The Influence of Stigma on Access to Health Services by Persons with HIV Illness

A community based research project

The Influence of Stigma on Access to Health Services by Persons with HIV Illness

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Final Report
September 2007

This report is dedicated to Dwayne Norris and Kevin Armstrong

who passed away while the research project was in progress.

Dwayne and Kevin were members of the Edmonton and Ottawa Community

Advisory Committee respectively. We are deeply indebted to their valuable

input and involvement with the project.

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Executive Summary

This report presents findings from the CIHR-funded research project titled: *The Influence of Stigma on Access to Health Services by Persons with HIV Illness*. The purpose of this report is to present an overview of the key findings from the project and the strategies (current and planned) to disseminate the findings. A more in-depth discussion of the study findings will be presented in the published papers that are currently being written.

The **purpose** of this research was to develop an intervention for the provision of health services to persons living with HIV that mitigated the impact of stigma and optimized access to appropriate health care. The **objectives** of the research were to: explore the practices in health care organizations that persons living with HIV perceived to be stigmatizing; develop an optimal design for health service delivery to eliminate stigmatizing practices; and describe the process required to reorient health services to incorporate the optimal design.

Design and Methods

Participatory action research (PAR) was used for the study, as it was the most appropriate design to answer the research questions. Data collection methods for the study included interviews, focus groups, and a document analysis. The study was conducted in collaboration with eight organizations in Ottawa and Edmonton between 2003 and 2006. Research capacity-building workshops were also conducted between November 2006 and February 2007 with our Aboriginal and non-Aboriginal community partners to design an intervention to reduce AIDS stigma and to develop dissemination plans for the project. Principles of ownership, control, access, and possession (OCAP) for research involving Aboriginal communities guided the project. Four health care organizations at each site, representing small and large organizations and using a variety of different approaches for the delivery of health care services to persons with HIV participated and assisted with the recruitment of participants. Participants included both persons living with HIV and health care providers working in the participating organizations. The multi-site, multi-organizational design enhanced the research team's understanding of the context of AIDS stigma in different settings.

Following ethical approval from the Universities of Alberta and Ottawa, local community advisory committees (CACs) were formed at each site to provide input on the ethical implications, cultural considerations, implementation process, and the dissemination of the findings from the study. The CACs included representatives from Aboriginal communities, persons living with HIV (PHAs), Aboriginal persons living with HIV (APHAs), and agencies providing services to PHAs and APHAs. Further, two of the investigators were Aboriginal and provided an Aboriginal perspective throughout project design, data collection, analysis, and interpretation.

The data collection process was iterative, with data from one source informing and guiding the data to be collected from other sources. For example, health care provider participants were asked to reflect on the practices that were identified by PHAs and APHAs as

stigmatizing and were asked to suggest changes that could be made to eliminate or minimize the impact of these practices.

Analysis

Interviews and focus groups were audio taped and transcribed verbatim. The process of analyzing the data from the interviews with PHAs and APHAs occurred simultaneously with data collection. The qualitative software program QSR N6 was used to assist with the labeling, revising and retrieving of codes. An inductive approach to analysis involved iteratively coding and identifying themes and discovering and disconfirming relationships among themes via systematic comparisons using matrices, negative cases and extreme cases. The focus groups and interviews with health care providers (HCPs) were similarly analyzed, and findings compared to the issues emerging from the data from APHAs and PHAs.

Findings

Convenience and network sampling were used to recruit Aboriginal persons living off reserve and non-Aboriginal participants for the study. In-depth interviews with 33 persons living with HIV, including 16 Aboriginal persons and 17 non- Aboriginal persons were completed. Many of the PHAs and APHAs lived very complex lives that included dealing with issues related to mental health, addictions and housing. Twenty-seven HCPs from the medical, nursing, social work, dental, and psychology professions participated in an interview or focus group. Seven of the HCPs participated in focus groups, while 20 participated in individual interviews. Concurrent with the interviews and focus groups with HCPs, the policies and practices from eighty-five local, national and international organizations were analyzed to identify those that might promote or inhibit stigma.

PHAs and APHAs described both physical and emotional responses to their diagnosis with HIV. In addition to being HIV positive, many of the participants were also dealing with other health issues such as Hepatitis C and tuberculosis. Almost all of the participants reported living through cyclical periods of wellness punctuated by bouts of illness. Emotional responses to HIV and AIDS were often related to the fear of dying or being rejected by others and were manifested in feelings of hopelessness, depression, and withdrawal from others. This resulted in some participants coping with their diagnosis through increased substance use. More than half of the APHAs and PHAs reported living with mental health issues, including stress and depression.

According to participants, AIDS remains a stigmatized illness in society that influenced the process of disclosure and often necessitated secrecy about their illness. Participants believed that negative views about HIV and AIDS were based on ignorance, the media portrayal of people with HIV and AIDS, and a lack of understanding of the difference between HIV and AIDS. Several participants felt that in their experience, the public still attributed blame to individuals who were HIV-positive, depending on how they became infected.

Most of the participants living with HIV experienced a layering, or a double (or triple) burden of stigma because they had become infected through a behaviour that was highly stigmatized (injection drug use [IDU], gay, commercial sex work), belonged to a culture (Aboriginal), gender (female), or social class (poor, prisoner) that was vulnerable to stigmatization or suffered from another illness (mental illness) that was stigmatized. Interestingly some of the participants believed that being gay and/or being an IDU was actually more stigmatizing than being HIV-positive.

The stigma and discrimination experienced by participants within health services varied depending on the social and environmental context in which care was provided. A positive, trusting relationship with HCPs was fundamental to the provision of non-discriminatory care. The physical layout of a facility or organization could contribute to stigma, particularly if confidentiality could not be assured. Protecting the confidentiality of PHAs and APHAs was an overarching concern expressed by both participants living with HIV and those providing care to them. Policies and practices in organizations could contribute to stigma and discrimination. For example, the consistent use of universal precautions was considered essential to safe practice, but at times the implementation of universal precautions could be a source of stigma. Finally, APHAs, PHAs, and HCPs believed that a flexible approach to service provision was essential to delivering non-discriminatory health services to persons living with HIV.

The majority of the documents reviewed in the analysis were from organizations and health centres whose mandate specifically targeted the under privileged and persons living with HIV. HIV-specific policies were present in over half of the documents reviewed. In other instances, documents were not HIV specific, but promoted non-discriminatory treatment of all people. The document analysis revealed that the majority of the policies and practices in the 85 organizations reviewed tended to inhibit HIV and AIDS related stigma, by promoting ethical, fair, and non-discriminatory care.

In order to assist the research team to make recommendations regarding the optimal design features in health services to eliminate AIDS stigma, three one-day workshops were conducted in Toronto, Calgary and Vancouver. Participants who attended the workshops received a summary of the project findings and were actively involved in the design of an effective intervention to reduce AIDS stigma for persons living with HIV. In addition workshop participants provided feedback on the processes required to reorient health services to incorporate the optimal design. Optimal design features to eliminate AIDS stigma in health care services must consider individual, organizational, and societal factors, and the policy context. Feedback from workshop participants suggested that they felt that by being part of the PAR process, they were an important partner in the development of research capacity both individually, and within community-based organizations.

Acknowledgments

Introduction

Early in the AIDS epidemic, stigma toward individuals with HIV was identified as a serious concern (Herek & Glunt, 1988). The source of AIDS stigma was argued to be due to the association of the disease with death and with already marginalized groups such as gay men. Since that time, there has been substantial discussion in the literature on the phenomenon of AIDS stigma. Knowledge of the phenomenon of AIDS stigma is important for health professionals because of its serious consequences: stigma has the potential to limit prevention efforts (AIDS Alert, 2002; Campbell, Foulis, Maimane, & Sibiya, 2005; Des Jarlais, Galea, Tracy, Tross, & Vlahov, 2006; Herek & Glunt, 1988; Herek et al., 1998); stigma may act as a barrier to diagnosis and appropriate treatment (Carr & Gramling, 2004; Chesney & Smith, 1999; deBruyn, 1998; Herek & Glunt, 1988; Link & Phelan, 2006; Muyinda, Seeley, Pickering, & Barton, 1997; Weiss & Ramakrishna, 2001); and stigma may induce psychological stress and result in a reticence to access health services (Carr & Gramling, 2004; deBruyn, 1998; Des Jarlais et al., 2006; Kang, Rapkin, Remien, Mellins, & Oh, 2005; Link & Phelan, 2006; Mallinson et al., 2005; Mwinituo & Mill, 2006). Many of these consequences of stigma result from individuals who are HIV sero-positive concealing their diagnosis in an attempt to mediate the effects of stigma (Carr & Gramling, 2004; Des Jarlais et al., 2006; Mallinson et al., 2005; Mill, 2001; Mill & Anarfi, 2002; Mill, 2003; Mwinituo & Mill, 2006). The decision by UNAIDS (2002) to focus on stigma and discrimination for the 2002-2003 World AIDS campaign, highlights the serious and far-reaching nature of this issue. UNAIDS argued that stigma and discrimination were the major barriers to effective HIV prevention and AIDS care.

Research Goals and Objectives

The **purpose** of this research was to develop an intervention for the provision of health services to persons living with HIV that mitigates the impact of stigma and optimizes access to appropriate health care. The **objectives** of the research were to explore the practices in health care organizations that persons living with HIV perceived to be stigmatizing, develop an optimal design for health service delivery to eliminate stigmatizing practices and describe the process required to reorient health services to incorporate the optimal design.

The following **research questions** were addressed in this study:

1) In what ways does stigma influence access to health services for persons living with HIV/AIDS (PHAs) and Aboriginal persons living with HIV/AIDS (APHAs)?
2) What practices in health care organizations are perceived to be stigmatizing by PHAs and APHAs?
3) What design features are optimal for the provision of health care services to PHAs and APHAs to eliminate stigma?
4) What processes are required in organizations to reorient health services for PHAs and APHAs in order to incorporate optimal design features?

Research Partners

This project brought together research team members and members from organizations with the varied and relevant backgrounds that were required to complete the research.

Academic Research Partner: University of Alberta
Dr. Judy Mill – Principal investigator, Faculty of Nursing
Dr. Wendy Austin, Faculty of Nursing
Dr. Stan Houston, Faculty of Medicine

Academic Research Partner: University of Ottawa
Dr. Nancy Edwards, Faculty of Health Sciences, School of Nursing
Dr. Lynne Leonard, Department of Epidemiology and Community Medicine
Dr. Lynne MacLean, Community Health Research Unit

Community Based Research Partner: Canadian Aboriginal AIDS Network
Mr. Randy Jackson, Canadian Aboriginal AIDS Network, Director of Research and Programs

Community Based Research Partner:
Ms. Claudette Dumont-Smith, Consultant, Aboriginal Health

Advisory Committees:
Local advisory committee (Edmonton and Ottawa) members came from organizations including:

HIV Edmonton, Edmonton, Alberta
Boyle-McCauley Health Centre, Edmonton, Alberta
Capital Health, Edmonton, Alberta
Health Canada, Ottawa, Ontario
Alberta Aboriginal Affairs and Northern Development, Edmonton, Alberta
Wabano Centre for Aboriginal Health, Ottawa, Ontario
Ottawa Hospital, Ottawa, Ontario
Oasis Centre, Ottawa, Ontario
Centretown Community Health Centre, Ottawa, Ontario
Canadian AIDS Society, Ottawa, Ontario
AIDS Committee of Ottawa. Ottawa, Ontario
National Aboriginal Health Organization, Ottawa, Ontario

Project staff:

We were very fortunate to have dedicated staff working with us on this project. Without their efforts, the project would not have been possible.

Frances Reintjes - Edmonton - Project Coordinator
Yelena Chorny – Ottawa - Project Coordinator

Joyce Seto - Ottawa - Project Coordinator
Jean Chaw-Kant - Edmonton - Project Coordinator
Tasha Cross- Research Assistant
Jean Groft – PhD Student
Nadine Moniz - MN Student
Añiela dela Cruz - PhD Student and Advisory Committee Member (Program Consultant, Public Health Agency of Canada)

History of Project

In the fall of 2002, the project received funding from a CIHR joint initiative "Improving Access to Appropriate Health Services for Marginalized Groups" co-sponsored by the Institute of Health Services and Policy Research, the Institute of Gender and Health, and the Institute of Aboriginal Peoples' Health. Table 1 shows the timeline of the project.

Table 1.Timeline of the Project

October 2002	Spring 2003	Fall 2003	2004-2005	2005-2006	Fall 2006 Spring 2007
Funding announced	Ethical approval- March Project start - June	Phase I recruitment and interviews with APHAs and PHAs commenced	Phase II, III Recruitment and interviews with health care workers began Dissemination of phase I findings Phase III Document Analysis	Data entry and Theme analysis Analyses and dissemination	Developing interventions Presentation of findings at conferences and community workshops

Protection of Identity

In order to protect the identity of parties directly or indirectly involved in this study during interviews or in the research process, all study participants were given pseudonyms and any information that could be used to identify study participants was excluded from this report. Identifying information was also excluded from transcripts and during the analysis of interview data. Names of third-party individuals mentioned by study participants were also changed to ensure anonymity. The research staff were obliged to respect the confidentiality agreements of clients and service providers.

Disclaimer

The content of this report reflects the views of the authors and does not necessarily reflect the viewpoint of the partner organizations.

Background and Literature Review

The term stigma originates from the concept of *stigmata* that was used by the Ancient Greeks to refer to a physical marking on an individual to expose a moral flaw in their character (Goffman, 1963). Stigma has been defined as a social process that is "…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). For the purpose of this study, we extended Weiss and Ramarkrishna's definition of stigma to include features of identity such as cultural background and sexual identity, in addition to a health problem. Individuals may experience stigma directly at the individual level in the form of feelings and behaviours or indirectly at the societal level through policies and popular discourse (Burris, 1999; Burris, 2006; Herek et al., 1998; Herek, Capitanio, & Widaman, 2002; Mill, 2003; Wahl, 1999). Shame and guilt can result in self discrimination for those that have stigmatizing diseases. Individuals may avoid situations in which their secret could be discovered or in which they might experience stigma (Burris, 2006; Mallinson et al., 2005; Mwinituo & Mill, 2006) 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 (Bates et al., 2002; Sayce, 1998). Discrimination refers to behaviour that results in unequal or unjustifiable treatment (Siyam'kela Project, 2006). Despite this emerging theme, we have chosen to focus primarily on the concept of stigma because it continues to be the predominant term used in the literature.

In relation to HIV, the research team recognized that sensitivity was required in selecting the terms used to describe not only the illness, but also the person who suffers from the illness. For example, we used the term HIV illness because it encompasses the individual, cultural and social responses to HIV infection, and is distinct from the concept of disease that refers primarily to the breakdown of a biological process (Kleinman, 1980). It may be problematic, however, to describe asymptomatic individuals as having HIV illness because of the meaning embedded in the term "illness". Individuals who are HIV sero-positive commonly refer to themselves as a "Person having HIV/AIDS" (PHAs), whereas among Aboriginal peoples, the accepted term is an "Aboriginal person having HIV/AIDS" (APHAs). In relation to stigma, AIDS stigma, as opposed to HIV stigma, is the more commonly used term. For this project we have endeavored to use the most appropriate terminology, however during the conduct of the research we were sensitive to each individual's preferences, by asking them how they referred to their HIV status.

As an illness, HIV may elicit profound stigma. Stigma has the potential to influence health and health seeking behaviours in a variety of ways and, therefore, is an important consideration for health care professionals. For example, stigmatized conditions may result in individuals and caretakers concealing their illness (Burris, 2006; Duffy, 2005; Mallinson et al., 2005; Mill & Anarfi, 2002; Mill, 2003; Mwinituo & Mill, 2006). Concealment has profound implications for the individual, and in the case of stigmatized conditions that are infectious, has additional implications for public health (Das, 2001; Goldin, 1994; Mill, 2003). Stigma may result in increased suffering and may lead to delays in seeking appropriate health services (Link & Phelan, 2001; Link & Phelan, 2006; Mallinson et al., 2005; Mill, 2003; Searle, 1999; UNAIDS, 2002; Wahl, 1999; Weiss & Ramakrishna, 2001).

The conduct of research on stigmatizing conditions such as HIV must consider local and cultural underpinnings and expressions of stigma. There is a complex relationship between stigma and context, and this relationship has an impact on people's lives (Link & Phelan, 2006; Weiss, Jadhav, Raguram, Vounatsou, & Littlewood, 2001). Research is required that is informed by the experiences of people with the illness (Link & Phelan, 2001), and that documents and compares how the experience of stigma differs between populations (Fife & Wright, 2000; Kaplan, Scheyett, & Golin, 2005; Weiss et al., 2001; Weiss & Ramakrishna, 2001). Kaplan, Scheyett & Golin (2005) noted that in order to develop successful interventions to decrease stigma for PHAs, relationships between the stigmatized and the stigmatizer need reassessment.

Stigma and HIV Illness

Several of the attributes of HIV illness increase the likelihood that its victims will be stigmatized: the illness is viewed as the result of individuals violating the moral order of society (Alonzo & Reynolds, 1995; Brandt, 1987; Brandt, 1991; Carr & Gramling, 2004; Fife, 2005; Herek & Capitanio, 1999; Kang et al., 2005; Mill, 2001; Mill, 2003; Mwinituo & Mill, 2006); the illness is seen as preventable (Borchert & Rickabaugh, 1995); the contagiousness of HIV illness is perceived to threaten society (Alonzo & Reynolds, 1995; Herek & Glunt, 1988; Herek & Capitanio, 1999; Kang et al., 2005; Mawar, Saha, Pandit, & Mahajan, 2005; Mill, 2003); HIV illness is viewed as a debilitating disease that results in death (Alonzo & Reynolds, 1995; Des Jarlais et al., 2006; Herek & Glunt, 1988; Herek & Capitanio, 1999; Mill, 2003); the symptoms of HIV illness become visible as the disease progresses (Hawkins, 2006; Herek & Glunt, 1988; Herek & Capitanio, 1999); it is transmitted sexually (Bunting, 1996; Mwinituo & Mill, 2006); and HIV illness has most frequently been associated with groups already marginalized in society (Brandt, 1991; Chesney & Smith, 1999; Herek & Capitanio, 1999; Mallinson et al., 2005; Mawar et al., 2005; Mill & Anarfi, 2002; Mill, 2003). Definitions and metaphors surrounding HIV infection and AIDS have also contributed to its stigmatization. Early in the epidemic, the definition of HIV as a sexually transmitted infection, rather than a viral communicable disease such as hepatitis B, had a significant impact on the social definition of the illness (Altman, 1994; Gilman, 1988). Military metaphors such as "war on AIDS" and the "invasion of cells" used to describe AIDS have also contributed to the stigmatization of the ill (Sontag, 1989). The media has sensationalized the image that HIV illness is a self-induced, sexually transmitted infection.

Researchers have documented the problem of stigma in individuals living with HIV in the United States (Carr & Gramling, 2004; Fife, 2005; Herek et al., 2002; Ingram & Hutchinson, 1999; Kang et al., 2005; Mizuno, Purcell, Dawson-Rose, & Parsons, 2003; Mizuno, Moneyham, Sowell, Demi, & Seals, 1998; Rudy et al., 2005; Sowell et al., 1997), Scotland (Green, 1995), India (Bharat, Aggleton, & Tyrer, 2001), China (Liu et al., 2006) and several countries in sub-Saharan Africa (Hamra, Ross, Orrs, & D'Agostino, 2006; IsraelBallard et al., 2006; Kielmann, 1997; Mill & Anarfi, 2002; Mill, 2003; Muyinda et al., 1997; Mwinituo & Mill, 2006). Reidpath, Brijnath & Chan (2005) undertook a six country Asia-Pacific study with the objective to investigate institutionalized forms of HIV/AIDS related discrimination.The importance of women's experiences of stigma, based on the association of HIV infection with sexual deviance and promiscuity, has also been highlighted (Carr &

Gramling, 2004; Lawless, Kippax, & Crawford, 1996; Mill, 2001; Mill, 2003; Mwinituo & Mill, 2006; Rudy et al., 2005). The stigma and discrimination experiences of gay men living with AIDS have also been documented (Schwartzberg, 1996). A recent report from the Canadian HIV/AIDS Legal Network (deBruyn, 1998) concluded that discrimination and stigma are still pervasive in the lives of Canadians living with HIV and that discrimination has a significant negative impact on the health of individuals. Similarly, research to document the prevalence and trends in the United States related to AIDS stigma found that although expressions of overt stigma had declined, more covert forms of stigma persisted, and in some cases increased, during the 1990s (Herek et al., 2002). Fear of PHAs, discomfort with having direct or symbolic contact with a PHA, and the belief that a person infected with HIV deserved to have AIDS were documented among participants. Several researchers have described differing levels of stigmatization among persons living with HIV. For example, persons with AIDS experienced higher levels of stigma compared to those with cancer (Crawford, 1996; Fife & Wright, 2000) and individuals in more advanced stages of HIV illness reported an increased level of stigmatization (Fife & Wright, 2000).

Stigma and Aboriginal Persons Living with HIV/AIDS

The rationale for focusing on Aboriginal people in the study is based on two major considerations. First Aboriginal people are over-represented in estimates of HIV infections in the Canadian population. Approximately 3% of the Canadian population reports an Aboriginal identity (Statistics Canada, 2006), however 14.4% of the total reported AIDS cases are Aboriginal (Public Health Agency of Canada [PHAC], 2005). "Evidence suggests that the HIV epidemic in the Aboriginal community shows no sign of abating" (PHAC, 2005 p. 61).

The second reason to include Aboriginal people in the current study is Aboriginal individuals living with HIV may experience stigma differently than non-Aboriginals. Aboriginal people, due to varying cultural constructions of stigma, differing beliefs about health, illness and healing, and the burden of having more than one attribute that evokes stigma, may differentially impact the stigma experience (Weiss & Ramakrishna, 2001). The Aboriginal population has a long history of being marginalized as a group within Canadian society (Royal Commission on Aboriginal Peoples, 1996). A discussion paper on the issue of discrimination toward APHAs argued that discrimination was "…reinforced by other forms of discrimination such as discrimination against two-spirited people[1], women, drug users, and Aboriginals generally" (Matiation, 1999b, p. 37).

Individuals already marginalized in society, and who develop a stigmatizing condition such as HIV infection, may experience a layering or double burden of stigma (Bunting, 1996; Chesney & Smith, 1999; Duffy, 2005; Herdt, 2001; Herek & Capitanio, 1999; Kowalewski, 1988; Mill, 2001; Reidpath & Chan, 2005). Reidpath and Chan (2005) state "there needs to

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[1] Two-spirited is often used to refer to Aboriginal people who identify themselves as gay, lesbian, bisexual, or transgender (Matiation, 1999a, p.7) because it is "…more culturally relevant to Aboriginal lesbians and gay men [and recognizes] the traditions and sacredness of [a] people who maintain a balance by housing both the male and female spirit…"(Deschamps, 1998, n.d., p. 10).

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). Das (2001) argues, "discourses on stigma are deeply implicated in the fault lines of racism, sexism and other forms of discrimination…" (p.9). This phenomenon was explored with HIV sero-positive women who were not considered marginalized, but rather, possessed one or more signs of "symbolic capital" including being White, heterosexual, educated and/or middle class (Grove & Kelly, 1997). The researcher concluded that symbolic capital provided some protection against stigma.

The Impact of Stigma on Access to Health Services

Research has documented that individuals living with HIV may be unable or unwilling to appropriately utilize the health care system. A fear of labeling may delay these individuals from seeking out, and engaging with, appropriate health services (Chesney & Smith, 1999; Herek & Capitanio, 1999; Mill, 2003; Rudy et al., 2005). For Aboriginal peoples, negative encounters with the health care system (Browne & Fiske, 2001) and differing beliefs about health and illness (Mill, 2000) may result in them feeling reticent to seek out, and engage with, biomedical health services. A recent study with two-spirited Aboriginal men across Canada, found that of the 49% of men in the sample who were HIV positive, only 42% were using any type of Western treatment or therapy (Monette & Albert, 2001). These participants identified the following barriers to accessing health and social services: feeling unwelcome, fear of health and social services workers and organizations, fear of discrimination and lack of transportation. Lost opportunities for early diagnosis and treatment have profound personal, social and economic costs. Patterns of health care utilization in individuals with HIV are significantly associated with survival time (Montgomery et al., 2002).

Sources of stigma and discrimination for individuals include communities, families, churches, and coworkers (Carr & Gramling, 2004; Parsons, Cruise, Davenport, & Jones, 2006) Health practitioners have also been identified as a significant source of stigma and discrimination for individuals living with HIV (Awusabo-Asare & Marfo, 1997; Bharat et al., 2001; Carr & Gramling, 2004; Chesney & Smith, 1999; Matiation, 1999b; Mwinituo & Mill, 2006). Recent studies in America (Carr & Gramling, 2004) and the Asia Pacific found that the most common context in which PHAs experienced stigma was health care settings (Bharat et al., 2001; Liu et al., 2006; Reidpath & Chan, 2005; Reidpath et al., 2005). Research on the attitudes of health care professionals toward individuals with HIV infection, however, is inconsistent. Research on AIDS stigma has identified both supportive and stigmatizing attitudes among clinicians in America (Carr & Gramling, 2004; Ingram & Hutchinson, 1999), India (National AIDS Research Institute, 2003) and Australia (McCann, 1997; McCann, 1999). Health practitioners may be more likely to provide discriminatory care to patients with AIDS when they do not perceive choice in providing care (McCann, 1999; Rudy et al., 2005). Although health care professionals may have positive attitudes toward individuals living with HIV, they may display behaviours that result in their clients being, or perceiving that they are, stigmatized (Mawar et al., 2005). This inconsistency may be partially explained by differentiating between "enacted" and "felt" stigma. Green (1995) defines enacted stigma as individual or collective sanctions applied to an individual with HIV illness, whereas felt stigma refers to fear of enacted stigma. The issue of disclosure of HIV

status to medical providers may provide an indicator of felt stigma. A recent American study found that approximately one third of participants did not disclose their HIV status to at least one of their medical providers, and that disclosure rates were influenced by race and immune status (Jeffe et al., 2000). The inconsistency in the research to date suggests that the relationship between the attitudes of health professionals in relation to stigma, and their behaviour, is complex.

Interventions to Minimize AIDS Stigma

There has been limited research to evaluate interventions to mitigate the impact of AIDS stigma. Brown, Trujillo and Macintyre (2001) suggest that AIDS stigma can be reduced through intervention strategies including information, counseling, coping skills and acquisition, and contact with affected groups. These authors highlight the need for the evaluation of interventions to reduce AIDS stigma using multiple channels and targeting entire communities. Widening the support system by disclosing one's HIV status to more than just one or two family members has been suggested as a way to actually decrease stigma and increase social support in Ghana (Mill, 2003). Training nurses in Ghana to provide counseling to individuals living with HIV could improve quality of care (Mill, 2003). Some authors (Reidpath, Chan, Gifford, & Allotey, 2005) have argued that the predominance of singular, education focused approaches that do not acknowledge the social "function" of exclusion is a major reason why interventions to reduce stigma have not been efficacious. A dramatic reassessment of the relationship between the stigmatized and the stigmatizer has been advocated (Kaplan et al., 2005).

