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Similar Epidemics with Different Meanings: Understanding AIDS Stigma from an International Perspective

**Nelson Varas Díaz¹
José Toro-Alfonso**

University of Puerto Rico, San Juan, Puerto Rico

“AIDS occupies such a large part in our awareness because of what it has been taken to represent. It seems the very model of all the catastrophes privileged populations feel await them.”

(Susan Sontag, 2001)

The HIV/AIDS have had a devastating impact in the world since its initial reported cases in 1983. The total number of people living with HIV at the end of 2005 is estimated in 40.3 millions with 4.9 new infections for that period (UNAIDS, 2005a). Figure 1 shows the estimated global number of people living with HIV from 2001 to 2005. Even though this numbers area astonishing, the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2005b) has tried through its reports to identify strengths and successes in the fight against the epidemic and has stated that the HIV infection rates have decrease in certain countries. However the United Nations have also reported that “overall trends in HIV transmission are still increasing...” (p. 1).

Rates of HIV infection range from .01% in some countries in Eastern Europe (Poland) and Australia, to .07% in Argentina, .06% in the United States, 1.7% in Surinam and the Dominican Republic; to 5.6% in Haiti. This information might be underestimated due to the fact that surveillance is

not done systematically in many countries (UNAIDS/WHO, 2004). The unequivocal fact is that the HIV/AIDS epidemic still disproportionately affects all countries in all regions of the world. In most countries minorities and marginalized populations are most affected; in the United States an estimated 40,000 people have been infected with HIV each year during the last decade. The epidemic is disproportionately lodged among Africa-American and Latino population, affecting mostly women (UNAIDS/WHO, 2004).

Sexual transmission is the most frequent infection route in most countries. With the exception of some countries, most of the HIV infection is related to unprotected intercourse. Most of the countries in the Caribbean, South America, United States, Canada, and Australia report high cases of sexually-transmitted infection either by heterosexual or homosexual unprotected intercourse. Some countries in Europe including Spain, the Russian Federation, and Poland report a higher number of infection related to injection drug use. A high number of AIDS cases in the northeastern part of the United States are also due to sharing unclean needles for intravenous drug use, especially among minority populations (Cáceres, 2004, UNAIDS/WHO, 2004).

Issues of access to care and prevention information are constantly discussed among health care providers and

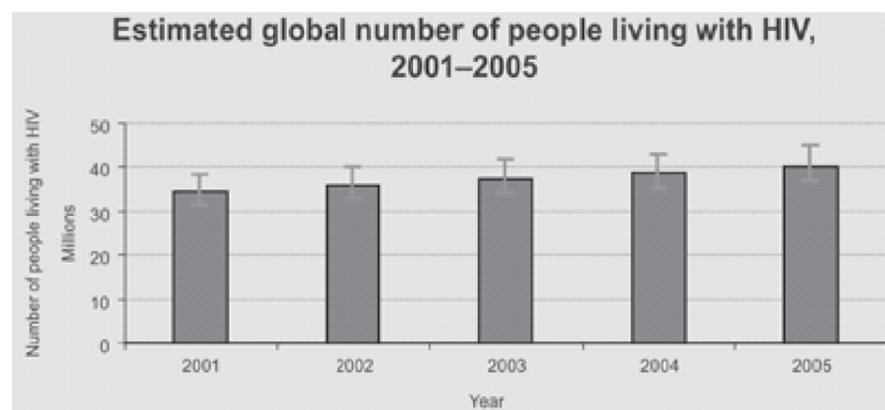


Figure 1. Estimated global number of people living with HIV, 2001-2205

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government officials. Besides the fact that many countries do have access to antiretroviral treatments, there are some regions where treatment and care are not accessible by most of the affected population. The high cost of treatment and the sophistication sometimes required for the administration of antivirals, make it difficult for disfranchised populations like the homeless and poorly educated patients in most of the America's.

The Roles and Limitations of Culture

Although the geographical contexts are different, it seems that there is ample evidence that culture and geography do play an important role in the way people conceive health and sickness. Access to health information and the development of a healthy sexual lifestyle are deeply interconnected to personal and cultural values (Valdiserri, 2002). But, "beyond the core or internalized influence related to race, ethnicity, and culture, sexuality is also affected by the attitudes of society as a whole" (Gómez, Mason, & Alvarado, 2005, p. 87). The global numbers of people living with AIDS and the rate of HIV infection remind us more of the role of our cultures, than of personal or individual vulnerabilities.

Be it through the culture of ethnicity, poverty or political environment, culture represents the social context of meaning of the HIV/AIDS epidemic (Duffy, 2005; Ogden & Nyblade, 2005). Globally, issues of sexuality, homosexuality, drug use or even premarital sex are still taboos associated with marginalized communities. Stigma and discrimination are part of complex systems of beliefs about illness and disease that are often grounded in social inequalities (Castro & Farmer, 2005).

Due to the social meanings attached to the epidemic, HIV produces social limitations which are mostly based on silence and invisibility. "HIV provides a unique opportunity, a window to explore the territories of secrecy, morality, and silence" (Klitzman & Bayer, 2003, p. 3). The truth of living with HIV is a constant reminder of the lack of acceptance and rejection found in our societies. Living with HIV demands silence and secrecy, because even in the best of cases people perceive rejection and lack of acceptance even from health care providers, including psychologists.

AIDS is a disease of social meaning (Varas-Díaz, Toro-Alfonso, & Serrano-García, 2005). Among other factors, this social meaning is disseminated through culture and the mass media that presents the epidemic as intimately associated to death and sickness; to the invisible lives of other people. In open contrast to other diseases portrayed by the media as generators of sympathy and motivation, AIDS is mostly presented as evidence of decadence and deterioration (Varas-Díaz & Toro-Alfonso, 2003). There are no attractive or romantic metaphors associated to AIDS (Sontag, 2001).

Stigma beyond Borders: International Perspectives on Stigma

The discreditable nature of people living with HIV/AIDS is based in the constant reminder that the information about their seropositive status could easily be identified by others (Goffman, 1963). The constant hyper-vigilance of living with the infection transcends geographical borders and cultures as is demonstrated by all the articles included in this special issue. Stigma and discrimination go beyond the borders established by languages, cultures, and sexualities.

Stigma can lead to discrimination and other violations of human rights which affect the well-being of people living with HIV in fundamental ways. In countries all over the world, there are well-documented cases of people living with HIV being denied the rights to healthcare, work, education, and freedom of movement, among others (Aggleton, Wood, Malcolm, & Parker, 2005). HIV-related stigma is also associated to economic and ethnic discrimination which co-exist to worsen the lives of people living with the disease.

The fact that stigma transcends borders presents us with an international challenge. As the HIV/AIDS epidemic continues to grow and impact the most vulnerable populations in our countries we need to identify and develop a global response. Stigma and discrimination combine non-normative behaviors which are usually criminalized by uneven power relations. An international review of the impact of stigma evidences the combination of stigma with disease, poverty, gender, social class, and nationality. Be it either HIV or Hepatitis C, located in the north or south of the America's, at the East of Europe or the Greater Caribbean, or in Australia; the testimonies and scientific evidence on the detrimental social and health implications of stigma is vast. As gender and sexuality become the target for exclusion, we will find women and sexual minorities separated and discriminated just for being who they are.

UNAIDS identified early in the epidemic the need for a global response to stigma as one of the most important prevention intervention in the world. The need to support human rights and citizenship among people in general and people living with HIV/AIDS in particular, represents the best public health intervention today. The limitations imposed to people with HIV/AIDS deny their rights to access care and prevention, limit the possibilities of providing a safe environment for them and their families, and hinder primary prevention efforts.

Testing and surveillance will only be effective in a safe environment. A call for universal testing for the so called "risk populations" including pregnant women will not be sufficient to halt the epidemic amidst a social environment that stigmatizes and excludes those who will become HIV positive.

Public health officials and governments must directly address stigma as a structural obstacle for ending the epidemic. Besides access to treatment and care, society must guarantee

SIMILAR EPIDEMICS WITH DIFFERENT MEANINGS

total citizenship and protection against discrimination. The international community has an enormous task in providing a safe environment and opening spaces for solidarity and acceptance for all people living with the HIV no matter their mean of infection. As long as society fosters the intention to deny human rights and full citizenship to a sector of the population on the basis of sexual practices or drug use behavior, stigma and discrimination will prevail.

Challenging HIV-Related Stigma

In order to challenge stigma and its multiple and complex implications we must address it in multifaceted and multilevel perspectives. Link and Phelan (2001) described that it must be multifaceted as to address all possible consequences of stigma, and multilevel because it must address issues of individual and structural discrimination. However, any intervention must address the fundamental cause of stigma, this is the “deeply held attitudes and beliefs of powerful groups that lead to labeling, stereotyping, setting apart, devaluing, and discriminating” (Link & Phelan, 2001, p. 381).

Understanding stigma and discrimination as an exercise of power requires that to change and transform stigma we must challenge the role of such groups in making their beliefs the dominant ones. Issues of heterosexism, morality, class, and exclusion of social sectors from access to work, wealth, and health care must be directly addressed in targeting stigma in general and HIV-related stigma in particular.

We coincide with Castro and Farmer (2005) when they “proposed structural violence as a conceptual framework for understanding AIDS-related stigma” (p. 54). Poverty and racism viewed as structural violence are intricately related to stigma. Poor people are the highest stigmatized group all around the globe, more so for poor people living with HIV/AIDS.

HIV/AIDS stigmatization results in silence, secrecy, lies, and denial (Klitzman & Bayer, 2003) that represent an obstacle for access to care and the possibility of survival for many people living with the infection. Although more than 20 years have passed since the report of the first AIDS case, the studies presented in this special issue clearly demonstrate that stigma is still in the realm of the lives of those more affected by the epidemic. Along with the development of new and better drugs for treatment there is an unavoidable task to overcome discrimination. This should be the agenda for the next decade.

The Content of this Special Issue

It is in light of the difficulties imposed by AIDS stigma that we decided to edit this special issue of the *Interamerican Journal of Psychology*. The issue is composed by 10 papers from 20 authors from nine countries: Puerto Rico, Dominican Republic, Argentina, United States of America, Poland, Suriname, Australia and Canada. The issue is divided into

three sections that reflect subjects of concern for the authors and areas of potential action.

The first section is entitled *The Personal Experience of Stigma: Migration, Co-infection and Everyday Life*. In this section we have included papers that evidence through social research the difficulties faced by PLWHA due to the manifestations of AIDS stigma. Several aspects of these manifestations are highlighted in each paper. Irene López Severino and Antonio de Moya contextualize the manifestations of AIDS stigma in the Dominican Republic in relation to migration routes from Haiti to the Dominican Republic. Their paper is an excellent example of the contextual nature of AIDS stigma. As it is combined with other pre-existing stigmas, AIDS stigma is worsened. Such is the case for migrant Haitian communities which are usually blamed for the spread of HIV/AIDS.

