

## **Accéder aux services de santé quand on vit avec le VIH/sida : la stigmatisation en tant que conjonction de facteurs**

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Lynne MacLean et Frances Reintjes**

La stigmatisation associée au VIH/sida a de lourdes conséquences. Nous avons cherché à examiner les pratiques qui, au sein des établissements de santé, sont perçues comme étant stigmatisantes par les personnes vivant avec cette maladie. De nature exploratoire et descriptive, notre étude s'inscrit dans une approche de recherche-action participative. Nous avons mené des entrevues et des groupes de discussion auxquels ont participé 16 Autochtones et 17 non-Autochtones vivant avec le VIH/sida, ainsi que 27 prestataires de soins de santé. La stigmatisation ressentie par de nombreux participants se conjugue souvent à d'autres facteurs qui accentuent cette perception, et qui sont associés au comportement, à la culture, au sexe, à l'orientation sexuelle ou à la classe sociale. On a constaté également que les politiques organisationnelles contribuaient à la stigmatisation et qu'elles se conjugaient parfois aux facteurs individuels. Les expériences de la stigmatisation et de la discrimination sont façonnées par les politiques organisationnelles (précautions universelles, modèles de prise en charge) ainsi que par l'aménagement (la disposition matérielle) des lieux où sont dispensés les soins. On a relevé dans les témoignages des participants un certain nombre de paradoxes relatifs au respect de la vie privée, au cadre de prestation des soins et à la conjonction des facteurs de stigmatisation.

Mots clés : accès aux services de santé, VIH/sida, Autochtones

# **Accessing Health Services While Living With HIV: Intersections of Stigma**

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AIDS stigma has serious consequences. This study explored those practices within health-care organizations that persons with HIV perceive as stigmatizing. It used an exploratory, descriptive design using a participatory action research approach. Interviews and focus groups were conducted with 16 Aboriginal and 17 non-Aboriginal persons living with HIV as well as with 27 health-care providers. The AIDS stigma perceived by many participants often intersected with other forms of stigma, related to behaviour, culture, gender, sexual orientation, or social class. In addition, policies at the organizational level contributed to AIDS stigma and at times intersected with stigma at the individual level. Participants' experiences of stigma and discrimination were shaped by the organizational policies (universal precautions, models of care) and design (physical layout) under which care was provided. Several paradoxes associated with secrecy, health-care settings, and the layering of stigma emerged in the reported experiences.

Keywords: access to care, AIDS, chronic illness, health services, HIV Aboriginal

## **Introduction**

Early in the AIDS epidemic, the stigmatizing of individuals with HIV was identified as a serious concern (Herek & Glunt, 1988). It was reasoned that AIDS stigma was due to the association of the disease with death and with marginalized groups such as gay men. Since that time, there has been much discourse on the phenomenon of AIDS stigma. Stigmatization is a social process “characterized by exclusion, rejection, blame or devaluation that results from an adverse social judgment about a person or group . . . based on an enduring feature of identity attributable to a health problem” (Weiss & Ramakrishna, 2001, p. 4). The concept of stigma and its application has been challenged as stigmatizing itself, and the notion of discrimination has been proposed as a more appropriate descriptor of the social process of exclusion (Sayce, 1998).

The purposes of this study were to explore stigmatizing practices within health-care organizations from the perspective of persons living with HIV (PHAs), both Aboriginal (APHAs) and non-Aboriginal, and

health-care providers (HCPs) and to recommend interventions to mitigate AIDS stigma. This article highlights experiences of both stigmatization and discrimination.

