented negative social and health impacts of stigma on Canadians living with HIV in general and ethnocultural communities in particular. The goal of this theoretically and empirically informed article is to provide insight for Canadian social workers on the challenges faced by newcomers infected with or affected by HIV. This is achieved by problematizing sociocultural contexts that sustain stigmatization and exploring how these interact with people living with HIV and AIDS (PHAs). Increased caseloads of migrant PHAs in Canada since early 2002 means that social workers throughout Canada have had to adjust and acquire new competencies. This article is informed by field research and social work practice with newcomers in three Canadian cities. HIV stigma is endemic in Canada, and this article posits that social workers with an increased critical awareness about stigma on individual, social and translocal levels can best support migrant PHAs. This article concludes with two key messages for social workers.

Keywords: HIV • stigma • Canada • immigration • people living with HIV and AIDS (PHA) • social work • newcomers • social interaction • critical theory • determinants of health • ethnocultural

Story and science are interrelated, interactive and ultimately constitute each other. The natural world and the cultural worlds share the burden of creating disease realities. (Goldstein, 2004, p. XIII)

One continually learns and relearns to live with as much as through one’s body, in its various states of health and illness, youth and old age, boredom and trauma, routine and instability. (Biehl, Good, Kleinman, 2007, p. 9-10)

There is a significant body of literature discussing the existence of HIV-related stigma in general (Canadian HIV/AIDS Legal Network [CHLN], 2004; Crawford, 1996; Derlega & Barbee, 1998; Roth & Hogan, 1998) and the persistence and implications of HIV-related stigma among newcomers and long-standing ethnocultural communities in Canada in particular (African Caribbean Council on HIV/AIDS in Ontario [ACCHO], 2006; Committee for Accessible AIDS Treatment, 2008; Lawson et al., 2006). Stigma is “an attribute that is deeply discrediting,” one that negatively impinges upon a person’s identity and self-worth (Goffman, 1963, p. 1). More recent discussions of HIV stigma (Elliott et al., 1986; Herek & Glunt, 1988; Madru, 2003), including feminist perspectives (Fortin, 2005; Goupil, 2002), have informed this article. Social exclusion, denial of HIV status, personal suffering and
delays in seeking social support and medical treatment are some of the effects of stigmatization. Social exclusion and marginalization augment health disparities, which are enablers of HIV transmission (Anand et al., 2004; Wagstaff, 2002). The seriousness of the social and health impacts of HIV stigma, together with its tenacity among racialized immigrant communities in Canada, is the reason that stigma lies at the centre of this critical analysis.

The points raised in this article represent the first steps in a process of critical reflection about the origins of health-based stigma and how HIV stigma relates to broader social processes in Canada. Although social workers often work with stigmatized populations, the impact of HIV upon almost every aspect of a newcomer’s daily life is particularly salient. The discussion of stigma is explored through Leary and Schreindorfer’s (1998) HIV-specific theoretical framework. This article proposes that social support to migrant persons to Canada living with HIV is most effective together with an increased critical awareness of stigma set within broader social and societal contexts. Critically, discussion is informed by empirical research and practice with newcomers living with HIV in Canada.

Much of the literature on HIV stigma has focused on subjective experiences of living and coping with HIV. This means there is considerable literature in Canada about experiences with HIV from biographical and autobiographical standpoints (Lévy, 2007; Rudd & Taylor, 1992; Saint-Jarre, 1994). Less critically explored are the relationships between newcomers managing HIV and Canadian society. In this article, the larger sociocultural contexts that sustain stigmatization and the interactions that members of society have to people living with HIV and Aids (PHAs) are the analytical focus. With a concern for providing practical messages for Canadian social workers, this article concludes with two key messages, outlined in text boxes.