The human rights situation of people living with HIV/AIDS is a product of the history of general ignorance regarding civil rights among the Dominican population itself; of the lack of a migration policy that respects human rights; of the history of conflicts between the two nations; and of the generalized stigmatizing of HIV/AIDS. As one key informant declared, the only right that people who are HIV positive appear to have in the bateyes — Dominicans as well as Haitians — is to die, without ever even knowing what they are dying from or why.

Irene López Severino and Antonio de Moya
Haiti/Dominican Republic

The second paper in this section was written by Mario Pecheny, Hernán Manzelli and Daniel Jones from Argentina. They provide us with an interesting analysis related to the hierarchies of meaning associated to different diseases. Although both HIV/AIDS and Hepatitis C are stigmatized diseases, the first still evokes more negative interpretations. The authors reflect on the combinations of different types of stigmas in the daily lives of PLWHA and how the transformations in the meanings of other diseases are a potential example for AIDS stigma eradication.

If discrimination is basically a social phenomenon, the actions taken by the victims become part of the public and political sphere even more so. The fact of taking the concealed and stigmatized dimension of the identity to the public sphere, transforms the nature of stigmatization itself.

Mario Pecheny, Hernán Martín Manzelli and Daniel Eduardo Jones
Argentina

In our third article Mariví Arregui present a compelling look at the everyday manifestation of AIDS stigma in the Dominican Republic. One of the particularities of her paper is that she provides us with an ample range of strategies for stigma eradication, most of which stem from her interviews with PLWHA. Her results evidence how the disease has different meanings for different sectors of the population and how self-hatred can be one of its consequences. She also argues for an approach towards sigma reduction that takes into consideration couples, families, communities, and the church. Although all of these institutions play a role in the stigmatization of HIV/AIDS, Arregui argues for their inclusion in efforts to eradicate it.

The first scenario affected by rejection and stigmatization associated to HIV/AIDS is the self image. An HIV positive person first reflects every prejudice and rejection learned in society onto himself/herself. He or she is flooded with rational and irrational fears. Fear and silence take control over the life of the person recently diagnosed with HIV. Fears clouds over the possibility of being recognized as an infected person, so he or she tries to hide what others don't know.

Mariví Arregui
Dominican Republic

In our fourth and final article of this section, Ida Roldán presents us with a compelling look at how culture fosters AIDS stigma among the Puerto Rican community in the United States. She argues that the culture's religious and spiritual roots have pushed HIV/AIDS into the realm of sin. This in turn has disastrous implications for prevention efforts and limits the manifestations of PLWHA.

Similarly, the Puerto Rican family's core beliefs about the causes of HIV/AIDS and illness in general shape their reaction and give rise to the complicated feelings and fantasies which are culturally derived. These beliefs are what drive the Puerto Rican family to act uncharacteristically distant and un-nurturing when faced with HIV/AIDS.

Ida Roldán
United States of America

The second section of the special issue is entitled *Facing Stigma in the Health Sector*. Although all manifestations of AIDS stigma have negative implications for PLWHA, when it is manifested by health professionals it can be severely worsened since it hinders access to health related services.

This worry regarding the use of sensitive data from PLWHA was corroborated when participants manifested the need to supervise and regulate those living with the virus. Instances from work scenarios to sexual activity were described as areas that needed to be regulated with the use of the gathered information in order to stop PLWHA from infecting others. The use of sensitive information, in light of these attitudes towards surveillance of the sick, poses a major challenge for PLWHA and a fertile ground for AIDS stigma.

**Yamilette Ruiz-Torres, Francheska Cintrón-Bou and
Nelson Varas Díaz**
Puerto Rico

In the first article of this section Yamilette Ruiz-Torres, Francheska Cintrón-Bou and Nelson Varas Díaz present data from their study with Puerto Rican health professionals. Their paper examines how AIDS stigma is used as a mechanism of social control over PLWHA. Through AIDS stigma human rights are restricted and the quality of services is severely restricted. Furthermore, surveillance and restriction of PLWHA is described as a technique used by health professionals to stop the epidemic.

The second article in this section examines stigma among Polish health professionals. Maria Gańczak examined mandatory HIV testing as a manifestation of stigma in Poland. Her results evidenced support for HIV testing of all inpatient admissions in hospitals and pre-surgery testing among both nurses and surgeons. Fear of becoming infected in the workplace is a strong initiator of stigmatizing attitudes, and the presented study evidences the extent to which health professionals will go to feel protected from the disease, and the people who live with it.

There has been vehement debate surrounding the question of preoperative HIV testing of patients. Opponents, represented by people who are professionally involved in HIV/AIDS problem, state that routine HIV antibody testing of patients is not recommended. The testing is opposed by many because of the civil rights implications of a positive test result and the fear that HIV-positive patients would receive sub-optimal treatment.

Maria Gańczak
Poland

In the third and final article of this section Winston Roseval explores manifestations of AIDS stigma among nurses in Suriname. His research shows an interesting trend among these health professionals. Participants tended to

SIMILAR EPIDEMICS WITH DIFFERENT MEANINGS

share amongst themselves confidential information regarding the serostatus of patients. This of course, is a blatant manifestation of AIDS stigma as confidentiality is breached and the process of sharing negative meanings regarding PLWHA is fostered. Still, these same nurses manifested the need to provide financial assistance and find work for PLWHA. This combination of stigmatizing behaviours and positive attitudes towards the needs of PLWHA is evidence that AIDS stigma can co-exist with more positive perspectives on PLWHA. This can hinder effective interventions to reduce it due to the difficulty entailed in its identification.

In Suriname a fairly reasonable amount of research has been done on HIV/AIDS. What is evident, however, is the fact that this research does not particularly address HIV/AIDS stigma and discrimination. In recent years researchers have acknowledged this gap and have endeavored to focus on the so called 'softer' side of science when doing research on HIV/AIDS.

Winston Roseval
Suriname

The third and final section of the special issue is entitled *Research, Social Action, and Intervention: A Potential Agenda* and is geared towards the establishment of strategies to understand and eradicate AIDS stigma. Articles in this section address the need for specific social research, structural interventions, and the use of legislation as tools for stigma reduction.

In the first article of this section Charles L. Law, Eden King, Emily Zitek and Michelle R. Hebl explore the future directions that research on AIDS stigma should take. This is done through a review of past research in the United States. They provide excellent examples of how stigma has been studied in the past, while providing guidelines for future efforts. They specifically argue for research that disentangles the stigmas of homosexuality, drug use, and AIDS. Research on the implications of AIDS stigma in the workplace is also identified as an emerging need.

Future research should consider the impact of the stigma of homosexuality on the AIDS stigma, the dynamics of the stigma of AIDS in organizational contexts, and strategies by which the stigma may be reduced or avoided. By thoroughly integrating behavioral and applied scientific approaches, we may begin to fully understand the problem of the stigma of AIDS and to identify and implement its solution.

*Charles L. Law, Eden King, Emily Zitek
and Michelle R. Hebl*
United States of America

In the second article of this section, Dennis Altman from Australia stresses the importance of structural interventions to reduce AIDS stigma. While honoring Jonathan Mann at the International AIDS Conference held in Bangkok, Thailand during the summer of 2004, Altman critically explores the concept of vulnerability in order to expose how risk behaviors are intimately linked to the environment in which they are manifested. Therefore, structural interventions that take into consideration this context are urgently needed.

The greatest tragedy of HIV/AIDS is that we know how to stop its spread, and yet in most parts of the world we are failing to do so. The literature tends to emphasize immediate problems—lack of condoms or clean needles, safe sex fatigue, unwillingness to interfere with the immediate gratification of sex or drugs. There is less emphasis on the political barriers that are accelerating the epidemic—the deliberate neglect by governments, the unwillingness to speak openly of HIV and its risks, the hypocrisy with which simple measures of prevention are forestalled in the name of culture, religion and tradition.

Dennis Altman
Australia

In our final article Josephine M. MacIntosh explores the role of legislation in the eradication of AIDS stigma in Canada. She stresses that while the prevalence of HIV/AIDS in Canada is relatively low, AIDS stigma is common. She presents the efforts of the Canadian HIV/AIDS Legal Network as examples of potential actions to prevent, reduce and eliminate AIDS stigma.

Ostracism of those infected or those at risk of infection often accompanies scapegoating. The practice of social ostracism is qualitatively different from the public health practice of quarantine. Ostracism implies a moral or value judgment about the individual afflicted with a disease rather than a medical judgment about the disease itself. The attachment of a stigma to an illness does little to eliminate contact with contagions, although this can provide an artificial boundary between *us and them*.

Josephine MacIntosh
Canada

In Conclusion

In this special issue we have aimed to evidence the diversity and similarities that the manifestations of AIDS stigma entail for our countries. We feel that although it is an important step towards reflecting and acting to reduce AIDS

stigma, much needs to be done in each of the described scenarios. We hope that the included articles are a stepping stone towards that goal.

Finally, we wish to thank all of the authors that have provided us with their time, ideas, and patience in the editing and publication process of this special issue. They all make important contributions towards the eradication of AIDS stigma.

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Migratory Routes from Haiti to the Dominican Republic: Implications for the Epidemic and the Human Rights of People Living with HIV/AIDS

Irene López-Severino^{1,2}
Antonio de Moya
Dominican Republic

Abstract

The presented study analyzes the possibility of a relationship between the migratory flow from Haiti toward the Dominican Republic and the spread of HIV/AIDS, as well as implications for the human rights of immigrants living with the infection. Its purpose is to identify possible areas of intervention and research in order to increase the participation of this population and its organizations in HIV/AIDS awareness and prevention efforts. The current study was carried out in three main phases: 1) review of existing documentation on the relationship between Haitian immigration, HIV/AIDS, and the human rights of infected people; 2) semi-structured interviews with key informants, authorities, and experts in the areas of concern; and, 3) eight case studies of Haitian immigrants living with HIV/AIDS in agricultural bateyes in the Dominican Republic. Results evidence the stigmatizing scenarios that immigrants living with HIV/AIDS face.

Keywords: Acquired Immune Deficiency Syndrome; stigma; migration; Haiti; Dominican Republic.

Rutas Migratorias desde Haití a la República Dominicana: Implicaciones para el Estigma Relacionado al SIDA y los Derechos Humanos de las Personas Inmigrantes Infechadas

Compendio

En el estudio aquí presentado se analiza la posibilidad de una relación entre la migración de Haití a la República Dominicana y la propagación del VIH/SIDA, a la misma vez que se exploran las implicaciones a los derechos humanos de los emigrantes que viven con el virus. Su propósito es identificar áreas de intervención e investigación para aumentar la participación de esta población y su organización en asuntos relacionados al VIH y su prevención. El presente estudio fue hecho en tres fases que incluyeron: 1) revisión de documentos existentes sobre la relación entre la migración Haitiana, el VIH/SIDA, y los derechos humanos de las personas infectadas; 2) entrevistas semi-estructuradas con informantes clave, autoridades, y expertos en el área; y 3) ocho estudios de caso de emigrantes haitianos que viven con VIH/SIDA en bateyes en la República Dominicana. Los resultados reflejan los escenarios estigmatizantes que enfrentan las personas emigrantes que viven con VIH/SIDA.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; migración; Haití; República Dominicana.