AIDS stigma is important for HCPs because of its serious consequences: Stigma has the potential to limit prevention (Des Jarlais, Galea, Tracy, Tross, & Vlahov, 2006), to act as a barrier to diagnosis and appropriate treatment (World Bank, 2007), and to induce psychological stress and reluctance to access health services (Des Jarlais et al., 2006; Mwinituo & Mill, 2006). Individuals who are HIV positive may conceal their diagnosis in an attempt to mediate the effects of stigma (Des Jarlais et al., 2006; Mwinituo & Mill, 2006; Ware, Wyatt, & Tugenberg, 2006). Thus, concealment is a primary pathway linking the experience of stigma and health-care utilization. Concealment has profound implications for the individual and, in the case of stigmatized conditions that are infectious, implications for public health (Des Jarlais et al., 2006).

Health-care providers have been identified as a significant source of stigmatization and discrimination for PHAs (Mwinituo & Mill, 2006), and health-care practice is the most common context in which PHAs experience stigmatization (Reidpath & Chan, 2005a). Stigma can be exhibited through poor quality of service or differential treatment by HCPs (Rutledge & Abell, 2005). Research on the attitudes of HCPs towards individuals with HIV infection, however, has identified both supportive and stigmatizing attitudes (National AIDS Research Institute, 2003). Although HCPs may have positive attitudes towards PHAs, they can display behaviours that result in their clients being stigmatized or perceiving that they are being stigmatized (Mawar, Saha, Pandit, & Mahajan, 2005). This apparent lack of congruence between attitude and behaviour may be partially explained by the difference between “enacted” and “felt” stigma. Enacted stigma refers to individual or collective sanctions against an individual, whereas felt stigma refers to fear of enacted stigma (Green, 1995).

Individuals who are already marginalized in society and who develop a stigmatizing condition such as HIV infection may experience a layering or double burden of stigma (Mawar et al., 2005; Reidpath & Chan, 2005b). Reidpath and Chan (2005b) argue that “there needs to be an understanding of the layering of stigma so that informed policies and interventions can be developed that will address the entire experience of stigma” (p. 431). AIDS stigma may be layered with and connected to race, sexual orientation, physical dis/ability, class, and gender (Skinner & Mfecane, 2004).

Globally, many authors and reports have highlighted the stigmatization and discrimination experienced by persons with HIV and AIDS (Bereket et al., 2006; Herek, Capitanio, & Widamen, 2002; Holzemer et

al., 2007; World Bank, 2007). Despite the vast literature on the stigmatizing experiences of PHAs, there has been limited rigorous research on the impact of stigma on AIDS care (Holzemer & Uys, 2004). Although Canadian studies (Olivier & Dykeman, 2003; Worthington & Myers, 2003) have documented stigmatization and discrimination with respect to PHAs, we found no published research exploring this phenomenon.

In this article we present findings related to the intersections of stigma at the individual and organizational level and highlight paradoxes that emerged in relation to the participants' experiences of stigma. Illustrative quotes (using pseudonyms and with identifying information removed) are used to highlight themes. Findings related to the unique experiences of Aboriginal persons living with HIV (APHAs) will be published separately.

### **Design and Methods**

An exploratory, descriptive design using a participatory action research (PAR) approach was employed. Participatory action research helps to ensure research relevance for individuals and communities and is an appropriate research design for use with Aboriginal communities (Macaulay et al., 1998). Its fundamental principles include a collaborative relationship with the research partners (Reason, 1994) and a valuing of popular experience and knowledge (Fals-Borda, 1991). Participatory action research is a spiralling process that involves planning, acting, observing, and reflecting (Kemmis & McTaggart, 2005). Several strategies were employed throughout the project to develop and maintain collaborative relationships with our partners and to ensure that their knowledge and experience were used. Following ethical approval, community advisory committees (CACs) were formed at each site to provide guidance on ethical implications, cultural perspectives, implementation, analysis, and dissemination strategies for the study. The CACs included representatives of Aboriginal communities, PHAs and APHAs, consumer groups representing PHAs and APHAs, and agencies providing services to PHAs and APHAs. Terms of reference for the CACs were developed in consultation with the committees.