Stigma, and the discrimination that accompanies it, are two of the most significant barriers to accessing appropriate health services by PHAs and APHAs. Individuals with HIV face discrimination from families, friends, communities and community organizations and health professionals. It was evident from the literature review, and the combined experience of the research team, that there was a need to explore the influence of stigma on access to appropriate health services from the perspective of individuals living with HIV. The literature also emphasizes the need to explore the burden of, and experience with, stigma across cultures. Aboriginal peoples represent a population that is marginalized, and therefore, those with HIV illness may experience a layering of stigma. In addition to describing the experience of stigma from the perspective of persons living with HIV, research was urgently required to determine the optimal design for interventions to eliminate stigma for persons accessing health care services. Furthermore, additional information regarding the sources and impact of stigma are needed from specific communities before effective interventions can be developed.

Research Design and Methods

Design

Participatory action research (PAR) was used for the study, as it was the most appropriate design to answer the research questions. As a methodology, PAR is flexible and provides a socially and culturally adaptable framework to guide the research process. The use of participatory action research helped to ensure research relevance for individuals and communities (Lindsey & Stajduhar, 1998) and is an appropriate research design when working with Aboriginal communities (Dickson, 2000; Kaufert et al., 2001; Macaulay et al., 1998). The ability to adapt methods for use in a range of settings, to explore local knowledge and to enhance the quality of the research by including the insights of local individuals are particular strengths of PAR (Cornwall & Jewkes, 1995). Fundamental principles of PAR include a collaborative relationship with the partners in the research (Reason, 1994) and a valuing of the experience and popular knowledge of people (Fals-Borda, 1991). In addition, knowledge that is "generated through PAR is no longer exclusively owned and disseminated by academia, but rather is shared by the community or group" (Mill, Allen, & Morrow, 2001, p. 115). PAR is a spiraling process that involves planning, acting and observing, and reflecting on these processes (Kemmis & McTaggart, 2000). Finally, consciousness-raising and change are central to the purpose of PAR. Participatory action research facilitates consciousness-raising and promotes critical thinking in individuals and communities to explore the root causes of their situation (Schoepf, 1994). The tenets of PAR were congruent with the goal of the current research to develop an intervention for the provision of health services to persons living with HIV that mitigated the impact of stigma on access to appropriate health care.

The research was conducted at two sites, Ottawa and Edmonton, and in eight organizations. Organizations that provided outpatient health services to individuals living with HIV participated and assisted in the recruitment of participants. For this study health services were broadly defined and included services such as medical, dental, laboratory, x-ray, counseling, and needle exchange programs. Four health care organizations at each site, representing small and large organizations and using a variety of different approaches for the delivery of health care to persons with HIV, participated and assisted with the recruitment of participants. A brief description of these organizations is provided in Appendix 1. The multi-site, multi-organizational design enhanced the research teams understanding of the context of AIDS stigma in different settings.

Sample

Convenience and network sampling (Brink & Wood, 1994) was used to recruit Aboriginal individuals living off reserve, and non-Aboriginals participants for the study. The term Aboriginal as used in this study included individuals who identified themselves as Métis, First Nation[2] or Inuit regardless of treaty status (PHAC, 2001). In Canada the term "status" Indian refers to those individuals legally recognized by the federal government under the Indian Act to be Indian (Waldrum, Herring, & Young, 1995). The inclusion criteria for HIV sero-positive participants included: over the age of 18; agree to participate in the study;

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[2] Today First Nation has replaced the term 'Native' in general usage (PHAC, 2001).

English or French speaking; HIV sero-positive; not currently an in-patient; lived in Canada at least 3 years; and have accessed health services (e.g. medical, dental, laboratory, x-ray, counseling) within the past 2 years. The inclusion criteria were prepared to ensure that participants were well enough to understand and respond to questions and were not in the process of adjusting to the Canadian health care system.

Data Collection Procedure

Following ethical approval, local advisory committees were formed at each site to provide further input on the ethical implications, implementation process, and the dissemination strategies for the study. Specific terms of reference for the advisory committees were developed in consultation with them. The advisory committees included representatives from Aboriginal communities, consumer groups representing PHAs and APHAs, and agencies providing services to PHAs and APHAs. The importance of obtaining community consent, in addition to individual consent, has been stressed for research with Aboriginal communities (Kaufert et al., 2001). Although consent from specific communities is not possible with the current research design, the participation of two Aboriginal co-investigators and the guidance of the advisory committees provided the necessary community perspective for the research.

A contact person at each organization approached potential participants who met the eligibility criteria to ask if they were interested in participating in the study. Information letters (Appendix 2) about the study were made available for the contact person to distribute to potential participants. If interested, the potential participant was asked to contact the research coordinator or research assistant to obtain more information about the study. This approach to recruitment ensured that the agencies did not need to release information about an individual's HIV status to the researchers.

The data collection process was iterative, with data from each source informing and guiding the data to be collected from other sources. The process was also reflective, with the health care workers being asked to reflect on the themes from the PHAs and the APHAs. Initially, in-depth interviews were conducted with PHAs and APHAs at each study site. They were asked to describe practices that they perceived to be stigmatizing when accessing health care services. Interviews are congruent with Aboriginal traditional storytelling methods of sharing information. The research coordinator conducted the interviews and focus groups in Edmonton and the research assistant conducted the interviews and focus groups in Ottawa. At the beginning of each interview, written informed consent (Appendix 3) was obtained from each participant. The interviews were approximately 1 hour in duration and completed over a one year time period. To obtain a deeper understanding of the participants' experience of stigma, the interviews were open-ended and did not impose categories a priori. Guiding questions (see Appendix 4) were prepared to assist the interviewer to focus the interview on the experiences of the participants in relation to stigma and to maintain a balance between consistency and flexibility in the interviews (May, 1991). Consistency in the type of questions asked is particularly relevant when using two interviewers to ensure that the topic is explored similarly with each participant. At the same time, flexibility is required to elicit each participant's unique experience, therefore the guiding questions changed as the interviews proceeded and themes emerged. The advisory committees were consulted about the guiding questions to ensure cultural appropriateness. Following informed consent,

interviews took place in each participant's home or at a location determined by them. For example, an interview could be carried out in a private room at one of the organizations participating in the study. The participants were given $25 to compensate them for their time.

Following the analysis of the interviews with PHAs and APHAs, focus groups or interviews were conducted with the HCPs. Five HCPs participated in one focus group, while two HCP participated in the second focus group. The focus groups were assembled according to profession and setting, to ensure that members of the focus groups shared a common experience (Asbury, 1995; MacDougall & Fudge, 2001). Two of the investigators conducted the focus groups, using guiding questions that were based on the themes emerging from the interviews with the PHAs and APHAs. The HCPs were asked to reflect on the practices that had been identified as stigmatizing and suggest changes that could be made to eliminate or minimize the impact of these practices. Written informed consent was obtained from each HCP participating in the study. The interviews lasted an average of one hour and the focus groups lasted approximately one to two hours.

The research team, in collaboration with the advisory committees developed a description of the optimal design features for the provision of health care services for persons living with HIV. Recruitment of HCPs was extremely challenging in some organizations. Difficulty in HCP recruitment was attributed to research fatigue and heavy workloads of HCP who were unable to schedule time to be interviewed.

Analysis

The interviews were audiotaped and transcribed verbatim. All interviewees were given a pseudonym and all identifiable information connected with the participant was removed from the transcripts. The process of analyzing the data occurred simultaneously with data collection and the qualitative software program QSR N6 was used to assist with the labeling, revising and retrieving codes during analysis. Memos were used within NUD*IST to record methodological decisions and analytic insights. Matrix methodology techniques described by Miles and Huberman (1994) were used in the analysis. First level analysis was used to assign a descriptive code (label) to a segment of the data to give it meaning. As the researcher became more familiar with the data, pattern coding was used to label emerging themes (Appendix 5). 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 case. The focus groups and interviews with HCPs were similarly analyzed, and findings compared to the issues emerging from the data from PHAs and APHAs (Appendix 6).

Responsibility for data analysis was shared by the principal investigator, members of the research team, and the research coordinator. Early in the analysis process, all members of the research team read three interviews to identify major themes in the data. The research team then met in person to develop a coding framework. Subsequent to this, the research coordinator had primary responsibility for the analysis of the interviews and focus groups to ensure that **consistency** was maintained during the analysis process. The principal investigator, and the other members of the research team, supervised the analysis process to ensure that the research coordinator accurately identified themes and relationships between themes. The principal investigator worked closely with the research coordinator and analyzed

several of the interviews completed by the research coordinator to ensure accuracy. The coding framework was discussed and revised during research team meetings as the analysis process progressed. Decisions made during analysis were documented to ensure that the analysis process was auditable, thereby enhancing the consistency of the analysis (Sandelowski, 1986).

Concurrent with the interviews and focus groups with HCPs, the policies and practices of organizations were analyzed to identify those that might promote or inhibit AIDS stigma. A document analysis was carried out to uncover the perspectives and priorities of each organization in relation to the care and treatment of persons with HIV. Qualitative methods, such as document analysis, are appropriate for gathering information about the context for implementing new policies or practices (Murphy, 2001).

Rigor

It was important to integrate strategies to ensure rigor (Guba & Lincoln, 1981; Meleis, 1996; Sandelowski, 1993; Sandelowski, 1986) in the current study. Meleis (1996) identified eight criteria to assess the rigor and credibility of culturally competent scholarship, including research with marginalized populations. These criteria were relevant to the assessment of rigor in the current research and included: contextuality, relevance, reciprocation, awareness of identity and power differentials, empowerment, communication styles, time, and disclosure (Meleis, 1996). The current research attempted to document one aspect of the _context_ of the lives of individuals with HIV illness. The literature review substantiated the _relevance_ of the issue of stigma in persons living with HIV and its potential impact on access to health services. Providing opportunities in the research to meet not only the goals of the researchers, but also those of the participants, resulted in _reciprocation_. The involvement of participants with HIV illness and the use of advisory groups helped to ensure that the relevance, context, and reciprocation criteria were met. In addition, the advisory groups ensured that potential _power differentials_ between the research team and participants were acknowledged. This was particularly important in the current research project that focused on the experiences of populations who were already marginalized. Inviting representatives from consumer groups to participate in the advisory group fostered the _empowerment_ of individuals living with HIV. The use of open-ended interviews was congruent with the _communication styles_ of the Aboriginal participants by acknowledging traditional story-telling methods. A _flexible approach to time_ was required throughout the research to enable the development of collaborative relationships based on trust and respect. This is extremely important in the conduct of research with marginalized groups and for research that is participatory in nature. Other strategies to assist with the development of trust included ensuring confidentiality of the data and anonymity of the participants. The use of strategies that build trust with the participants facilitated their ability to _disclose_ their experiences, which in turns contributed to the authenticity and rigor of the research.

Ethical Considerations

Once funding was obtained, ethical approval was sought for the study. In Edmonton, ethical approval was obtained from the Health Ethics Review Board (Panel B) at the University of Alberta, to access sites in Edmonton. Within the sites in Edmonton, operational approval was

also granted by Capital Health to conduct research at their facilities. In Ottawa, ethical approval was obtained from the Ottawa hospital, General site and the University of Ottawa. The tenets of PAR are congruent with the essential principles for the conduct of research with Aboriginal communities: ownership, control, access, and possession [OCAP] (Patterson, Jackson, & Edwards, 2006; Schnarch, 2004) the use of culturally appropriate methodologies; and the adherence to community controlled collaboration (Smylie et al., 2004). These OCAP principles included: the involvement of Aboriginal communities in all stages of the research process; the promotion of equity in collaboration between members of Aboriginal communities and academic communities; the acknowledgement that the lived experience of participants belongs to Aboriginal communities; the need for methodological rigor; and the acquisition of appropriate ethical review. Community control of research is fundamental to ensure the protection of indigenous knowledge within communities (Battiste & Henderson, 2000). Participatory designs have been advocated for research with Aboriginal communities to ensure that the ethical implications for individuals and communities are considered (Kaufert et al., 2001). In addition, the current research *process* and design incorporated the philosophy of respect, enabling, healing and education that is central to community-based Aboriginal research (Smith, 1999).

Research on the topic of HIV illness requires the exploration of highly sensitive topics, including sexual behaviour and sexuality that, in turn, raise complex ethical issues (Ringheim, 1995). In addition, individuals with HIV illness are vulnerable to stigmatization from families and communities (Carr & Gramling, 2004; Parsons et al., 2006). The participants in the current study may have been marginalized due to their use of injection drugs or their involvement in the sex trade. The Aboriginal participants may also have been marginalized due to their cultural background (Matiation, 1999b; Minister of Supply and Services Canada, 1996). Individuals with HIV illness may experience a double burden or layering of stigma if they are already marginalized within society (Bunting, 1996; Chesney & Smith, 1999; Duffy, 2005; Herdt, 2001; Herek & Capitanio, 1999; Kowalewski, 1988; Mill, 2001; Reidpath & Chan, 2005). The vulnerability of this population, therefore, necessitated that the anonymity of participants was maintained and the confidentiality of data was ensured.

Another ethical consideration relevant to the current study related to the possibility that one of the HIV sero-positive participants might disclose to a research team member that they were engaging in activities that were considered "high risk" (e.g. needle sharing or unprotected sex), but had not disclosed their HIV status to their partner. In anticipation of this possibility, the research coordinator and assistant were provided with training to enable them to respond appropriately should this situation arise. The response would be congruent with current public health practice, by focusing on the provision of HIV prevention information and referral sources to the participant. Additional ethical and legal requirements relating to this issue, and specific to each site, were incorporated into the ethics proposals that were submitted to the University of Alberta and University of Ottawa.

Findings

Chapter I. Description of Participants

Demographics of Sample

Thirty-three HIV sero-positive individuals (16 Aboriginal and 17 non-Aboriginal) (Table 2) were recruited to participate in in-depth interviews. The Aboriginal identity of the APHAs included First Nations (10), Metis (3), Inuit (2) and unknown (1).

Table 2. Demographic profile of APHA and PHA study participants

Participant		Gender		Age		Time since diagnosis (years)		Transmission *, **	
APHA	16	Male	22	Mean: 40.6		<1	5	MSM	16
		Female	9	Range: 31-56		2-5	10	IDU	17
PHA	17	Transgender	2			6-10	10	Blood	1
						>11	8	WSM	3
								Unknown	2

*   Some participants indicated more than one mode of transmission.
**   MSM =Men who have sex with men, IDU = Injection drug use, Blood = Blood transfusion, WSM = Women who have sex with men.

Twenty-seven HCPs including physicians, nurses, social workers, psychologists, and a dentist participated in an in-depth interview (20) or a focus group (7) (Table 3).

Table 3. Professions of health care provider study participants

	Professions	
Male	Nurses	8
3	Community Workers	6
Female	Physicians	3
24	Social Workers/Counselors	3
	Psychologists	2
	Blood Technician	1
	Outreach Worker	1
	Emergency Medical Technician	1
	Grief Therapist	1
	Dentist	1

PHA and APHA Life History

Participants shared stories relating to their life history and experiences living with HIV. More than half of the participants stated that mental health, including stress and depression, was a concern for them and that living with HIV could be extremely stressful. For some PHA/APHAs, stress was strongly associated with ill health:

"…psychologically the stress that I've experienced has been pretty intense sometimes. Last, earlier this year in February, January, February I had to, I had to acknowledge my frailty and take a leave, stress leave from work."(Gordon, PHA, 39 years)

"…I've always been stressed out. If it isn't one thing it's the other." (Jenny, APHA, 44 years)

"The stress was killing me and then after court was all over, my counts were back up to normal and everything. So, like, the doctor just told me before he went on holidays I HAVE to start the meds. My body needs the help, so. But yeah, stress, from what I understand too from a lot of people it's the worst thing going. You get stressed out and you get sick. So I try to, I TRY to lead a stress-free life. It's not easy…" (Kory, PHA, age unknown)

Participants described various symptoms and experiences related to depression, however they often did not explicitly state that they were depressed:

"I'm REALLY down. I'm really, you know I'm just not, but you know, I don't feel, I told him, I don't feel depressed or anything, but you know, I don't have as much, you know, enthusiasm as I usually did." (Alfred, APHA, 54 years)

"I withdrew from the world and I thought a fix would make it better." (Jenny, APHA, 44 years)

Dennis noted that when new drugs and treatment methods became available, his outlook on life changed for the better.

"The depression isn't as bad as it used to be. I don't see as many people depressed or myself being as depressed as I used to be because there is kind of a little hope out there that you're going to go farther" (Dennis, PHA, 41 years)

During the interviews and focus groups, the HCPs commented on the complexity of the lives of persons living with HIV and described the many issues that their clients were dealing with in addition to their HIV positive status:

"The majority are street, inner city street people…. Addiction issues, housing issues, mental health issues would be the three top things, in addition to their HIV or Hep C status". (Unice, Social Worker)

"…Never mind the stigma and discrimination that comes from the outside world, it comes within their own community as well…it's just ongoing and pervasive. [pause] I think a lot of people don't realize that people get involved in drug use and alcohol abuse because, in many situations, that IS their coping mechanism". (Veronica, Grief Therapist/Counselor)

"we're talking about people with horrendous histories of abuse who develop the predictable addiction problems which go along with abuse, who also have head injuries, who also suffer with anxiety and depression, which is also related to childhood abuse, and who, on top of that, develop HIV. You know, so research is starting to discuss how to work with people with dual diagnosis; these are people with half a dozen diagnoses." (Sandra, Psychologist)

One of the physicians emphasized the importance of understanding the clients that she worked with in the inner city. She believed that HCPs must be very sensitive toward who should be offered an HIV test:

"It's really where they're at, to be honest, and some of them, it's [HIV treatment] just so far down the road in a priority that, housing is an issue for them, food is an issue for them, um, the whole thought of sending them on, I will encourage them to go for their own education, I will encourage them to go to make those relationships…you're very careful about who you test, because, like, a lot of them are just not, um, [pause] there yet to be able to deal with that information, or they want to know, but to be honest, um, because again, of, [pause] I don't know why, often I find there's certain individuals who just never quite get around, you give them the slip, but they never quite get around to having the blood work done." (Amanda, Physician)

Some of the HCPs believed that individuals were more likely to experience stigma and discrimination related to their mental health or psychiatric illnesses than in relation to their HIV status:

"…not related to the HIV; I think more related to sometimes the psychiatric disorders that some of our clients have, that THAT'S where maybe some of the stigma has, or some of the negative treatment that's come out." (Charles, Physician)

HCPs also explained that some clients were very reticent to access services due to their cultural or religious beliefs:

"Unfortunately, a lot of times, because of the level of stigma and the issues around disclosure, the few [immigrants] that I see ongoing for therapy, it [group therapy] would just be really traumatic for them. It's all they can do to come in here, and a lot of them don't even like mental health professionals. Like, in Africa, nobody sees psychologists, psychiatrists, unless you're, quote, unquote, 'crazy!'" (Jane, Psychologist)

Description of Sample: Health Care Providers

A sample of 27 HCPs participated in the project. HCPs came from diverse backgrounds including nursing, medicine, psychology, community development, dentistry, and infectious diseases. Three of the participants were male and 24 were female and two of the 27 HCPs were Aboriginal. Many of the HCPs had experience in acute care and in community settings. The research team tried to purposefully sample nurses working in emergency departments

based on the finding that several PHA/APHAs experienced discrimination in emergency settings. Despite this attempt only one emergency room nurse participated in the study.

When asked about their roles and responsibilities as HCPs, participants identified key areas of involvement such as: individual and group care, treatment and support, counseling, referral services for clients, client teaching and education and community development work. In addition, HCPs described roles in research and outreach-related work.

Through individual interviews and focus groups, HCPs provided background information about their work. This data provided an understanding of HCP motivations, perceptions and attitudes towards HIV and AIDS work. When asked about the reasons for choosing HIV/AIDS work, HCP participants provided insight related to why they chose to work in the area of HIV and AIDS, why they continued to work in the area of HIV and AIDS, and how they perceived their work in the area of HIV and AIDS. For example, many HCP participants explained a personal connection to the area of HIV and AIDS as a reason for their current work involvement. Several HCPs reported that their initial experience in HIV began through student practical placements or professional training placements. As a result of these educational training experiences and mentorship from other HIV/AIDS HCPs, participants had developed an interest in HIV/AIDS work that motivated their continued involvement in this area:

> "…I did my internship here in psychology, and stayed on within the area of HIV with [physician], and really, really enjoyed that experience. That was my first actual opportunity to work with HIV positive individuals, and absolutely loved it, and really wanted to continue on with both clinical work, as well as research… So I love the area." (Jane, Psychologist)

Others reported a more personal connection to HIV/AIDS as a reason for choosing their current work. For example, some described the experience of working in the field of HIV/AIDS over a period of time, watching the evolution of HIV throughout the 1980s and into the 21st century:

> "…it was almost like there was this bigger plan for me, 'cause it seemed like every rotation I did in my training, my internal medicine, I was on an HIV unit, in my medical school training physical exam skills, I was on an HIV unit in the mid-80s, early, like, '87 when HIV was at a very different stage. So I have watched the progression. I worked at [large hospital] in [eastern Canadian city B], so that was very much the community hospital for people with HIV/AIDS. So I had had a lot of exposure along the way, but I never deliberately set out to make this the population I worked with. That said, I have a comfort with it…" (Amanda, Physician)

Another HCP reported that his motivation was to make a difference in the system because he had been affected by HIV through his own life experience:

> "I went to medical school to do HIV/AIDS. A number of things: I started doing HIV research before I went to medical school, so I became really interested in the virus

and immunology. I'm gay, I have a number of friends who are HIV positive and I knew a lot of people who, and that was in the early '90s, were accessing health care and being, frankly, poorly treated. And not to sound arrogant, but I thought I probably could do a better job. And maybe by virtue of being gay, it could be to serve that community with a little bit more sensitivity than what it sounded like a lot of my friends were getting." (Ian, Physician)

Aboriginal HCPs also described their motivation to work in the area of HIV/AIDS. The main reasons for becoming involved in HIV/AIDS work was connected to participants' personal relationships to the Aboriginal community and the need to contribute to their community in a meaningful way:

"I just found this would be a really wonderful learning experience for me. I'm not that knowledgeable when it comes to HIV and AIDS, so I just, when the opportunity came, I jumped at it. For me, I guess I look at the fact that because I am Aboriginal, hopefully, I can get out into those communities and do some prevention, to do some education, to make them aware. And in that way, I feel I'm helping my people." (Wendy, Community Development Worker)

Still, other HCPs reported the desire to work in the area of HIV/AIDS as a result of personal choice. While many HCPs reported a personal desire in choosing to work in the area of HIV/AIDS, some reported no specific reason for working in their current roles. One HCP reported that his care to HIV patients was only a portion of his overall patient case load.

HCP participants were also asked to describe their motivations to remain in the field of HIV/AIDS. Several HCPs commented on the opportunities to engage in working with clients and patients with a more holistic approach and the idea that care and support for HIV positive clients involved a wide scope of practice:

"I really enjoy community because there's several [pause] it just feels like you get to really [pause] use your full scope of practice in terms of teaching, educating, diagnosing, prescribing. I feel like you get the best opportunity to really use your full scope. And it's really interesting to me, too, to do family practice, because there's always new stuff to learn, and it's not just a single area of specialization, but there's always just, it feels like infinite opportunity to learn and grow… it's where I choose to be…" (Andrea, Nurse Practitioner)

Some HCPs described their ability to provide non-judgmental care and support to their clients and patients, recognizing that many of their clients and patients were engaged in high risk activities and were street involved. The HCPs were sensitive to the broad societal factors that influenced the vulnerability of their clients to HIV infection. Several HCPS expressed satisfaction with providing good health care to this challenging population:

"Some of your values have to be turned off, 'cause in the end, in the job, my biggest value is providing good health care, and that means turning off some of my own judgments and not, doing my best not to let that interfere. I don't think anyone could

say that they could turn their own judgments off a hundred percent, 'cause we're human, but I just think that's [pause] consciously something I do every day. 'Cause you have to, I think, to provide good health care in this community, or any community, for that matter, I think." (Andrea, Nurse Practitioner)

"And I mean, had I ever been a street-involved injection drug user myself, I might have a better understanding of how strong an addiction can be, and what it can lead a person to do. I mean, I also have the belief that part of the reason why people do that, I don't think that they're doing it because they're bad people; I think they're doing it because we don't have harm reduction strategies in place to support them." (Brian, Social Worker)

"… I think that everybody deserves a certain level of health care, housing, and basic needs, AND social support, regardless of what they've done and regardless of who they are. I mean, I don't even support a death penalty for murderers, so why would I think that it would be okay to give less than subsistence to somebody just because they've made some bad decisions in their life?…not going to freeze to death or starve to death. So, I mean, when we're, we're swimming against that kind of a society, the kind of things that I'm, again, like, nine times out of ten, that I'm not only happy to do, but that I'm excited about being part of being able to do it." (Brian, Social Worker)

A few HCPs expressed a passion for the work they were involved with and a compassion for the people they cared for or treated. As one HCP participant described:

"There's over-identifying, and then there's not identifying enough. I mean, I have certain core political beliefs that really drive my work here around social justice, around socialism, around how people deserve to be treated, and while I may not feel a passionate connection to the individuals that I work with, I feel a passionate connection to the issues of society that have put them where they are. And I mean, I have a structural kind of view of how and why they, you know why a lot of our clients are where they are, and I think it's needless that there's that much poverty, it's needless that social assistance doesn't actually pay people enough to even get an apartment any more, let alone have housing and food. So I, I think as long as I have that on that level, there's a certain amount of me that's motivated that I, you know, I never dread coming to work…" (Brian, Social worker)

HCP participants were asked to describe the emotional impact their work had on their individual health. Several HCPs spoke of death, dealing with loss, the loss of patients and clients and the impact this has had on them as individuals. HCPs also expressed coping mechanisms to deal with death and loss of clients. At times, HCPs described becoming so busy that they set their emotional responses aside. Some remarked that they had set emotions aside for so long that they were afraid to deal with them now for fear of "losing control." For example, one HCP described a reticence to acknowledge the grief:

"…at this point, now, we've shoved that [grief] down so far that people are afraid to go there. They're afraid of what it's going to bring up. [Pause.] There's something (as convoluted as this sounds) there's some sort of safety in keeping it all bottled up. However, we see it manifest here in all kinds of different ways. I mean, we see [pause] people sitting in their offices with the door closed, with notes on their doors saying… ? They tell themselves that this is so that they can work done. I think it's a barrier. Like I think it's something that they put up there so that they will feel protected, protected from anything that's going on outside that door. So they can shut the door and not have to deal with that." (Veronica, Grief Therapist/Counselor)

Organizational Features

Philosophy of Organizations

There was a wide range in the organizations represented by the HCPs who participated in the study. Also, the mandate and types of services offered by the organizations varied widely. For example, the focus of one health centre was to provide access to HIV testing services and referral to treatment services for clients who tested positive. This health center provided a wide range of health services, in addition to HIV testing, and had a multi-disciplinary team on staff. A client could be seen by a nurse one week for HIV testing, and could return the following week for follow-up counseling with a social worker. For other organizations, continuity of care was embedded within the philosophy of care. These organizations tried to ensure that clients saw the same staff person when they accessed services:

"I can't speak for the clients, but the feedback that I've gotten from them about it is that that's one of the things that they like most about this agency is the fact that they, they know who they're going to see when they come in." (Brian, Social Worker)

One HCP spoke of her organization's multidisciplinary approach to patient care and the benefits this approach had on patients:

"…but it's a new program and we're a new team, but all of us, I think, love the work and the population…We're all committed to the clients, we kind of decided that it would work out better if I went to see them. And then with the street clients, when I first started, I knew that a large percentage of our clientele were street people, and they don't like coming to the hospital; they've had bad experiences in the hospital. And I started these [outreach groups in inner city agencies] shortly after I started here. And that was to be here the street people are so that they can get to know me in their environment, and it worked! It worked." (Sandra, Psychologist)

The provision of holistic care, including non-judgmental care was considered an essential aspect of HIV care, particularly when dealing with vulnerable, inner city clients.