**Background**

Since 1990, Canada has received approximately 230,000 immigrants annually (Vissandjee et al., 2007), and nearly one in five resident persons in Canada is foreign-born (Statistics Canada, 2006). Social workers employed in HIV clinics and those working in front-line AIDS service organizations in Canada have witnessed sharp increases in the number of clients after January 2002 (Duchesneau, 2004). In 2002, mandatory HIV screening was introduced into the immigration medical examination. As a result, all applicants for Canadian permanent residency are currently being tested for HIV antibodies (Klein, 2001). Indeed, many people learn of their HIV status through immigration medical testing, as recent data testify (Text Box 1).

The increased caseloads of migrant PHAs in Canada has not been accompanied with increased financial or human resources; thus, social workers have had to make adjustments in light of this demographic change (Duchesneau, 2004; Lacroix, 2004, 2004–2005). Complex client cases have also meant that health care providers have had to acquire new competencies and responsibilities, while seeking support from networks of peers working with PHA newcomers throughout Canada (Munoz & Chirgwin, 2007).

“Global forces impact on front-line practitioners in a number of diverse ways that lead to the internationalization of social problems” (Chitereka, 2009, p. 46).

Newcomers to Canada living with HIV soon learn that their health condition is classified chronic and manageable because of the quality of health care and availability of medicine. While health providers draw parallels between living with HIV and having diabetes, due to the chronic nature and required daily treatment for both patient groups, PHAs disagree with this comparison (Bisaillon, 2008a, 2009); AIDS service providers hasten newcomers to selectively disclose their HIV status not only because of an upswing in criminalization linked to HIV-positive status in Canada since 2005 (CHLN, 2009) but also due to the stigmatization of HIV (De Bruyn, 2004; DesJarlais et al., 2006; McCann, 1999).
The subjective “othering” of non-citizens (Bibeau, 1991; Clatts et al., 1991; Corin, 2007; Woodsworth, 1972), constructions of women living with HIV (Hogan, 2001; Mensah, 2003; Treichler, 1999) and exclusionary immigration policies based on health (Coker, 2006; Gostin, 2004; Schloehardt, 2005; Worth, 2005) have been widely investigated. Unlike in many of the countries of origin of recent immigrants to Canada, HIV is not the object of mainstream population health interventions in this country. This outlier position of HIV can come as a surprise to newcomers, particularly if they hail from a country where HIV is endemic, where the infection is a central focus of health campaigns.

Field reports from work with immigrant and refugee applicants living with HIV in Canada reveal that persons are concerned about the framing of foreign-born persons as disease importers in the Canadian media (Bisaillon, 2008a). This negative press coverage associates newcomers with disease importation (Kaufman, 2008) and undermines public health efforts, creating false impressions that HIV is not of consequence to the health of all Canadians. Migration is a risk factor for HIV transmission, and rates of infection post-arrival in Canada are of concern (ACCHO, 2006; Vissandjée et al., 2007; Worth, Patton & Goldstein, 2005), pointing to continued relevance for sexual health programming in this country.

**HIV-based stigma**

This article proposes that HIV stigma is unavoidable and endemic in Canada because of dominant social constructions that support, rather than reduce, the stigma associated with disease. Discourses about resilience and emphasis on individual strength have contributed to intolerance of and blaming weak, ill, low-income, elderly and immigrant individuals (Blais & Mulligan-Roy, 2001; Dubos, 1961; McLaren, 1990). Discourses in this article refer to institutionalized thinking and speech that provide the contours for what is conventionally acceptable (Butler, 1997). Increased technocracy and emphasis on biomedical dimensions of health care, which have eclipsed humane forms of care for the sick, have been lamented by numerous authors (Blais, 2008; Farmer & Kleinman, 1998; Illich, 1999). Campaigns of health promotion (Becker, 1986) and the pursuit of perfect health as an ideal—as an end in itself and not a state of being—is what Zola (1981) attributed to the medicalization of Western societies.