Community consultation workshops were also used to engage our community partners. Following preliminary data analysis, 97 Aboriginal and non-Aboriginal community partners attended a 1-day workshop in one of three Canadian cities. The purpose of the workshops was to meaningfully engage HCPs and decision-makers providing health services to APHAs and PHAs in the design of an intervention to reduce AIDS stigma. Following an overview of the key findings from the research project, the workshop participants were asked to help design the

intervention. The development of best practice guidelines (Mill et al., 2007) for the provision of health services to PHAs and APHAs was an outcome of this process and is described elsewhere.

In-depth interviews and focus groups were used to collect data between 2003 and 2006 at two study sites, Edmonton and Ottawa, Canada. At each site, four health-care organizations were purposively selected. These included both small and large organizations using a variety of approaches to care delivery (e.g., acute care, primary health care) and providing access to Aboriginal populations. Recruitment within these organizations helped to ensure the inclusion of Aboriginal peoples, who are over-represented in HIV and AIDS statistics (Public Health Agency of Canada, 2007). Convenience and network sampling were used to recruit participants. During an interview, PHAs were asked to relate their experiences with HIV generally and their experiences accessing services specifically. Following initial analysis, HCPs were asked to participate in an interview or focus group in order to reflect on the themes identified in the PHA interviews, including those practices that had been identified as stigmatizing. The interviews were conducted primarily by the research coordinator at each site and lasted 1 to 2 hours. Focus groups with HCPs took place on the premises of one of the participating organizations, were conducted by two members of the research team, and lasted approximately 2 hours. All interviews and focus groups were conducted in English. Guiding questions were used to maintain a balance between consistency and flexibility (May, 1991). The data-collection process was iterative and reflective, with data from the PHA interviews informing and guiding data collection with the HCPs.

The inclusion criteria for PHAs were: over the age of 18; English- or French-speaking; not currently a hospital in-patient; living in Canada at least 3 years; having accessed health services in the past 2 years. Inclusion criteria for HCPs were: English- or French-speaking; health professional or community worker at one of the participating organizations. Due to resource limitations, the research team was unable to conduct interviews in an Aboriginal language.

Ethical approval was obtained from the research ethics boards at the University of Alberta and the University Ottawa, while community approval was provided by the CACs. Each PHA was given \$25 as compensation for his or her time, while compensation for the HCPs' time was provided to their organization, to minimize the likelihood of HCPs feeling coerced to participate. One person at each organization assisted with recruitment. Informed consent was obtained from all participants. The interviews and focus groups were audiotaped and transcribed verbatim. The principal investigator, members of the research team, and

the research coordinators developed a coding framework that was revised during team meetings. The principal investigator worked closely with the research coordinators and re-analyzed several of the interviews analyzed by them to ensure accuracy. The analysis process took place simultaneously with data collection, using the qualitative software program QSR\**N6* to assist with labelling, revising and retrieving codes, and writing memos. Matrix methodology techniques described by Miles and Huberman (1994) were applied. First-level analysis was used to assign a descriptive code (label) to a segment of the data to give it meaning. As the researchers became more familiar with the data, pattern coding was used to label emerging themes. An inductive approach was used to analyze the data involving, iteratively, coding and identifying themes and discovering relationships among themes via systematic comparisons using negative cases and extreme cases. Decisions made during analysis were documented to ensure that the process was auditable, thereby enhancing consistency of the analysis (Sandelowski, 1986).