The type of care that was offered to clients depended on the mandate of the organization. For example, two of the health professionals who provided "drop-in" or "walk-in" services did

not feel that they were always able to provide continuous, comprehensive care. In this passage a physician compares his ability to provide care as a family physician to that of a "walk-in" physician:

> "Over HERE, I can extend the care beyond a walk-in. So if somebody has other issues, I can do more continuing pieces of care for somebody, such as ordering the MRI test; that can sometimes take 18 months to come back, and at a walk-in space, you can't necessarily ask for an MRI if you don't know are they going to be staying in town for even the next 18 hours! [Laughs.] So that kind of stuff allows me to do a little bit more in-depth work here, because they're, I guess, I'm making a commitment to them to be their family doctor…" (Charles, Physician)

Some HCPs were comfortable providing only some of the services related to HIV care and treatment. For example, one HCP stated that she was comfortable with providing HIV testing, but was not necessarily comfortable in providing services to individuals who were HIV sero-positive:

> "I mean, I feel comfortable in the sense that we're not, we're here for testing, we're not necessarily here for all of it, and we do have agencies in [in the city] that are specialized in that area, so we would always try to refer them to the people who know the most". (Focus group member, Community worker)

Service Mandate of Organizations

Though many of the organizations had different mandates, some organizations developed a reputation for their expertise in working with specific populations. For example, HCPs described their organizations' reputation for working with the gay, lesbian, bisexual and transgendered (GLBT) community, street involved, homeless, immigrant, middle class and/or Aboriginal populations:

> "…through staff meetings, saying, 'We really need to do something in, you know, the GLBT population,' and that's how it's sort of unfolded…I think it's partially that this centre has just developed expertise, a special interest in serving specifically the GLBT population…So, I mean, for instance, the GLBT community, I think [community health centre] very much recognizes as their area of interest and area of expertise." (Amanda, Physician)

> "…The groups of people would be gay men, people who are sort of inner city street people, Aboriginal people, and immigrants, with a smattering of others. Right? I mean, HIV doesn't discriminate; [chuckles] it can affect anyone. But that tends to be the population." (Sandra, Psychologist)

> "…The clinic is, being inner city, the majority of our patients are homeless…you know, there's just so many other things that affect that, that it just goes hand-in-hand that with the majority of our patients being homeless, that you would have to look at

them as a whole when dealing with an issue…I'd say maybe 50 percent of the people that come in a day are Positive." (Zara, Licensed Practical Nurse)

"…We don't have big Aboriginal community here, maybe like you have out west, so most of them that we have are street person. They're poor, they're already stigmatized with other things than HIV…IV drug use, alcohol…No fixed address. So they have lots of problems, and it seems like HIV's not such a big issue for them, as somebody else who would only have HIV. It seems like the other factors are more [pause]…upfront." (Focus group member, Registered Nurse)

"I think for HIV, it tends to be a little bit more middle class community that tend to come to our walk-in…I think we have [unclear] more gay men than straight…middle class people…a lot of different nationalities, too, I would say…some recently arrived, and some who have not…a little [Aboriginal clients], but not a lot in the HIV." (Focus group member, Community Worker)

"You know, the majority of our clients are Aboriginal. I really wanted to learn the Aboriginal culture, and I wanted to be able to incorporate that; I felt it was really important. So I guess it was working on both our sides." (Veronica, Grief Therapist/Counselor)

While several of the HCP organizations primarily provided HIV services, others offered other types of services to a wide range of clients. Furthermore, HCPs reported that their organizations differed in terms of how explicit they were about the services they provided. For example, one participant stated that the mandate of his organization was HIV, however this wasn't always explicit:

"[Our] mandate is HIV, and a lot of people know that, so while they're there, it's not quite, it's not quite as open as maybe [HIV/AIDS service organization program] or the drop-in where they know if you're there, you're HIV positive." (Charles, Physician)

Several HCPs commented on the growth and evolution that had taken place within the organizations they worked in:

"But there again, having been here for five years, it's been nice to watch [Aboriginal community health centre] grow, and they are incorporating more pieces around addiction here, so initially, it was quite difficult, and there were mismatches. But I think there's been a lot of good learning that happens here." (Charles, Physician)

"As we've grown as an organization, and as we've become stable, there's been changes in the clinic. Yeah, I'd say it's more evolved…Well, I guess [pause] from a Nurse Practitioner point of view, we've tried to institute changes that lead to more continuity of care, so that's one way. [Pause.] And we've tried to sort of work at becoming more of a team so the communication between providers I think has

probably increased, and because of that, it has become more stable, so that's sort of led to some changes." (Frieda, Nurse Practitioner)

Chapter II. Experiences of HIV Illness

This chapter demonstrates the complexity of the HIV illness experience. Participants shared their physical and emotional experiences living with HIV, highlighting complex aspects of living with the illness including the coping skills that had been utilized. In addition participants shared their views of HIV, and described their personal experiences of stigma and discrimination, including perceptions of why HIV is stigmatized. There was limited explicit discussion about how stigma influenced their access to health services.

Experiencing the Physical Aspects of HIV illness

Several participants described their health status as being affected by multiple health issues, as a result of HIV illness, and experiencing a cyclic nature of illness. Participants reported other physical illness they experienced through multiple diagnoses, such as co-infection with Hepatitis C or tuberculosis. Some participants discussed being treated for multiple medical issues:

> "Then I started to get sick with all the diseases that (are) associated with HIV and AIDS, but until your viral load can come down to 200 you're perfectly normal. Yeah." (Nesta, PHA, 39 years)

> "I had pneumonia a couple of times, nothing major, no really severe infections. I was hospitalized just for pneumonia, but I also had a kidney stone at the same time. But I've been out of the hospital for, I'm not taking the medication, for HIV; so, my general health has been not so bad, so far." (Cecil, PHA, 48 years)

> "I don't know but anyways. I know that I do have it because of my CD4 count is [unclear] my Hepatitis C is dormant right now. Like I have antibodies but the disease itself is dormant, so I'm not on any medication for that." (Otto, APHA, 31 years)

Participants also reported living through cyclical experiences of wellness and illness. The cyclical nature of HIV whereby life was punctured by bouts of illness followed by episodes of wellness was described by nearly all participants. When asked how one participant's health had been over an 18 month period, he responded:

> "Turbulent. Turbulent. It's been … spring was really bad for me; my viral load started to increase, my T4 cells started to decrease, and I just looked sick. I felt sick all the time. So I left; I took a summer for myself and I went out to the bush with my dog, [laughs] and I put on weight, and I got healthy then I came back a new person ready to do another year battle, you know?" (Ethen, PHA, 36 years)

Others spoke of experiencing extremes of health (illness and wellness) over time. As one participant noted:

> "I moved back into the hospital a week later and they really didn't think I was going to survive. I did, I've always came back you know these people who go right to the

edge, right back again. So my family's had to go through that at least a few times over the time since I have been diagnosed." (Jon, PHA, 34 years)

Experiencing the Emotional Aspects of HIV Illness

Both PHA and APHA participants described the emotional impact of HIV on their lives. Emotional impacts were often related to fear of rejection by others, dying, feeling hopeless, depression, and withdrawal from others. Similar to the cyclic physical experiences of HIV illness, participants also reported emotional "ups and downs", often described as "being on a roller coaster":

> "I don't know what it was, emotional roller coaster, I don't know. The whole thing is an emotional roller coaster. I'll tell you right now, you know. Ups and downs." (Fred, APHA, 32 years)

> "Yeah. You know I'm a very outgoing kind of person. When I say outgoing, I like to make people laugh and I like to have a lot of company around. But since I've been diagnosed as HIV positive I'm sort of withdraw within myself, you know? I do the best I can to avoid people. I don't go around with a happy face like before, you know, and [pause] well, I don't know if I'm wrong, but I'm just not the same person knowing that I have, it's like, what do I say? It's like a verdict hanging over my head, you know? If you know you're in prison and you're on death row, okay? You can laugh and have a limit because you know you're going to die soon, so that's how I feel." (Nesta, PHA, 39 years)

Several individuals talked about the difficulties associated with a resignation of hope, including: challenges to treatment adherence, substance use to cope, suicidal tendencies, a need "to keep (too) busy" to avoid negative thoughts, uncertainty about prognosis, feeling like "nothing can be done about HIV," difficulty to "see much of a future;" and having a lack of ambition. One participant even expressed that his dreams in life had been taken away due to his illness:

> "Before, it was like, I'll have a house, I'll have a car, I'll have a wife, I'll have this, I'll have that. Now it seems to be, well, I've had those things, and they're the past now …" (Cecil, PHA, 48 years)

Some participants talked specifically about a fear of dying:

> "Like sometimes, the thought sometimes in me is, when I'm dying, the day I'm gonna die, the day this overtakes my body and kills me. That's the scariest thing. [Crying.] I don't want to leave my family. I've got four children, and I got three grandchildren. And through my own stupidity I got into this." (Genie, APHA, 44 years)

> "I was so young and I was like, 'Holy cow.' Like how am I gonna, you know. I was only 21 and I got all these years ahead of me, I'm not going to see them and I just. I was scared yeah I was scared. I didn't know how to deal with it. May as well just kill

myself now 'cause I'm already dead. That's the way I felt back then." (Otto, APHA, 31 years)

Coping with HIV Illness

Participants reported various ways of coping with their illness. Some participants reported the use of substances to cope with the stress of life and living with HIV illness. Others reported "white-knuckling" and making it on their own (maintaining independence) rather than seeking help. For others, past history provided the skills they required to deal with stigma and discrimination associated with HIV and AIDS. Participants coped with their illness in diverse ways:

> "I'm doing it on my own. I feel comfortable with it. I know I can get the help. I'm trying to help other people. I've accepted it. I'm on my meds, and I'm doing a hell of a lot better than I ever thought ….I'm seeing [psychiatrist], a doctor at the [large hospital]… But I'm wingin' it, by myself. I got no moral support, no doctors, no answers, no professional. I'm doing it MY way [becomes emotional]. I'm not giving up. I've lost fuckin', I've lost 14 years. How will they put those back. I don't intend to, but I paid the price and I don't owe anything to anyone…" (Jenny, APHA, 44 years)

Support following diagnosis was mentioned as a strategy to cope. One PHA recommended that a buddy system be established so that newly diagnosed individuals would have someone to contact at any hour of the day or night:

> "You know for some people that [self-help group] works very well, but that doesn't work for me. But I did think to myself that a buddy system or a one-on-one kind of system where at least you would be able to, again you run into the confidentiality aspect…" (Bob, PHA, 47 years)

Other forms of support were described by participants and included culturally sensitive support such as: recognition of cultural and linguistic diversity; and recognition of the need for targeted programs that service a specific population (i.e., need for services specific to substance users).

Resignation of hope could be alleviated by health services that consistently encourage attempts to remain on or try treatment for HIV infection. As one APHA shared:

> "I kept saying 'No,' because I didn't care no more. Gradually I started listening to him, that he wants me to get on medication…" (Mona, APHA, 41 years)

Also, for some participants, living in the moment could be helpful:

> "I don't know how long I'm going to live, and I'm not making plans, 'eh. I'm just taking everything now. Today is today, and tomorrow, we'll worry about tomorrow, tomorrow." (Cecil, PHA, 48 years)

For APHAs, coping with HIV meant connecting with Elders in their community. However, APHA participants reported that they did not exclusively access support from Elders. For example, APHAs reported the use of combined approaches to support through mainstream and Aboriginal services. APHAs reported this approach as a way to cope with the emotional repercussions of living with HIV illness. For other participants (PHAs), accessing mainstream services, such as those of a social worker or psychiatrist were means of coping.

It was interesting to note that participants spoke of "speaking up" as a way to cope and manage their diagnosis. For example, many shared stories of speaking up in the face of inappropriate treatment (drawing blood without gloving) or stigmatizing experiences (eg. breaches of confidentiality or refusal to provide treatment based on HIV-status) when accessing health services. Otto shared his reason for speaking up:

> "I have rights just like anybody else, so hey." (Otto, APHA, 31 years)

Another participant recalled being denied dental services.

> "Trying to book an appointment, or you know you book in and they say, 'Do you have any medical conditions?' And I'd go, 'Well, yeah.' I have no problem telling people even over the phone. Then it's kind of hard to find me a slot to fit me in, you know, 'The girl who was going to do your cleaning, she isn't in today.' Just LITTLE things like that that just irritate me." (Dennis, PHA, 41 years)

In contrast, others stated that they would avoid certain health care services in the future if negative attitudes or treatment experiences persisted. As one participant shared:

> "I was ready to walk outta there Monday morning. I was gonna rip out the catheter, the whole nine yards. Fuck it. I don't give a fuck one way or the other. Get him out of my face or I'm outta here." (Jenny, APHA, 44 years)

Reconciliation with Death

Confronting issues of mortality was difficult, as described by both PHA and APHA participants. Reconciling with death often involved planning for the future and making difficult decisions. Participants shared how this struggle plays itself out:

> "Forty plus and I'm going to start planning for my own funeral. So it's paid for. I don't want to burden anybody in at least 10-20 years. I don't want the government stepping in and saying, you have it at this church or whatever. I want an executor from my family to take care of it so it's all handle(d) and without my family having to pay for anything." (Nolan, APHA, 41 years)

However, some acknowledged that reconciling with death or dealing with the illness and death of others was not as common now as it was before the introduction of anti-retrovirals.

Participants did describe, however, that with the possibility of longer life comes increased uncertainty. As one acknowledged:

> "Because of dealing with, years ago we used to deal with lot of death and dying, you know; people came in and talked to us about their HIV and AIDS, well we were making funeral arrangements and talking about, 'Well, what would you like at your funeral?' You know?… Nowadays we don't do all that, so a lot of it was just going there and taking about being MORTAL. The loss of what you may or may not have later on. Like I'm a parent to three, a grandfather to two and one on the way; where am I going to be in ten years? Will I be at the graduation, be at the wedding, or you know?" (Dennis, PHA, 41 years)

Fatalism

Fatalism dominated the experience of HIV/AIDS and for some, it influenced the ability or desire to access health services. For example, several participants explained that the diagnosis of HIV felt like a "death sentence", creating fear in oneself. Some also spoke of the uncertainty that an HIV diagnosis brought into one's life. This uncertainty resulted in not knowing how to make decisions about one's health and life. Others spoke of the resignation of hope, not caring about adhering to treatment, or using ineffective coping mechanisms. Some participants described the inability to see the future or not being able to see beyond the immediate future, after HIV diagnosis.

For a few of the participants, HIV diagnosis meant that they did "anything and everything" following their diagnosis and didn't take care of themselves because they felt they were going to die anyway. One male participant said he was on a "suicide mission" after his diagnosis believing that he would die of something else (e.g. an overdose) before he would die of AIDS:

> "I was on a suicide mission I would rob and cheat people, use as much drugs as possible because I figured I'm on the death sentence as it is so, you know but I've come a long way. I haven't done IV drugs I figured it upstairs with the [HIV specialist] 11 years now…I guess I never took it seriously. I never did like I said I always thought I was going to die of something else and but now it has come into a reality play and I don't want to die from it that's for sure…" (Colin, PHA, 37 years)

Similarly, one young woman felt that there was nothing left to live for after receiving her diagnosis:

> "And I went on meds two and a half years ago [coughs], but from the time I found out until the time I went on meds I just gave up…I didn't much feel like there was anything left to live for after I had been diagnosed…Then it's like a death sentence, and to my belief after that's exactly what I did there, I just gave up. I didn't care. I did everything and anything after that, as far as I didn't take care of myself, I just didn't really want to live actually. I didn't have nothing to feel, to live for…I can see people committing suicide or taking pills or doing somethin', like, you already feel worthless

because you know, you're gonna die. You don't know if these meds are gonna keep you alive, I mean, who's to say?" (Kelly, APHA, 34 years)

One woman on the other hand said that her diagnosis had changed her life. Although HIV stands as a blockade in front of her, with support she had been able to come to terms with her illness:

"Well, HIV is like a wall. It's like a barrier in front of you. Okay, when you don't know you're Positive, well, you're a joyous kind of person. But when you're Positive then it stands out in front of you. And for you to bring down that wall you have to be strong. One, you have to have a friend that you can truly confide in, because I tell you, when you are HIV you truly need people around…You need to be reassured that this is not the end of life, because if you're not, you're going to kill yourself. If you are shunned or deserted, you're definitely going to kill yourself. And the hope is in you as a person, as an individual. You've got to make it happen. You've got tell yourself, I'm not going to, I'm going to break down this wall." (Nesta, PHA, 39 years)

Financial Impact

Participants shared stories of financial hardship, which resulted in increased levels of stress and feelings of discrimination. For example, participants reported difficulty finding employment and accessing government disability/income support programs. One of the most frequently mentioned financial concerns for the participants was related to barriers accessing government support programs for disabled persons. Participants commented on the complex processes required to access such programs, including the "bureaucratic red-tape". As a result, many participants had to use food banks to survive and search for affordable housing. They shared their experiences of eviction, or concerns about eviction, from their homes:

"Well, I couldn't FIND a place to live, that's why I was at the women's shelter, I got evicted from my house and there was a real housing shortage then…was tired of living at the woman's shelter and they were gonna take, they wouldn't have given me a welfare cheque unless I lived somewhere." (Megan, PHA, age unknown)

" I use to ask for, uh, food hampers from [HIV/AIDS service organization] because they were better to go through than going to the [Western Canadian city] food bank. They like give you the run around…the next thing I'm gonna go and try to do the impossible, is get my, uh Canada Pension goin' again. They rejected me because [HIV/AIDS specialist] didn't word it right… they said the way he worded it meant that I could do some type of labour, that's, that's their only excuse. And they wouldn't give me no cash." (Peter, APHA, 56 years)

"Every 6 to 8 months they send me all these red tape forms for doctors and nurses and counselors and everybody to fill out and I have to get around…with deadlines and yeah. And then they'll cut me off because I didn't get it in on time, or if the doctor

didn't fill it out and get it to them on time. Then I'll go without for the money for a month, you know? Really hardship stuff" (Louis, PHA, 43 years)

In addition, one HCP commented that the financial challenges that her clients experienced also included difficulties paying for anti-retroviral medications:

"I think more of the challenges that I have from that group is the financial, so the working poor. So how they actually pay for those drugs, the challenges they have around the fact that they'll often end up on drug trials 'cause that's the only way they can afford the drugs." (Amanda, Physician)

Fear of Infecting Others

Many participants described feeling contagious and expressed concern that they would infect others. As one participant commented:

"Sometimes I'm scared if, like if I cut my hand or something or scrape my hand, I'm scared for, if my dog, I wonder sometimes if my dog can get it if she licks my hand, and I just get so, 'cause one time I did cut my hand and I caught her licking. I was laying in bed and I caught her licking my hand."(Kelly, PHA, 34 years)

Other participants shared similar concerns about infecting others through contact. As a way to manage this fear, participants reported careful attention to cleanliness and being careful not to infect others, while some avoided contact with others and ensured safe sexual practices:

"Like to me, that's how I was. I'd contaminate something, I thought I might spread it. I tried to be clean." (Genie, PHA, 44years)

" I'm not going to make them [kids] sick, and they're so afraid, so I take all necessary precautions in the house, you know? I'm very careful when I hug my daughter. I'm very careful when I eat with them. I'm very careful when I use the washroom and all that. I am very, very careful. So I've got all these little pamphlets and booklets for them to read, for them to know and understand that I'm not going to make them sick?" (Nesta, PHA, 39 years)

Experiencing Blame

Several of the participants felt blamed by others, as a result of becoming infected with HIV:

"And she [sister] would be the type to say, 'It serves you right. You people.' She calls gays 'you people'. 'I know what 'you people' are like.' I can tell that she's very bigoted. She's not bigoted about nationalities or races but she is about gays. …That's a lifestyle 'you people' lead. Promiscuous people 'you', and you're doing things against God's nature and God's will and that's what you get for the type of lifestyle you lead.' That's kind of her attitude [laughs]." (Oliver, PHA, 45 years)

"Gay men also think, and I have fought this, even before I found out that I was HIV positive, before I was diagnosed, that you deserve it because you're a whore. That's how you got it. It's like, no." (Aaron, PHA, 37 years)

Participant Perceptions of Stigma

Many participants perceived that some people in society were still fearful of HIV and anxious that they could catch it from others (e.g. drinking from the same cup). Participants believed that the negative views were based on ignorance, the media portrayal of people with AIDS (for example, images of AIDS patients in the later stages of the disease with significant wasting), and lack of understanding about the difference between HIV and AIDS.

Several participants were quite sensitive to the confusion between the terms HIV and AIDS. For example, one young woman reported that when she completed a medical history form she would "…scratch out *AIDS* and put *HIV positive.*" (Megan, PHA, age unknown).

In relation to terminology, participants felt that there was still confusion around the terms HIV and AIDS and argued that the two should not be used interchangeably.

"So people are ignorant of HIV. You know, they haven't had, they haven't really studied HIV. They haven't really studied what AIDS is. Some people don't know the difference between HIV and AIDS, okay?" (Nesta, PHA, 39 years)

"…Like I don't have AIDS, right? I'm HIV positive. And until I get AIDS, until I'm diagnosed with AIDS…until I get an opportunity [opportunistic] infection, I'm not positive. You know? I don't have AIDS. I'm, you know, I'm not going to die, or you know, as far as, I'm, I'm healthy…" (Alfred, APHA, 54 years)

"…I said I don't have AIDS, I got HIV [laughing]. I used to have AIDS but now I only got HIV. And I'm really excited about the new therapies that are coming out so." (Howard, PHA, 34 years)

A few participants did not understand themselves, the difference between the two terms. As one participant commented:

"People, and AIDS, like even myself, there's a lot I don't know about it. I don't know the difference between HIV and AIDS. Is AIDS more an advanced level of HIV? In fact, I forget what the 'H' stands for." (Oliver, PHA, 45 years)

When speaking of their own perceptions and attitude towards HIV, many participants described their stories through metaphors like "death sentence":

"I kind of shut everything out. It was like, 'No, I can't be.' You always hear it's like a death sentence, and that's the first thing that comes into your mind when they, well what came to MY mind anyway when they told me that." (Cecil, PHA, 48 years)

"It's like a creeper. It creeps up. But until they find a cure, which I HOPE they do in the near future, [pause] it is like a death sentence in a sense, when I first found out, but then with the new medication coming out, everyday they're learning more and more and more." (Fred, APHA, 32 years)

"I was only 21 and I got all these years ahead of me, I'm not going to see them and I just. I was scared yeah I was scared. I didn't know how to deal with it. May as well just kill myself now 'cause I'm already dead. That's the way I felt back then." (Otto, APHA, 31 years)

Many participants spoke of stigma associated with HIV and AIDS because it was considered an infectious disease. Oliver commented:

"…and you know it is only natural that people are nervous about any infectious disease. The word infectious means just what it says. It's infectious and that means somebody else could catch it somehow…. So there's a stigma attached to this. I mean, am I gonna be touched? Am I going to be shunned? Am I going to be? The stigma attached…' (Oliver, PHA, 45 years)

Several participants commented that AIDS stigma necessitated the need for secrecy about their diagnosis. One recently diagnosed participant felt the need to keep her diagnosis to herself because of the stigma around HIV. The need for secrecy was sometimes related to concerns about the reaction of family and friends and decisions about disclosure were often made on a "need to know basis":

"No. I, like I said, 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. Especially down [Name] Avenue there." (Cecil, PHA, 48 years)

"And I tend not to want to tell anyone. I inadvertently told a couple of people when I came out of the hospital and I really regret it….when anything has a stigma you tend not to want to tell people…when you have HIV or AIDS you tend to keep it to yourself and you can't share that with people, and they don't have the same type of feelings towards you." (Oliver, PHA, 45 years)

"I wasn't ready to address my HIV because of the simple fact that I'd seen other girls in the system [prison] being shunned from having friends and going out and doing things, and it was AWFUL. And I knew I had this deep little dark secret behind me that I was sick, and I thought, I can't even express how I feel now, because look at the way they're treating that girl." (Kelly, APHA, 34 years)

Secrecy surrounding disclosure also extended to health care settings. In the following passage one of the participants described how he informed some of the staff in an emergency room:

> "For instance if I'm in an emergency room upstairs I'll go 'you got a pen', or something, I say and I'll slip it to them or I'll go [gestures], you know what I mean? Half the time they catch on pretty quick. So I hate having to do that but you know what I mean, it's got to be done." (Colin, PHA, 37 years)

While some participants described difficulty in disclosing or sharing their HIV diagnosis with others, one participant did feel that it had been easy for him to share his diagnosis with his family because they were all well educated about HIV by the time he was diagnosed in 1994:

> "To me it wasn't a big deal. Like when I told people, like even my parents and stuff, I just phoned them up and said, 'Well, I have AIDS.' Nine years of living with someone that already had it, it wasn't, you know, NEW news to anybody about, you know, what it is or how it's spread. They were all educated by then, so it was quite easy for me to just sort of SLIDE it in there and, you know, just go about things." (Dennis, PHA, 41 years)

Several participants discussed their perception that AIDS stigma was greater than the stigma associated with other diseases such as cancer or Hepatitis C:

> "But this is, this umm, it's, why is this disease so much more, worse than other diseases? Why do they make it seem so bad? HIV is almost a swear word compared to a lot of diseases. Cancer, you know what I'm saying?" (Kelly, APHA, 34 years)

> "They are really nice to me when I tell them I have Hepatitis C - that's fine I got it through a blood transfusion, that's fine. But then when I tell them I have HIV they completely turn; they're not the same kind of people they don't even want to touch you. They're not the same anymore… It's happened right here at this hospital. When I came in the hospital I said I have Hepatitis C and they were really good and I thought, I was being brought into the hospital and then I told them I had HIV and their attitude completely changed." (Dorothy, PHA, 45 years)

A female participant believed that AIDS stigma was more pronounced in Aboriginal communities:

> "I said, I told you, a lot of Native people are really SHOCKED by it. Not so much white people as much, but Natives are REALLY like, if somebody, if, Natives are scared to tell their family or anything 'cause their family won't have anything to do with them. It's like they're, they'll, they just throw the person right out of the, you know, whatever." (Megan, PHA, age unknown)

Several participants felt that stigma had decreased over time because the public was more aware of the disease and there was more general acceptance of it and that "it's out there":

> "I've had a few bad reactions but not as much as I would have expected now. Like five or six years ago I wouldn't be this open but now I'm like, since about '98 I've been fairly open about it and I haven't had that much bad reactions from people, so. I look healthy so people don't really worry too much about it." (Jon, PHA, 34 years)

> "Well, people I work with, if I would have disclosed my status to them in the '80s I think I probably would have had a much more NEGATIVE reaction than the last three years. I mean, a lot of the fear and the apprehension and the knowledge about how you can GET HIV, a lot of people understand it now." (Brent, PHA, 49 years)

Living With Stigma and Discrimination

Nearly all of the participants described experiences of stigma or discrimination. Participants reported feeling stigmatized by different people including family, HCPs, employers, the police and even landlords.