Despite increases in life expectancies for Canadian PHAs, attitudes about HIV have been slow to evolve, partly because HIV has achieved disease “super status” (Goffman, 1963, p. 8), where discourses are laden with exaggeration and morality (Sontag, 1989). Persons living with HIV have been described as internalizing and assimilating dominant societal views of the disease (Duffy, 2005; Mendês-Leite & Banens, 2006), and PHAs have perceived the effects of HIV stigma as being greater than the seriousness of the illness (Fife & Wright, 2000). Leary and Schreindorfer (1998) developed a framework for understanding HIV stigma, drawing from social interaction theory under the sociopolitical lens rather than that of the individual (Derlega &
The authors write of PHAs’ propensity for “social dissociation” in reaction to the factors discussed below (Leary & Schreindorfer, 1998, p. 3). This framework can be generalized to other chronic health conditions, allowing social workers to apply it to other serious conditions.

**Threatening public health**
Leary and Schreindorfer (1998) write that PHAs have historically represented a menace to public health. However, since 1991 in Canada, PHAs are not officially considered a threat to the public by virtue of their health status (Bailey et al., 2005). While applicants for Canadian permanent residency are currently assessed for the impact they may have upon public health and public security as well as the projected costs over 10 years to public social and health systems, only excessive costs to the latter will make an HIV-positive applicant ineligible for permanent settlement (Canadian HIV/AIDS Legal Network, 2009; Citizen and Immigration Canada, 2002).

HIV stigma is in large part a product of the construct of perceived danger or threat. These two elements are embedded in rhetoric and discourses and inscribed in historical narratives on immigration, wellness and social policy in Canada and abroad (All-Party Group on AIDS, 2003; Joint Committee on Human Rights, 2007; Stauffer et al., 2002; Wiebe, 2008). African and Caribbean communities in Ontario have made links between HIV stigma and persistent associations with sexual taboos, sexual orientation and lifestyle choices (African and Caribbean Council on HIV/AIDS in Ontario, 2006; George et al., 2008; Tharao et al., 2006). Patton (1986) wrote about the irrational fear of sexuality as a generator for the spread of illness, persistence of HIV stigma, health-based discrimination and denial of civil rights in a U.S. context. Public education has had limited success in reversing negative behaviours and attitudes towards persons living with HIV (McCann, 1999), and Crawford (1996) has suggested that adjusting expectations about the outcomes of public education related to HIV is more effective than trying to eradicate stigmatizing behaviour and attitudes.

**Violating mainstream norms**
People living with HIV face stigma because these individuals are associated with lifestyles popularly framed as morally wrong. Becker (1986) noted that there is generally low tolerance for those who transgress mainstream social norms (Text Box 2). In his research with health care providers, McCann (1999) described the reluctance, bias and moral judgment of physicians and nurses towards PHAs because of the negative opinions of those who use drugs. One doctor was noted as opting out of treating a PHA because the mode of infection was drug use; implications were that the patient was guilty of “negligence” and “deserving of sickness” (p. 360). A surgeon commented, “It is human nature if someone acquires something accidentally to be more sympathetic…. I think…professionals try hard not to make the distinction, but…others and maybe myself do…make that distinction” (p. 363).

However, there is evidence that health care providers attempt to keep bias at bay when working with PHAs. For example, Canadian social workers have said that although they may disagree with client-patient lifestyle choices, they recognized that care is absolute and not conditional on adherence to conventional norms.
Social workers in the Mill et al. (2007) study acknowledged that if mental illness and addictions are more prevalent within some populations than others, there is shared responsibility between society and the individual for the generative forces of asymmetries and ill health. While most newcomers with HIV will not have contracted their infection through drug use, the previous examples are reminders that ethical and moral judgments are invariably brought into the workplace; acknowledging and reflecting upon how these judgments influence work practices is critical to social work practice.

Social workers can imagine the world from the standpoint of the newcomer PHA, reflecting on how their cultural references and frameworks position them differently from clients and as “more aware of international issues.”

Failing to be “productive” to the public good
Individuals and groups are often stigmatized if they are perceived to be inadequately contributing to society. Wiebe (2009) and Abu-Laban (1998) historicize Canadian immigration law, policy and practice showing that applicants have had to comply with productive economic goals of the state to be admitted to the country, which often excluded admitting the ill. Constructions of newcomer PHAs only marginally contributing to the Canadian purse (through taxed labour market activities) can erroneously conceal and distort their varied contributions (Doyal, 1995; Simich, 2003).