This investigation was part of a multicentric study on the human rights of people living with HIV/AIDS, carried out simultaneously in Argentina, Ecuador, Mexico, the Dominican Republic, and Venezuela by the focal points of the Latin American and Caribbean Council of AIDS Services Organizations (LACCASO) in those countries for the Joint United Nations Program for HIV/AIDS (UNAIDS). This project should be seen as the exploratory stage of a broader study that must be made of this long standing and complex problem between two nations, a problem that must be redefined in light of recent events relating to the HIV/AIDS pandemic. Its goal is to provide new and culturally appropriate alternatives in response to the challenge that this disease presents, not only to the population of the entire island, but also to its diaspora in the Caribbean, North America, and Europe.

The study that has been carried out analyzes the possibility of a relationship between the migratory flow from Haiti toward the Dominican Republic and the spread of HIV/AIDS, as well as implications for the human rights of immigrants living with the infection. Its purpose is to identify possible areas of intervention and research in order to increase the participation of this population and its organizations in HIV/AIDS awareness and prevention efforts. Due to time and budget constraints, we are currently unable to enter in detail into the important consideration of the human rights of uninfected Haitians and Dominican Haitians (known as *Arrayanos*³), in terms of their possibly coming under suspicion of being infected, i.e., of their being collectively stigmatized. It should be remembered that, at the onset of the epidemic in the U.S. in the 1980s, Haiti was already thought of as an "international pariah because of AIDS" (Chaze, 1983).

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² This paper was initially presented as a report to the Latin American and Caribbean Council of AIDS Services Organizations (LACCASO) and the Joint United Nations Program for HIV/AIDS.

³ From the Spanish "raya," meaning "line" or "border; refers to Dominican-born children of Haitian or Haitian and Dominican parents. The term is not considered pejorative.

The main objectives of the study were to: 1) Gather and analyze existing documentation regarding the HIV/AIDS situation in Haiti and the Dominican *bateyes* (settlements of sugar cane workers) and the relationship of that situation to Haitian immigration and the human rights of Haitian immigrants living with HIV/AIDS in the Dominican Republic; 2) Obtain information from experts on the core issues regarding migratory routes and modalities, both traditional and recent; 3) Analyze the possible connection between migratory routes, including the relevant socioeconomic factors, and the spread of HIV among the immigrant and resident populations of Haitians, *Arrayanos*, and Dominicans; 4) Gather information on the management of the human rights of Haitian immigrants infected by HIV.

Migration and Health

The relationship between migration and emigrant health is one of the most controversial topics in international health, one that has inspired passionate discussions for centuries. Some researchers identified the main sources of problems relating to the health of immigrants in their countries of destination. Prominent among these are: 1) their socioeconomic status compared to the host population; 2) differences in worldviews concerning issues of health and disease; 3) educational difficulties and the lack of access to necessary resources; and 4) the impotence of medical personnel in the face of many diseases. Research of the migrants' views on their health problems reveals concrete barriers for obtaining medical attention, including but not limited to mistrust among health personnel, degenerative diseases, wandering from one service to another, and financial problems. In recent years a notion has gained ground that some of these problems may be resolved by seeking help from religious or traditional healers. In this study, perhaps for the first time in the Dominican Republic, the voices of Haitian immigrants and of those who live and work with them are heard, in an attempt to better comprehend from within their understanding of HIV/AIDS.

Immigrant Women and Children

There is little doubt that immigrant children and women are capable of understanding and learning a new culture and a new language, but there is a need to study in greater depth how this can be a function of the degree of marginalization from social contact with the host culture that many immigrant women may experience, particularly those who do not work outside the home.

Studies on migration classify women and children in terms of their general vulnerability, predominantly associated with the lack of command of the host country's language. Ford, King, Nerenberg and Rojo (2001) pinpoint three levels of risk among migrant women. The most marginal and vulnerable group consists of women who do not speak the language of the country of destination and children born in

their mothers' country of origin. This group is followed by one consisting of women with a basic knowledge of the language and children born in the host country and who speak the language. The final group includes women who are native or who arrived at an early age and speak the language, and children of mixed unions who were raised speaking the host language.

The majority of the women in the world who are infected by HIV live in the poorest countries and communities, because poverty and gender inequalities increase women's risks. Farmer, Connors and Simmons (1996) state, for example, that *serial monogamy* is a common practice among poor Haitian women. "These are weak monogamous unions leading to the procreation of a child but generally lasting no more than a year. Once such unions are dissolved, the women are left with new dependents and an even greater need for reliable partners. The instability of these unions aggravates their financial situation and may place the woman at high risk of contracting HIV or other STDs" (Farmer et al., 1996). It is often the case that a woman, who has been infected, upon the death of a partner with AIDS and needing to quickly establish relations with another partner for reasons of survival, places the new spouse in a situation of high risk of acquiring the infection.

International Migration and HIV/AIDS: Recent Studies

Some recent studies on the relation between migration and the risk of acquisition and transmission of HIV in various societies emphasize the risk factors and the necessity of HIV counseling and the control of other STDs. Adrien et al. (1998), for example, found that unprotected sex during return trips of Haitians from Canada to Haiti may be a risk factor for HIV infection. In Zimbabwe, Gregson, Zhuwau, Anderson and Chandiwana (1998) report that the perception of personal risk among migrant men was quite high (42%) and was correlated to bachelorhood, exposure to the media, and contact with medical services. In Holland, Fennema (1998) found that more than three fourths of HIV positive heterosexuals of both sexes were foreigners. In Italy, Suligo and Giuliani (1997) highlight the need to increase awareness of the spread of STD risk factors among immigrants. In the Russian Federation, Tichonova et al. (1997) confirm the finding that the transmissivity of HIV is increased by infection with STDs.

The Dominican Republic and Haiti: Historical Relations between the Two Countries

The island of Hispaniola is shared by two nations, politically organized as the Dominican Republic and Haiti. Along with Tierra del Fuego, Saint Martin, Ireland, and New Guinea, it is one of only five cases in the world of an island shared between two countries (Vega, 1988). The ethnic, cultural, political, and historical development of the two societies has been different

yet intertwined since the seventeenth century, although their destinies might appear to be joined by their common geography and ecology. We Dominicans and Haitians are the children of slave owners and slaves. Our mothers were Taíno mestizas, our fathers were Caribes, Europeans, Africans, Asians, and Americans. Despite this vocation for diversity, or perhaps precisely because of it (“to be and not to be the other”), the Divided Island, today menaced by its regional HIV/AIDS subpandemic, has been an imperial borderline of racism in the Americas.

The Border between the Dominican Republic and Haiti

According to the historian Frank Moya-Pons (1998), the treaties of Aranjuez, Basilea, and Ryswick were signed by Spain and France in the seventeenth and eighteenth centuries, establishing the territorial boundaries of their respective colonies that shared the island of Hispaniola. In 1795 the Spanish part was ceded to France in consequence of the French (1789) and Haitian (1791) Revolutions. In 1794 Toussaint L'Ouverture occupied land that had formerly belonged to Spain. This occupation was never acknowledged by the authorities of the Spanish part, Santo Domingo, after the so-called War of Reconquest in 1809. In 1822 the Haitian government once again occupied the entire island, incorporating the former Spanish territory into Haiti. This action was again repudiated in 1844 when the new Dominican Republic was founded. The Dominicans continued to claim sovereignty over what they considered to be Haitian-occupied territories, and there was war between the two nations for a number of years. The year 1861 saw the Annexation by Spain of the Dominican territory. The War of Restoration, however, blocked that plan and achieved the Dominican Republic's separation from Spain, leaving the boundaries as they had been defined by the Haitian government between 1822 and 1844.

In 1867, the Dominican Republic signed the first Treaty of Peace, Friendship, Trade, and Navigation with Haiti. The two governments signed various treaties and agreements in 1874, 1880, 1884, 1895, 1899, and 1900. There were more talks in 1911, 1929 and 1935. At the 1935 meeting, the construction of an international highway was agreed upon; some sections of this highway were to mark the boundary line between the two countries.

The Dominican Sugar Industry: Sugarmills and Bateyes

According to the sixteenth-century *Indian Chronicles*, the term *batey* was used by the Island's aboriginal Taínos to designate the plazas where ceremonial ball games and other social and ceremonial activities took place. This word has been carried over into the Spanish language, principally to refer to the communities where the laborers from the sugar mills live with their families (Ramírez, 1992).

According to Cedeño (1993) there are two basic types of bateyes in the sugar industry: the central (headquarters)

and the agricultural (outlying). The central batey is located very close to the factory; it is typically semi-urban or just urban. Its inhabitants are involved in the industrial labor of the actual grinding of the sugarcane and with the major portion of the administrative process over all the personnel and equipment for the agricultural and industrial areas of the sugar mill. The agricultural batey is a rural community; the majority of its population works at tasks related to planting, cutting, carrying, weighing, and transporting the sugarcane to the sugar mills.

One peculiarity of the agricultural bateyes is the ethnic composition of its inhabitants, which is greatly determined by the presence of immigrant labor, usually cheaper than native labor, primarily Haitians and their descendants. The sugar industry has used the importation of workers as a resource since the late nineteenth century, in order to keep wages low and reduce production costs (Ferrán, 1986). Starting with the final quarter of the nineteenth century, when the sugar industry began its ascendancy, dozens of sugar processing plants were founded. Many of these would later close, as the profitability of sugarcane production decreased during the final third of the twentieth century. Until the late 1980s, when two government-owned centrals were closed, the number of sugar mills remained steady at 16 (Ferrán, 1986).

It should be pointed out that the bateyes are not necessarily limited to the context of the sugar industry; rather, the term is being applied to marginal urban barrios when a Dominican Haitian and Haitian population is present. Moya-Pons (1999) indicates the manner in which the gradual occupation of land surrounding the old sugar mills has given form to important settlements.

A phenomenon worthy of study is the change in these growing towns from sugar-processing centers to cultural centers, where a community of migrants, instead of looking for work in a sugar industry, may perhaps come in search of a familial community where they will not meet with *quite so much* discrimination. (p. 25)

Legality and Illegality of the Haitian Immigrants

The clandestine and illegal manner in which Haitian immigrants arrive is the point of departure for the super exploitation of thousands of Haitians who work in the sugarcane plantations, the construction sector, and other local agricultural crops such as coffee, cacao, and rice. The Haitian often enters the country illegally and then, when the sugarcane harvest is over, stays illegally to work in other areas. Haitian immigrants are not protected by the Labor Code in effect in the Dominican Republic, nor by any other legal provision of any sort (Cedeño, 1993; Veras, 1986).