Participants noticed changes in how they were treated at work and how their duties at work changed as a result of disclosure of their HIV status. For example, one participant was no longer being allowed to cook food and was asked to wear gloves and a hairnet. The following quotes capture some of the participants experiences of stigma and discrimination:

> "When I was in the hospital…I don't know, they [nurses] were kind of mean to me. But the other nurses were [pause] well, like me I'm just kinda like a 'I don't care' attitude, eh. I don't care, fuck. I mean, excuse me for swearing, eh?...But I noticed my cousins, my cousin and my other cousins they kind of like, they put me down. Only when they're drunk, they put my down.' Get outta here. You got HIV….You're …AIDS-infested." (Genie, APHA, 44 years)

> "Aboriginal people get treated differently than myself. I'm white. Angers me beyond belief that women get treated differently. I'm a male. HIV. My cousin was treated like crap and that's blunt. All the cards are on the table. She got treated terribly. It's because she was a female…I think in the health care profession, everybody should be treated equally. Everybody should be just a canvas, and the work that you do on that canvas, it's a valuable canvas. Like, every person that's on this earth is valuable." (Aaron, PHA, 37 years)

> "I was working part time when I first found out, I was helpin' out at an AA club and I noticed, because my boss didn't want the older members to find out, my duties in the kitchen got cut, there was no more cooking. They were scared in case I cut myself and stuff like this…." (Kory, PHA, age unknown)

> "No because they made, they made me wear gloves [exaggerated]. I mean the other staff I saw they wouldn't do that. They wouldn't wear hair-nets, stuff like. And they

made me dress up like some sort of space person [laugh]. Because they thought, 'Oh this person!' Oh stop it. I just felt very ostracized…" (Quinn, APHA, 38 years)

"She was just a walk-in clinic type doctor. And new. Young. Family oriented. And I think she had her strong suspicions of my sexuality, and THAT plus my newly diagnosis. No. She wasn't ready, which was fair of her but I felt discriminated against a bit. I was hurt a little bit." (Louis, PHA, 43 years)

One participant recalled a past discriminatory experience that he felt was due to the visibility of the disease:

"From '95 to '97 I wasn't healthy and I did look very sick and people were very nervous around me type thing at that point. But they didn't know I was HIV positive they just knew I was sick or something. So people had the tendency to shy away from me type of thing. On buses and things like that and this is a very different reaction to it." (Jon, PHA, 34 years)

Another participant felt that the extent of stigma experienced by an individual might be related to his appearance and perhaps "social class":

"…because I was so anxious to avoid it [stigma] and, I would be dropping in a shirt and tie, relatively presentable, and I think that in itself might make it a little bit different than somebody who has, you know, come from the street… I think still for most of us one's appearance makes a big difference. And so perhaps that might be another reason why I might have been fortunate there." (Bob, PHA, 47 years)

Layering of Stigma

Most of the participants living with HIV experienced a layering, or a double (or triple) burden of stigma because they had become infected through a behaviour that was highly stigmatized (injection drug use, gay, commercial sex work), belonged to a culture (Aboriginal), gender (female), or social class (poor, prisoner) that was vulnerable to stigmatization or suffered from another illness (mental illness) that was stigmatized. Interestingly some of the participants believed that being gay, being an IDU, or suffering from a mental illness was actually more stigmatizing than being HIV-positive. One of the male participants felt that his peers were more shocked by his disclosure that he was gay than his HIV positive status.

Although there was a sense that stigma and discrimination had decreased over time, a few participants were not sure which of their personal attributes resulted in them being stigmatized. One of the male participants, himself being gay, summed up the layering of stigma in a very powerful manner:

"And there's a lot of hatred out there amongst all kinds of people…hatred is a terrible thing and when you are 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. It

could be a family member. Like I say, my sister hates me. Hates gay people. So you've got to be very careful when you fall into a category of being, Jewish, imagine if you're Jewish with HIV and you're gay, you could be, you're a triple target in certain areas of society. Or how Natives are picked on and they're stereotyped. People are stereotyped when they fall into a minority bracket." (Oliver, PHA, 45 years)

Interestingly, HCPs also described many of their clients as being vulnerable to stigma for reasons other than their HIV status: mental illness, addictions, homosexuality, poverty, homelessness, having lice or abscesses, being unreliable, disruptive and/or violent, being deaf, being an immigrant, being non-Caucasian, or being a sex worker. This was congruent with experiences reported by PHAs and APHAs.

Discrimination due to sexual orientation was described by several participants, particularly gay men. Many of the participants perceived that HIV infection was still associated with being gay. Some of the participants spoke about keeping their sexual orientation hidden due to negative societal attitudes towards homosexuality.

"There's a lot of AIDS jokes and gay jokes, and hatred and bigotry, so it's better to keep it hidden and keep it to yourself and then you won't get picked on, or ostracized, or shunned...you could get shunned or ostracized very quickly by a group of people and then sit around and watch who comes to socialize with you." (Otto, APHA, 31 years)

One of the gay, male participants believed that his experience dealing with stigma and discrimination related to being gay had taught him skills to deal with discrimination related to being HIV positive:

"I know I probably have a thick skin in DEALING with stigma and discrimination because I've had to DEAL with it as a gay man before I had to deal with it as an HIV positive person, and that sort of gave me some, a skills set in coping with it, that perhaps somebody who didn't have to go through that process has." (Brent, PHA, 49 years)

Some participants described negative encounters with health care providers who were homophobic. For example, one participant recalled an experience with HCPs during a hospitalization:

"He was recommended to me by my family, my parents' doctor. He was an older gentleman, and very pro-family. I heard him make comments during my initial meeting with him, 'Oh, you're one of those,' and I had an uneasy feeling about it…I referred to my partner, I'm very private about having a partner, as my partner in life and he said, 'What's her name?' and I said, well, actually it's a gentleman and at that point a wall went up. I had felt that and I noticed his, his manners toward me changed. The bedside manner changed. There was distance. Literally physical distance between us at that point, and, and I thought, okay, this is not a good sign…

…and I have Kaposi's on my left foot, on my large toe and Kaposi's it looks like a big, black bruise and so she [nurse] asked me what it was and I explained it to her and she said, 'Why are your toenails painted?' And I looked at her and I said, well they're not, that's part of the illness. And she said, 'What?' And I explained to her, I said, well, and I kept my voice down, and I said, 'Well, I'm HIV positive.' And she went, 'What?' I said [whispered, lowered voice], '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, 37 years)

Though some participants described experiences of compromised health care as a result of their sexual orientation, a few participants did not think that their health care had been compromised due to this reason:

"I don't think I've been treated any worse. I'm gonna put that in perspective though, because I've always been treated in large urban centres where health care, and I go to health care practitioners that have a large base of gay clientele. I think if I were a gay man in [rural town] perhaps I'd have a more difficult time than I do in [urban area]. You know? So, I think, I think THAT's one of the keys." (Brent, PHA, 49 years)

Impact of Stigma and Discrimination on Disclosure

Disclosure was described as being one of the major issues that PHAs and APHAs have to cope with. As one HCP commented:

"One of the biggest issues for people that are living with HIV, be it gay men or straight women or straight men…who to disclose to, how to disclose, when to disclose, [laughs] and just the stigma that can go with that. So I would say, yeah, probably disclosure is the biggest, it's definitely the biggest issue." (Jane, Psychologist)

Disclosing HIV positive status to HCPs was described as a stressful experience. Participants reported feeling an obligation to disclose their positive status to a HCP, while at the same time feeling the risk of receiving compromised health care or services from the HCP. Other participants chose to not disclose their HIV positive status for fear of rejection or refusal of health care services. For example, several participants described feelings of stigma and discrimination after being referred to another HCP for care:

"…like [specialist], after…after he found out that I was HIV positive …he referred me to another doctor…" (Fred, APHA, 32 years)

"[Dentist], he was a dentist in [small town] he basically referred me to another doctor. He says he doesn't deal with that kind of people." (Fred, APHA, 32 years)

Some participants also reported avoiding HCPs altogether in order to avoid disclosure of their HIV positive status. While some described the stress and anxiety associated with

disclosure, others reported that disclosure to HCPs was a routine thing to do, causing little or no anxiety.

Experiences in the Health System

Several participants received advice from physicians not to disclose their HIV positive status. For those who were co-infected with Hepatitis C, they were advised to disclose Hepatitis C positive status rather than their HIV positive status. Some participants reported a difference in reactions to disclosure of Hepatitis C infection versus HIV infection and sometimes used Hepatitis C as a means to diminish stigma:

> "He [doctor] was very good about, 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…" (Dorothy, PHA, 45 years)

> "They are really nice to me when I tell them I have Hepatitis C that's fine I got it through a blood transfusion, that's fine. But then when I tell them I have HIV they completely turn; they're not the same kind of people they don't even want to touch you. They're not the same anymore." (Dorothy, PHA, 45 years)

> "I had Hep C before and [GP], I've had dental appointments and the doctor said, 'You don't have to go out and tell them that 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, 48 years)

Participants also reported experiences where HCPs became angry or upset when participants did not disclose their HIV positive status, even with a substantial medical file or chart documenting their HIV illness. Participants felt it was not necessary to disclose their HIV positive status with the HCP during every visit given that participants had well-documented files and patient charts. Participants expected their HCPs to know about their medical condition, and provide appropriate care, with the appropriate precautions.

> "I had a migraine or something, I went in and I guess she didn't look at my file and I wasn't in the mood to talk to anybody and she overhead the doctor talking to somebody else that I was HIV positive. She came in and FLIPPED on me. And then I flipped back at her and said, 'Listen it's all over my chart, so if you don't read my chart too bad.' And she came back and apologized later. She said it was her fault, she should've wore gloves to begin with and I said, 'Yeah, I'm in no shape to talk to you let alone tell you, usually I tell everybody if they're gonna take blood, 'I'm HIV or whatever'. I just so happened this time I wasn't in the shape to talk because my head was killing me.' And she put an IV or something in me without gloves and she flipped. That hurt because I felt like I DID something wrong, but it's all over my file, like I don't hide it." (Kory, PHA, age unknown)

Coping With and Managing Stigma

Being Open

Being open with others about HIV was a coping strategy mentioned several times by participants. One participant had known of his diagnosis for nine years at the time of his interview. He believed that stigma and discrimination had decreased over time:

> "I think for me being OPEN has made it easier with doctors and nurses and clinics. Like I'll walk into my walk-in clinic in the [location], and they know I'm Positive and I'll be yakking to the nurse at the front and I don't care if everybody in the waiting room hears me…Overall, I think people that work in health care are very knowledgeable and very good at what they do. I don't feel that I'm stigmatized all the time, not anymore; not so much now as a few years ago, and it's starting to get easier." (Dennis, PHA, 41 years)

Family and Peers

Family also plays an important role in providing support to both APHAs and PHAs as they manage the experience of HIV and AIDS. However, disclosure of HIV remained a difficult hurdle to overcome. Both APHAs and PHAs reported that they did not disclose their HIV positive status to all friends or family.

> "I wanted to let somebody KNOW in the family, where I was at. I ask them to be honest with me about how things are with them down there, so I figure I may as well be honest with them up here." (Cecil, PHA, 48 years)

> "I haven't talked to her since, actually. Um, but I don't know, I THINK she knows I'm positive, I'm not sure. Uh, I've never. I haven't talked to her since then. But my nieces know, and my brother was my best support person, my contact person. My mother died, she knew I was positive."(Alfred, APHA, 54 years)

> "My family has always been very supportive of me. And that's why I'm glad I told them when I did, it wasn't a double shock. My father didn't know. He was the only one that …so I wasn't in contact with him at [one] point." (Jon, PHA, 34 years)

However, some participants also reported that their families were not as supportive as they had hoped. When PHAs and APHAs disclosed their HIV positive status to their families, they reacted differently, depending on the families' level of knowledge and awareness of HIV and AIDS.

> "Yeah, my mom cries all the time. When she [thinks] about the way I was and the way I am now. I get a little emotional sometimes. Yeah, she cries all the time. It used to break me up when I was in the hospital. I'd see her leave and she'd be crying. [Long pause] It's tough to take." (Howard, PHA, 34 years)

Interacting with peer support networks or with other HIV positive persons was a valuable source of social support. Through those networks, PHAs and APHAs were able to access additional information to learn to deal with challenges associated with infection. Peer support also appeared to reduce stigma and consequently social isolation that could accompany living with HIV. It is important to note that the value of peer support appeared unrelated to cultural background. In other words, whether a person was Aboriginal or not did not appear to influence whether an individual found value in the support of other peers. Peer support might be associated with disclosure to wider audiences:

> "I met a lot of people then. And I hadn't met anyone who was HIV positive previously. So that was a good start, to my coming out thing" (Alfred APHA, 54 years)

> "I wouldn't share that I was sick, but since I've been on medicine now I've even told other people about where I go. Here's a place that will help. The other people are sick that go there. You're not stopped from doing anything. Nobody puts you down. Everybody's all sick, got the same thing, you know"? (Kelly, APHA, 34 years)

> "I find out little bits from other people that are HIV. I go to [HIV meds/support program for marginalized persons] every day, and I pick up little things from there again, from other people that go there. Just little things, like things you shouldn't do or things that you should have or you shouldn't be taking, or what they feel is good for them. I wonder if I should try it for me, or if they're getting their, they're finding this out from their doctor or where they're finding it out from." (Kelly, APHA, 34 years)

> "I like it here. It's nice. I mean, you feel kind of safe, you know, it's, people know what you've got. Nobody attaches, puts a sign on your back. It feels comfortable; a comfortable feeling around here." (Cecil, PHA, 48 years)

However it is important to note, attention to cultural diversity may determine participant satisfaction with organized peer support networks.

> "Cause on Mondays, Wednesday and Fridays I can come here from 12 till three and be with the people that are positive. And the women's group, they don't have that at [the Aboriginal centre] so. Sometimes it's not comfortable just being Aboriginal here. They're starting to be, more from the ten years that I've been going there. They're starting to be more Aboriginal now." (Mona, APHA, 41 years)

Faith and Spirituality

Peers, family/friends, and/or spirituality and faith were valued as important sources of support to reduce social isolation and stigma. For some participants faith and spirituality were important sources of support to deal with their illness. For at least one participant, HIV illness helped him to rediscover spirituality as a tool to cope with an HIV positive diagnosis. In the following quotes, participants discussed the importance of spirituality:

"So the first thing I did; there was a Catholic church across the road. That's where I ran. It was open. I ran in there. I remember sitting on the bench, and I knelt down and I said a prayer…I started asking God why? Why me? And I said, well, you know best." (Nesta, APHA, 39 years)

"…if I hadn't had my church I wouldn't have made it though that really bad time when I was really, really sick they kept me here. That and my family, between the two [enunciates slowly] definitely was my anchor." (Jon, PHA, 34 years)

"I'm thinking on more spiritual levels than I ever have in my life." (Louis PHA, 43 years)

Chapter III. Stigma within Organizations

Stigmatizing Behaviours of HCPs

Both HCPs and PHA/APHAs reported examples of HCP behaviours and practices that led to stigma and discrimination for PHA/APHAs during care, treatment and support. These behaviours included: not engaging the client in decision-making; making assumptions and judgment; and lack of "universality" in universal precautions.

Not Engaging the Client in Decision-Making

Participants described situations when PHAs and APHAs were not included in the decision-making related to their care. Alfred recalled not being consulted by his physician prior to having an HIV test:

> "They tested me for everything. BUT they never asked me if I wanted an HIV test. Um, my doctor was, uh, an old man and he had a resident. And I was sick, uh, ten days, and I, you know…I was REALLY sick…and I've never been that sick before in my life. So, uh, they did the, HIV test, I guess, at one point or another..." (Alfred, APHA, 54 years)

One HCP suggested that in her experience, if a patient did not give consent for an HIV test, it would often be done anyway:

> "Well, then it goes above their head, kind of thing, 'cause it has to be done…It's consent if, we prefer you to say yes, [laughs]. Then we have to go through other channels…yeah, because we probably already have some blood of yours anyways. So even if they refuse to let us poke again, there's something up in the lab." (Jane, Psychologist)

Similarly, another HCP noted that pregnant women were often not asked for consent to be tested for HIV, a practice that contradicts practice standards for informed consent for HIV testing in Alberta:

> "…when they find out you're pregnant, automatically would do an HIV test …They actually are supposed to ask consent; the thing is, they usually don't. The test is just done. And that's very bad, because there's no pre-test counseling. So we have people come in, and they find out that they're Positive, and they're freaking, right; it's very scary". (Trish, Social Worker)

Participants believed that excluding PHAs and APHAs in decision-making related to their care resulted in a lack of trust in HCPs.

Making Assumptions and Judgments

PHAs and APHAs described feeling judged based on their appearance or diagnosis when they sought care:

> "They treated me pretty good, really. Except for when they made out an accident report from up here, they put on there that [I] reeked of alcohol and they thought I had an alcoholic seizure. I never had a drink of alcohol in years. Must have been damn good alcohol that I had!" (Peter, APHA, 56 years)

Similarly, HCPs described instances when their assumptions and judgments towards clients impacted the provision of health care services. One HCP described an experience of treating a client who was HIV positive, deaf, with mental health illness, addiction issues, and a history of head injury. When the client presented for health care services, he presented as "very, very disoriented and psychotic", which was out of the ordinary for this client. The HCP described how her colleagues made assumptions and judgments towards her client. For the HCP who knew this particular client and his history of a previous brain injury, this HCP was able to recognize that something serious was happening to him, whereas other HCPs judged his behaviour before beginning any medical intervention to treat the client.

Another HCP, an outreach worker, described how the physical presentation of a client, such as scar tissue or collapsed veins could physically mark the person, identifying an individual as an intravenous drug user.

> "When they're there at the HIV clinic or the HIV doctor, and they want to start medication, it's the same issue. Well, first the approach was, 'Look, once you get your addiction under control, we'll address your HIV'." (Grace, Outreach Worker)

Lack of "Universality" in Universal Precautions

Several participants believed that the practice of universal precautions impacted the care of patients and the experience of stigma. The inappropriate application of universal precaution procedures could create stigmatizing experiences for PHA and APHAs.

One HCP stated that in her health care organization staff were not allowed to draw blood that was known to be HIV or Hepatitis C positive. This was based on a policy that this blood needed to be packaged in a specific manner to meet Ministry of Transportation standards. As the health care provider described:

> "There's a barrier right there for clients with HIV/AIDS. If it is a known HIV, AIDS, [or] Hep C, we are not allowed to draw… It's the Ministry of Transportation, for one thing, so anything that their driver picks up from us has to be properly packaged for them to transport. I guess there are insurance regulations that anything their drivers are picking up, and to be insured properly, it is wrapped properly, packaged properly, and handled properly." (Ellen, Blood Technician)

A HCP reported that universal precautions were not adhered to appropriately in her agency. A new HCP in her agency communicated to staff that she could not take blood or initiate intravenous access to clients because she was not trained yet. However, as this HCP described:

> "We learned after, yes, she was doing it elsewhere, but not here.You wouldn't think somebody would do that, you know, being a professional." (Kim, Registered Nurse)

Another HCP, whose duties included taking blood for HIV tests, was very aware of how her behaviour might be viewed by the client:

> "So I treat them all equally, not knowing what kind of disease they might be carrying. And I, of course, clean the site properly, glove up. Sometimes I really do wish I could wear goggles, but you can't; I mean, that would be just discrimination right there, but sometimes I personally do even get a little nervous when drawing the blood." (Ellen, Blood Technician)

Some of the HCPs mentioned that the use of gloves by health professionals could be seen as stigmatizing, but on the other hand the lack of gloves could be viewed as poor practice due to the risk of infection to both the client and the HCP. One HCP commented on the challenges she had experienced in deciding when to wear gloves:

> "Like, if you're not wearing gloves before you go in to see someone, and someone sees you, you're often, like, 'What are you doing? Put your gloves on'….We don't go in and chart, do vitals with gloves on, necessarily, 'cause I find that very impersonal, and people-stand-offish. You know, like, 'What does she think I have?' Like, 'Oh, my God, what's wrong with me?' " (Carmen, Registered Nurse)

HCPs also described clients' reactions to universal precaution practices. Some clients had shared that: 'As soon as I say I'm HIV positive, they double-glove.' There were issues around whether or not universal precautions were practiced in a standard way among all HCPs. One HCP, a dentist recalled an experience when a colleague behaved inappropriately during the care of a Hep C positive client:

> "…and said to me, 'Be careful; he's Hep C positive'... I just said to her, 'you know, it really doesn't matter. It shouldn't matter to you whether he's 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, Dentist)

Another HCP was in contact with a wide range of patients for short periods of time, and she described her belief about infection control and universal precautions:

> "I mean, our number one concern is to protect us; you know, to protect yourself and then your partner. And sometimes we don't always get reports from nurses, because they feel that they don't need to give us one, or that we can pull up whatever information from the chart. But it is, just like being HIV positive is the same as a

patient having diabetes or having paralysis on one side, it is important information" (Rachael, Emergency Medical Technician)

There were also experiences when HCPs did not adhere to appropriate universal precaution standards. At times clients would remind the HCP of appropriate practice:

"When I'm taking care of somebody who's HIV positive, most of the time, I'll already know that they are, but sometimes not, but in any case, I just use Universal Precautions. But many times this has happened before, where I've started caring for someone, and I don't have gloves on right away, if it's something where I'm not touching anything; like, I have NO fear of touching someone. You know when I know that there's no exposure…once I start touching them, before I even think that there's a risk, or I would even think to put gloves on, they'll say, 'Oh, I'm HIV positive.'…I find the patient wants to protect me more than I will protect myself…" (Andrea, Nurse Practitioner)

Stigmatizing Practices in Organizations

Service Delivery and Physical Layout

Several PHAs and APHAs described situations when service delivery contributed to stigma and discrimination. For example, one participant believed that treating HIV positive clients differently than non-HIV positive clients might promote discrimination. In this passage an APHA described feeling discriminated against because she was offered different food at a shelter:

"When I have to get specials foods and go near a shelter. Course they [non-HIV positive clients] get jealous. I don't know - I used to get mad and say 'Hey you can have what I eat if [you] want my disease.' I said 'I don't wish it on you'." (Fiona, APHA, 40 years)

Similarly, two of the male participants were concerned that accessing an AIDS Service Organization [ASO] might identify them as being HIV positive:

"I really didn't want to come in there [ASO], you know, oh, who's going to see you go in or go out of the office, and what are they going to think. But I came in here and got to know the people here and the staff are great…Like, I haven't had any problem with health services. And I haven't been really, really sick either." (Cecil, PHA, 48 years)

"They run their general clinic, and then a lot of times they'll run the AIDS clinic at the same time, which is really good, but you go to some clinics and they have just Tuesdays and Thursdays are AIDS clinics, and that's ALL they do. Well, it kind of tells people, you know, if I pop in on that day, I can see what's going on." (Dennis, PHA, 41 years)

Sometimes the physical layout of organizations or clinics made it difficult for some PHA/APHAs to access services. Obvious signage on HIV clinics made it awkward to enter or to approach the site for some participants, while others experienced no difficulty. One of the male participants described his experience entering an HIV clinic:

> "Having this SIGN glowing at the top of our building is appalling to me. I don't think that we need to put 'HIV' up at the front of our building….we don't need that. People need to be able to come in and out of here without that stigma being attached to them. I stand out there for a CIGARETTE, and people drive by and they're just LOOKING and then they drive by again the other way when you KNOW they could have went around the block. They just went around, turned around, and came back again. They're curious. And you know, I'm not here to be displayed to the public." (Dennis, PHA, 41 years)

One HCP believed that clients might feel stigmatized if they had to go to a general health care facility for care:

> "If they go to a facility or place that doesn't routinely provide care to HIV positive people, then it's like there is this level of discomfort that the staff have 'cause 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, Social Worker)

Several HCPs and PHAs shared other experiences that created feelings of discrimination. For example, routines and practices could be stigmatizing even when staff were following protocol when dealing with clients with HIV or other infectious diseases. One HCP described the treatment a friend's brother who was HIV positive received at a major hospital:

> "And the way he was treated [pause], like the nurses were standing there, and they had this disgusting look on their face, and gloving up, and gowning up and everything, masking up. I'm sure if they could have went in there with some kind of space suit, they probably would have…so you kind of wonder what happened to those people and compassion." (Wendy, Community Development)

In smaller clinics participants commented on the cold, impersonal, rushed diagnosis, especially when it was given over the telephone. When asked about his nurse, an APHA commented:

> " 'Cause it was like, cold. The way she explained herself…Yeah, I wanted to, but we were in the STD clinic. I couldn't. I found that in talking to her, she was like wanted to go on to the next patient, 'Next', you know what I mean?" (Paolo, APHA, 40 years)

Some participants described documents such as "caution sheets" which were placed on client charts to alert HCPs of an HIV positive client. Participants perceived such documents unnecessary and possibly stigmatizing. When asked about such documents, one HCP noted:

"…it contributes to the stigma and fear piece. Like, all of a sudden there's this glaring caution sheet as soon as you flip the chart, and you go, 'oh, caution. What should I be looking out for?' Usually, they're used for allergies, sensitivities, or, 'oh, you know, they're allergic to penicillin, so don't prescribe anything with penicillin in it." Then you look down and see they're HIV [unclear]; why does this, why, to me, it's a question of why does this need to be on the front of the chart. So that part [pause] to me it just contributes a little bit more to the whole fear of 'oh, this person's got HIV. You have to be extra safe.' [Unclear] practicing universal precautions for everybody, 'cause you don't know who's HIV and who isn't. THEY may not know they're HIV positive or not, so it should be practicing the same safety pieces around drawing blood, or procedures that you're doing. But there really shouldn't be a need for a caution sheet." (Charles, Physician)

Not Maintaining Confidentiality

Participants emphasized the importance of maintaining and respecting the confidentiality of clients when providing health care services. Participants were very concerned when confidentiality was breached:

"I've seen the doctor come into [partner]'s room and start saying, when she's in her hospital bed and sharing a room with somebody and the doctor comes out and starts saying this about her HIV that she's got it and everything and her face just dropped pale and it's like 'Llisten you', you have to pull him aside and say 'Listen not everyone knows she's got it you can't be just [pause]… You know if her daughter had of been in that room her life would've been over and she would've never, that's the way her daughter is she would've never been able to see her grandkids again'." (Colin, PHA, 37 years)

Confidentiality was also critical in public areas and clinic reception areas as well as in public hospital rooms. One participant described his experience during a period of incarceration.