Strategies to ensure rigour in conducting research with marginalized populations (Meleis, 1996) were incorporated into the research design. The study attempted to document one aspect of the *context* of the lives of PHAs. The literature review substantiated the *relevance* of the issue of stigma for PHAs and its potential impact on access to health services. Providing opportunities to address the goals of not only the researchers but also the participants resulted in *reciprocation*. The involvement of PHAs and the use of CACs also helped to ensure that the relevance, context, and reciprocation criteria were met. In addition, the CACs helped to ensure that any *power differentials* between the research team and the participants were acknowledged. Inviting representatives from consumer groups to participate in the CACs fostered the *empowerment* of PHAs. The use of open-ended interviews was congruent with the *communication styles* of the Aboriginal participants in that it acknowledged traditional storytelling methods. A *flexible approach to time* was necessary throughout the study to enable the development of collaborative relationships based on trust and respect. Ensuring confidentiality of the data and anonymity of the participants also helped to build trust and to encourage participants to *disclose* their experiences. Finally, the use of PAR, the development of Principles for Research Collaboration for both community and academic partners, adherence to the principles of Ownership, Control, Access, and Possession (Patterson, Jackson, & Edwards, 2006), and the involvement of Aboriginal investigators helped to ensure that the research was authentic, rigorous, and culturally appropriate.

## Findings

The sample included 16 Aboriginal and 17 non-Aboriginal PHAs. The term Aboriginal as used in this study includes individuals who identify as Métis, First Nations, or Inuit regardless of Treaty status (Ermine, Sinclair, & Jeffrey, 2004). The average age of PHAs was 40.6 years (range: 31–56 years) and their gender was male (22), female (9), or transgender (2). The primary mode of HIV transmission for the sample was injection drug use (IDU) ( $n = 17$ ) and men having sex with men ( $n = 16$ ). The sample also included 27 HCPs (3 male; 24 female) from diverse disciplines: nursing, medicine, social work, psychology, community development, dentistry, infectious diseases, and laboratory medicine. Of the 27 HCPs, 7 took part in focus groups and 20 in individual interviews. The HCPs were recruited from the eight participating organizations reflecting a wide range of work settings, including small community health centres, infectious disease clinics in large referral hospitals, and AIDS service organizations (ASOs). A few of the HCPs worked in non-specialized health-care settings and provided care for PHAs as required.

Persons living with HIV described both physical and emotional responses to their HIV diagnosis. Many of the participants were dealing with a dual diagnosis, including hepatitis C or tuberculosis. Almost all of the participants reported cyclical periods of wellness punctuated by bouts of illness. Emotional responses to HIV and AIDS were related to the fear of dying or being rejected and were manifested in feelings of hopelessness, depression, and social withdrawal, with some participants increasing their substance use as a means of coping.

Participants believed that negative societal views of HIV and AIDS were based on ignorance, including ignorance about the difference between HIV and AIDS, and negative media portrayal of PHAs. Ethan (age 36) captured the essence of this sentiment: “If you’re HIV positive, you’re treated like you were never part of the status quo in society.” Several of the participants stated that the public still puts the blame on individuals who are HIV positive, depending on how they have become infected.

### *Intersections of Stigma*

**Individual layering of stigma: “You’re a triple target.”** The AIDS stigma experienced by many of the participants often intersected with other forms of stigmatization and discrimination, resulting in layering, or a double (or triple) burden of stigma. This occurred when an individual became infected through a behaviour that was highly stigmatized (e.g., IDU, commercial sex work), belonged to a culture (Aboriginal), gender (female), sexual orientation (e.g., transgendered, gay), or social

class (e.g., poor, prisoner) that was vulnerable to stigmatization, or had another illness (e.g., mental illness) that was stigmatized. There was a sense that overt stigmatization and discrimination had decreased over time. Interestingly, some participants believed that being gay and/or an IDU was more stigmatizing than being HIV positive. For example, one man believed that his associates were more shocked by his homosexuality than by his HIV disclosure, while another stated that there was “more stigma . . . in my life right now with regard to being a drug addict than there is [with] my HIV and hep C status” (Louis, PHA, age 43). Some PHAs did not believe that they were treated differently due to their membership in “other” groups (e.g., gay, IDU, Aboriginal) or were unsure which of their personal attributes resulted in stigmatization. Oliver, who was gay, summed up the layering of stigma in a powerful manner:

*Hatred is a terrible thing, and when you're a victim — if you're Black, or a religious designation, or social or sexual orientation, and somebody picks on you and you don't know who it is . . . So you've got to be very careful when you fall into a category . . . imagine if you're Jewish with HIV and you're gay — you could be . . . a triple target in certain areas of society. Or how Natives are picked on and . . . stereotyped . . .* (Oliver, PHA, age 45)

A number of participants experienced discrimination because they were gay, Aboriginal, or female. Some participants described negative encounters with homophobic HCPs. Aaron had had a traumatic experience with a nurse during hospitalization:

*I kept my voice down and I said, “Well, I'm HIV positive.” And she went, “What?” I said [whispering], “I said, I'm HIV positive.” And she just had a blank look on her face and she walked out to another nurse and she said, “Why didn't you tell me there's a fag in there that has AIDS?”* (Aaron, PHA, age 37)

Several participants commented on the heightened stigma surrounding AIDS in Aboriginal communities. One woman said, “Natives are scared to tell their family . . . because their family won't have anything to do with them” (Megan, PHA, age unknown). Some Aboriginal participants shared racist comments that had been directed at them. Fred was dealing with multiple stigmas:

*. . . I caught it. It was really kind of like a Black labelling almost. “Watch that guy, he's HIV,” you know, like there was a lot of ignorance toward it. I just didn't want to be put in that category, because I was already dealing with a lot of other issues . . . one, being Native, [pause] two, being in jail because I'm, you know, a Native.* (Fred, PHA, age 32)

A few Aboriginal participants, however, did not feel that they had been treated differently:

*No, I don't think so. I don't think I've ever had an experience where someone's treated me differently . . . because I'm Aboriginal. No, I've never. No, it's never been a problem.* (Otto, PHA, age 31)

Gender intersected with AIDS stigma through societal attitudes towards women. Jane, an HCP, believed that women experienced more stigma and discrimination because an HIV diagnosis is associated with being “loose” and having “slept with a lot of men.” This view was echoed by several of the PHAs, who felt that women were discriminated against when they accessed health services.

**Organizational layering of stigma: “Radar, radar.”** Policies and practices at the organizational level contributed to AIDS stigmatization and discrimination, and at times intersected and overlapped with stigmatization at the individual level. Participants’ experiences were shaped by the organizational policies (universal precautions, models of care) and design (physical layout) under which care was provided. The consistent use of universal precautions was considered essential to safe practice yet also stigmatizing. Decision-making related to the use of gloves was a complex issue for some HCPs. For example, an HCP might decide not to use gloves to demonstrate their comfort with the HIV-positive patient, thus protecting neither themselves nor the patient. One HCP said that a client told her, “As soon as I say I’m HIV positive, they double-glove.” Another HCP recalled that some of her colleagues used the phrase “radar, radar!” to communicate a client’s HIV status to other HCPs. Despite universal precautions, participants’ experiences revealed that fear of contagion can result in inequitable treatment. A dentist recalled a disturbing incident in her private practice. She was seeing a client with hepatitis C when a colleague approached her and said:

*“Be careful, he’s hep C positive.” I was almost disgusted with that. I just said to her, “You know, it really doesn’t matter. It shouldn’t matter to you whether he’s [got] hepatitis C . . . Are you not as careful with all your other patients? Because they just may not be telling you if they have a transmissible disease.”* (Belinda, HCP)

Health-care providers suggested that models of care, including specialized HIV services, impacted on stigmatization and discrimination. They expressed a preference for AIDS-specific organizations or units where staff are knowledgeable about the diagnosis and treatment of HIV and AIDS:

*If they go to a facility or place that doesn't routinely provide care to HIV-positive people, then it's like there's this level of discomfort that the staff have, because they don't do it on a day-to-day basis, so they don't think about how their behaviour might make a person feel. (Eunice, HCP)*