According to the Dominican Constitution, children of Haitian parents who are born on Dominican soil have the right to Dominican nationality in accordance with the principle

of *Jus soli*; this contradicts the Haitian Constitution, which establishes that any child of a Haitian is Haitian, regardless of the place of birth, in accordance with the principle of *Jus Sanguini*. This discrepancy has generated conflicts surrounding double nationality or absence of nationality. Children of Haitian immigrant fathers and Dominican mothers grow up without any documentation whatsoever. Reliable sources report that for some time birth certificates have not been issued to any children of Haitian descent born in the territory, which causes repercussions for the child's education within the formal school system, since the schools require a birth certificate in order to register a student.

From 1940 until 1952, Haitian braceros worked illegally as a consequence of clandestine trafficking. In 1952 an agreement was reached under which Haitians could be hired in Haiti and enter the Dominican Republic as temporary workers. This agreement was passed in conjunction with a labor contract form to be signed by the company that would employ the bracero and by the worker himself. In 1959 and 1966 similar agreements were reached. There does not appear to be a consensus today as to whether these agreements are still in effect through automatic renewal or whether they have expired.

Anti-Haitianism

The anti-Haitianism of broad segments of the Dominican population is a complex phenomenon rooted in the ethnic and economic development of the parallel Spanish and French colonies on the island, in their historic struggles for independence, in the border disputes to define the two territories, and in the presumed economic pressures that generate immigration. According to Vega (1988), Dominican anti-Haitianism in the nineteenth century was based on "the Haitian objective of controlling the eastern part of the island". We must, however, deconstruct these attempts to localize the fault for anti-Haitianism on the acts of the Haitians themselves, i.e., blame the victims for their victimization.

It is important to point out that many of the central figures of Dominican national history are the creatures of their resistance to the Haitian occupation of the eastern part of the island in the nineteenth century. There is apparently an effort by the dominant classes to maintain the rejection of the "negritude" of the Haitian and defend the "Spanishness" of the Dominicans. This type of anti-Haitianism, which according to Vega (1988) is self-defined as a deliberate effort to place the *mestizaje* [racial mixing of Europeans and indigenous peoples], Hispanism and Catholicism" of the Dominicans in direct opposition to the "Africanism and negritude" of the Haitians, also reflects the racial prejudice against even Dominican blacks that has existed since the colony was founded. Around the late 1930s, however, perhaps reflecting the Nazi policy of ethnic and racial extermination, arises what Vega (1988) dubs "Trujillo-Era Anti-Haitianism," based now on the physical presence of

Haitians in the country and in the supposed threat to national culture. Vega indicates that following the Massacre [of Haitians in 1937], Trujillo "invoked anti-Haitianism as official policy", probably as a unifying factor by means of the manipulation of terror.

Situation of the Population Regarding Human Rights

The Dominican Republic has ratified the principal agreements and treaties of the Member States of the United Nations. This requires the nation to comply with the Universal Declaration of Human Rights, the Supplementary Convention on the Abolition of Slavery, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the [Political] Rights of Women, the International Labor Organization, etc. In addition, the Constitution of the Republic takes into account various aspects of civil and political rights.

However, the country has historically turned its back on considerations of people's rights, resulting in visits from human rights commissions, including that of 1976. As a result, economic sanctions were imposed on the country because the work conditions of Haitian's braceros were seen as the practice of slavery.

Regarding persons living with HIV/AIDS, their rights as citizens are allocated within the constituent regulations that govern the country, specifically AIDS Law 55-93 and internal bylaws. This law contains provisions regarding diagnosis, guidelines for prevention, the rights and duties of citizens whether infected or not, and sanctions against those who violates the rights and guarantees established by said law (Raful, 1995). López-Severino (1999) states that the counseling process is not regulated and that the task has often fallen to a handful of non-government organizations. Law 55-93 establishes counseling, but limits it to before and after the tests for HIV.

Cáceres et al. (1998) found in a survey that the majority of people living with HIV/AIDS in the D.R. remains anonymous because of the social and job implications of publicly acknowledging their stigmatized seropositivity. Existing self-help groups are concentrated in Santo Domingo, which limits the participation and empowerment of the immigrants in the bateyes. In many cases, the families of these people attempt to conceal their condition; others receive support on a small scale from their social networks. De Moya, Soriano and Rowinsky (1998) indicate that many infected persons as well as their family members and neighbors were unable to think about or pronounce the word AIDS without an intense emotional reaction, thus suggesting the ominous character that the term has acquired.

Cáceres et al. (1999) state that access to health services is conditioned upon the individual's purchasing power, on the private level. On the public level there is a serious lack of diagnostic instruments, protective measures, and

medications. There are also problems with the willingness of health personnel to treat people who are infected. People who are HIV positive continue to be identified, stigmatized, and discriminated against within the health sector, and involuntary tests for HIV continue to be administered. Goyanes (1999) adds that antiretroviral medications are not available through the public health system. Laboratory controls for the proper use of these therapies are not currently available in the country, and appropriate training of health personnel for follow-up on patients undergoing treatment is deficient.

The HIV/AIDS Epidemic in Haiti

According to Farmer (1992), an analysis of the AIDS pandemic in the Caribbean reveals that it is composed of multiple sub epidemics of HIV transmission, initially derived from the broader pandemic in North America. Farmer states that epidemiological investigation has shown that the virus came to Haiti, the Dominican Republic, Jamaica, Trinidad and Tobago, and the Bahamas from the United States, probably by means of tourism and through migrants returning home from foreign stays. He believes that more powerful explanatory frameworks should reveal the transnational links that are evaded in many accounts based on national reports.

The first cases of AIDS on the island of Hispaniola occurred in the late 1970s and early 1980s (Guerrero, De Moya, Garib, Rosario, & Duke, 1985). Koenig et al. (1987) and Farmer (1992) identify sex tourism as the most probable route for the introduction of HIV/AIDS into the Dominican Republic and Haiti, owing to sexual contact between male homosexual tourists and Dominican and Haitian men who sell sex to men. De Moya and García (1999) add the link of organized homosexual tours with common destinations between Santo Domingo and Port-au-Prince for middle-aged North American and European tourists during the boom in the 1980s. This appears to be one of the oldest HIV/AIDS vectors on the island.

Two studies with female sex workers demonstrate that these workers had very high seroprevalence rates (over 60%), at least in some locations. Low-income groups (1989) and women patients at STD clinics up to 1993 surpassed a 10 percent infection rate, while this rate is almost three times higher (28%) in men with STDs. Parturient women under 25 years of age (1991-92) and pregnant women in at least two sentry posts (1992-93) had passed the critical level of 5 percent, suggesting a concentrated epidemic. Blood donors (1992) were close to that level. The PAHO/WHO report does not provide data for seroprevalence studies after 1993.

Two qualitative studies on the situation in Haiti have been published in recent years. Ulin, Cayemittes and Metellus (1993) studied Haitian women's role, in their country, in making sexual decisions. Their results demonstrate that there

was little understanding of the danger of vertical transmission; women who have no way of earning a living were less respected and had little influence on decisions in the home and in sexual negotiations; interest in protecting the couple relationship leads many women to forgive or ignore the men's sexual activity outside the home; and women advise other women to abstain from any kind of sex with a promiscuous man, or even to leave him if unable to convince him to be faithful to her.

The HIV/AIDS Epidemic in Dominican Bateyes

HIV infection rates in different bateyes have varied considerably and are, therefore, difficult to compare. The principal risk factors identified for all dwellers of these communities are having had syphilis and the amount of time of residing in bateyes. For women, receptive anal sex, professional sex work, head-of-household status, and being younger than 35 were associated with risk. Half of the HIV positive women had not had more than two sexual partners (Brewer et al., 1996). Capellán (1992) and Brewer et al. (1996), found higher rates among Haitian subpopulations of both sexes, followed by Arrayanos and Dominicans. The first two of these three studies conclude that the majority of HIV transmission appears to occur within the bateyes.

Attempts to Establish HIV Preventive Action in Dominican Bateyes

Diligent attempts to prevent the transmission of HIV/AIDS have been carried out by Dominican national organizations such as PROCETS (Program for the Control of STDs and AIDS), SESPAS (Office of the Secretary of Public Health) (Mañaná & Gamboa, 1989), IDSS (Dominican Social Security Institute) (Arbaje, Cruz, Thormann, & González, 1992; Millord, Cize, & Arbaje, 1992a, 1992b), and the Reproductive Health Program of the CEA (National Sugar Council). Other non-government organizations have also participated, such as SSID (Social Service of Dominican Churches) and the donor agencies *Medicus Mundi* and PREVIHSA, the European Union's HIV/AIDS Prevention Project, to name a few. However, so far no reports or significant evaluations have been published that assist in understanding the concrete situation in the bateyes. IDSS hospitals offer general medical attention, and specialized attention is offered at the Salvador B. Gautier Hospital to insured Haitian braceros in the CEA and private bateyes, and to their wives and children as well. Early in 1999 the P. Juan Montalvo Study Center (CES) and the Jesuit Refugee Service (SJR) published a catalog of organizations and institutions that reported that they work with Haitians and with Dominicans of Haitian descent in the Dominican Republic. The catalog lists 41 non-government organizations (NGO's) and 14 ecclesiastical, seven peasant, seven union and five municipal community organizations.

The reality is that despite great efforts, we still do not know the implications of these investigations and their significant results. From this standpoint we proposed for ourselves this project as a way of examining concretely the implications of migration for the HIV epidemic.

Method

The current study was carried out in three main phases: 1) Review of existing documentation on the relationship between Haitian immigration, HIV/AIDS, and the human rights of infected people; 2) Semi-structured interviews with key informants, authorities, and experts in the areas of concern; and 3) Eight case studies of Haitian immigrants living with HIV/AIDS in agricultural bateyes in the Dominican Republic, based on semi-structured interviews with these persons and/or confidants (close relatives and neighbors) who gave their informed consent to participation.

Two guides for semi-structured interviews were prepared, one for key informants and the other for immigrants from Haiti who are living with VIH in sugarcane agricultural bateyes. The guide for key informants consisted of 11 dimensions of the participant's experience and knowledge of the migratory routes from Haiti to the Dominican Republic, points of origin, stations, and destinations, variation and motivation for changes in traditional migratory routes over time, comparison of the HIV/AIDS situation between Haiti and the Dominican Republic, knowledge about violations of the rights of immigrants living with HIV/AIDS, community support, the role of magic-religious beliefs, available health services (including their quality and the level of satisfaction with them), the participation process, and discussion of proposed legislation on migratory control, etc.

The interview guide for people living with HIV/AIDS and/or their confidants consisted of 33 questions. These questions were on the following topics: demographic profile, migratory process, means of handling the lack of documentation, the human rights situation, the manner of detection of their infection, the condition of spouses and children, knowledge regarding the disease, symptoms, medical attention, social support and community relations, as well as any incidents of discrimination in the areas of employment, health, housing, and freedom of movement.