Social support work in Montréal shows that it is common for newcomer women living with HIV to work in factories as a first point of entry to the Canadian job market (Bisaillon, 2008b). Employment for these women in the manufacturing sector is often informal, irregular, seasonal and underpaid. Work in factory settings can also be undocumented and unregulated. Fatigue is a documented side effect of advanced HIV infection (Adinolfi, 2001). The fact that some jobs are less suitable for PHAs, for example manually intensive work, does not mean that newcomers to Canada do not engage in work practices in settings that are adverse to their health. Furthermore, if contribution to Canadian society is not framed to include unpaid labour that women engage in, then such investment in and engagement with Canadian society could readily be devalued or entirely unaccounted for (Gastaldo, 2004; Moussa, 1991).

Central messages for social work practice
While there are provincial variations in the ways newcomers with HIV experience health and social systems after arrival to Canada, the following suggestions are pertinent for social work practice across the country.

First, it is necessary to be aware of the broader sociocultural contexts. Discourses of health, wellness and sickness are constructions and reflections of a society’s normative value system. These are powerful communicators of the mainstream relationship with life’s milestones such as birth and death, including the esteem with which the sick are held. Such constructions have contributed to the tacit tendency—in practice, politics and policy—for culpability and intolerance of persons with chronic illness (Dubos, 1961). Social workers can imagine the world from the standpoint of the newcomer PHA, reflecting on how their cultural references and frameworks position them differently from clients and as “more aware of international issues” (Chitereka, 2009,
Newcomers to Canada discover sociopolitical processes and health systems that are often different from those in their country of birth. Critical awareness that the terms Canadians commonly employ—health, well-being, sickness and illness—are culturally situated is useful to understand the responses and effects of HIV upon newcomers (and their dependents and extended families). For example, in a pilot study with women applying for refugee status, informants problematized “health” (Text Box 4), while others avoided verbalizing the terms HIV and AIDS (Bisaillon, 2008a). Other informants in this research explained that they rejected the “sick” label, often employed by health providers, because they did not consider themselves to be ill, particularly when they were asymptomatic (of AIDS-defining illnesses). Descriptors assigned to migrant women such as “fragile” or “vulnerable” have entrenched the mystique of their vulnerability and de-emphasized their strengths, explaining the rejection of these descriptors by feminist scholars who debunk mythologies about migrant women (Moussa, 1993; Pittway & Pittway, 2004).

Second, independent of the setting (i.e., clinical, community, educational, other), social workers must plan interventions that take into account the complexities and ambiguities of overt and covert factors that have an impact on the health and well-being of newcomers to Canada living with HIV. Determinants of health are “the conditions in which people live and work that affect their opportunities to lead healthy lives. Good medical care is vital, but unless the root social causes that undermine people’s health are addressed, the opportunity for well-being will not be achieved” (Labonte & Schrecker, 2007, p. 2).

Text Box 5 summarizes a range of factors that reflect the determinants of health shown to influence the integration of newcomer PHAs in Canada (Bisaillon, 2008b, 2009). Of particular interest, HIV-related health concerns are eclipsed by seemingly more immediate, tangible and challenging factors (Galabuzi & Labonte, 2002; Lefranc, 2007; Marmot & Wilkinson, 2006; Public Health Agency of Canada, 2009). These factors may include, but are not limited to securing good quality, affordable housing; organizing family reunification and supporting absent families; deciphering and navigating the immigration system, including retaining legal counsel with adequate experience; and devising strategies for finding suitable employment in keeping with PHAs’ expertise and prior training.