However, another HCP suggested that treating HIV-positive clients differently is discriminating in itself. Some PHAs also said that being treated differently based on HIV status might contribute to discrimination. For example, Fiona felt very uncomfortable when offered different food at a shelter:

*When I have to get special foods at a shelter, . . . they [non-HIV-positive clients] get jealous. . . . I used to get mad and say, "Hey, you can have what I eat if [you] want my disease . . . I don't wish it on you." (Fiona, PHA, age 40)*

All participants, HCPs and PHAs alike, suggested that a flexible approach to service provision was essential to delivering non-discriminatory health services. Many of the HCPs reported that their own organization tried to adopt this approach. For example, several of the organizations tried to accommodate clients who were "under the influence" as long as they were not disruptive. The smaller ASOs, health centres, and drop-ins were very aware that the client behaviours they tolerated would not be acceptable to mainstream organizations. Their tolerance reflected a commitment "to serve the most difficult to serve" (Brian, HCP). The following comment by Wilma reflects this flexibility and the "harm reduction" philosophy of her organization:

*Normally when we have [traditional Aboriginal] medicines in our room, people under the influence shouldn't actually be coming in, but I've been really flexible in allowing them to come . . . because if they come a little bit under the influence of something today, next week they may make an effort to come sober or to come clean. (Wilma, HCP)*

The design and organization of services, including physical layout, could also contribute to an individual's experience of stigma. The assurance of confidentiality was particularly important in relation to physical layout. Participants explained that they were reluctant to verbally state why they had an appointment when they arrived at an organization:

*She [receptionist] wants to know why you want to see your doctor. There's a room full of junkies and people behind me, no partition in between us, and she wants to know or she wants me to explain to her why I'm there to see my doctor. I don't see what business it is of hers. If I want to see my doctor, that's my right. (Ethan, PHA, age 36)*

Similarly, participants did not want to be identified as HIV positive because they were accessing care at a particular organization:

*Having . . . our building identified [as an ASO] is appalling to me. I don't think that we need to put "HIV" up at the front of our building . . . People need to be able to come in and out of here without that stigma being attached to them. (Dennis, PHA, age 41)*

Some of the health-care facilities addressed this concern by ensuring that non-HIV services were offered at the same time as AIDS-specific services:

*We were always infectious disease, but there were certain days just HIV. So what we try to do now is we put other patients in, so we have different clientele in the waiting room. So this way, you don't know why [a person is] there. (Haley, HCP)*

As participants described their experiences of stigma, several paradoxes emerged in relation to their strategies to mitigate stigma and the types of services that they accessed.

### **Paradoxes of Stigma**

**Secrecy versus disclosure.** There was tension between the participants' need to keep their HIV diagnosis secret and their need to disclose it to family members and health-care workers. This created a paradox in that some PHAs used secrecy to mitigate the impact of stigma and others saw disclosure as an essential strategy for reducing stigma. Ethan argued that secrecy accentuates stigma:

*You're encouraged not to tell people because of the stigma attached to it. But if more people would tell people, there would be less stigma because more people are involved. Confidentiality is the creator of some of the stigma that surrounds our illness. (Ethan, PHA, age 36)*

Failure to disclose HIV status was associated with failure to access health services and with treatment delays. Decisions about disclosure were often made on a "need to know basis":

*I haven't told anybody that didn't need to know. I wouldn't, like, walk down with a placard on my back saying, "I've got HIV. What do you think of me?" I wouldn't want to try that — probably end up dead. (Cecil, PHA, age 48)*

Participants with more than one infectious disease sometimes kept their HIV status secret but disclosed a less stigmatized illness. A hepatitis B or C diagnosis was perceived to garner less stigmatization and discrimination and therefore was at times disclosed instead of the HIV-positive

diagnosis. Both Dorothy and Cecil had been advised by HCPs not to disclose their HIV status:

*[The doctor] was very good about [it], but he told me if I ever go to the hospital or anything else just tell them I have hepatitis C, do not tell them I have HIV . . . When I came in the hospital I said, "I have hepatitis C," and they were really good . . . and then I told them I had HIV and their attitude completely changed. (Dorothy, PHA, age 45)*

*The doctor said, "You don't have to go out and tell them you've got HIV now, because they already know you have hep C. They'll take the same precautions as if — as they do for HIV." (Cecil, PHA, age 48)*

For Dorothy and Cecil, hepatitis C was used as a means to mitigate stigma.