They had a like a day timer board on the table, and if you looked at it you could see everybody's name and your ASSIGNED cell. Well, above the ones that were Positive they had 'HIV positive' written. You know? Hell!" (Dennis, PHA, 41 years)

Another participant, on the other hand believed that the emphasis on confidentiality could create more 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 of a stigma because more people are involved. Confidentiality is the creator of some of the stigma that surrounds our illness." (Ethen, PHA, 36 years)

Participants also spoke of the importance of having physical space that was conducive to protecting and respecting client confidentiality. For example, it was perceived that clinic

reception areas should have more space for clients to speak to the receptionist without having people in the waiting room hear why they were in the clinic. In addition, HCPs also wanted space that was designed to ensure their safety when dealing with potentially violent clients.

Chapter IV. Design Features to Reduce Stigma in Organizations

This chapter will highlight findings that detail individual provider practices to reduce stigma in HIV services, organizational design features to mitigate stigmatizing experiences and strategies to re-orient health services to incorporate optimal design features. Respect for privacy and confidentiality for PHAs and APHAs was perceived as central components to health care services. In addition, specific organizational and agency policies and principles were identified as being key to the delivery of care and support for PHA and APHAs.

Individual Provider Practices

Respect for Privacy and Confidentiality

The importance of respect for privacy and confidentiality for persons living with HIV was highlighted by both PHAs, APHAs and HCPs. The ability to access HIV care services without being labeled as "HIV positive" was seen to be very important from the perspective of the HCPs:

> "Because of the transient nature of the clientele that we're dealing with, when we ask them to give us a couple of snapshots of what they thought of our service, they always tell us they like the fact that no one can label them as having HIV just because they've seen them here. A lot of them wouldn't come in if seeing them here would mean that everyone else that saw them here would know they had HIV."(Brian, Social Worker)

Another HCP stated that confidentiality was the most important policy in her organization in relation to client care. Several other HCPs emphasized the importance of confidentiality and described how it was maintained in their organizations. For example, HCPs described the need to discuss client information in a team setting, while adhering to client confidentiality:

> "…and almost everyone gives me consent to discuss things with the team, and even if they don't give consent to discuss things with the team, they usually give consent to discuss things with specific members of the team. So, you know, I discuss this with patients in the first or second session that I meet with them, talk about the benefits and downfalls of having, [pause] you know, working with the team rather than just the client and I." (Sandra, Psychologist)

Further, as one HCP noted, confidentiality of client information fosters trusting relationships with the client:

> "I've never had somebody seem like they had a problem with sharing that information [HIV status]. I think they have, they seem to have a sense of trust that what they share with us is confidential, and that we're there to help." (Andrea, Nurse Practitioner)

Participants also described the need for greater confidentiality in correctional facilities in order to keep HIV status confidential (closed doors, no visible posting of status). It was recommended that there be fewer special treatment indicators of HIV status (e.g. double meals), quicker access to treatment and medication, and greater awareness on the part of Corrections Officers to treat HIV-positive individuals with greater sensitivity.

Several of the HCPs described ways that their organizations protected confidentiality of their clients. For example, one HCP described several strategies to protect the confidentiality of clients:

> "…charts are always turned facing the wall, so that if anybody happens to walk by, they can't read that demographic label about their name, their address, their telephone number. In the Aboriginal population, confidentiality is such a [pause] people are so afraid of their confidentiality being breached here, that we are constantly, you know, on the lookout." (Ellen, Blood Technician)

> "So, any of our labels, any of our lab reqs, copies, anything like those, any kind of client identifier on it is put into that shredder box. Any letters that are typed are destroyed after 24 hours off of your computer. There is a chain here that, once it is read, if it is about a client, it might only have their initials or a chart number, but once it is read by all the members who need to read it, it is shred as well and removed from the computer where it was typed."(Ellen, Blood Technician)

A few organizations had specific policies for interacting with clients outside their organizations and in public places:

> "…you never acknowledge somebody outside the clinic... So outside, we're not to, of course, acknowledge anybody outside…The information can spread very quickly…" (Darlene, Registered Nurse)

Although HCPs felt they needed to know when a patient was HIV positive in order to provide optimal care, they tried to ensure that this information was communicated on the client's chart in a sensitive manner:

> "…it's not like we come down the hall and say, 'Everybody move. This patient has HIV,' or 'This patient is Hep C positive,'or whatever… But, yeah, no, we just include it in our, it's obviously, it's written on the paperwork in an obvious spot, and then we just verbally tell the primary person that's receiving this patient." (Rachael, Emergency Medical Technician)

Maintaining confidentiality, privacy, and anonymity were also perceived by HCPs as being very important in their practice. Practices included: not discussing client information in public, not using client names in open areas of a clinic or agency and using shredders for client documents. These practices were perceived to prevent stigma and make people feel comfortable. Some key areas of concern that emerged in the data were reception areas,

charts, service visibility, care and respect. One PHA noted his experience with anonymity at a clinic:

> "…things are explained to you, things are explained to you PRIVATELY, they're not out there where everybody can hear. Your file isn't marked with a little red dot to say that's an AIDS file. That kind of stuff is what, the environment that would make us feel better." (Dennis, PHA, 41 years)

HCPs described the importance of keeping charts "safe" from those who were not involved in the client's care and described measures to protect the confidentiality of their patients' charts. These measures included turning charts to the wall or placing them away in drawers; and not flagging them with obvious symbols indicating HIV/AIDS status. Further, HCPs noted the importance of keeping unnecessary information out of other medical databases:

> "And some people, if they're a health care worker, are very worried about confidentiality, and that is something that's stressed right off the bat: that we have clinic charts here, the blood work does not go down to the medical records, there are two separate charts. And if somebody were to look up blood work on them, they would not see anything that would say that there was HIV. There might be 'Hep B, Hep C,' but all the other stuff is not disclosed on a hospital chart." (Focus Group of Registered Nurses)

Care and Respect

Several HCPs mentioned the importance of providing care to clients that was respectful, caring, and non-judgmental. One of the HCPs made the following comment when asked about her organization's policies for the provision of care:

> "…I think in policy, there is [pause] you know, the goal is to serve people, care, they use the word 'care'…Respect. I don't think it's a policy matter so much as to how it's implemented. You know, like, when the nurses meet, do they really discuss how to CARE for the client? ...When APPROPRIATE services are provided, by appropriate I mean non-judgmental, competent, culturally appropriate, clients will come." (Sandra, Psychologist)

Another HCP commented:

> "I recall, like, my boyfriend also saying, 'Well, they're nice to the [needle exchange program] gang because, like, we're giving' them condoms and clean rigs'. But it's more than that; it's, like, friendship and respect, caring and stuff like that." (Eunice, Social Worker)

Providing client-centered care was another aspect of respectful care. One HCP stated that his approach to care emphasized working with the client, based on where the client was at in their life and their circumstances:

"I make it a policy of never trying to tip the balance one way or another in pushing someone one way or another to either decide to get tested or not to get tested. So it would be them talking their way to that on their own." (Brian, Social Worker)

Several HCPs described the positive impact of HCPs sharing similarities with their clients. This could contribute to the development of trust with clients. As one physician commented, some of his clients felt at ease when they learned that he shared some of their experiences:

"…and they're, like, 'Really?' You know, there's this moment of, like,'What?' And then you can just see them relax, you know, that that's totally okay, you know...and it's the same thing with a woman going to a gynecologist, right? You know, probably easier to talk to a woman gynecologist, [laughs] so, I think it's just the same kind of comfort level…" (Ian, Physician)

Organizational Design Features to Mitigate Stigmatizing Experiences

Several features in organizations were felt to be essential to mitigate stigma and discrimination for persons living with HIV and AIDS. These features included: harm reduction, reducing barriers to services, a flexible approach to care, a shared care approach, supportive work environments, culturally-appropriate care, building and maintaining connections, and knowledge and information.

Harm Reduction

HCPs described harm reduction philosophy as an important feature of non-stigmatizing care and services. Several HCPs commented on this approach:

 "…we used the harm reduction model, though it's not quite [laughs] going to stop him using cocaine, it's 'What is it that brings you to the point where you're sharing needles with someone who's Positive? What can we do about that to try and avoid that situation…' " (Darlene, Registered Nurse)

"You know, in our HIV meetings, we discuss the needs of the clients in a pretty broad way, and try to meet that, and we work with a harm reduction approach to addictions, and we work with where clients are at. And I think that every profession teaches that, but how is it implemented?" (Sandra, Psychologist)

Similarly another HCP spoke of her organization's approach to harm reduction:

"We definitely practice harm reduction kind of stuff around here, so you know, safer sex. If people are IV drug users, using clean needles." (Andrea, Nurse practitioner)

Reducing Barriers to Care

HCPs spoke of different strategies used in their organizations to maximize access to care, treatment and support services. For example, HCPs stated that a fundamental aspect of his

organization's mission was to ensure health services were accessible, with minimal barrier to access. In order to do so, for example, screening processes were kept to a minimum, anonymity was provided if requested by the client, and questions asked of clients were confined to those that were necessary for care:

> "…we were set up in order to serve clients who had difficulty accessing medical and social services elsewhere. So there isn't any screening process for someone who wants to come in to our drop-in; they can just walk past the front desk, come in. And no one, they don't even have to give us their name if they don't want to…it's very few questions asked." (Brian, Social Worker)

Another HCP spoke about her organization's ability to offer anonymous HIV testing as a way to reduce barriers to care:

> "The walk-in is anonymous, whereas if you go to the doctor, then it's no longer anonymous." (Focus Group of Community Workers)

Some of the HCPs reported that they felt very uncomfortable when asking clients about their past or current "risk behaviour". HCPs in one focus group were asked if they asked clients about previous or current risk behaviours prior to HIV testing. For the most part, HCPs did ask these questions, however they agreed that exceptions could be made to this practice:

> Participant #1: …We have had updated education sessions, quick ones, on which ones [questions] are absolutely essential and mandatory. Now, in terms of the risk, do you remember what it is?
> Participant #2: I fill it in, I know, but I don't know whether it's mandatory.
> Participant #1: We aim to fill it all in, but I mean, we've made exceptions in the past.
> Participant #2: Initially, we were really encouraged to follow step-by-step, but now it seems a lot more …
> Participant #1: Relaxed.

Another HCP suggested that asking the risk behaviour questions should be universal to all clients he sees.

> "You are looking for risk factors, 'Are your partners male, female or both?' those kinds of things. And I typically ask that question of everybody, so some people, I've had in my career, I've had one person become very offended when I asked that question…. and then you have to go backwards and say ' I asked that question because I can't tell if I look at you.' " (Charles, Physician)

Flexible Approach to Care

Many of the participating organizations reported a high degree of flexibility in the provision of care and services. For example, in one clinic, clients were given the flexibility to decide whether they would be seen by the same physician or by another HCP who was on staff:

"…some patients like the flexibility of booking on any day that they may be off, and that would be with the understanding that they will see whichever doctor is on that day. For patients who prefer to be followed by one doctor specifically, then they know which day is my day, which is Mondays, and they'll book in specifically with me on the Monday. So it's really left to whatever the patient is more comfortable with." (Ian, Physician)

While tolerating some degree of inappropriate behaviour, organizations had very specific policies to help manage such behaviour in a respectful and appropriate way. Managing inappropriate behaviour among clients was a serious issue:

"…if I'm the one dealing with someone at the front and I feel that they should be banned, I would definitely tell them, 'You're banned until further notice,' and then I do discuss, we have a weekly meeting, like a lunchtime meeting type thing where we'll discuss little issues that come up, where we'll discuss what a particular person has done, and how long of a ban they should get." (Zara, Licensed Practical Nurse)

Generally, HCPs spoke about the need to "bend the rules" and be flexible in order to provide care to their clients:

"…we're always super flexible with somebody. I don't think there really is a hard and fast, even if it is written somewhere, I can tell you nobody goes by it that way." (Andrea, Nurse Practitioner)

"…officially, you cannot participate in a program or you can't even attend that program if you're intoxicated, so that's been a bit of an issue for me…that's been, again, a growing piece therefore that strict policy piece that's still there is being relaxed; we're bending the rules a little bit." (Charles, Physician)

Shared Care Approach: Team Work

One HCP spoke of the need for a "shared care" approach to providing care to patients who are HIV positive. Shared care involves the use of teams that include both generalists and specialists:

"…sometimes the complexity of the issue is so much that I need assistance in terms of starting somebody safely. So what I'll typically do is refer up to the specialist to start, but then ask them to send them back to me, and I'll do regular monitoring and follow-up from there, and then we do a shared care model." (Charles, Physician)

HCP teams (i.e., case management approach) were described as having benefits such as sharing workloads and providing continuity of care to clients.

"…we have weekly case conferences at which we discuss patient needs, and so when we have a new patient come in, for example, we'll discuss the patient at a case conference, and discuss all of the patient's needs: their psychosocial needs as well as

the medical needs. So as a team, we decide how to best serve that patient." (Sandra, Psychologist)

Several HCPs commented that a team approach came with its own concerns around confidentiality. One way to deal with this was to be explicit about sharing information with the rest of the team, and gaining written consent from the client:

"And as a psychologist, usually we take a very narrow view of confidentiality, and what we discuss in my office is it. But my initial form has a section in there, 'Can I discuss your situation with the team?'" (Sandra, Psychologist)

"We are very vigilant as a team; I think we're extremely vigilant as a team. We don't release anything without written consent, we're very careful about where we hold conversations about clients and not using clients' names. We discuss this on a regular basis, and I think we're just very, very vigilant about this." (Sandra, Psychologist)

"Our typical line is, 'Well, we work with a team.' Particularly here at [Aboriginal community health centre], since I'm only here a day and a half, I have to let people know 'I'm only here a day and a half, so there will be other people who will be involved in your care,' because a day and a half isn't really enough time to [unclear] access to their family doctor. So that gets addressed usually in that way, and then also making sure they're aware that 'Only people who need to have access to your chart will have access to your chart, and only people who, and everybody who takes an oath of confidentiality.' And then try to [unclear] them on what are their particular concerns around that." (Charles, Physician)

In addition to a shared care approach, HCPs commented on the need to integrate community based care and support into the continuum of care. Community-based care was considered particularly valuable shortly after being diagnosed with HIV, before there was a need for tertiary level health care services:

"But I think, again, we've discovered with my population that they do much better at a community level clinic than a tertiary level. So maybe that would be a way of helping some people access care better. Um, and I think what we also have learned is that, okay, at first maybe they only can access care if we come to them; then with some trust and time, they can access care by coming here; and then maybe with some time and trust, they can eventually access some care at the tertiary care place, but that maybe we need some more creative options in between where they're at in the hospital." (Amanda, Physician)

However, as one HCP described, establishing trust with clients depended on the availability of resources:

"[We need] more money for more services. More counseling; you know, more counseling services. We don't lack at all for physical end of things, the usual human contact. We could have more counselors, more complementary care. We certainly don't lack being able to provide people with some of the medical, from the medical

point of view of prescriptions, but [unclear]….For me, more nurses, you can do counseling. For me, it's just counseling. People have the opportunity to talk to an individual. Addictions counseling, specifically, would be great." (Darlene, Registered Nurse)

Supportive Work Environments

HCPs also highlighted the importance of managers modeling respectful behaviour and supporting staff in a complex work environment:

"…but managers, like, you know, your leaders really say, 'This is our, we're part of this team, and this is what we project to other people. This is how we treat clients, and I want to see all of my people doing this,' People will, I think, pay more attention to it than any booklet on respectful workplace." (Trish, Social Worker)

"But I think the other piece of it that CAN be done is leadership. You know, like, why does our program run so well? Really, I give a tremendous amount of credit to [Infectious Disease Specialist A]. He's non-hierarchical. He sees, although he's a physician, he sees his patients in a holistic view, and he supports holistic approaches." (Sandra, Psychologist)

"It's [morale] very high right now because I think we have good leadership in terms of understanding some of those factors, and really being flexible around time away, etc." (Andrea, Nurse Practitioner)

Culturally-Appropriate Care

Many HCPs described a need for culturally appropriate services particularly for Aboriginal clients. This included providing opportunities for Aboriginal ceremonies, working with people in the community such as Elders to provide care and hiring Aboriginal staff.

When providing services to Aboriginal clients, several HCPs described the need for services with an Aboriginal focus and for HCPs to be sensitive to their client's cultural backgrounds:

"I realize this is not a Native organization, but I really do appreciate the fact that at least they try to incorporate a part of community development geared towards Aboriginal people and Aboriginal communities. So I think that's a step forward." (Wendy, Community Development)

"We are a unique service for the Aboriginal peoples in [eastern Canadian city]. So yes, if you are Aboriginal, you're most likely coming here, unless you have that mistrust of your own people, let's say. And some will not come here because of that. So this, yes, is a unique service centre for Aboriginals that has their culture component, plus their health care." (Ellen, Blood Technician)

"... and then our social worker is a Métis woman who previously worked at [HIV/AIDS service organization A], and again, the clients know her. So I think that the First Nations clients and inner city clients, feel very safe at our program, and I think that that's unique… And I think that creating an atmosphere of safety and a nonjudgmental atmosphere is another very critical piece, along with being culturally appropriate, for our clients, you know, to feel comfortable in coming in." (Sandra, Psychologist)

Further, HCPs who shared similar cultural backgrounds with clients, or who were perceived to be "non-mainstream" allowed some clients to feel more comfortable. As one HCP described:

"And [pause] to have somebody who is [Aboriginal] or Native often helps them, because there's just [pause] I remember once asking a Native person why they wanted a Native worker, 'cause they had specifically requested that. And she said, 'Because I don't have to explain anything to them; they just know.' So I think that kind of covers it. I think she was talking about lifestyle, about being poor or those kind of things. Understanding that it's not as easy for them to, there are more barriers to their being able to access services, the same as there are with immigrant people." (Trish, Social Worker)

In contrast, several PHAs and APHAs felt it was beneficial having a HCP who was from an ethnic community other than their own. Specifically, if a participant belonged to an ethnic group that was small, having a HCP from outside the community was more desirable. As one HCP said:

"I think that having a white doctor hasn't been a big issue, because I think actually having a doctor that's from their community probably would be more traumatic. They don't want anyone to know from their community that they're HIV positive, so I don't think that's been so much a barrier." (Carmen, Registered Nurse)

One HCP described additional privacy concerns for Aboriginal persons living with HIV:

"In the Aboriginal population, confidentiality is such a [pause] people are so afraid of their confidentiality being breached here, that we are constantly, you know, on the lookout…" (Ellen, Blood Technician)

Building and Maintaining Connections

Building and maintaining connections emerged as a theme from PHA, APHA, and HCP interviews. Building and maintaining connections occurred on three main fronts: with clients, within staff from agencies, and with other service providers involved in the care of clients.

HCPs discussed important aspects of relating to clients in helpful and therapeutic ways. These included advocacy and building relationships. Several HCPs spoke of acting as an

advocate on behalf of their clients, in a variety of contexts, including those outside the clinic or health services setting. For example, one HCP spoke of advocating on behalf of his client, who was also a refugee:

> "Yeah, we've advocated for a number of people, actually. And not just disability, but again, coming back to our refugees, I've written letters when they go for the refugee hearing, and made it abundantly clear that if these people are sent back, that their health was at risk. I've come right out and said,[chuckles] 'Let's be honest: if you send them back, you're sending them to their death. So don't be an idiot. [Chuckles.] They need to stay'." (Ian, Physician)

Sometimes HCPs were very active in ensuring their clients' health needs are supported. Being aware of where to refer clients was an important measure to ensure clients received non-stigmatizing health services. HCPs also ensured they were aware of HCPs and agencies that were known to be non-judgmental and respectful:

> "…word of mouth. I guess really, it comes from the clients. If they had gone some place and they've had good services, I'll often ask them, 'Where did you go?' and, you know, stuff like that…and I might say to a client, 'I've heard this guy does really good work, and other people have been happy with him.' (Trish, Social Worker).

HCPs also assisted clients by providing support when a client needed to access the services of a specialist. Such preparation helped reduce clients' anxiety while, allowing for seamless or continuing medical care. Two HCPs described their advocacy work with PHA and APHAs:

> "We try to walk them through what a typical visit will be to the specialist: you may only see the person for a little while, you may not get all your answers, but that's okay, you can come back and ask us some of the questions we can try to answer them. And if there's been a negative experience, we [pause] one of the nice things about sharing is that we can still do their care with the family med piece for a little while, and then refer them back up, once we've tried to intervene or do some advocacy work on both sides, because sometimes there's miscommunication on both sides." (Charles, Physician)

> "And we will acknowledge it afterwards, absolutely, you know, and debrief with the person, and talk about it and see what we could do, and sometimes, you know, offer them, let them know what their rights are; like, if you want to write a letter or whatever, absolutely, you can do that. You know, see where they want to take it." (Grace, Outreach Worker)

Other examples of advocating on behalf of clients included helping people find funding resources for medications, and helping people navigate the system. This was best done early in the process of working with people, and could involve advocacy, networking, and searching for creative alternatives. As one Registered Nurse reported:

"…sometime they'll go and they'll get counseled by a Social Worker, so maybe they'll leave a job in order to keep healthier, and then they have more access to these programs." (Focus Group with Registered Nurses)

"So they don't have coverage at all, and they don't have much money, you know. They live there, they're all provide for where they live, so they don't have a big income. That's where you mentioned compassionate relief, sometime the doctors will request a company to provide the meds for this special patient on the basis of whatever." (Focus Group with Registered Nurses)

Non-stigmatizing relationships between clients and HCPs were described as requiring trust, flexibility, non-judgmental care, warmth, being able to speak in the client's language, and seeing the client as a whole person as opposed to a person with a disease. HCPs also believed that developing trust was important, and was more likely to result in clients continuing with their HIV care and treatment.

"Okay, obviously, it's not good clinical medicine to offer this person antiretrovirals. But we'll still monitor them, we'll still get to know them, we'll still build a relationship so that, hopefully, some day when they are ready, we've, we've done a lot of the trust-building ahead of time." (Amanda, Physician)

HCPs also described the importance of being accountable for their practice and behaviour and ensuring that they do not practice in a way that would stigmatize their clients. One of the HCPs talked about the importance of being aware of their own judgments and of how this could potentially impact clients and client care.

HCPs discussed the need to work well within and outside of their organization. In order to care for clients effectively, it is essential that HCPs work together to provide and improve support services, including health care services for clients:

"I think that the easy thing is to develop more programs like [program], that provide a holistic approach to treating clients. However, we cannot work in isolation. We cannot provide for the needs of all of our patients, and so we do have to work with other systems. We do have to work with [emerg], and our efforts so far at advocating for our clients and educating [emerg] staff have, for the most part, not made a very big dent." (Sandra, Psychologist)

"…we try to do that, because we, well, it's to their, our patients' advantage if they get good dental care or good whatever kind of support. If we send them to a particular counselor, addictions counselor, who, you know, gets them hooked up with services right away and is friendly with them and stuff, then it's good for their mental health, right? And it helps us, because sometimes there's just too many patients. You can't possibly do all of the paperwork that's involved. And that's a part of this job, is networking; like, making links with [disability income support program] workers and different people. And after a while, you get a kind of a sense of which ones are more helpful, [chuckles] and then hopefully, you can talk, you call them, and get them to

help you if you're having problems maybe getting assistance for a client or whatever." (Trish, Social Worker)

HCPs also spoke of the importance of connecting with others beyond health service organizations. For example, connecting with communities to build awareness of HIV/AIDS was done informally:

"... I think what we've done overall with most of the tenants in the building is change their view about who it is that we're serving. And you know, when we first opened, we did an open house, and we phoned. They knew exactly who we were, who we were serving, and why we were here." (Brian, Social Worker)

In addition, HCPs devoted time and energy interacting and building relationships with people outside their agency (i.e., educating the neighborhood about HIV/AIDS, safer sex practices, etc.) and felt that this contributed to a safer neighborhood. Further, HCPs described how communities became supportive of the services provided and of the individuals who access those services:

"We've done a lot of PR with our neighbors …The building will look at us and say though we deal with a clientele that is PROBABLY more likely to want to break into your car or steal your bike or whatever, that there was probably more of that going on in the vicinity of this building before we moved in than there is now." (Brian, Social Worker)

Knowledge and information

Many of the participants called for more knowledge and information exchange with the general public as a strategy to eliminate stigma and discrimination.

"…Ignorance. There's a lot of people out there who just don't understand what it is. And generally people on any disease are ignorant. If you don't have a certain disease you're not going to know much about it." (Oliver, PHA, 45 years)

"I felt that the biggest thing that, one of the biggest barriers in dealing with stigma and discrimination is that everybody thought it was happening to somebody else. They couldn't put a name and a face to it, so I made the decision three years ago, when I was Chair of [ASO], to come out with my HIV status in the media." (Brent, PHA, 49 years)

"I'll DO newspaper, I'll DO TV, I'll do THOSE spots, and I don't really care what the public thinks. That's how I'm going to get the message [out], I will put a face to this if I have to." (Dennis, PHA, 41 years)

"More knowledge, more people like me, basically talk to people, to know this is, you can have a sick person here you know, that's dying of AIDS in a wheelchair, whatever, and have me beside them." (Fred, APHA, 32 years)

Re-Orienting Health Services to Incorporate Optimal Design Features

In the first section of this chapter, HCPs, PHAs, and APHAs described their perceptions of factors that help reduce the stigma of HIV illness, in the context of the health care services and support they receive. Participants described *individual factors* (respecting privacy and confidentiality and providing care and respect) and *organizational features* (harm reduction, reducing barriers to care, a flexible approach to care, a shared care approach, supportive work environments, culturally appropriate care, building and maintaining connections, and knowledge and information) that mitigated stigma. The following section describes findings related to the processes required to reduce stigmatizing experiences among HIV positive individuals: reducing barriers to care, treatment and support; implementing a shared care approach; creating supportive work environments; support; and advocacy.