In clinical settings, social workers will continue to play the complex role of mediator between medical staff and PHAs in the areas of client-patient advocacy, support with observing medicine regimes, client-patient understanding of medical jargon, education and prevention (e.g., condom use), access to medication, hidden health care costs and strategies for addressing stigmatization in personal and public spheres (e.g., workplace, child care). Critical and creative seeing, listening and doing from within a determinants-of-health framework will give the social worker an opportunity to gain a nuanced understanding of what the members of this subpopulation (and their families) may be experiencing after migration. With such a perspective, the social worker can be a strategic, upstream actor who connects the dots between individual, social and translocal factors—ones that converge to influence the quality and character of newcomer integration to Canada—that may otherwise go unnoticed or appear disparate.

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**Text Box 1**

**Immigration and HIV in Canada**

Persons from countries where HIV is endemic are over-represented in Canadian HIV prevalence (Haag & Gilbert, 2007). However, the overall number of HIV-positive applicants admitted to Canada is small, both in proportionate and in real terms relative to the increase in the population through immigration and the resident HIV-positive population. In Canada, there are an estimated 70,000 persons known to be living with HIV, with one third of these people unaware that they are HIV-positive (Canadian Public Health Association, 2006). In 2006 and 2007, there were 1,050 HIV-positive applicants for Canadian permanent residence (Tessier, 2008). Of these applicants, 994 were family members or persons in need of protection (i.e., refugee or refugee applicant) and eligible to remain in Canada. Many of these persons applied from countries in which HIV is endemic (Falconer 2005; Réseau des chercheures africaines, n.d.). Since mandatory HIV screening was inserted in the immigration medical examination in 2002, 258 PHAs have been inadmissible to Canada for anticipated prohibitive costs to public health and social systems (Tessier, 2008). Annually in Canada, “2,000 visa applicants are rejected on health grounds” (Wiebe, 2009, p. 135).

**Text Box 2**

**HIV stigma in Canada**

HIV stigma has been unevenly felt at different times in Canada. Belonging to a community with a high prevalence of HIV can mean that stereotypes and negative associations persist (Adrien, 1993; Adrien et al., 1999). For example, the label “4H” was introduced in household parlance in the 1980s, setting Haitians, homosexuals, heroine users and hemophiliacs apart from the Canadian mainstream (Gilmore & Somerville, 1994). While hemophiliacs living with HIV have aroused sympathy in practice and imagination because of the constructed meaning of their infection as victim of the contaminated blood affair (Orsini & Scala, 2006), the other groups within the “4H” category have not received the same empathetic treatment.

**Text Box 3**

**Practical considerations for social workers in Canada**

**TREATMENT**—Medicine for chronic conditions can come with unpleasant side effects as well as demanding and time-sensitive regimens (e.g., anti-retrovirals for HIV, insulin for diabetes). Newcomer PHAs are generally aware that access to medication is a life-saving opportunity. They are thankful for the care, support and access to subsidized drugs in Canada. Nevertheless, respecting the demands of medicine regimens is a considerable challenge for many people with chronic illness. Reluctance to taking medicines should not be construed as reckless resistance.

**Consider:** Some Canadian literature analyzes the complex relationship between pill-taking and PHAs. Social workers with newcomer PHA clients will find this literature relevant to their practice. See Making Care Visible, Research Group, 2002; McCoy, 2005; Mykhaylovskiy & McCoy, 2002. See also Kelleher (1988) on coping with the demands of chronic illness.

NUTRITION—Healthy diets are necessary to support the effectiveness of HIV medications. Social workers may refer PHAs to food banks, either those serving the general population or those tailored to PHAs. For numerous reasons, such as concern about stigma (i.e., being identified when frequenting services), loss of social status or shame (i.e., accessing government and other subsidies), PHAs may decide not to access services at food banks geared towards PHAs. The social worker refers the person to such services with the understanding that the person may or may not, for a complex set of reasons, actually act on the referral, and that it may take the person a long time to adjust to accessing cost-free services like food banks.

Consider: Social workers can consider accompanying clients to food banks. Alternatively, PHAs can be linked with service organizations for immigrants or people with AIDS that have buddy systems in place. In AIDS service organizations, peer outreach workers are often trained to accompany PHAs to medical appointments and other locations such as food banks.