During the visits to the bateyes an observational context guide was also used, describing the communities being studied and illustrating the existence or lack of local services. This guide included a register for data regarding streets, housing conditions, sanitary facilities, electrical power, disposal of solid wastes (human waste and trash), schools, churches, business activity in the community, health services, internal community organization, and means of transport.

A list of possible key informants was compiled, including representatives of the Diplomatic Corps, Amnesty International,

the International Labor Organization (ILO), the Office of the United Nations High Commissioner for Refugees (UNHCR), the Organization of American States (OAS), the Latin American Social Sciences Faculty (FLACSO), the Secretariat of Foreign Relations, the general management of Migration of Prisons, the National Committee on Human Rights, the Human Rights Commission, the Dominican Haitian Women's Movement (MUDHA), the Haitian Workers' Sociocultural Movement (MOSCTHA), university professors and social communicators.

We were able to carry out five semi-structured interviews with key informants who had experience in community work with immigrant women and Haitian prisoners, migration, foreign relations, and human rights. A sixth interview dealt with AIDS-related funeral rites in the bateyes as a magic-religious cultural expression. These interviews were recorded with the permission of the interviewee, and were then edited, summarized and tabulated for individual and group analysis.

The next phase consisted of an exploration, through semi-structured interviews, of the experiences of Haitian immigrant men and women who were HIV positive or had AIDS. To this end we contacted health personnel of the National Sugar Council (CEA) and of community organizations with whom the authors had previously carried out preventive actions between 1992 and 1997. Their collaboration was requested in recruiting patients of theirs who would be willing to give them orally their informed consent to participate in the study, voluntarily and anonymously. The consent included that the spouse, children, and other confidants could participate as interpreters, if the person being interviewed did not feel that this violated his/her right to privacy and confidentiality. Doctors, nurses, and health educators were given training to prepare them to explain to the candidates the purpose and objectives of the study, and to obtain the informed consent of the patients. In one case, in which the patient was in the terminal stage of the disease, his wife and children consented to give the interview. Selection criteria included being born in Haiti, being HIV seropositive or with AIDS, and living in batey colonies.

In the end, four semi-structured interviews with women and four with men were held in their homes. These interviews were also recorded with the patient's authorizations, edited, summarized, and tabulated for analysis. The research team provided antiparasitic medications, condoms, and educational materials to the health educators in each batey they visited, to be distributed later to the inhabitants.

To complete the gathering of data for the eight case studies, additional individual interviews were carried out as key informants (confidants) with 10 neighbors, an evangelical pastor, one husband and one wife of patients, one sister-in-law, two community leaders, three health educators, one nurse, three medical doctors, and two batey supervisors.

The analysis strategy included the three phases of the study: first, the documents were studied (laws and treaties, books, university theses, organizations' reports, and newspaper clippings); second, the semi-structured interviews with key informants were analyzed in terms of recurring themes and their reciprocal relationships; and third, the same was done with the semi-structured interviews with the Haitian immigrants who were HIV positive or with AIDS and their confidants.

Results

Interviews with Key Informants

Those interviewed agreed that, in general terms, the magnitude of the AIDS epidemic in Haiti is greater than in the Dominican Republic. They emphasized that health conditions are very poor and unsanitary in that country, with little access to health services, and they acknowledged that living conditions were similar in the Dominican bateyes, where Dominicans, Arrayanos and Haitians live together.

The participants reported violations of the human rights of the immigrants in general, such as bribes being demanded in order to cross the border, women being deceived and raped there, the postponement of rape lawsuit trials, the absence of women from the sugar mill payrolls, and the denial of housing to women unless they had children old enough to cut sugarcane.

Three informants reported knowing of cases of persons with HIV/AIDS, both Haitians and Dominicans, in the bateyes. One of the informants stated emphatically that "the right they have is the right to die, because there isn't anything else for them in the batey." They reported various human rights violations, such as the restriction of their freedom of movement (the inhabitants obstructed their access to the community), the avoidance of physical contact (leaving food for them from a distance, without coming near), compulsive sanitation (washing for a long time the containers from which the sick people ate), discrimination (health personnel not providing medical help or making excuses for not giving it), and ostracism (deporting Haitian residents who were HIV positive when they attempted to renew their visitor's permits). They also mentioned having little access to health and education services.

Some of those interviewed, however, considered that the isolation or the release of infected prisoners from jails and the deportation of seropositive foreigners were done with the consent of HIV positive persons or as a response to pressure from groups and communities.

According to the informants, the response of the Haitian population to the HIV/AIDS crisis in the Dominican Republic is conditioned upon the rights that the country and its institutions recognize or deny to them. One of the informants explained that "historically, a Haitian is not treated like a

person" in the Dominican Republic. This is in addition to the stigma attached to the condition of being HIV seropositive, whatever one's nationality. They mentioned ignorance of the right to nationality for their children born in the country, to the lack of legal documentation, and to the lack of immigration officials who speak Creole.

The main obstacles faced by this population, in the judgment of those who were interviewed, are the language barrier, the deplorable living conditions (sanitation, housing, education, health), the high illiteracy rate, and the widespread use of the sex trade as a survival strategy.

They acknowledged that when they arrive in the Dominican Republic, the majority of Haitians do not appear to have any intention of returning to their own country, and they keep moving from place to place in order to escape migration controls and insert themselves into other productive areas. They focused on popular religion as a facilitator, in some cases, and an obstacle in others, to AIDS prevention and treatment. They believe that people resist accepting their own illness, believing that "somebody put a curse on them".

Regarding HIV/AIDS preventive action in the bateyes and other areas where the Haitian population lives, the informants said that the organizations that work with them should take a greater interest in making this topic a priority. They suggested preparing educational messages in two languages, Spanish and Creole; distributing prophylactics; improving the quality of life of infected persons, assigning not only economic resources to that task but also trained and sensitized human resources. They also propose providing basic medications to people who are seropositive, Haitians as well as Dominicans.

One of the informants, however, argued that "it is not the government's responsibility to give health care to foreigners, because it would be impossible to cover the high cost that that would involve". This person expressed a strong interest in learning the true scope both of the Haitian migration and of the HIV epidemic among immigrants.

The representatives of the participating organizations declared that there was little coordination among them regarding human rights work. Three of them characterized these groups as being interested only in denouncing irregularities (imprisonments, deportations, repatriations). Only two of them related having carried out joint actions, such as presenting proposals for discussion within the process of the National Dialog, and accusations before the United Nations High Commissioner for Human Rights. Two of the institutions related to the governmental area are in the process of revising or discussing migration laws with a view toward a new project and a common agenda between the two nations, for a new meeting of the two Heads of State.

Case Studies of Persons Living with HIV/AIDS in Dominican Bateyes

The ages of the female HIV positive cases interviewed were between 24 and 45. They were women who had not mastered Dominican Spanish, could not read or write, and whose work before becoming ill was "selling things", washing and ironing clothes for money, or picking coffee on small private farms (*conucos*). They report having had two to five serial monogamous unions, and each had three or four children by different fathers. Two women had small children with signs and symptoms of HIV infection. Two had been widowed from men who they suppose died of AIDS. One of them knew that he had been infected by a former wife who was HIV positive. The two infected women had both formed unions immediately with other men of the batey. The other two women were also living with partners. Some of them had met their partners in Haiti and others in the batey where they live.

Three of these women had entered the Dominican Republic from Haiti by land, and one had come by sea; they had come from towns in the north and the south, to different Dominican communities. They made at least two migratory stations before settling where they are now. All of these women were without documents. However, they said that they went wherever they wanted without being bothered by immigration agents or being asked for their papers. On the other hand, they tried not to attract much attention in the community. Several of the women interviewed said that Hurricane Georges "took away my papers".

Three of them said that they felt sick with fever, diarrhea, parasites, kidney infections, skin problems, and "stomach problems". None of them mentioned the word AIDS. Only one, whose infection was detected during her last pregnancy eight months ago, claimed to have no health problems, but her baby "is always sick". All had sought medical attention. This attention was short term in two cases; in another, when she gave birth; and in the other, systematically in recent days. They had received help from husbands, children, in-laws, neighbors, and religious pastors. The interviewed women complained that no one had told them that they had to go back to the doctor, that no one gave them medications, or that they had no money to go to the doctor or to buy medications. They said that they had not had problems with the community or with health or immigration officials. People visited them, they give them food when they could, and they helped with some of the household chores. They reported that they were treated well at the health centers where they had gone. Sometimes they were seen quickly, but apparently they were not examined with care nor did anyone pay much attention to them. These centers lacked medications and the necessary equipment to examine the patients. The women generally had to leave their communities to gain access to health services.

The ages of the four men who were interviewed ranged from 37 to 63 years. Health educators and neighbors, with the consent of everyone except one patient who was in the terminal stage, helped spontaneously as interpreters, as had been the case with the women. The men lived in agricultural bateyes; two of them lived with a woman and children. Although they had wives before, two of the men were living alone, without a relationship with a partner. In one case, his wife had left him and formed another union with a neighbor, although she visited him and gave him things to eat. The other received weekly visits from his wife and children, who lived in another batey and who brought him food.

The migratory routes that they used were at the border, from the north and from the south, and in one case, by sea, landing in Pedernales. All but one had lived in various migratory stations. One of them claimed to have walked almost all over the country, reporting 15 places of residence. Three came alone and one came with his wife and a small child, to work cutting sugarcane in the bateyes. All were without documents, although they had been living in the country for more than 10 years. As to their handling of the lack of documents, none mentioned having had problems with the authorities.

These men said that they felt sick with "amoeba", "colerín" (little cholera), and diarrhea. One explained that his illness was due to a blow on the head that he had received years before. In no case did anyone mention the word AIDS. Two of them said that they had been tested for HIV in public hospitals. One was retired. In general, they did not know exactly what sickness they had or why they were sick. One said that he had hopes that God would take away his illness. All of them had quit working in the cane fields due to their illness, but some of them planted *yuca* and *batatas* in small *conucos* "to have something to eat".

All four reported having sought medical attention within or outside their community, or by means of a health educator. One showed how happy he was to be taking medications. Another went to a nearby batey for a medical consultation, but neither personnel nor medications were available. All received food from their families. They said they got along well with the rest of the community. In one case, a neighbor said that people took care not to let children step on his saliva nor sit where he sat. In another case, the man had to be moved to another house, apparently over conflicts with a neighbor related to his seropositivity.

Discussion and Conclusions

Immigration, HIV/AIDS and Human Rights: Tomorrow will be too Late

The principal studies consulted and the data from the case studies tend to support the notion that most HIV transmission takes place in the Dominican bateyes, rather

than as a product of new waves of Haitian immigrants. Dozens of new HIV positive cases in the disease phase are appearing in these communities where abject poverty holds full sway. Every day more adults and children die without knowing exactly what they have or how to find relief for the suffering caused by the disease.