Reducing Barriers to Care, Treatment and Support

Several participants spoke of factors that helped reduce barriers to care, treatment and support from clinics and from community-based agencies. With fewer barriers to care, treatment and support services, PHAs and APHAs believed that they would be more comfortable accessing the health services they required.

Communication was perceived as a key factor to ensure a supportive care environment for PHAs and APHAs. Several HCPs also described the need to be sensitive to their clients needs through personal and responsive communication:

> "So it's all about NOT talking, sometimes; not so much talking, but not talking. And the Aboriginals tend to pause a lot between [pause] when they're talking, so a pause, and you think they're finished, so you try, you almost want to jump in, but you have to learn to just sit back. And sometimes, it might take five minutes to get out one point for them. So patience, or not patience; I've had to learn to slow it down, slow it down, and let it come out as they're comfortable letting it come out. Nonverbal communication is huge in this population. Like I said, I don't need to talk sometimes, I just need to make eye contact and shake my head or, you know. So, and there's tons that I still don't know, and I just need to continue to attend cultural training workshops here that are offered. I attend the feasts, the gatherings." (Ellen, Blood Technician)

> "I can give you the standard answer that's written in all the literature, but the long and the short of it is: understand the implications of the test, understanding the window period, understanding risk factors, understanding how to protect yourself in the future, and most importantly, I found with a lot of my clients, is 'How are you going to deal with this information? Are you ready to deal with this information?' So that's kind of what I, I do." (Amanda, Physician)

Many HCPs spoke of working with a unique population, specifically with clients who present with addiction issues. HCPs described the need to be sensitive to the special needs of individuals trying to cope with their addiction issues:

"…particularly as staff get trained in how do you deal with somebody who's intoxicated. Somebody who's intoxicated isn't necessarily at risk, it's more when you ask them to abstain that they get more at risk!" (Charles, Physician)

"You don't want people to be abusing drugs, and you don't want to have people coming here drug-seeking, so we try to minimize that as much as possible. Yet at the same time, if I think that they are maybe in pain afterwards, I'd rather give them something that's cleaner than something they're buying off the street." (Belinda, Dentist)

HCPs also spoke of the need to recognize people who are newly diagnosed with HIV and their need for special care. Newly diagnosed HIV positive clients may feel more vulnerable and may potentially need more care and understanding from the staff. A HCP recalled an incident when a newly diagnosed man was sent away because a new staff member did not manage his care appropriately:

"I still remember the man's face. Like it was this horrendous thing we did …besides the fact that in a newly diagnosed client, the risk of suicide is very high, we may have contributed to that person going out and saying 'Well screw it' … and you know when things like this happen, you know, I mean hopefully we learn from our mistakes." (Veronica, Grief therapist, Counselor)

The provision of flexible and accessible services to clients is important to consider when reducing barriers to health and support services. For example, as several HCPs noted in the following examples:

 "[Lab company] does have specific dates and times to go have their blood drawn if they're HIV positive, which is another barrier…most of our clientele have can't follow time very well, you know, and something else will come up, and their hours of operation just are not convenient." (Ellen, Blood Technician)

"I think the biggest challenge I've had is one around the issue of trying to get blood work; like having to send them to two specific places, which I can't remember, at certain times. I've um, found it challenging the fact that the majority, the care is provided in a hospital setting and a tertiary care setting; um, that's certainly been intimidating to certain people who just don't do well in that setting." (Amanda, Physician)

Several of the HCPs also spoke about the need for flexibility or to "bend the rules" in providing care to their clients:

"…we're always super flexible with somebody. I don't think there really is a hard and fast, even if it is written somewhere, I can tell you nobody goes by it that way." (Andrea, Nurse Practitioner)

"…officially, you cannot participate in a program or you can't even attend that program if you're intoxicated, so that's been a bit of an issue for me…that's been, again, a growing piece therefore that strict policy piece that's still there is being relaxed; we're bending the rules a little bit." (Charles, Physician)

Another important consideration in reducing barriers to health and support services is ensuring that clients feel safe in the health services setting. There is a need for programs delivered by people with experience, who can make clients feel safe. One HCP noted the importance of understanding the complexity of clients and avoiding treating just the physical aspect of the illness:

"I would not refer them [clients] to my colleagues that are taught to deal with depression and anxiety, because they're going to miss the other dynamics that need to be addressed, and the clients' needs will not be met." (Sandra, Psychologist)

Another HCP described the need to understand the complex issues that PHAs and APHAs must cope with:

"I think the biggest gap is the narrow mindedness in, of fellow professionals in dealing with our clients that have multiple co-morbidities." (Sandra, Psychologist)

Respecting confidentiality and privacy was also seen as a major factor to reducing barriers to care, treatment or support services. HCPs need to recognize the importance of protecting client privacy. For example, when dealing with confidentiality, HCPs must be aware of when to appropriately disclose information for the benefit of the client. Allowing for private space at the front desk may reduce stigma associated with seeking treatment. As one HCP worker described:

"We do ask them at the front desk, considering because we do have to do some form of triaging, right? And I have run into people who are hesitant to say what they're here for, and I won't push it, because obviously, I can tell that it is a sensitive topic. Like I'll so anything from taking them off to the side, or writing on a piece of paper, and they can either say yes or no if it is something that I think they are here for. But it is completely up to them what they want to say at the front desk." (Zara, Licensed Practical Nurse)

Implementing a Shared Care Approach: Team Work and Integration of Care

Many HCPs discussed the value of using a case management approach, when deciding as a team on the best care plan for any one client. Case management has been described as a way to improve holistic care that is better received by clients:

"We have weekly case conferences at which we discuss patient needs; And so when we have a new patient come in, for example, we'll discuss the patient at a case conference, and discuss all of the patient's needs: their psychosocial needs as well as the medical needs. So as a team, we decide how to best service that patient…I think

provide a much better service for the clients as a result; a more holistic approach … that most clients can really see the benefit of a team approach and signing consent for that." (Sandra, Psychologist)

Working as a team also allows for continuity of care for clients. For example, during busy periods, another team member can care for the client if one staff member is not available for a client:

"Like, the mental health team or nurse, they're nurses that'll come down because the pysch residents are usually too busy. I think is what started. They'll do their pre-assessment, and if they think they need to be admitted for further assessment, then they'll call the psych resident. So we all kind of cover for one another. And so I think it helps in terms of burnout, you know. When you feel that team support, then it's not so much pressure; we don't feel it's all on MY shoulder." (Jane, Psychologist)

"By recognizing you can't do it all. But also, because we have a good team, like, I don't have to do it ALL myself. It's, like, if [psychologist A] knows she's going to be away, she might have certain patients on her case load, and [psychologist B]'s not available, then she might know, say, three clients in a week that are [psychologist A]'s, just to provide emotional support and make sure that they're not falling on the wayside while she's away." (Trish, Social Worker)

HCPs also acknowledged factors needed to build a cohesive team. For example, trust among team members was an essential attribute for the team. Building trust required time and effort to get to know who the team members are:

"In our department, it works very well (i.e., case management). It takes time for the docs to trust the nurses, I think, in what we know, what we can do, before they order stuff. Just their comfort level with us knowing what we're doing, kind of thing. Because there are two docs in the department, so they rely on us heavily; like if something's happening to someone, don't just try and, you know, do what you have to do and then go get him, or whatever." (Carmen, Registered Nurse)

"I get some referrals from [infectious disease specialist A] and [infectious disease specialist B] from their HIV [practice]. The nurse over there, also will, they're very familiar with me, so if they have somebody come in, they'll refer them to me themselves, even before the doctors see them. You know, if they are new Positive, or if they think they have social work needs." (Trish, Social Worker)

HCPs also discussed the challenges related to working within a team environment. For example, there was the possibility that team members might not contribute fully to the team or adhere to team norms:

"The other thing that makes it really easy to work as the team here is physicians that truly work in a team kind of way. Because if you have even ONE person in a team

that doesn't work in a team kind of way, there goes the team." (Carmen, Registered Nurse)

Recognizing the Complexities of Client Care

Many HCPs spoke of the importance of recognizing the complexities of client care. For example, one participant described the need to ensure holistic care involving not only the physician but other health care workers who could address the emotional and mental health needs of clients. Participants mentioned key health care workers involved in their care including, physicians, nurses, and social workers, who were able to provide a "supportive ear" to tend to their emotional and mental health needs.

Other HCPs spoke of the diverse needs of clients from a health determinants perspective. HCPs must consider the overall health and social issues surrounding HIV illness. For example, several HCPs spoke of need to assist clients in finding affordable or temporary housing such as shelters.

> "With the street people, they'll either refer them on to their own social worker or phone their social worker themselves, usually, oftentimes, arranging to see if they can get their prescription filled, or get some clothing, get a ride home, where they're going home to; all that basic kind of stuff. Like, "Once you leave us, where are you going?" Get them hooked up with [men's shelter], get them a hotel, wherever, [provincial substance abuse treatment organization], all that stuff, they do it." (Carmen, Registered Nurse)

> "You know, [pause] what I would really like is, that I would think would be really important,[pause] the majority of the clients that we have now access many different services. Like, we are but just one. And what I would see as an ideal health service to them would be having at least some of us in the same building as, like, I guess you'd call it holistic, as in the whole [unclear]. You know, people come to us and they want, we give them vouchers to go and get, it's called a starter kit, here they get sheets and they get a pillow from [inner city organization A] right, or sometimes we'll get people, like tonight, with [HIV/AIDS service organization B] where we have a sharing circle and we have food. I would really, like, to me, that would be an ideal thing, and I actually never thought of that before, where a client could come in and have access to not only us, but have access to physicians, have access to somebody to talk to them about nutrition, [pause] access to, even if it was just [pause], even if it was like a food, even it was just a food voucher that they could take from us to go somewhere else. But you know, that must be a horrible thing to have to go from place to place to place to place." (Veronica, Grief Therapist/Counselor)

HCPs also described the importance of meeting the unique needs of Aboriginal clients, including the provision of culturally sensitive care. Meeting the spiritual needs of clients was considered important for Aboriginal individuals:

"I think we do that here, also, too. I referred a women last week to an Elder at [Aboriginal community organization] so that, in conjunction with the psychological things that I'm doing with here, and although I am quite culturally aware, there's still a spiritual side First Nations piece that can help her that I would not provide. And so I refer her to appropriate resources that way." (Carmen, Registered Nurse)

When participants spoke of referrals being made to other HCPs, they described the need for referring HCPs to be aware of discrimination against HIV in Aboriginal communities. As one participant noted:

"[When] referring them to people in THEIR communities who are aware of HIV and who won't discriminate against HIV, and to provide information to people in their communities about HIV on a, you know, yeah. So, I think that [pause] the other thing about providing good services is not to see one's role as 'This is my job' but to see 'What does the patient need, what piece can I provide, and what pieces can someone else better provide, and how can I hook them up with those people that can provide those pieces'." (Carmen, Registered Nurse)

Creating Supportive Work Environments

Staff Orientation to Organizational Policies

Although HCPs described the importance of having staff orientation and organizational policies, HCPs described the challenges experienced within organizations that impact service provision to clients. For example, HCPs spoke of high turnover rates among staff, orientation processes for new staff, and the impact that organizational policies and procedures had on service provision. The high turnover rate within organizations could impact the orientation process and subsequent care for clients:

"Sort of learned that [policies of organization] on the run and from my own questions. I think when I started [pause]. You know, this is an agency that goes through a lot of changes with staff, and so they didn't know how long I was going to stay, so it's sort of, like, how much effort do you invest in a person that might only be here for 45 hours? " (Veronica, Grief Therapist/Counselor)

One HCP shared the process for orienting new staff in his organization:

"We have, I can't say that there's, like a template that everyone gets; everyone gets oriented, everyone has to understand [pause] certain basic premises about what our agency's philosophy is, even the volunteers. They have to understand harm reduction; they have to understand our approach, the nonjudgmental approach; they have to understand some things about HIV, but, I mean, depending on their role, I mean, if they're going to be a nurse, they have to know more than if they're gong to be a counselor…" (Brian, Social Worker)

In several instances, HCPs were unaware of the explicit policies of his or her organization:

"…they're understood [the policies], and they're probably written, but I haven't seen that. [Laughs.] Well, that's [pause] I haven't seen that in clarity, I guess. The understood policy is that as long as the person is not disruptive or abusive or threatening, they're welcome…I said, 'You know, we have to have some sort of protocol that we follow when we have somebody that's newly diagnosed,' and she said, 'Well, there is' . Well, [name F] didn't know about it, I didn't know about it, and I think probably a lot of people, even the counselors, don't know about it." (Veronica, Grief Therapist/Counselor)

"…we have a whole book of policies and procedures, and I even know how to get them, but I'm not great about referring to them. I know we have a policy around discrimination, I know we have a policy around access, I know we have a policy around universal body fluid." (Amanda, Physician)

Another HCP explained that the policies and procedure in her organization were always kept current:

"And our policy and procedures, we're pretty up-to-date, and we're always really, that's one of the main things that we are always concerned with, to make sure that all the I's are dotted and the T's are crossed, so that we can be consistent with the delivery and the focus that we're supposed to be having…" (Grace, Outreach Worker)

Another HCP felt that she learned more from staff meetings than from written policies because of the need for flexibility in how policies were operationalized:

"I'd say I actually learned it [policy] more from being part of the meetings weekly, because it does exist, it's there, but I'd say that we're very flexible in how we play that out. So that's kind of a skeletal structure for it, and I'd say more of it is [pause] organic and alive and changing." (Andrea, Nurse Practitioner)

Providing Safe Work Environments

Protecting the safety of HCPs and clients was an important consideration in several of the organizations. Some of HCPs, particularly those dealing with individuals who were more likely to be violent (e.g. clients who were using substances), stated that their organizations offered training in non-violent crisis intervention:

"And we're all trained to go into non-violent crisis intervention, which allows us to stop things from escalating to the point that we HAVE to press our security button…" (Darlene, Registered Nurse)

"Everybody gets non-violent crisis intervention. Tthat's mandated by the organization…" (Brian, Social Worker)

"One thing that we have, actually, gone on here, it wasn't part of my initial orientation, and I do believe that administration is trying to make this a yearly thing…but it is out at [mental health hospital], and it deals with dealing with aggressive behaviours, as well as some self defense although I don't think we really have to focus that much on the self defense…" (Zara, Licensed Practical Nurse)

"Very high levels of staff safety, client safety, colleague safety, occur here. We have banning policies here for aggressive behaviour; we have their chart flagged if they are aggressive, not that the client would know…We have a daily check-in that happens here; it's kind of like hospital rounds, where we go through who's coming in today, who could be a potential for violence, who's aggressive, who just doesn't like this or doesn't like so-and-so…I've had several courses in the non-violent crisis intervention, so that has made me more comfortable with dealing with situations, and so have my colleagues, and we have done a workshop here all together." (Ellen, Blood Technician)

Education and Training

Another aspect of creating supportive environments for HCPs is ensuring adequate education and training, including ongoing professional training for HCPs. HIV is an incredibly complex disease for HCPs to manage effectively. As such, regular, on-going training is vital to providing quality care. As an example, several HCPs spoke of an HIV Primary Care Group which is a group of different HCPs involved in the care of HIV positive clients. Such multidisciplinary groups meet regularly to discuss different clients as case studies, but also to invite HCPs from other health care facilities to discuss new approaches to HIV care, treatment and support. HCPs felt that this was an effective way to maintain a current knowledge base for practice and to learn from their colleagues.

One HCP spoke specifically about teaching clients about their rights:

"And we will acknowledge it afterwards, absolutely, you know, and debrief with the person, and talk about it and see what we could do, and sometimes, you know, offer them, let them know what their rights are; like, if you want to write a letter or whatever, absolutely, you can do that. You know, see where they want to take it. And that always gives us an opportunity to speak more of the individual's OWN feelings." (Grace, Outreach Worker)

HCPs described various training and education opportunities that they had been involved with through their work and care of HIV positive clients: in services, peer groups, multidisciplinary discussion groups, buddy systems among staff, self-education or learning modules, and preceptorships and internships of HCP students. HCPs noted that employers show their support for further education and learning by allowing staff to have paid education or professional development days during each year. Conferences were also an important way to learn and share learnings with other HCPs outside of one's workplace.

Staffing Issues

HCPs spoke of challenges related to staffing which could have an impact on the overall workplace environment. With decreasing resources and increasing workloads, processes which assist HCPs to manage the stress of daily routines might help prevent staff burnout.

> "I think one of the things that people have to recognize is that a lot or workers do not have the ability for debriefing, and that with the cutbacks, their loads have multiplied, so you're putting them under extreme emotional stress lots if times and they will be more reactive than you know proactive." (Zara, Licensed Practical Nurse)

HCPs also described the importance of advocating for those they served and voicing their concerns regarding government cutbacks and cancellations of programs:

> "And I think it's agencies' responsibility as well that they do not go into denial as bigger governments and parties do, that they need to take the initiative to voice their concerns over programs being removed, because it just adds to a larger burden to the people that are out there. So rather than, maybe it might just be in our city, I don't know but as they erode human rights and the quality of health care, and the agencies acknowledge it, it is always baffling that nothing's being done. So I sometimes wonder if the helplessness that we see in our clients does not overflow in to the agencies, because there does not seem to be a unified front fighting for those that we're trying to protect." (Zara, Licensed Practical Nurse)

Organizations providing care, treatment and support to PHAs and APHAs must ensure that adequate staff orientation and on-going training for all staff members are a priority. Staff training may help reduce the overt or covert stigma faced by PHAs and APHAs when they seek health care services. One HCP spoke of the need for training related to health insurance coverage:

> "Just in terms of my own personal comfort, I say it would be nice to kind of know a little more about the treatment; implications in terms of insurance, etc. Not that I get a lot of questions about it, but I would feel more comfortable. 'Cause I did have this one client who was positive and had a million questions about insurance, etc. that I was not able to answer'." (Focus Group of Community Workers)

Another HCP noted that education to reduce stigmatizing practices needed to start when HCPs were students. She was concerned that HCPs become complacent and behaviours difficult to change over time:

> "I find it [pause] I think as you develop certain habits, or as you develop certain ways of doing things, it is difficult to change, especially if you're comfortable with them. Integrating new ideas and having that learning curve or going through a learning curve to obtaining skills sometimes is a difficult hump to get over… I found it much more, a lot easier, especially when I was younger, to acquire new skills, and I think

sometimes as you habitualize in a certain manner, sometimes it can be difficult to acquire new skills." (Belinda, Dentist)

HCPs also suggested that processes be developed to balance patient and staff safety and adequate resources be maintained to serve the most difficult to serve. HCPs talked about the need to serve the few clients who were intoxicated, under the influence of drugs, or violent, while at the same time caring for the majority who were non-violent:

> "There are also big security issues at [community health centre] because of the nature of the clientele; you know actively using drugs, often fairly volatile personalities, so we have a strong security system." (Darlene, Registered Nurse)

> "This is a thing that we really have a tough time with, 'cause we're here to serve the most difficult to serve, yet the REALLY most difficult to serve we can't serve, 'cause we haven't been given the resources to deal with …And these are the people who, in my opinion, you couldn't safely serve unless you had paid on-site security, because these are the people who either could or have physically assaulted people." (Brian, Social Worker)

Providing Culturally Sensitive Care

Providing HCPs with training about Aboriginal culture was also seen as a strategy to reduce stigma and to provide a more welcoming approach to treatment for Aboriginal clients. As one participant noted:

> "And I think that creating an atmosphere of safety and a nonjudgmental atmosphere is another very critical piece, along with being culturally appropriate, for our clients, you know, to feel comfortable in coming in." (Sandra, Psychologist)

Another participant provided his insight about the advantages of being cared for by HCPs who have had cultural training:

> "They have sort of a cultural type of thing. I know out at [Aboriginal traditional healing organization C], there was, I did [Aboriginal traditional healing organization C] training, and there was some doctors that had come out there. And I think that's really kind of a plus. But then you've got these others. Or let's say you're going to work in a northern community; you know like, [pause] what kind of [pause] you just graduated, and you take this position? Like, ooh. So yeah, I think something like that would be good. I'm not saying it has to last, like could be let's say a week, and you try to get as much as you can in that week. Or even just people, like, I have some friends that they're very interested in the native culture so they come and they do things with us. Like, they come to sweats, they come to ceremonies, and it's a matter of them being interested right, in learning the culture. So yeah, I think something like that would help. I'm not going to say it's going to take all the stigma and discrimination away, but at least they'd have a little, maybe a better understanding." (Wendy, Community Development)

Advocacy

Two processes stand out that may assist in re-orienting health services to address the impact of stigma for persons living with HIV and AIDS. First, service providers need not just be knowledgeable about treatment of HIV, but also have a working knowledge of income/disability support programs in the community. For individuals living with HIV and AIDS, income security becomes extremely important. One individual talked about incorrectly worded forms that resulted in denial of services. For physicians and others working in HIV and AIDS (particularly where they are responsible for completing income support program forms), professional development could be offered to ensure services were not denied to individuals living with HIV and AIDS.

Second, advocacy is required to representatives of government disability support programs to incorporate changes that recognize the nature of HIV and AIDS. Advocacy is also required to orient and address shortages in affordable housing. As a key determinant of health, several individuals talked about long-waiting lists to gain access to affordable and stable housing. As well, reducing bureaucratic red-tape to access income/disability support programs is needed. Advocacy is also required to increase income available under support programs and to make HIV treatment available as a benefit (rather than welfare which offers less income than other programs).

Learning from other groups experienced in advocacy work was another strategy mentioned to assist with intervention design. Several participants mentioned that the gay community had done a lot more for the AIDS movement than the general community did. Therefore, the gay community could be used a resource in the design of interventions to reduce stigma. On male participant felt that his experience had opened his eyes to a lot of things and made him more accepting of the gay community:

> "Like I used to be I guess you'd call it, I don't know, I never would talk to gay people and I got involved with the [HIV/AIDS service organization program] and I met a lot of gay guys there and I find the gay community does a lot more for the HIV and that than the straight community. [Pause.] They're human too and I never thought that before, you know, you're gay [laughs]." (Kory, PHA, age unknown)

Document Analysis

Policy and practice documents from 85 local, national and international organizations (Appendix 7) were collected concurrent with the interviews and focus groups with PHAs, APHAs and HCPs. The policies and practices of these organizations were subsequently analyzed to identify those that might promote or inhibit HIV and AIDS related stigma. When a disease such AIDS is stigmatized, health care policy can help to protect those who are ill from prejudice, or it can promote discrimination toward them. It was within this context that the policy and document analysis was completed.

The majority of the documents reviewed in the analysis were from organizations and health centres whose mandate specifically targeted the under privileged and persons living with HIV. HIV -specific policies were present in over 50% of the documents reviewed. In other instances, policies were not HIV specific, but promoted non-discriminatory treatment of all people. The document analysis revealed that the majority of the policies and practices from the 85 organizations reviewed tended to inhibit HIV and AIDS related stigma, by promoting ethical, fair, and non-discriminatory care.

Policy makers and health care providers must be knowledgeable of the specific statutory laws and policies specific to their jurisdiction. Such knowledge is the crucial foundation for any intervention. It is with this knowledge, that a provincial-level policy on HIV-related discrimination can in turn influence policy development at a regional level that impacts programs and services for persons living with HIV and AIDS.

Key Recommendations

1. Maintain the current policy framework. Current policies, at all levels, tend to advocate for the fair and non-discriminatory treatment of individuals, regardless of religion, gender, sexual orientation, lifestyle and medical diagnosis. Regardless of whether policies are HIV- specific or general in focus, current policies provide the necessary policy framework to reduce or eliminate stigma.

2. Develop a framework to assist with the formulation of HIV specific policy. This framework will assist with the creation of policies to promote non-stigmatizing and non-discriminating practices. A standardized tool may help to streamline future policy development and provide guidelines related to the creation and implementation of policy to affect change in an organization, health care facility or program.

3. Investigate and evaluate other factors contributing to AIDS-related stigma. HIV-positive individuals are still experiencing stigma and discrimination and therefore other contributing causes need to be researched. The multi-faceted and complex nature of stigma and discrimination means that policy can only partially address the issue of AIDS stigma. Societal perceptions and stereotypes, health care workers personal belief systems and institutional culture are a few examples of factors that may influence the stigma experienced by HIV-positive individuals.

Chapter V. Intervention and Dissemination

Intervention

Two research questions for the "Stigma project" related to the development of an intervention to eliminate stigma in the provision of health services for PHAs and APHAs. These were:

1) What design features are optimal for the provision of health care services to PHAs and APHAs to eliminate stigma?

2) What processes are required in organizations to reorient health services for PHAs and APHAs in order to incorporate optimal design features?

In order to assist the research team to answer these questions, three one day workshops were conducted in Toronto, Calgary, and Vancouver (see Appendix 8 for further details) to consult with community partners about the srtudy findings from the study and the design of the intervention. The workshops were an enhancement to the original "Stigma project" protocol and were funded by CIHR's HIV/AIDS Community Based Research program. The workshops were a collaborative initiative that included all of the research team members and the advisory committee members from the "Stigma' project". The primary goals of the workshops were: to share the findings from the 'Stigma' project and develop dissemination plans; and to design an intervention to reduce AIDS stigma. In addition to meeting the goals of the research team, the intervention design workshops provided an excellent research capacity building opportunity for the participants. Approximately 100 individuals participated in the workshops and an additional 200 individuals participated in a plenary session prior to the Vancouver workshop. Workshop participants included PHAs, APHAs, advisory committee members, health care providers (including students), representatives from AIDS Service Organizations, decision-makers, and research team members.

Optimal Design Features in Health Care Services

The design of health services to ensure that PHAs and APHAs do not experience stigma and discrimination must consider individual, organizational, and societal factors, and the policy context. Based on the study findings and the consultation workshops, the following key recommendations are made for the design of health care services to eliminate stigma for PHAs and APHAs:

Individual Factors
1. Ensure respectful, non-judgmental relationships
2. Provide culturally safe care
3. Recognize the complexities of clients lives
4. Build and maintain connections
5. Adopt universal precautions
6. Be a role model - HCPs who are "HIV specialists" must be role models with "generalist" HCP colleagues – eg HIV specialists must intervene and challenge discriminatory practice and inappropriate behaviour (we all share responsibility as the perpetrator, victim or the bystander).