**Health-care settings.** The care setting provided another paradox of the stigma experience. Several of the participants had different experiences, depending on whether care was provided in rural or urban settings. However, the findings were not consistent. Most participants found that care in a smaller setting was more stigmatizing. Aaron had had a disturbing experience while on vacation:

*I was rushed to hospital in [small town]. It's a country hospital and I whispered very quietly to the emergency room nurse, "I'm HIV positive." And she goes, "Okay, the kid's HIV." And she yells it out and it's busy and it was my first time since this whole thing started — outside my little cluster — that I've had to deal with non-professionalism. (Aaron, PHA, age 37)*

A few participants, on the other hand, found care in a small town to be superior to that in a larger centre. Ethan shared an experience accessing care in a small town:

*I had a lung infection while I was out there, and I had to go to a small-town hospital. And I got better care there than I ever received in the city. And yet they don't deal with it on a daily basis [laughs] . . . But there was no freaking out. There was none of this "Quick — get the gloves!" . . . [laughs] There was none of that kind of stuff from them. They were very professional. (Ethan, PHA, age 36)*

This finding challenges the premise that urban settings are more likely to have health-care providers who are experienced and educated in AIDS care and who consequently are less likely to provide discriminatory care.

With the changing epidemiology of the illness, more HIV-positive women are accessing health services. Despite this change, a few participants noted that HIV-positive heterosexual women might have more

difficulty accessing care because they are identified as part of mainstream culture. Also, because many of the AIDS services have been developed by and for gay men it was thought that women might not feel comfortable using them. Aaron summed up the issue:

*The people who get the raw end of the deal, really, are straight women whose partners or husbands cheat on them, become carriers, [and] infect the women. These women have no place to go, because they're not lesbians, they're not gay.* (Aaron, PHA, age 37)

At times, AIDS services that had been developed primarily in response to the needs of gay men became stigmatizing and non-responsive to the needs of women.

**Layering of stigma.** Although layering was a potent force in fuelling stigma, the relationship between each element of the layer was complex and at times unexpected. For example, Ethan was living with both mental illness and HIV and he was able to obtain some financial benefits because of his HIV diagnosis:

*They're much more giving to people that are [HIV] positive than to people that have mental illnesses . . . I could not function in society because of my mental health. I was depressed, anxious, and paranoid . . . but that's not a reason to put a person on [disability income].* (Ethan, PHA, age 36)

The physical diagnosis of HIV, in comparison to the less visible diagnosis of mental illness, provided the evidence he required to qualify for disability benefits.

## Discussion

The findings on the physical and emotional responses to HIV reinforce our existing knowledge, while those related to the intersections and paradoxes of stigma provide new insights into this complex phenomenon. Both covert and overt forms of stigma were described by the participants. A recent Canadian study (Bereket et al., 2006) also documents the ongoing presence of stigma while suggesting that stigma may be more “difficult to detect and insidious” now (p. 17) than it was during earlier phases of the epidemic. Similarly, an American study (Herek et al., 2002) reports that during the 1990s expressions of overt stigma declined while more covert forms of stigma persisted and in some cases increased.

Disclosure of HIV status continues to be problematic due to fears about stigmatization and discrimination. Participants in a recent American study (Ware et al., 2006) invested a great deal of effort in concealing their HIV status to avoid stigma, and even compromised adher-

ence to antiretroviral therapy in order to safeguard social relationships. Our findings are of particular concern because of the difficulties encountered by PHAs in disclosing their HIV status not only to families and communities but also to HCPs. These results have profound implications for the provision of care and treatment of HIV and AIDS.