The human rights situation of people living with HIV/AIDS is a product of the history of general ignorance regarding civil rights among the Dominican population itself; of the lack of a migration policy that respects human rights; of the history of conflicts between the two nations; and of the generalized stigmatizing of HIV/AIDS. As one key informant declared, the only right that people who are HIV positive appear to have in the bateyes — Dominicans as well as Haitians — is to die, without ever even knowing what they are dying from or why. A substantial number of them are mothers who become infected and infect others due to the need to maintain serially monogamous relationships as a survival mechanism.

Flexible, Dynamic, and Changing Migratory Routes

The migratory routes from Haiti and their destinations in the Dominican Republic are many and varied, involving diverse areas of the host economy and new means of clandestine access, such as by sea. The interviews with key informants and the case studies show two main migratory routes, one in the south and the other in the north. The migratory currents cross the border primarily through checkpoints and local roads. The intensification of the migratory flow appears to depend on the precise political and economic situation of the two nations. However, the process looks like a permanent phenomenon of osmosis of part of the excess of the Haitian population toward Dominican territory, as a result of the ecological degradation of Haiti. This excess will continue to assimilate culturally and ethnically with the Dominican population through their descendants, who within two generations will be impossible to distinguish from either group. The Arrayano population, lasting only one generation since its children will be Dominicans, will continue to increase.

Recognition of the Role of Poverty in Facilitating the Epidemic

The intensification of the pandemic in the bateyes occurs mainly because of the conditions of poverty and inequality in which its inhabitants are living and which increase their vulnerability to the infection. A history of syphilis in persons of either sex and, in women, sex work, anal sex, head-of-household status, and youth are recognized as individual risk factors for infection. But the fact of a woman's being the head of the household requires a more structured and deeper analysis, which goes beyond the objectives of this study. An epidemiology that localizes the "blame" for the spread

of the virus in the victims themselves, solely because of their individual behavior, is an epidemiology that attempts to ignore social structures such as poverty, which may be the most important risk factors, perhaps even greater than the effect of undocumented migration.

As did Aggleton and Bertozzi (1997), we found in this study that in the Haitian homes we examined, which included at least one family member infected by HIV, changes had occurred in the socioeconomic structure and the functioning of the family, such as the loss of employment for pay, low levels of seeking attention, and denial, ostracism, and partial desertion. Nevertheless, probably because of the abject poverty of the cases, there has not been any increase in taking out loans, nor in selling possessions as the illness becomes more serious. Farmer, Connors and Simmons (1996) reminds us that although the majority of epidemiologists still do studies in populations, they do so in order to study individual, decontextualized risk factors, instead of studying population factors in their historical and social context. Recognizing the role of poverty is contextualizing individual "risk" behaviors in the "pandemiology" that we use to describe HIV/AIDS.

In conclusion, these considerations reaffirm the belief that the epidemics in Haitian territory and in Dominican bateyes are closely linked. Increases in the prevalence rates in Haiti should correspond to increases in the rates of infection among the new immigrants entering the country. However, the epidemic situation in the bateyes allows for an inference that there is a high risk of infection for the susceptible Dominican, Arrayano, and Haitian populations, particularly women and young people entering the country and natives and residents who are beginning to be sexually active. Likewise, each year repatriated Haitians should have, in consequence, rates of infection that are probably higher than those of immigrants who come to the Dominican Republic for the first time.

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The Experience of Stigma: People Living with HIV/AIDS and Hepatitis C in Argentina

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Abstract

This article compares the experiences of people living with HIV/AIDS with those living with Hepatitis C in Buenos Aires, Argentina. In both cases, people learn to live with the illness, and get to know about symptoms, treatments, diagnoses, and future perspectives. In the end they become "experts" on the matter. At the same time, they are forced to deal with the "synergy of stigmas" associated with deadly diseases, and in most cases related to sexual behaviors and lifestyles historically stigmatized. Selected by availability we interviewed 27 people living either with HIV, Hepatitis C, or both; and 20 health care professionals. Through out this paper we trace similarities, differences, and articulations in terms of the management of the information on homosexual identity, being drug users, and living with HIV/AIDS and Hepatitis C. We analyzed these issues as non-evident traits of discreditable individuals, which allow a relative concealment and their fears on revealing their secrets.

Keywords: HIV; Acquired Immune Deficiency Syndrome; stigma; Hepatitis C; Argentina.

La Experiencia del Estigma: Las Personas que Viven con VIH/SIDA y Hepatitis C en Argentina

Compendio

Este artículo compara las experiencias de personas que viven con VIH/SIDA con las de personas con Hepatitis C en Buenos Aires, Argentina. En ambos casos, las personas aprenden a vivir con la enfermedad y a conocer sobre síntomas, tratamiento, diagnósticos y perspectivas futuras. Al final se convierten en "pacientes expertos" en la materia. Al mismo tiempo son forzados a manejar la "sinergia de estigmas" asociadas con enfermedades letales, en la mayoría de los casos relacionados a conductas y estilos de vida históricamente estigmatizados. Seleccionados por disponibilidad, entrevistamos 27 personas que viven con VIH, con Hepatitis C o con ambas, y a 20 profesionales de la salud. A través de todo el trabajo trazamos similitudes, diferencias y articulaciones en el manejo de la información sobre la identidad sexual, el uso de drogas y la vivencia con el VIH/SIDA y la Hepatitis C. Analizamos estas cuestiones como rasgos no-evidentes de individuos desacreditables, lo que permite una relativa simulación, y los temores que dichos individuos albergan sobre la revelación de sus secretos.

Palabras clave: VIH; Síndrome de Inmunodeficiencia Adquirida; estigma; Hepatitis C; Argentina.

In this article we compare the experiences of people living with HIV/AIDS with those living with Hepatitis C. Both illnesses are chronic and serious; they are treated more or less effectively with medication, and are characterized by uncertainty. The first one has been loaded with different meanings, frequently negative, since very early on; the second one was almost unknown to most people, who would mistaken it for common hepatitis. To compare daily life and how to manage the illness in people living with HIV/AIDS to the lifestyle of those living with Hepatitis C, seems an interesting exercise to emphasize the social connotations that

distinguish and imply stigma for HIV/AIDS, and the apparent lack of symbolism of Hepatitis C.

In both cases, people learn to live with the illness, and get to know about symptoms, treatments, diagnoses and future perspectives. In the end they become "experts" on the matter. At the same time, they are forced to deal with the "synergy of stigmas" (Parker & Aggleton, 2002) associated with deadly diseases, and in most cases related to sexual behaviors and lifestyles historically stigmatized.

Our proposal will describe and analyze life with one or both pathologies, emphasizing the synergy of stigmas, the different ways social discrimination is manifested (directly or indirectly, executed or anticipated, at different levels and spaces), and the learning or "expertise" processes acquired in order to live with the disease and deal with its negative social consequences.

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Background

During the 1980's in Argentina, HIV/AIDS was considered an epidemic that affected primarily homosexual men; in the 90's the main mean of transmission was through injected drug use. Today the panorama reflects a relative predominance between heterosexual contact and the other two categories. That's why we found that our research sample was infected through one of these different ways. In addition to some of the injection drug users (IDU) that got infected with Hepatitis C, there were others that got infected with the virus presumably by sexual contact, a blood transfusion, or by unknown reasons.

In this country, antiretroviral treatment is universally available but treatment for hepatitis is not widely guaranteed. In 1991 a law to protect people living with HIV was approved, making the fight against AIDS even stronger. It was a law that includes access to treatment at the public health sector. Two laws approved in 1994 and 1995 make HIV treatment coverage mandatory for both the public and private health insurances. This is why in 1997 when HAART² started in Argentina, we were one of the few middle class countries with universal health insurance coverage for HIV treatment. At the same time, during the last two decades of fighting against the epidemic, a true national social movement was built around HIV/AIDS issues and the most vulnerable population groups.

The situation of people living with HIV makes evident the social and political complexity that relies in discrimination and social acknowledgement, what we could name as "incoherence". During the 80's and early 90's, the law protected people living with HIV, even with positive discrimination measurements, while at the same time daily life discrimination -associated to HIV/AIDS and to other conditions related to (homo)sexuality and other lifestyles- was terribly obvious. In our study we couldn't verify hostile attitudes towards people living with HIV (for example homosexuals), even when in Argentina, like the rest of the world, those fears were exacerbated in the 80's. Furthermore, we could conclude that the epidemic, with all the pain that it brought, permitted a social learning in terms of acceptance and visibility of differences (Pecheny, 2002).

Theoretical Context

Stigmatization is a way of discriminating. Now, if the verb "to discriminate" is synonymous with "to distinguish" and "to differentiate", it is convenient to describe which forms of discrimination can be considered violations of the human rights. In those terms, we talk about social

discrimination when the State, society, a social group or individual separates, excludes, expels or kills a person or a specific group; when their dignity is attacked and when the exercise of their rights is taken away or denied just because that person or group is different.

Our analysis of HIV/AIDS, and Hepatitis C, regarding the homosexuals' social status and the use of drugs, demonstrates that discrimination isn't a standard phenomenon. We found that discrimination is exercised directly and indirectly. The latter applies when discrimination appears to be a universal rule or action, but it only negatively affects a specific group. We also found distinctions between exercised discrimination, and anticipated discrimination (when an individual anticipates a form of rejection and decides to conceal what ever the motive of discrimination might be).

Among people living with HIV, indirect and anticipated discrimination seem to be more common forms of discrimination than directly and exercised discrimination. But their effects are not less brutal for those affected (Green, 1995). The absence of discrimination doesn't mean that differences should be concealed, or ignored; it is about the recognition of the difference and allowing of its manifestations from the State and the society in general. That is why we emphasize the conceptual difference between social discrimination and social acknowledgement (Habermas, 1985; Pecheny, 2001; Taylor, 1995). Discrimination and acknowledgement have different ways of manifestation depending on the social contexts. In a public/collective level, there is no homogeneity between legislation, public policies, media's point of view, and situations in the workplace, the family, and in peer groups. In a subjective individual level rarely there is coherence between values, discourses and practices. It is very important to assess the different levels in order to get a wide idea on how they work together.

Finally, social discrimination can be analyzed according to political, cognitive, and normative (related to human rights) dimensions. The power dimension is part of discrimination, defined as a specific social subordination relationship. The cognitive dimension exists if there is a distortion or a more or less systematic negative construction of the discriminated group image. The normative dimension intervenes to crystallize and question discrimination relationships. It is necessary to deal with the interaction of these three dimensions in any type of empirical analysis. In that sense, social acknowledgement implies that groups or individuals could increase their relative power, build new images and social recognitions, and modify their legal and normative status at the core of the society. This multiplicity of dimensions is reflected in the stigmatization process, a very particular form of social discrimination. As noted by Goffman (2001b) the stigmatized individual finds him/herself at the center of a territory where arguments and discourses are being debated, mostly about what they should be thinking about themselves and about their own identity.