Organizational Factors
1. Maintain privacy and confidentiality
2. Adopt a harm reduction policy
3. Ensure that clients feel a sense of belonging
4. Reduce barriers to care in order to maximize access (eg adopt minimal screening procedures)
5. Adopt a flexible approach to care
6. Implement a shared care approach
7. Provide a safe working environment for clients and staff
8. Ensure a supportive working environment
9. Provide continuing education and training for staff – sensitivity training is an ongoing process
10. Sites of specialized HIV knowledge (eg ASOs) must be catalysts for change
11. Establish processes for clients to evaluate health care services (including staff behaviour)

Societal Factors
1. Education – start anti-stigma education at an early age. Increase HIV/AIDS content in university curriculum for health professionals – link this to certification or licensing process. Use anti-oppression education as a model.
2. Influence portrayal of HIV in the media – need to ensure that the positive stories are shared
3. Greater Involvement of Persons Living with HIV (GIPA)
4. Develop a "bill of rights" for PHAs so that they will know what they can expect in health care services
5. Normalize HIV testing – consider other areas where this has been done (eg Calgary Regional Health Authority has implemented universal domestic violence screening)

Policy Context
1. Maintain the current policy framework. Current policies, at all levels, tend to advocate for the fair and non-discriminatory treatment of individuals, regardless of religion, gender, sexual orientation, lifestyle and medical diagnosis. Regardless of whether policies are HIV- specific or general in focus, current policies provide the necessary policy framework to reduce or eliminate stigma.
2. Develop a framework to assist with the formulation of HIV-specific policy. This framework will assist with the creation of policies to promote non-stigmatizing and non-discriminating practices. A standardized tool may help to streamline future policy development and provide guidelines related to the creation and implementation of policy to affect change in an organization, health care facility or program.

Incorporating Optimal Design Features in to Health Care Services
1. Build on existing frameworks and best practices from other fields. For example consider the intervention strategies that have been used in the mental health field to decrease stigma related to mental health illness. It was also suggested that some of the interventions that are being used to address bullying may be relevant to interventions

to address stigma. Look at the stigma toolkits that have been developed at other centers and in other countries (eg U of California, San Francisco, British Colombia person living with HIV/AIDS)

2. Consider innovative strategies such as drama and narratives to implement changes in health care services.
3. Acknowledge and plan diversity in intervention strategies – it may not be possible to generalize best practices across all settings. There need to be general principles that can be adapted to different settings. Interventions need to be tailored depending on the target population – therefore require multiple interventions.
4. Specialized sites of knowledge must act as catalysts for change.
5. Ensure that persons living with HIV/AIDS and men are included in community consultations and in the planning of interventions.
6. Develop mechanisms to create and sustain partnerships across agencies serving different populations

Dissemination

Traditionally dissemination has been seen as a distinct phase in the research process, generally occurring once data analysis is complete. The iterative nature of the current research however, enabled dissemination to occur simultaneously with data collection and analysis, as the research team believed that one process informed the other. For example, the HCPs developed a heightened consciousness about the issues related to stigma and access to health, when they were asked to reflect on the themes from the interviews with the PHAs and APHAs. Consistent with PAR, responsibility and control for dissemination was shared equally with the research team members, the participants, and the advisory committee. The research team worked with the advisory committees to identify both traditional and non-traditional methods of dissemination. The dissemination of the findings from this study targeted a variety of audiences, including HCPs, managers and decision makers responsible for the provision of HIV services, and professional organizations (e.g. Canadian Association for Nurses in AIDS Care). Strategies to disseminate the research (see Appendix 9) have included presentations, workshops and the final report and several manuscripts are in preparation. The first manuscript from the project is currently in review and at least three additional manuscripts are in development. A more in-depth discussion of the study findings will be presented in each of the manuscripts.

The intervention design workshops were also used as a strategy for dissemination of the findings. APHAs, PHAs and HCPs from the participating organizations as well as other AIDS organizations were invited to attend the workshops. This process helped to validate the optimal design for health care services that was developed during the research project. At the time of writing, the research team was also planning to prepare a pamphlet series to disseminate the findings to the CAAN membership.

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Appendix 1: Participating Organizations.

In Edmonton:
HIV Edmonton: HIV Edmonton is located in Edmonton. The mission of HIV Edmonton is to educate, support, and advocate for those infected and affected by HIV and related issues. The goals of the society are; to collaborate with organizations and institutions, communities, and populations around issues related to HIV; to advocate through collective efforts for individuals, communities and populations around issues related to HIV; to provide support and enhance the lives of those infected and affected by HIV; and to limit the transmission of HIV particularly through population health strategies including health promotion and harm reduction. HIV Edmonton has recently added a youth and Aboriginal portfolio to their program areas. In a six month period, HIV Edmonton sees approximately 140 individuals, most of whom are HIV sero-positive.

Boyle-McCauley Health Centre: The mission of Boyle McCauley is to provide and facilitate appropriate health care that will meet the evolving needs and promote optimal well being in the community. The center works with residents and community partners to promote personal and collective well-being in Edmonton's inner city communities. Using an interdisciplinary team approach, Boyle Street focuses care on all aspects of health promotion and disease prevention. The health services delivery model is accessible, responsive, participatory, and culturally sensitive. The mandate of the health center is to address the broad social determinants of health including housing, nutrition and substance abuse.

Streetworks: Streetworks is a collaborative program that is jointly governed by an interagency council in Edmonton. The mission of Streetworks is to address the issue of HIV infection among injection drug users and sex trade workers in Edmonton based on the principles of harm reduction, health promotion, and primary health care. The Streetworks program has 12 staff positions that include primarily registered nurses and outreach workers. The program offers six fixed daytime sites, a mobile van operating six evenings per week, and foot outreach to provide needle exchanges, condom distribution, referrals, health education and nursing services to clients.

Capital Health: Capital Health is one of the largest health regions in Canada funded by the Government of Alberta. Capital Health provides complete health services to one million residents in the city of Edmonton and surrounding cities and counties. In addition to emergency and acute care, home care services, outreach programs, continuing care, public health, specialty clinics and mental health services are provided. Its mission is to deliver excellence and leadership in people-centred health, education and research.

In Ottawa:
Wabano Centre for Aboriginal Health: Wabano is located in inner-city Ottawa and has a mandate to prevent ill health, treat illness, and provide support and aftercare programming for all Aboriginal peoples. The center provides an integrated, holistic approach to health encompassing physical, emotional, mental and spiritual aspect of well-being for individuals. The center provides a wide range of services including youth programs, family and individual counseling, a mobile health team for street involved and homeless Aboriginal people, addictions programs,

laboratory services and a diabetes program. Wabano also offers HIV and Hepatitis C prevention and intervention programs including anonymous testing, needle exchange, support groups and peer education and training.

Ottawa Hospital-General Campus, Comprehensive AIDS Care Clinic: The Comprehensive AIDS Care Clinic has been actively involved in HIV/AIDS care for the past 15 years in Ottawa. During this period the clinic has been involved in the diagnosis, treatment and education of a diverse population and currently has 850 active patients. The clinic utilizes a multidisciplinary model based on the belief that successful therapy is dependent on the individual patient context including medical, psychological, social, and family environments. The clinic staff includes 8 physicians (including part-time), 5 nurses, 2 social workers, one psychologist, 1.5 pharmacists, a part-time dietician and 2 clerical staff.

Oasis Centre: Oasis is a special program of the Sandy Hill Community Health Centre and is located in inner city Ottawa. The mission of the center is to provide an "oasis" for people concerned about HIV/AIDS. Oasis offers services to individuals (and their families and friends) living with HIV/AIDS and to those at risk of HIV because of unprotected sex or sharing needles. Oasis is open to anyone in the Ottawa-Carleton area, and especially welcomes the poor, homeless, and individuals using street drugs or alcohol. Oasis runs a drop-in center, provides medical and counseling staff who are available without an appointment, confidential HIV testing and treatment, needle exchange services and street health outreach.

Centretown Community Health Centre: Centretown is committed to the health and well-being of all people within the community and provides services to the Centretown (Bronson, Glebe, and Old Ottawa South) area of Ottawa. The center offers health and social services that are responsive to the changing needs of community members and that are accessible to all. Through leadership and support, the center fosters the active participation of individuals and groups in a common effort to build healthier communities. Services provided by the center include primary care, community health and social services, counseling, seniors services, and infant development services.

Appendix 2. Information Letters to Participants

Information Letter for Participants
Project: **The Influence of Stigma on Access to Health Services by Persons with HIV Illness**

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We would like to ask you to participate in a study that is being done in Ottawa and Edmonton. The study is to examine the influence of stigma on access to health services by persons with HIV. We hope that the information that we learn from the study can be used to design health services that do not discriminate against persons with HIV.

If you agree to participate in the study, we will ask you to take part in an interview. You may be interviewed in your home, an agency, or another location of your choice. You will be asked about your life since you were diagnosed with HIV. We are interested in hearing how you have been treated when you have been to see health care workers. The interview will last about one to one and a half hours and will be tape-recorded. You will be given a small gift to thank you for your time. If you would like to be more involved in the study, you may also be asked to work in a small group with other persons who have HIV. The working group will meet about 4 times each year to assist the research team.

Your name will not be used in the study. The interviewer and Dr. Mill will be the only people who know that you took part in the study. The other members of the research team will only see the interviews after the names have been removed from them. All information will be kept private, except when professional codes of ethics or the law requires reporting.

The information that you provide will be kept in a locked filing cabinet for at least 5 years after the study is done. The information that we learn from the interviews may be used for the teaching of others or for writing papers. It will be only used for future research if further ethical approval is obtained.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study, you may help other men and women in the future. If you become upset discussing your experiences, the interviewer will refer you to a counselor. You may ask questions about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. You may also decide not to answer one of the questions in the interview. Your care will not be affected by these decisions.

If you have any questions about the study, you may contact any of the researchers listed on the first page. Should you prefer to participate in the study in French, please let the researcher know. If you have any concerns during the study, please call collect to Dr. Kathy Kovacs Burns. Dr. Kovacs Burns is not associated with the study.

Dr. Kathy Kovacs Burns
Director, Research Planning and Development
Faculty of Nursing
Email: Kathy.kovacsburns@ualberta.ca
Phone: 780-492-3769

Thank you for your consideration of this request.

_____   _____
Initial of researcher reviewing letter   Initial of participant

Information Letter for Health Care Providers
Project: The Influence of Stigma on Access to Health Services by Persons with HIV Illness

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We would like to ask you to participate in a study that is being done in Ottawa and Edmonton. The study is to examine the influence of stigma on access to health services by persons with HIV. We hope that the information that we learn from the study can be used to design health services that do not discriminate against persons with HIV.

If you agree to participate in the study, we will ask you to take part in an interview or a focus group. The interviews and focus groups will take place in a private room in your organization. If you participate in a focus group, before the group discussion begins, the researcher will remind the group that what is said needs to remain confidential. Anonymity cannot be guaranteed if you participate in a focus group. If there is something you would not like discussed or known, please do not feel any pressure to share it with the group. It is anticipated that interviews will last one hour and focus groups will last one to two hours. The interviews and focus groups will be tape-recorded. You will be asked to reflect on data that we have collected from individuals who are HIV sero-positive. We are interested in hearing your opinion about practices that have been

identified as discriminating, by individuals with HIV. We would also like to hear your suggestions about changes in health care services that could eliminate practices that may be discriminatory.

Your name will not be used in the study. The interviewer and Dr. Mill will be the only people who know that you took part in the study. The other members of the research team will only see the interviews after the names have been removed from them. All information will be kept private, except when professional codes of ethics or the law requires reporting. The information that you provide will be kept in a locked filing cabinet for at least 5 years after the study is done. The information that we learn from the interviews may be used for the teaching of others or for writing papers. It will be only used for future research if further ethical approval is obtained.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study, you may help the research team learn the best way to provide health care services for individuals with HIV. You may ask questions about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. You may also decide not to answer one of the questions in the interview.

If you have any questions about the study, you may contact any of the researchers listed on the first page. Should you prefer to participate in the study in French, please let the researcher know. If you have any concerns during the study, please call collect to Dr. Kathy Kovacs Burns. Dr. Kovacs Burns is not associated with the study.

Dr. Kathy Kovacs Burns
Director, Research Planning and Development
Faculty of Nursing
Email: Kathy.kovacsburns@ualberta.ca
Phone: 780-492-3769

Thank you for your consideration of this request.

_____   _____
Initial of researcher reviewing letter   Initial of participant

Appendix 3. Informed Consent for Participants

Project: **The Influence of Stigma on Access to Health Services by Persons with HIV Illness**

Part 1: Researcher Information		
Name of Principal Investigator: Dr. Judy Mill Affiliation: Faculty of Nursing, University of Alberta Contact Information: 780-492-7556		
Name of Co-Investigator: Dr. Lynne MacLean Affiliation: Community Health Research Unit, University of Ottawa Contact Information: 613-562-5800 (ext 8024)		
Part 2: Consent of Subject		
	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		
Part 3: Signatures		
This study was explained to me by: _____ Date: _____		
I agree to take part in this study. Signature of Research Participant: _____ Printed Name: _____		
Witness (if available): _____ Printed Name: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. Researcher: _____ Printed Name: _____		
* A copy of this consent form will be given to each participant.		

Appendix 4. Modified HIV Stigma Interview Guide

Diagnosis
- ❑ When/how long ago?
- ❑ Who told you (health care setting)?
- ❑ What made you go and get tested?

Disclosure
- ❑ Are you selective with who you tell?
  - o family context
  - o health care context
  - o other contexts
- ❑ How do people react when you tell them you are HIV-positive?
- ❑ Why/why not keep it a secret? Strategies to keep it secret?

How has your **health** been?
- ❑ Any hospitalizations
  Health care providers/settings accessed since diagnosis? Different experiences?
  - ❑ ER, Medi-centres
  - ❑ Family doctor, HIV clinics/specialists
  - ❑ Nurses
  - ❑ Dentists
- ❑ Have you ever changed to a different health provider (i.e. doctor, clinic, modality – from bio-medical doctor to complementary therapy practitioner)?
- ❑ Have you not gone for help when you needed it?
- ❑ How often do you access some sort of care? For what reasons?

Experiences asking for **advice or assistance**?
- ❑ Pharmacy
- ❑ Social workers
- ❑ Community workers
- ❑ Housing

Comparing **life/experiences** before or after diagnosis, what's different or the same?
- ❑ How you think of yourself
- ❑ Health care context
- ❑ Family context
- ❑ Community context
- ❑ People you work with

If you had a **good experience**, what was good? What does it mean to be treated well?

If you had a **bad experience**, what was bad? What does it mean to be treated poorly?

Can you describe for me what your ideal health care experience (accessing health care services) would be like?

How would you like to be treated by health care workers?

Can you suggest health practices, procedures, policies that would be effective in reducing stigma toward yourself or other people with HIV?

Do you think the way you have been treated has been better or worse because you are Aboriginal [gay, IDU]? Do you think your care or the treatment you have received has been different that any other person? Any other HIV-positive person?

Are you aware of any rights you have as a patient? Have you heard of a patient bill of rights? (Show examples)

For Aboriginal interviewees: Do you have any ties to your home community? Have you accessed any care there?

Appendix 5. Emerging Themes (Nodes) for Persons Living with HIV

Demographics

Life History
- Complex Life
    - Issues in Life other than HIV
- Reason for Testing
    - Consent
- Mode of Infection
- Finding Out or Receiving Diagnosis
- Multiple Diagnoses
- Mental Health
- Relationships
    - Family
    - Friends
- Self-Image or Self-Identification
- Family Member or Friend with HIV
- Aboriginal Background

Health Care Environments
- Rural & Urban
- Small & Large
- Health Care Setting
    - Hospital
        - Emergency
        - Inpatient Ward
        - HIV Outpatient Clinic
    - Clinic
    - GP's Office
    - Prison
    - Community Organization
    - HIV-Specific
- Participant Attitudes & Views About
- Participant Misunderstandings About
- Privacy In

Stigma & Discrimination
- Societal Views of Illness
- Layering of Stigma
- Racism
- Sexual Orientation
- Sexism
- Attributing Blame
- Participant Attitudes & Knowledge About HIV

Telling & Disclosure
- Being Open

- Being Selective
- Secrecy
- Confidentiality
- Getting the Message Not to Tell
- Cancer as Comparison
- HC Providers
- Deciding to Tell or Not
- Breach of Confidence
- Afraid of Telling

Reactions to Disclosure
- Friends
- Family
- HC Providers
- Fear of Contagion

Care
- The Disciplines
    - GPs or Family Doctors
    - Dentists
    - Nurses
    - Social Workers
    - Physiotherapists
    - HIV or Infectious Disease Specialists
    - Counsellors
    - Other
    - Pharmacy
- Respect & Engagement
- Professionalism
- Knowledgeable & Competent
- Universal Precautions
- Symptom Management
- Indifference & Disrespect
- Discrimination
- Fostering Hope
- Forgiving Attitudes
- Health Care Team
- Approved Providers
- Isolation Procedures

Impact of Diagnosis
- Turning Point
- Personal Growth
- Paradox
- Relationships
- Making a Difference & Advocacy
- Second Class Citizen
- Meaning of Diagnosis
- Immediate Reaction

- Work

Living with HIV
- Support
  - Peers
  - Family
  - Pets
  - Faith or Church
- Health Status
- Treatment Attitudes & Behaviours & Experiences
  - Biomedical (ARVs)
  - Traditional
  - Self-Care
- Coping
- Reconciliation with Death
- Emotional
- Financial issues
- Fatalism
- Resignation of Hope
- Having to Speak Up
- Fear of Dying
- Being Clean
- Becoming Informed

Access to Health Care Services
- Gate-Keeping
- Attribution of Worth
- Reluctance or Refusal to Treat
- Adequacy
- Negotiating the HC System
- Impact of HIV on Other Services
- Family & Partner
- Drug Plans
- Accessibility

Recommendations
- Illness
- HC providers
- HC Environment
- Getting the Word Out
- Vision of the Ideal

Quotable

Questions for HCP Focus Groups

Aboriginal Identity, Culture, Roles (experiences unique to Aboriginal participants)

Stigma Project

Appendix 6. Emerging Themes (Nodes) for HCPs

Health care provider
- Title, role, area(s) of responsibility
- Influences
  - Professional background, training, career path
  - Personal path to this work
  - Attitudes & beliefs

Organization/agency
- Mandate, services
  - Evolution of programs
  - Mission/philosophy
  - Control over practice
  - Policy (awareness of, policy vs practice, safety, security)
  - Process
- Population served
  - Characteristics/qualities of clients (mental illness, addictions and intoxication, poverty, high risk for violence, criminal activity)
  - Expectations & preferences of clients
- Reputation (threats to, positive)
- Funding
- Leadership
- Resources
  - Staffing issues (selection, stability, training)
  - Infrastructure & layout

Experience of caring for clients/the marginalized
- Discriminatory practices (refusal of care, labeling)—"stigma"
- Becoming marginalized yourself
- Compassion fatigue, emotional reckoning
- Strategies/interventions/approaches
- Nature of the client (& their situation)—where we think the stigma lies
  - Layering, untouchables, outcasts, hard-to-serve, complex trauma, multiple co-morbidity

What is working
- Training, education
- Being proactive
- Client advisory committees
- Attention to physical space
- Collaborative approach
- Primary, holistic health care
- Networking
- Strategies for dispelling/avoiding/diffusing stigma
- Positive effects/outcomes of interventions
  - Empowerment
  - Advocacy
  - Enhanced health, well-being

Challenges (barriers to providing the "best care")
- Organizational/Agency issues
  - Resources
  - Knowledge, awareness
  - Continuity of care
  - Confidentiality
  - Outsider, othering
  - Balancing safety of many with needs of a few
- Systemic issues
  - Models, process, & structures
  - Cracks, barriers, & tensions
  - Societal views
  - Need for advocacy within
  - Lying re status

Recommendations
- Client
- HC providers

Quotables

Appendix 7. Policy and Practice Documents from 85 Local, National and International Organizations.

National
Government of Canada

Organization	Document Title	Publication Date	HIV Specific	Document length
Government of Canada	Strategic Approaches: Renewing the Response (Canada's Repost on HIV/AIDS 2004)	2004	Y	50 pp

National
Health Canada

Organization	Document Title	Publication Date	HIV Specific	Document length
Health Canada	Infection Control Guidelines: Preventing the Transmission of Bloodborne Pathogens in Health Care and Public Service Settings	May 1997	N	43 pp
Health Canada	Canada Communicable Disease Report: Blood-borne Pathogens Routine Surveillance System Report (Volume 2052)	July 2002	N	59 pp
Health Canada/The College of Family Physicians of Canada	HIV Care: A Primer & Resource Guide for Family Physicians	March 2001	Y	~200 pp
Health Canada	About Health Canada	2003	N	3 pp
Canadian Strategy on HIV/AIDS	Leading Together: An HIV/AIDS Action Plan for All Canada 2004-2008 (Draft)	2003	Y	42 pp

National
HIV/AIDS Organizations

Organization	Document Title	Publication Date	HIV Specific	Document length
Canadian HIV/AIDS Legal Network	Discrimination Report	2004	Y	122 pp
Canadian AIDS Society	A New Look at Homophobia and Heterosexism in Canada	2003	N	95 pp
Canadian AIDS Society	HIV and Disability Policy: Evaluating the Disability Tax Credit and Medical Expense Tax Credit (A Brief Prepared for the Technical Advisory Committee on Tax Measures for Persons with Disabilities)	August 2003	Y	15 pp
Canadian HIV/AIDS Legal Network & Canadian AIDS Society	HIV Testing and Confidentiality: Final Report (2nd Edition)	March 2001	Y	10 pp
Canadian HIV/AIDS Legal Network	Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada	2004	Y	87 pp
Canadian HIV/AIDS Legal Network	A Plan of Action for Canada to Reduce HIV/AIDS Related Stigma and Discrimination	2004	Y	147 pp
Canadian Aboriginal AIDS Network	Foundations of a Good Practices Approach	2004	Y	33 pp

**National
Aboriginal**

Organization	Document Title	Publication Date	HIV Specific	Document length
Assembly of First Nations	Assembly of First Nations HIV/AIDS Action Plan	February 2001	Y	9 pp

**National
Other**

Organization	Document Title	Publication Date	HIV Specific	Document length
Public Service Alliance of Canada	PSAC Policy 28 – Infectious Diseases: PSAC Policy on AIDS and HIV	2003	Y	8 pp
Treasury Board of Canada Secretariat	Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)	1999	Y	6 pp
Canadian Council on Health Services Accreditation	Code of Ethics	No date. Retrieved online 8/24/2004.	N	1 p
Canadian Red Cross	Client Bill of Rights	2004	N	2 pp
The North-South Institute	A Plan of Action for Canada to Reduce HIV/AIDS Related Stigma and Discrimination	2003	Y	16 pp

Provincial

Organization	Document Title	Publication Date	HIV Specific	Document length
Ontario Human Rights Commission	Policy on HIV/AIDS Related Discrimination	1996	Y	16 pp
Ontario Ombudsmen	The Complaint Process	No date. Retrieved online 8/24/2004.	N	1 p

**Regional (Edmonton)
Capital Health Authority**

Organization	Document Title	Publication Date	HIV Specific	Document length
Capital Health	Annual Report of the Medical Officer of Health: How Healthy Are We? 2003	2003	N	37 pp
Capital Health	Capital Health Authority Annual Report 2001-2002	2002	N	34 pp
Capital Health	Mission, Vision and Values	October 31, 2002	N	1 p
Capital Health	Communicable Disease Guidelines for Health Care Workers: Regional Occupational Health, Safety and Wellness	February 3, 2003	Y (parts)	~90 pp

Regional (Edmonton)
University of Alberta Hospital

Organization	Document Title	Publication Date	HIV Specific	Document length
University of Alberta Hospital	Section 3.0 - Isolation Precautions (In University of Alberta Hospital Infection Control Manual)	2001	Y	~30 pp
University of Alberta Hospital	Section 12 – Infection Control (In University of Alberta Hospital Infection Control Manual)	1998	Y	~50 pp

Organization	Document Title	Publication Date	HIV Specific	Document length
HIV Edmonton Policy Manual: Policies	1. Conduct and Ethics	2004	Y	3pp
	2. Support Groups and Workshops	2004	Y	2pp
	3. Loss, Grief, Bereavement Support	2004	Y	2pp
	4. Memorial Quilts Policy	2004	Y	1p
	5. Confidentiality	2000	Y	12pp
	6. Ethical Fundraising & Financial Accountability Code	2000	Y	4pp
	7. Ross Armstrong memorial trust Fund Terms of Reference	2003	Y	4pp
	8. Management of the HIV + Health Care Worker	1992	Y	1p
	9. Policy making policy	1998	N	2pp
	10. Gifts and Bequests	2004	N	1p
	11. Financial Management Policy	2004	N	2pp
	12. Planned Giving	1999	N	3pp
	13. Directors' Code of Conduct	1999	N	2pp
	14. Board Nomination Committee Policy	2004	N	1p
	15. Communicable Diseases (Tuberculosis)	2004	Y	1p
	16. Volunteer Service	1999	N	6pp
	17. Board of Directors List	2004	N	1p
	18. Professional Development Policy	2004	Y	2pp
	19. Harm Reduction	2004	Y	4pp
	20. Board Attendance Policy	2004	N	1p
	21. Incident Policy	2003	N	4pp
	22. Governance Policy	2004	N	14pp
	23. Board Orientation Policy	2004	N	1p
Position Statements	HIV and AIDS Education in the Schools	2001	Y	2pp
	Palliative Care	1993	N	1p
	HIV Sero testing of Health Care Workers	1992	Y	1p
	End of Life Issues	2001	Y	1p
	Blood Borne Pathogens Hepatitis B and C	2002	Y	3pp
	Declaration of Commitment on HIV and AIDS (UNGASS)	2003	Y	10pp

HIV Edmonton Employee Manual	Section 1- Who we are	2001	Y	4pp
	Section 2- The Way we work	2001	N	15pp
	Section 3- Pay and progress	2001	N	9pp
	Section 4- Time away from work	2001	N	10pp
	Section 5- Benefits	2001	N	3pp
	Section 6- On the job	2001	N	23pp
	Section 7- Future consideration	2001	N	1p

Regional (Edmonton)