The findings suggest that AIDS stigma presents several paradoxes. *Secrecy* was considered by some participants to be essential to mitigate stigma when accessing HIV treatment. However, some participants viewed secrecy as the “creator of stigma surrounding the illness” (Ethan, PHA, age 36). A *health-care setting* established specifically for the gay community became stigmatizing for women who were heterosexual and thus a minority in that setting. *Rural health services* were more stigmatizing for some participants, while others found them to be superior to those in urban settings. Finally, although *layering of stigma* is assumed to increase its burden, for some participants the dual diagnosis of HIV and hepatitis B or C may have served to mitigate AIDS stigma.

Layering, or the double burden of stigma experienced by persons with HIV, was identified early in the epidemic (Kowalewski, 1988) and is consistent with our findings related to the intersection of multiple stigmas. Women with HIV may well be enduring more stigma than men (International Center for Research on Women, 2006). Researchers have argued that disentangling and assessing the layers of HIV-related stigma are critical to the development of effective interventions (Reidpath & Chan, 2005b). They suggest that stigma may be unique (e.g., related to IDU or bisexuality), shared (overlapping stigma from two attributes), or synergistic. Reidpath and Chan’s conceptualization of stigma, though an important contribution, fails to acknowledge stigma that operates beyond the individual level.

In our study, AIDS stigma at the individual level often intersected with social stigma related to gender, Aboriginal background, sexual identity, and organizational policies and norms. Conceptualizations of stigma must move to explanatory frameworks that acknowledge the social and structural influences on AIDS stigma (Parker & Aggleton, 2003). Interventions to address AIDS stigma must “be complemented by actions that have as their starting point the deeper social, political and economic causes of stigma and discrimination” (Parker & Aggleton, p. 21).

The experiences of stigma at the individual level intersect and overlap with the broader context of health care, including health-care providers, the health-care system, and society. This makes it difficult for HCPs and PHAs to mitigate stigma. The development of effective interventions must be predicated on an understanding of the context of AIDS stigma (Skinner & Mfecane, 2004). Holzemer and colleagues (2007) conclude that stigmatization occurs in the context of the environment, the health-

care system, and individual agents. The narratives of the participants in our study demonstrate the complex and layered nature of AIDS stigma and the complexity of the task of disentangling those layers to develop interventions.

During the process of analyzing the data, the research team became increasingly aware that the narratives of the PHAs were very similar to those of the HCPs, even though the guiding questions were different. The similarity may be related to the data-collection settings. Because they were recruited from settings that provide services to PHAs, the HCPs may have been particularly sensitive to the issues faced by this population. This finding may highlight a limitation of the study: homogeneity of participating sites. We recommend that future researchers sample a wider range of health-care organizations, to ensure that the HCPs have a broad range of experience in working with PHAs. Also, given the variety of Aboriginal groups and provincial health-care systems across the country, and their intersections with the federal health-care system dedicated to Aboriginal needs, future research could include replication in other regions. This not only would allow for comparison across sites but would elicit information on specific intervention needs across Canada. Generalization using quantitative methods could be explored as well. Further research is also needed to determine the best entry point for reducing stigma when it is layered, as well as to evaluate the interventions designed as a result of the community consultation workshops.

## Conclusion

The findings from this study provide a compelling account of the ongoing experiences of multi-layered stigma among persons living with HIV and AIDS in Canada. The use of universal precautions, the model of care, and the design of services could either contribute to or reduce the experience of stigma. The findings also suggest that AIDS stigma presents many paradoxes. Therefore, a single approach to health-care delivery intended to reduce AIDS stigma will be insufficient to meet the needs of all clients. The development of interventions to create an environment of care that mitigates AIDS stigma is a complex and multi-level process. This is the goal of the next phase of our project and will be the focus of a future publication.

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