² Highly Active Anti Retroviral Treatment – it is a combination of two or more medicines to reduce the HIV viral load.

If discrimination is basically a social phenomenon, the actions taken by the victims become part of the public and political sphere even more so. The fact of taking the concealed and stigmatized dimension of the identity to the public sphere, transforms the nature of stigmatization itself.

In the same way as discrimination, the fight for social acknowledgement can be seen at different levels: an individual level, an intermediate social and public level (family, significant others, colleagues...), a general social level, and in a state wide level. Discrimination and social acknowledgement operate at these different levels that determine a set of very diverse individual and social strategies (Pecheny, 2001; Terto, 2004).

Summarizing, the conceptual opposition of discrimination vs. social acknowledgement operates at different levels - depending to the different degrees of "publicity"- and implies political, cognitive and normative dimensions. To assess discrimination and stigmatization should include all these levels and dimensions.

This article focuses upon the experiences of stigma of people living with HIV/AIDS and/or Hepatitis C in Argentina, paying attention to the process of dealing with information regarding their stigma. Our theoretical framework comes from Erving Goffman (2001a) and his distinctions between stigmatized individuals that suppose their difference is well known or obvious to others (the discredited); and those who believe their difference is almost imperceptible to others (the discreditable). In this case the problem is dealing with concealed information that could make the *self* discreditable to others.

This work is about the stigmas that affect people and make them discreditable, and how they overcome the challenges of dealing with the information concerning those stigmas: living with HIV/AIDS, and/or Hepatitis C, the practice or identity of their homosexual sexuality, and/or past and present drug use. The condition of discreditable of this people permits different ways of dealing with information depending on who's who, the context, and time. This "dealing with" is usually very structured, and makes the person's daily life to be out in the open.

It becomes important at this point to ask ourselves: who can be seen as a possible communicator or concealer of these stigmas? What are the coincidences and the differences of each case (HIV and/or Hepatitis C, homosexuality, drug use)? The answer to these questions will help us to examine other types of stigmas. Recent studies have analyzed how HIV stigma is built upon other bigger stigmas like homosexuality or drug use (Kornblit, 2000; Manzelli & Pecheny, 2002; Parker & Aggleton, 2002; Varas Díaz, Serrano García & Toro Alfonso, 2004). In our study we will describe how these combinations of stigmas have repercussions in the "patient role" (diagnoses and treatments), and in their daily lives.

Method

The main objective of this study is to understand the daily lives and the ways people living with HIV/AIDS and/or hepatitis deal with their lives. We used qualitative methodology and the instrument to gather information was the semi-structured interview. Our population was adults from both sexes, HIV positives, positive to HCV (Hepatitis C Virus), or with both infections, that lived in the metropolitan area of Buenos Aires, Argentina. We also interviewed health professionals in the private, social security, and public health services sector, in the same metropolitan area. Interviews were recorded, with the interviewees consent, and a written survey was completed during the interviews (adapted from Pierret, 1998). The interviews were set as a one-time meeting of an approximate length of about an hour and a half. The written survey filled out during the interviews helped us to make a quick analysis of the interviewees' basic socio-demographic characteristics, and it also guided us through the transcription process.

We selected our sample directly not randomly, since our study did not seek statistical representation. The criteria to determine the size of our sample were: relevancy, theoretical purposes, and theoretical saturation (Glaser & Strauss, 1967). The relevancy criteria entails selecting interviewees that could widen the heterogeneity range seeking to find new categories of analysis that could also guide us in the search for new cases. The number of interviewees needed reflected the heterogeneity or homogeneity of the group. The theoretical purpose defined the initial criteria of our intentional sampling which came from previous information gathered from theoretical debates regarding the topic. From that framework we defined each group according to the relevant "theoretical" characteristics of the interviewees. In the case of people living with HIV and/or Hepatitis C, the criteria were: type of infection, mean of infection, gender, and age. In the case of health professionals the criteria were: medical specialty, and health sector they worked at (public or private). We selected a number of interviewees that would allow us to make comparisons between them. The "theoretical saturation" of the sample depended on whether or not we could find anything new about relevant dimensions, and this in turn depended on the complexity of the dimensions that were being analyzed (Glaser & Strauss, 1967).

The sample of people living with HIV and/or HCV consisted of 27 interviewees and the sample of health professionals of 20. Of the people infected with either virus 13 of them were only HIV positive, 5 were only HCV positive, and 9 of them had both. From the interviewees, 8 got the virus from injected drug use, 11 through unprotected heterosexual sex, 7 through unprotected sexual relationships with other men (MSM), and one of the interviewees got infected with HCV from a blood transfusion.

Sixteen of the interviewees were men, with an average age of 34 years. All but one of the interviewees knew of his infection before 1987, the rest got their diagnoses in the 90's although they could have been infected in the previous decade. Some of them had developed different degrees of the illness, while others had not. None of the interviewees were hospitalized at the moment of the interview.

In the health professional's sample of 20 interviews: 8 were infectious diseases specialists, 7 hematologist physicians, 3 nurses, and 2 female pharmacists. From the total sample, 4 worked exclusively in the private sector; the other 16 were from the public sector. Still, most of the interviewees declared to alternate from public to private even when they belonged mainly to the public sector. All of the interviewed nurses (2 male, 1 female) worked in the public sector. Both female pharmacists worked in the public sector.

Our first contact with people living with HIV or/and HCV was through health services, civil organizations (of people living with HIV, gay groups, and former or current IDU), we also used a snowball technique to complete our sample. To initially contact health professionals we went to health centers following leads and suggestions from people living with one or both viruses.

We followed strict ethical considerations in a study with these characteristics (Lee, 1993; Macklin, 2001). Participation was voluntary, and their consent was sought after we explained the objective of the study. Confidentiality was guaranteed for all the information obtained through the interviews. The interviewees were informed about the availability of the information they gave if they wanted to know. At the end of the interview they were given time to ask any question they might have about the interview or if they needed any other information themselves. They were given the contact information of the principal investigator in case they needed to make any further consultations. To analyze the data we used a grounded *theory* approach (Glaser & Strauss, 1967) in order to access the universe of meanings³.

³ In this work we decided to use some concepts of theories that seemed useful at the moment of the analysis of our research problem. However, we must clarify that this study was not designed following only one way of addressing the problem (on the issue of analysis, coding, and interpretation of qualitative data see Strauss, 1987; Dey, 1993; Bryman & Burgess, 1994; Denzin & Lincoln, 1998; and an application in Jones, Manzelli, & Pecheny 2004). In this sense we agree that qualitative research can be seen as a *bricolage* and the researcher as a *bricoleur* (Nelson, Treichler, & Grossberg, 1992). The qualitative researcher as a *bricoleur* conscientiously uses the tools of his methodological work unfolding any available strategy, methods or empirical materials. From this point of view the combination of multiple methods, empirical material, perspectives, and focused observers in a singular theme should be understood as a strategy that adds rigor, broadness, and depth to the researcher's work (Denzin & Lincoln, 1994).

Results

Some of the results related to stigma associated to HIV/AIDS and Hepatitis C, as well as those related to homosexuality and the drug use are presented as follow.

HIV/AIDS and Hepatitis C

If we consider HIV/AIDS and Hepatitis C as individual and collective experiences, with meanings that should be contextualized accordingly to the lifestyles of the subjects (Grimberg, 2002), the moment of diagnosis is very important. A diagnosis implies, from the physician's perspective, a definition of what the illness is, a definition that is embedded in the previous knowledge the patient might or might not possess. In that sense, almost every one of the interviewees had very ample knowledge of what AIDS was, at the moment of their diagnosis. Meanwhile, almost none of them had any knowledge about what Hepatitis C was. Any illness diagnosis allows the possibility to identify it, certify it, and normalize it, establishing certain limits where cure and death are the extreme ends of the horizon. Now, in the cases we are analyzing, not only the horizon is uncertain, but the limits are blurry: neither for AIDS nor chronic Hepatitis C there is a cure, and the "survival" time is undetermined (until recently, a more or less accurate "survival" time was established after an AIDS diagnosis was given out, this was modified with treatment cocktails).

Furthermore, the diagnosis constitutes a milestone, a starting point for a personal situation in which the individual must learn to live with a virus that modern medicine has been unable to eliminate. A diagnosis works like a "before & after" (Pierret, 1998, p. 6). In addition, the ability to analyze the amount of antibodies infected with HIV has allowed physicians to make a specific category diagnosis: seropositive. The moment of the diagnosis is crucial in the biography of individuals affected by HIV, since it does not constitute a mere medical diagnose; it will define also the person's identity. With Hepatitis C, the self identification in relation to the virus is also common, but with two main differences: first, it is less strong than those living with HIV (some people said "such and such *is* HIV", or "I was not aware I *was* HIV"); and second, it is true for people that don't have both pathologies, when they are positive to both virus it all becomes part of the HIV/AIDS diagnosis, and Hepatitis C seems not to have any weight at all in determining someone's identity, neither from the point of view of the infected person nor from the people surrounding them.

The people with a positive diagnosis are challenged with whether or not to tell everybody about their test results. Why is this a challenge? First and foremost, because a positive diagnosis implies a series of changes, the reorganization of daily life and, redefinitions of identity and relationships with others, all of this alters life as they knew it. Second, because particularly in the case of AIDS, to our

society and to those affected by it, a positive diagnosis is linked to a series of meanings over toned with morality, death, homosexuality, promiscuity, and hazardousness. Third, because people living with HIV that do not possess visible marks of the illness, have the capacity of simulation, and concealment that makes them discreditable subjects.

In the case of our interviewees with both infections, they first came to know about their infection with HIV, and then in subsequent tests they found out about their infection with HCV. This has to do with the invisibility of Hepatitis C up until now. Most of our interviewees knew about having the HCV virus when they were already in treatment for HIV. The only interviewee that came to know about both diagnoses at the same time was a woman that went into rehab for drug use. Most of our interviewees were informed about their diagnosis being by themselves; only 4 of them went to get the results with a friend or their significant other. On one hand we have the situation of an HIV diagnosis in which the first reaction is to think about death and in which access to information about the illness and its treatment is an encouragement and a possibility of suggesting a new life project that allows the patients to keep about with their daily normal life. On the other, an Hepatitis C diagnosis first reaction is astonishment, or open ignorance, since accessing information about the virus and its treatment gives a wide identification of the real dimensions of the illness, that leads to despair. These reactions to diagnosis are closely related with the degree of foreseeability of the infection, and with the impact of knowing what a positive diagnosis could have in someone's biography. In terms of access to information, non-governmental organizations (NGO's) seem to be a resource for some gay and IDU on the sample, but not for the rest of the interviewees.

Hepatitis C can represent extreme changes in someone's daily life, but usually it doesn't have visible marks, which allows the person living with it to control the information about it. In comparison to HIV/AIDS, there are no social images related to Hepatitis C. Before knowing of their positive diagnose to HCV, our interviewees didn't know about its existence, or what it implied.