Organization	Document Title	Publication Date	HIV Specific	Document length
Boyle McCauley Health Centre	Confidentiality Oath	**Unknown**	N	1p
Boyle McCauley Health Centre Human Resources Manual	Section 1- Introduction	**June 2000 August 2002 (revised)**	N	3pp
	Section 2- Mission and Philosophy	**June 2000**	N	3pp
	Section 3- Code of Ethics	**June 2000**	Y	7pp
	Section 4- Definitions	**June 2000**	N	4pp
	Section 5- Information Management	**June 2000**	N	6pp
	Section 6- Employment	**June 2000** August 2002 (revised)	N	43pp
	Section 7- Employee Leave	**June 2000** August 2002 (revised)	N	11pp
	Section 8- Personnel Relations	**June 2000**	N	18pp
	Section 9- Position Management	**June 2000**	N	3pp
	Section 10- Salary and Benefits Administration	**June 2000** August 2002 (revised)	N	7pp
	Section 11- Practicum Students, Volunteer, and Volunteer Practices	**June 2000**	N	3pp
	Section 12- Health and Safety	**June 2000**	N	8pp
	Section 13- Personnel Training and Development	**June 2000**	N	9pp

Regional (Ottawa)
The Ottawa Hospital

Organization	Document Title	Publication Date	HIV Specific	Document length
The Ottawa Hospital	Administrative Policy and Procedure Manual: Code of Conduct	2001	N	2 pp
The Ottawa Hospital	Administrative Policy and Procedure Manual: Conflict of Interest Policy	2001	N	4 pp
The Ottawa Hospital	Administrative Policy and Procedure Manual: Communications Etiquette Policy	2002	N	10 pp
Ottawa General Hospital Immunodeficiency Clinic	Standards of Care	1994	Y	14 pp

Regional (Ottawa)
Wabano

Organization	Document Title	Publication Date	HIV Specific	Document length
Wabano Centre for Aboriginal Health	HIV Train the Trainer: Keeping the Circle Strong	Unknown	Y	37 pp
Wabano Centre for Aboriginal Health	Job Description: Family Support Worker Protocol for HIV Positive Test Results	Unknown April 2002	N Y	4 pp 2 pp

Regional (Ottawa)
Centretown Community Health Centre

Organization	Document Title	Publication Date	HIV Specific	Document length
Centretown Community Health Centre	Mission, Vision and Diversity Statement	Unknown	N	3 p
Centretown Community Health Centre	Primary Care Policy and Procedure Manual (incomplete hard copy)	Unknown	Y	~50 pp
Centretown Community Health Centre	Position Description: Physician Position Description: Nurse	2004 2004	N N	3 pp 5 pp
Centretown Community Health Centre	Interview Questions Student Orientation Checklist/End of Student Placement Checklist Diversity Statement	Unknown Unknown March 2004	N N N	1 p 4 pp 1 p
Centretown Community Health Centre	Section 2: Personnel	May 2004	N	24 pp
Centretown Community Health Centre	A Proposal to Enhance GLBT Cultural Competence in CHCs & CRCs GLBT Cultural Competence Self-Assessment CCHC Action Plan for Self Assessment GLBT Cultural Competence Self-Assessment Centretown Community Health Centre: Summary Report	2003 January 2004 March 2004 July 2004	N N N N	8 pp 44 pp 3 pp 8 pp

Stigma Project

	Counsellor Training-Intervention with GLBTTQ Clients Enhancing GLBT Cultural Competence Project	Unknown	N	3 pp
	Outline of Basic Training on Working with GLBTTQ Population	Unknown	N	4 pp
	Project Update August 2004	August 2004	N	3 pp
	Ethnocultural Model	May 2004	N	1 p
	GLBT Basic Training Evaluation Form	Unknown	N	2 pp
	Coalition of Community Health and Resource Centres of Ottawa Interclinic Education Workshop: Evaluation Report	May 2004	Y	8 pp

Regional (Ottawa)
Oasis

Organization	Document Title	Publication Date	HIV Specific	Document length
Oasis	Volunteer Manual	June 2002	N	~ 50 pp
Oasis	Policies Regarding Clients	June 1999	N	~30 pp
Oasis	Universal Precautions	Unknown	Y	3 pp
Oasis	Needle stick Injury Guidelines for Shelters and Drop Ins	Unknown	Y	12 pp
Oasis	Policy and Procedure for Wife Assault	Unknown	N	15 pp
Oasis	The Living Room- Policies on Complementary Therapies	1996	N	18 pp
Oasis	Oasis Manual	Unknown	Y	~25 pp
Oasis	Partners Step by Step	1996	Y	~60 pp
Oasis	Policies Regarding Safety	Unknown	N	5 pp
Oasis	Oasis Advisory Committee "Terms of Reference" and "How do we make decisions?"	Unknown	N	4 pp
Oasis	Job Descriptions:			
	Clinical Nurse Specialist	2003	Y	2 pp
	Clinical Nurse Specialist/Team Leader	2001	Y	3 pp
	Director	1997	N	3 pp
	Drop-In Volunteer	2003	Y	1 p
	Life Skills Drop-In Worker	2002	Y	2 pp
	Main Greeter	1995	N	3 pp
	Medical Receptionist	2003	Y	2 pp
	Physician	1995	N	2 pp

	Practical Assistance Worker	1998	Y	4 pp
	Street Outreach Worker	1997	Y	1 p
	Volunteer Drop-In Coordinator	1997	Y	3 pp
Oasis	Oasis Clinic Coordination	Unknown	Y	5 pp
Oasis	Mission Statement	Unknown	Y	1 p
	Integrated HIV/AIDS Program Mission Statement, Principles, Goals and Objectives and Values	Unknown	Y	4 pp
	Client Services Policy, Values and Principles	Unknown	Y	2 pp
	Oasis Program Planning Matrix	Unknown	N	1 p
	Oasis Medical Services	Unknown	Y	1 p

Regional (Ottawa)
Sandy Hill Community Health Center

Organization	Document Title	Publication Date	HIV Specific	Document length
Sandy Hill Community Health Center	Values	Unknown	N	1 p
Sandy Hill Community Health Center	Dealing with Client Complaint	2001	N	3 pp
Sandy Hill Community Health Center	Policy: Concept of Health	1989	N	1 p
	Policy: Corporate Mission, Goals and Objectives	1989	N	1 p
	Policy for Incidents of Risk	1997	N	2 pp
Sandy Hill Community Health Center	General Staff Requirements;	1995	N	1 p
	Sandy Hill Community Health Center Job Descriptions (listing)	1999	N	1 p

Professions
Dentists

Organization	Document Title	Publication Date	HIV Specific	Document length
Centers for Disease Control and Prevention	Guidelines for Infection Control in Dental Health-Care Settings-2003	2003	Y	108 pp
Canadian Dental Association Board of Governors	Considerations Re: Infection Control Procedures	1999	N	2 pp

Professions
Nursing

Organization	Document Title	Publication Date	HIV Specific	Document length
Canadian Nurses Association	Fact Sheet: Occupational Exposure to Blood-Borne Pathogens	November 2000	N	2 pp
Canadian Nurses Association	Position Statement: Blood-Borne Pathogens	November 2000	N	2 pp
Alberta Association of Registered Nurses	Position Statement on Client Advocacy	January 1999	N	4 pp
Alberta Association of Registered Nurses	Disclosure and Reporting of Infection with Blood-Borne Pathogens: Guidelines for Registered Nurses	February 2000	N	5pp
Alberta Association of Registered Nurses	Position Paper on Vulnerability	September 1998	N	7 pp

Professions
Physicians

Organization	Document Title	Publication Date	HIV Specific	Document length
College of Physicians & Surgeons	Patient Advocate	No date. Retrieved online 08/24/2004.	N	2 pp
College of Physicians & Surgeons of Alberta	CPSA Guideline: HIV Infection in Health Care Workers	September 1992	Y	4 pp
Canadian Medical Association	Counselling Guidelines for HIV Testing	1995	Y	24 pp (booklet)
Canadian Medical Association	CMA Policy: Acquired Immunodeficiency Syndrome (update 2000)	Updated in 2000	Y	2 pp
Canadian Medical Association	CMA Policy: HIV Infection in the Workplace (Update 2000)	Updated in 2000	Y	4 pp
Canadian Medical Association	Guideline Digest: Management and Treatment for the Care of HIV-Positive Pregnant Women: Putting Recommendations into Practice	No date. Retrieved online 8/23/2004.	Y	4 pp
Canadian Medical Association	Code of Ethics of the Canadian Medical Association	October 15, 1996	N	1 p
Health Canada/The College of Family Physicians of Canada	HIV Care: A Primer & Resource Guide for Family Physicians	March 2001	Y	~200 pp

Professions
Psychiatrists

Organization	Document Title	Publication Date	HIV Specific	Document length
Canadian Psychiatric Association	Position Statement on HIV Disease	1996	Y	2 pp

Professions
Social Workers

Organization	Document Title	Publication Date	HIV Specific	Document length
Canadian Association of Social Workers	Module 6 Psychosocial Care: Comprehensive Guide for the Care of Persons with HIV Disease	1997	Y	164 pp
International Federation of Social Workers	International Policy on HIV/AIDS	2000	Y	6 pp
Canadian Association of Social Workers	Social Work Manifesto on HIV/AIDS	2000	Y	3 pp
Canadian Association of Social Workers	HIV/AIDS Skills Building Workshop (Moncton, June 8, 2002): Final Report	2003	Y	14 pp

U.S. Organizations

Organization	Document Title	Publication Date	HIV Specific	Document length
Centers for Disease Control and Prevention	U.S. Public Health Service Guidelines for Testing and Counseling Blood and Plasma Donors for Human Immunodeficiency Virus Type 1 Antigen	March 1996	Y	15 pp
Centers for Disease Control and Prevention	Recommendations for Prevention of HIV Transmission in Health-Care Settings	1987	Y	18 pp

International and WHO

Organization	Document Title	Publication Date	HIV Specific	Document length
Canadian Red Cross	Client Bill of Rights	2004	N	2 pp
UNAIDS/WHO	UNAIDS/WHO Policy Statement on HIV Testing	June 2004	Y	3 pp
World Health Organization	25 Questions & Answers in Health & Human Rights (Health and Human Rights Publications Series, Issue No. 1)	July 2002	N	33 pp
Written Submission by the World Health Organization	United Nations Commission on Human Rights: Sixtieth Session (Items 6, 7, 10, 12, 13, 14, 15 and 18 of the provisional agenda)	No date. Retrieved online 08/24/2004.	N	13 pp
Engender Health	Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers	2004	Y	93 pp

Appendix 8. Community Consultation to Design an Intervention to Reduce AIDS Stigma
     Final Report.

Community Consultation to Design an Intervention
To Reduce AIDS Stigma
Final Report

Dr. Judy Mill, University of Alberta

Dr. Wendy Austin, University of Alberta

Dr. Nancy Edwards, University of Ottawa

Mr. Randy Jackson, Canadian Aboriginal AIDS Network

Dr. Lynne Leonard, University of Ottawa

Dr. Lynne MacLean, University of Ottawa

June 2007

This report presents findings from a Canadian Institutes for Health Research (CIHR) funded project to support a capacity building workshop entitled "Community Consultation to Design an Intervention to Reduce AIDS Stigma". This project was funded by CIHR's HIV/AIDS Community Based Research program. This workshop was a collaborative initiative by researchers at the Universities of Alberta and Ottawa and the Canadian Aboriginal AIDS Network (CAAN). CAAN participated on the project as the community based research partner. In addition, the workshops were conducted in partnership with the Ontario HIV Treatment Network (OHTN) and the Alberta Community Council on HIV (ACCH) who actively supported the workshops and assisted with the advertisement and recruitment of workshop participants.

Three 1 day workshops were conducted as an enhancement to the CIHR-funded research project entitled "The Influence of Stigma on Access to Health Services by Persons with HIV Illness". Research capacity-building workshops were used with our Aboriginal and non-Aboriginal community partners to design an intervention to reduce AIDS stigma and to develop dissemination plans for the findings from the "Stigma project". This is congruent with the principles of Ownership, Control, Access and Possession [OCAP][1] that are fundamental to working with Aboriginal communities and with the Principles of Research Collaboration that the research team adopted. Community consultation workshops to design an intervention to mitigate AIDS stigma were an appropriate and meaningful way to bring the community-based "Stigma project" to a successful conclusion.

Some of the key findings from the "Stigma project" included:

- Stigma and discrimination influences the decision to disclose HIV status and the decision to access health services
- Stigma related to being HIV positive is layered with stigma related to other illnesses (e.g. mental health problems), lifestyles (e.g. being gay, working as a prostitute), behaviours (alcohol and drug use), gender (female), culture (e.g. being Aboriginal) and social class (e.g. being poor).
- Protecting the confidentiality of persons living with HIV (PHAs) and Aboriginal persons living with HIV (APHAs) was a concern among both persons living with HIV and health care providers (HCPs)
- Policies and practices in organizations could contribute to stigma and discrimination.

Design features to eliminate/minimize stigma in health care services

Organizational
- Policies and practices to minimize or eliminate stigma in organizations were identified based on the study findings. Organizational features included: ensuring respect for privacy and confidentiality; adopting a harm reduction philosophy; maximizing access to care and support service (eg minimal screening processes); adopting a flexible approach to care; adopting a shared care approach; providing safe working environments; providing education and training for staff; and ensuring supportive work environments.

Individual
- In addition to organizational features, several individual attributes of HCPs emerged as essential to non-stigmatizing care. These attributes include; respectful, non-judgmental relationships; the provision of culturally appropriate care; recognition of the complexities of clients lives; and building and maintaining connections.

Dissemination is arguably a key component of community-based research, yet dissemination planning has been identified by CAANs environmental scan[2] as a research skill that is not particularly strong in community-based organizations. Therefore, the **goals** of our community consultation workshop were two-fold:

1) to build research capacity among our community-based partners as it relates to designing an intervention to reduce AIDS stigma; and
2) to engage community partners in designing culturally and community-appropriate dissemination strategies for the CIHR-funded 'The Influence of Stigma on Access to Health Services by Persons with HIV Illness' project.

The purpose of each one-day community consultation workshop was to meaningfully engage PHAs, APHAs, HCPs and decision-makers 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 assist with the design of the intervention. The development of best practice guidelines for the provision of health services to PHAs and APHAs was an outcome of this process. Engaging the community in the design of the intervention helped to ensure that the resulting intervention was culturally, socially, educationally, and linguistically appropriate for the community for which it was designed[3]. Furthermore by engaging HCPs and people living with HIV in the design of interventions the likelihood that the interventions will be implemented is enhanced. This increased community support for the intervention and increased the likelihood that the intervention would have a direct policy impact[4]. This approach assisted in building research capacity in workshop participants to translate research findings into actionable policy interventions and to participate in future CBR projects[5].

Description of the Outcome Objectives for Workshops

The initial objective for each 1 day workshop was to increase the participants' knowledge of the research results of the "Stigma" project. The intermediate objective was to increase the knowledge and skills of participants in the design of an effective intervention to reduce AIDS stigma for persons living with HIV, including the process required to reorient health services to incorporate the optimal design. The long-term objective was to build research capacity in community-based organizations related to designing and implementing dissemination strategies. As well there was the potential to build upon the outcomes of the workshop by developing further research projects with the participants and their organizations.

Workshop Activities and Methods

The workshops were advertised and promoted via email using CAAN's membership network. The Ontario HIV Treatment Network (OHTN) also assisted in advertising the

Toronto workshop by sending out an email to all of their annual conference delegates. Alberta Community Council on HIV/AIDS (ACCH) assisted in the advertising and promoting the Alberta workshop. Similarly, CAAN ensured that all of their members attending their HIV/AIDS CBR Capacity Building Conference in Vancouver were informed about the workshop.

Each workshop employed a combination of instructional and participatory learning strategies that recognized the capacities and learning needs of the researchers and the workshop participants (see Table 1 for workshop agenda). The underlying principle in this mixed-method approach was 'learn by doing'. Following in-depth discussion of the research results and the factors involved in designing and implementing interventions to reduce AIDS stigma, workshop participants were asked to brainstorm ideas for culturally and community-appropriate strategies that would reduce AIDS stigma and facilitate access to health services. Key questions were asked to guide these small group discussions:

- Are you aware of additional best practices to reduce AIDS stigma?
- How do you integrate best practices into health services?
- How can best practices be maintained across settings?
- What is the role of HIV 'specialists' in the education of 'generalist' health care providers?

Strategies to reduce AIDS stigma that were generated from the discussions were evaluated by the participants for merit, efficacy and feasibility for health care organizations to implement. The workshop participants were then asked to evaluate the processes that are required for organizations to implement these strategies. The active participation and full engagement of the workshop participants in designing the intervention ensured that participants gained a better understanding of the processes involved in developing HIV interventions. The primary responsibility of the research team and staff were to facilitate this process. Handouts, work books and summaries of the key findings of the "Stigma" project were distributed to workshop participants.

Table 1. Workshop Agenda, Toronto November 29, 2006

Time	Activity	Presenter
8:00 am	BREAKFAST	
8:30-9:30 am	Opening Prayer and Introduction	Elder (prayer), Randy Jackson
9:30-10:00 am	BREAK	
10:00-12:00 am	Overview of Research Findings	Judy Mill
12:00-1:00 pm	LUNCH	
1:00-2:45pm	Designing AIDS Stigma Interventions – Small group sessions	Tracey Prentice as facilitator and members of research team
2:45-3:00 pm	Wrap-up and Closing Prayer	Elder (prayer), Judy Mill

Stigma Project

Summary:

Workshop #1, **Toronto, Ontario November 29th, 2006- Hilton Hotel - Designing Interventions to Reduce AIDS Stigma**
Judy Mill, Randy Jackson, Wendy Austin, Nancy Edwards, Lynne Leonard, Lynne MacLean, Claudette Dumont Smith & Stan Houston

After discussions with Ontario HIV/AIDS Treatment Network (OHTN), the research team decided to hold the "Ontario" workshop in Toronto in conjunction with the OHTN Annual Research Conference. The OHTN were supportive of the objectives for our workshop and felt that this workshop would complement the OHTN conference, and be of interest to their membership. The OHTN provided financial support for the workshop which enabled participants from outside of the metropolitan Toronto area to attend. The costs associated with out of town participants were not part of the original workshop budget. Forty participants attended the workshop, including PHAs, APHAs, and representatives from Aboriginal communities and agencies providing services to PHAs and APHAs. Registered nurses and students from health disciplines, advisory committee members and researchers also attended the workshop.

Workshop #2 Calgary, Alberta February 6th, 2007 – Four Points Sheraton Hotel - Designing Interventions to Reduce AIDS Stigma
Judy Mill, Wendy Austin, Randy Jackson, Nancy Edwards, Lynne Leonard, Lynne MacLean, Claudette Dumont Smith & Stan Houston

The "Alberta" workshop was held in Calgary in partnership with the Alberta Community Council on HIV/AIDS (ACCH). 47 participants attended the workshop which was conducted prior to the bi-annual ACCH Conference. ACCH, a consortium of AIDS service organizations from across Alberta, assisted in advertising the workshop to their member organizations. Participants included APHAs, PHAs, registered nurses, registered social workers, nursing students, and representatives from AIDS service organizations.

Workshop #3. Vancouver, British Columbia February 14th 2007 – Empire Landmark Hotel - Walking a Path to Wise Practices: 1st CAAN HIV/AIDS CBR Capacity Building Conference.
Judy Mill, Randy Jackson, Wendy Austin, Nancy Edwards, Lynne Leonard, Lynne MacLean, Claudette Dumont Smith, Stan Houston

The research team was invited by the Canadian Aboriginal AIDS Network (CAAN) to conduct a third workshop in Vancouver in conjunction with a HIV/AIDS CBR Capacity Building Conference. During the Vancouver workshop, the research findings were highlighted in a 1 hour plenary session attended by 201 individuals, approximately two-thirds

of whom were First Nation, Métis, or Inuit. Following the plenary session, 10 individuals participated in a workshop to provide feedback and assist with the design of interventions to reduce AIDS stigma. CAAN provided technical support by advertising the sessions to their members, and financial support related to the costs of the plenary and workshop sessions. The Vancouver workshop was in addition to the two workshops proposed in our application under this funding call. The support provided by CAAN enabled the research team to engage more Aboriginal peoples in the research process. This approach is consistent with principles of active engagement and OCAP.

Workshop participants:

- ✓ received up to date knowledge of the research results from the project titled "Influence of Stigma on Access to Health Services by Persons Living with HIV Illness".
- ✓ were involved in the design of an effective intervention to reduce AIDS stigma for persons living with HIV including the process required to reorient health services to incorporate the optimal design.
- ✓ were engaged in building/increasing research capacity between researchers and community based organizations related to the designing and implementation of dissemination strategies.

Key intervention strategies developed by the small group discussions to reduce AIDS stigma: (Findings from 3 workshops)

- Best practices to reduce AIDS stigma
  - o Ensure that clients feel a sense of belonging and cultural safety
  - o Start [anti]-stigma education at an early age
  - o Consider work that has been done in other settings
  - o Ongoing training of health workers (eg anti-oppression)
  - o Adopt universal precautions

- Integrating best practices into health services
  - o Build on existing frameworks/best practices from other fields (eg. mental health, addictions)
  - o Include PHAs and men in intervention design and implementation
  - o Influence portrayal of HIV in media
  - o Consider innovative interventions (drama, narrative)
  - o Increase HIV/AIDS curriculum in university curriculums for health professionals

- Maintaining best practices across settings
  - o Implement interventions at places people go
  - o Acknowledge diversity - best practices cannot be generalized

- Role of HIV 'specialists' in the education of 'generalists' health care providers
  - o Be a role model

- o Intervene and challenge bad practice
- o Sites of specialized knowledge must be catalysts for change
- o Keep stigma on the agenda

Sample of Feedback from Participants

Most informative. We need to make sure that this research project gets to the grassroots organizations to implement. So many good research project end up in shelves gathering dust. Thank you for doing the work.

I thought the breakout groups were a great idea. There were a lot of feedback and networks! I like the handouts I can take them and read for later.
This was a wonderful learning experience especially from a community level all the way to health care institutions. There were a lot of interesting ideas.

PAR design is highly congruent with topic. Although I've studied about some this was my first experience with being involved with PAR. Thanks. Opening/closing speaker (Casey Eaglespeaker (Elder) is inspiring.

Thank you for the opportunity to participate in the workshop. I believe that the education and knowledge I obtained can be utilized within my practice and allow me to increase the knowledge within my community.

The discussion in small groups, demonstrated the difficulty of identifying and focusing on feasible and specific interventions. (This is not intended as a criticism; it is meant as an observation on the difficulty of the task).

References

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2. CAAN (2004). *Final Report: The Community-Based HIV/AIDS Research Environmental Scan,* pp9. Ottawa: ON: CAAN.
3. Majumdar, B., Chambers, T., & Roberts, J. (2004) "Community-based, Culturally Sensitive HIV/AIDS Education for Aboriginal Adolescents: Implications for Nursing Practice." *Journal of Transcultural* Nursing, 15(1):69-73.
4. Smylie, J., Kaplan-Myrth, N., Tait, C., Martin, M., Chartrand, L., Hog, W., Tugwell, P., Valaskis, G., & Macauley, A. (2004) "Health Sciences Research and Aboriginal Communities: Pathway or Pitfall?" *Journal of Obstetrics and Gynecology Canada* 26 (3):211-216;
5. Fisher, Andrew & Foreit, James (2002) *Designing HIV/AIDS Intervention Studies: An Operations Research Handbook*, pp. 109-114. New York, NY.

Appendix 9. Community Meetings, Presentations and Conference Proceedings

Canadian Aboriginal AIDS Network AGM 2004: April 1, 2003 to March 31, 2004-
Annual Report summary: The Influence of Stigma on Access to Health Services by Persons with HIV Illness.
Randy Jackson

CHSFR/CIHR Summer Research Internship Program, Dialogue & Debate Session: Ottawa. May 25, 2004
The Influence of Stigma on Access to Appropriate Health Services by Persons with HIV Illness. Presented by Joyce Seto, Ottawa Project Coordinator

CIHR Institute of Gender and Health symposium, Montreal, October 25, 2004
The Influence of Stigma on Access to Health Services by Persons with HIV Illness
Phase 1 of project presentation of results.
Judy Mill, Wendy Austin, Claudette Dumont-Smith, Nancy Edwards, Stan Houston, Randy Jackson, Lynne Leonard, & Lynne MacLean

Ontario HIV Treatment Network, Toronto, Ontario, November 25, 2004
The Effect of HIV-Related Stigma on Access to [Health] Service[s]: Voices of Aboriginal People Living with HIV/AIDS
Randy Jackson, Judy Mill, Frances Reintjes and Claudette Dumont-Smith

CIHR Institute of Gender and Health symposium, Vancouver, November, 2005-
The Influence of Stigma on Access to Appropriate Health Services by Persons with HIV Illness
Randy Jackson, Judy Mill, Frances Reintjes, Lynne MacLean ,Wendy Austin, Lynne Leonard, Claudette Dumont-Smith, Nancy Edwards, and Stan Houston

14th Annual Conference, Canadian Association of Nurses in AIDS Care Conference, Montreal, April 8-11, 2006, Conference proceeding.
Being Real: Relationships between Persons Living with HIV and Health Practitioners
Wendy Austin, Judy Mill, Randy Jackson, Lynne Leonard, Lynne MacLean, Nancy Edwards, Frances Reintjes, Claudette Dumont-Smith

CIHR Institute of Gender and Health symposium, Edmonton, May 11 2006
The stigma within the stigma: Accessing health services when you are living with HIV
Judy Mill, Wendy Austin, Claudette Dumont-Smith, Nancy Edwards, Stan Houston, Randy Jackson, Lynne Leonard, & Lynne MacLean

Canadian Working Group on HIV Rehabilitation. Annual General Meeting, Toronto. June 9, 10 2006.
The influence of HIV-related stigma on access to health services
Jackson, R. Mill, J., Reintjes, F., Leonard, L., MacLean, L., Austin, W., Edwards, N.,Dumont-Smith, C.

15th Annual Canadian Conference on HIV/AIDS Research, Quebec City, May 25 to 28, 2006, Conference proceeding
The stigma within the stigma: Accessing health services when you are living with HIV
Mill, J., Reintjes, F., Leonard, L., MacLean, L., Austin W., Jackson, R. Edwards, N., Dumont-Smith, C.

XVI International AIDS Conference, Toronto, Ontario, Canada – August13-18, 2006, Conference proceeding.
Time to make health services safe from stigma: voices of Canadian Aboriginal people living with HIV/AIDS and health care providers
Jackson, R., MacLean, L., Leonard, L., Mill, J., Reintjes, F., Austin, W., Dumont-Smith, C. and Edwards, N.

Fourth International Conference, International Society for Equity in Health, Adelaide, Australia, September 11-13th, 2006- Conference proceeding
Stigma in health care for persons living with HIV
Nancy Edwards, Judy Mill, Randy Jackson, Wendy Austin, Lynne MacLean, Frances Reintjes, Claudette Dumont-Smith & Lynne Leonard