DISCLOSURE—The decision to discuss a chronic health condition is a right that belongs strictly to the bearer of the condition. Under no circumstances should the social worker discuss the client’s health status without the client’s consent. Where the social worker deems it appropriate to disclose a client’s health status, a respectful, detailed and clear discussion must take place with the PHA about why disclosure by the social worker—to an AIDS service organization, fellow health provider or other party—is perceived as appropriate.

Consider: Disclosure of serostatus by the social worker can further stigmatize the health condition. Newcomers with HIV are often surprised that their personal health information is shared among colleagues in the form of electronic data sharing and during medical rounds in clinical settings. Discussions about how and when their personal information will (and will not) be discussed shrinks the power imbalance between the client and the social worker. Confusion and conflict can in this way be abated.

Resource (bilingual): www.catie.ca/Eng/LivingWithHIV/justdiagnosed.shtml

MIGRATION—This is a time of loss and gain, a notion that may be hard for Canadians to understand, particularly if they themselves have not themselves been immigrants. Migrant persons lose supports of all kinds when they resettle. Gaining new networks will happen, but will occur incrementally over time. In addition, many persons discover their HIV-positive status through Canadian immigration procedures and are often not favorable to disclosing their status over the telephone to persons in their country of origin. Concealing their serostatus (and possible denial), immigration delays and costs as well as family separation all generate stress. Basic needs (as per the determinants of health) are sometimes prioritized before biomedical health.

Consider: Social workers can learn the basics of the Canadian immigration system as it relates to the newcomer PHA. There are links at the websites below to national resources suitable for social workers. In every province, legal aid lawyers with expertise in immigration are available. It is often by word-of-mouth that lawyers with relevant expertise are identified.

Resources: www.catie.ca/eng/myh/ch17.shtml (bilingual); www.hivimmigration.ca/publications.html (English only); www.cleo.on.ca/english/pub/onpub/subject/refugee.htm (multilingual fact sheets, audio links); www.cic.gc.ca/english/resources/publications/index.asp#immigrating (range of bilingual government publications)

Source: Author’s collaboration with N. Alain, 2010
Themes voiced by HIV-positive women refugee applicants to Canada

1. There is a universal quality to health; health is synonymous with life.
2. Organized religion provides comfort, security and hope; it can be of vital importance.
3. Learning and sharing occur as a result of trusting relationships cultivated overtime with fellow HIV-positive women and recognizing differences between women.
4. Immigrating is a stressful process, and impediments to easily adapting to Canada induce sustained worry over time (often linked to financial health).
5. HIV status is but one of a multitude of factors that make post-migratory life complex.
6. HIV is a serious condition that changes a life, both in terms of health and social status.

Source: Bisaillon, 2008a

Factors affecting integration of newcomers to Canada affected by HIV

1. Stigmatization in a professional or personal milieu
   - Stigma, both real and perceived, of HIV and the PHA in the context of a “healthy” country (i.e., where HIV is not endemic and where life expectancy is long)
   - Advantages and disadvantages of accessing services and employment as related to HIV status (i.e., categorization of the PHA as “disabled”; provincial variations in health and social services)

2. Bureaucratic delays associated with official procedures
   - Securing working permits
   - Appearing before the Immigration and Refugee Board of Canada (i.e., protracted delays and hearing postponements; reliving traumatic events through retelling in a “performance” to government officials)

3. Legal system challenging to navigate
   - Official costs and processes associated with obtaining legal counsel
   - Masked costs in retaining legal counsel (i.e., monetary “incentives” requested by lawyers)

4. Refugee and immigrant support services
   - Ad hoc or disjointed connection between services (i.e., housing, food bank, health, social, legal, education)
   - Connections contingent on goodwill and established networks of care providers (i.e., often social workers)

5. Secular and individualist society
   - Different world views (ontology) from those seemingly held by mainstream Canada
   - Predominantly secular society with disconnect to spiritual supports

Source: Bisaillon, 2008a, 2009
References


### Biographical notes

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