In the cases of people infected with both viruses, HIV/AIDS was paid more attention to and there were more worries about it. Hepatitis C was relegated to a second place. Furthermore, if the patient was in a process of drug detoxification, Hepatitis C could be placed in a third level of importance. At this moment we asked ourselves what were the reasons for this phenomenon? Either it was because of self experiences in terms of body reactions to the illness, or for the individual or collective perception of the seriousness of the virus or its real pathologies. At the same time we asked, if this could be explained in biomedical terms, and in terms of its symbolical construction.

Back to HIV/AIDS, a good indicator of the wideness and complexity of the dimensions affected by stigmatization represents exactly what happens in the process of

communicating or revealing the serological status of a person. As noted by Varas Diaz et al. (2004, p. 113), if stigmatization wasn't a serious problem, revealing a serological status would be equal to the diagnosis process of any other illnesses to which there are less negative metaphors in society. These authors analyzed the process of communicating the serological status which stands as a crucial moment in which social interaction can be perceived as stigmatizing. As part of the dealing process that implies living with the virus, a very important dimension has to be addressed: how to deal with the information. That is why we asked our interviewees if their "significant other" knew they were living with an HIV positive person, and how they came to know that information. These questions dealing with the notion that family, workplace, faculty, partners or possible partners, among others, constitute crucial contexts in the stigmatization processes.

Regardless of the interviewee's gender, the mother and friends were preferred and trusted with the information of a positive diagnosis to HIV. Fathers, work and faculty companions were mentioned in second place. The situation with partners or significant others was very important. Efficient and/or expected reactions from partners of people living with HIV/AIDS determined not only the quality of life and their mood, but also their propensity to engage in risky or healthy behaviors. In terms of whether or not to trust their partners with their diagnosis information, our study coincided with Green and Sobo (2002) where the nature of the relationship was central to decide this question. Our interviewees trusted their partners with their serological status if they were a stable couple. Sharing this kind of information was not that frequent with occasional sex partners. Some thought it was not convenient to share the fact that they were living with HIV during the first dates or sexual encounters. Meanwhile, others stated it was very important in order to decide whether or not to start a serious relationship. Several of our interviewees said they had sexual relationship usually with other HIV positive persons, which apparently made the sharing of their serological status much easier.

The criteria to share their serological status differed widely among those living with HIV. Different strategies were developed depending with whom they were sharing the information. In terms of their significant other the criteria was: length of the relationship or the amount of sexual encounters, the serological status of the other, the expected reaction from the other, the tests (to prove to the other that it is possible not to get infected), and the type of relationship that had been constructed. All these elements were interconnected, and they might have been, or not, present in all relationship, and have different relevance for each case. Our interviewees accepted there was some kind of secrecy around their serological status, and were conscious

of the strategy of “feeling out” or “sizing up” the other in order to decide whether or not to share their information.

The interviewees stated that one of the reasons not to say what was happening to them was because they thought it was unnecessary (“not to those it is unnecessary for them to know”) or useless (“it has no use for me that they know”), simply because they are not interested in sharing it with others, because they are afraid of being excluded or rejected, and/or to prevent pain to others or to avoid family conflicts. These criteria on whether or not to share information were very well delimited by two motives. In one hand, there was the latent risk of being stigmatized, particularly for homosexuals and IDU’s, since, still today, AIDS represents a powerful social stigma embedded into wider social rejections, like homophobia, or discrimination and branding toward drugs users, specially those who inject themselves. In those terms, many homosexuals and IDU’s perceived themselves as a devalued group inside another devalued group. Besides the stigma of living with HIV or/and Hepatitis C, both groups carried the weight of having to be visualized as responsible or guilty of getting infected by some sectors of society, other people living with HIV, or even by their own family members.

There were other reasons for a person living with HIV not to share his/her information with others. These included: to avoid pity from others, to try to keep daily routines, or to avoid potential discriminatory situations. There was a particular case in which a mother did not tell her son or his school officials, because she knew about other non-infected kids that were discriminated against because their parents were infected. Most mothers living with HIV perceived discrimination against their children as worse than discrimination against themselves. These situations make evident what Goffman underlined before us; there is a tendency to pass on stigma from the stigmatized individual to their closest relationships with others.

There was fear of being discriminated at the workplace because one was living with HIV. This entailed loosing respect at work (“being looked at differently”), having others treat you differently which implies pity, or being the object of jokes or suspicion (of being homosexual and that’s why he got infected with HIV), to simply fear of getting fired. People living with HIV also avoided talking about the matter with people outside their own support network, or that were not familiar with the subject because they believe those people could not be useful at all, and also they did not know what reaction to expect since in most cases they had never talked about it with any of them. In order to decide whom to talk to first about the diagnosis, some mentioned the closest person at the moment (the one that went with them to pick up the results, or the one who waited at home when they got back). It was obvious the need for a buffer zone to handle the impact and the weight of getting a positive

diagnosis, and/or warn people around them in case something happened to them (like getting very sick, or even dying). The also mentioned it to a person from their family (usually the mother), that could have a strategic role in dealing with the information. Generally, a person living with HIV only shared the information of his/her serological status with their most intimate people, or with those who he/she believe were strictly necessary or useful.

In the cases of those infected with both viruses, people tended to focus less on Hepatitis C than on HIV. This was evident for both the patient and people around them. First, for the person infected, the most important information in terms of diagnosis was the one related to HIV, and it was in the reactions to this information where all the fears and expectations were based. Consonant to this, and in second place, people living with HIV perceived that communicating that they were *also* living with HCV was a fact of less importance, because of the relative small space that it occupied in their lives, and also because of its social “insignificancy” in comparison to the charged meanings of AIDS (“a lot of people don’t even know what C means”). Finally, when both diagnoses were communicated at the same time, the emphasis of those listening was on HIV, leaving Hepatitis C at a second place of importance. Those with only a diagnosis of HCV seemed to have less problems sharing the information, although they accepted they concealed the information from their smaller children (just as people living with HIV, or with both viruses). To see the difference between sharing information about being infected by one virus or the other, it is useful to hear Nestor’s testimony (former-IDU, HCV+, HIV-):

“I know that when I start the treatment (for hepatitis) I will have physical symptoms, like bags under my eyes, I wouldn’t be able to be in the same places I was before, in this case it is better for me to tell everyone, if not the fantasy would grow and they will start saying anything like that I am HIV...and between the social burden that would imply that everyone believed I have HIV, and them knowing that I have Hepatitis C, I rather choose the less harmful, I am still thinking about it.”

What happens after making the decision of sharing the status information, and it is actually communicated? The reaction towards a positive diagnosis was conditioned by the type of relationship between the HIV positive person and the person listening to the information, and the way this information was shared. How these reactions were perceived are key elements in the biography of our interviewees. For them, the positive or negative reactions of their families were more important than the reactions of friends and work companions. After sharing the information, the patient usually received a supportive response from nuclear family members (parents, siblings) and /or it made relationships even better. In contrast, there were some cases in which there was indifference from a family member,

generally when the person living with HIV didn't cleanse their family situation. This is the case when the family knows (generally father and mother) but they "don't get involved", keeping the information silenced, for example.

After sharing the information about HIV with a wide circle of people, some situations associated to discrimination (not getting jobs, close people that left the circle because they didn't know how to deal with the information, difficulties seeing extended family members like nephews, and feeling alone) lead to not wanting to keep sharing the information of them living with HIV to an even larger group of people.

In the specific case of the IDU, when the condition was known (especially HIV) the issue was well discussed. In most cases, they talked about how they got infected, although some family members preferred not to talk about it. In another cases, the HIV diagnosis made the parents to take care of something they knew but were trying to conceal: their son was an injection drug user. This family at first reacted with a lot of reproach for the kind of life he had lived that ended in HIV. Another woman was reproached by her significant other when she communicated her serological status (he got tested and was positive) resulting in separation when she got blamed of infecting him.

Homosexuality

As part of our sample, we interviewed men that had sex with men that identify themselves as homosexuals. In Argentina, like everywhere else, homosexuality constitutes a motive of stigmatization, discrimination, and exclusion. Because homosexuality is not necessarily a visible trait, individuals tend to control the information concerning their sexuality. In a discriminatory context, the capacity to control the information is a way of protection. This source of stigma was not usually shared with the main socialization circle (family, childhood and teenage friends), this is why a teenager discovering his desire towards persons of the same sex won't find support in that immediate circle, and eventually would find rejection from that same circle. In a smaller scale, that interaction lived as a conflict remained throughout the whole life. It was an interaction that is characterized by tension (and relieve) of keeping a secret, or letting everybody know, and to live it more or less publicly (Pecheny, 2003).

Generally, coming out is a selective action. In terms of coming out to their families, the anticipated discrimination (the one that the individual feels can be exposed to) appeared to be stronger than the real or effectively executed discrimination. This anticipated discrimination worked strongly regarding the father figure. None of our interviewees had told their fathers. Other participants said they did not tell their brothers or sisters, with the intention of preventing them, and themselves, of pain and conflict. For the family, knowing a sibling was gay would be a source of pain. To the interviewee, pain would come from rejection after the confession. Furthermore, the interviewees

mention how inappropriate it was to tell them at certain moments, leaving open the possibility to tell them later on. Sometimes, HIV infection played a forced revealing role.

In most of the cases where they came out to their families, the attitude of the nuclear family was of acceptance and communication. This occurred mainly with the mother and siblings; generally the father was not included. In terms of the rest of the family's reaction, our interviewees mentioned acceptance as an attitude, and in the worst cases a "silenced" acceptance of their homosexuality. There was an apparent better acceptance when our interviewees decide to break out the secret of their homosexuality to their family members, instead of them finding out through a third party.

Most of the participants mentioned that all of their friends (gay or not gay) knew about their sexual preference, and that they were the only ones with whom they could talk about homosexuality, even when their friends were not gay. To some, the fact that someone might know about and accept their sexual orientation was fundamental to consider them as friends. When asked about work or school companions, our interviewees shared their sexual preference with a few people using the criteria of closeness and depth in the relationship. Those who knew usually accepted them and talked about it. At the end, "society" or "undetermined others" were perceived as "discriminatory" or "ignorant".

Finally, we should mention that in Argentina also, to fight the AIDS epidemic, the gay community was fundamental in building up material and affective support networks for people living with the virus –including the non-homosexual.

Drug Use

In Argentina there is a strong legislation that forbids the use and possession of a series of drugs, and there is also a high degree of discrimination against those who use them, especially injection drugs. Even among drugs users there is a depictive mark towards those who dare inject themselves with drugs. They are called "pinchetos" (junkies or shooters). In order to avoid rejection or discrimination from their parents, users tend to not talk about drugs with their family; most probably IDU's will distance themselves from their family and develop a stronger bond with their peers with whom they share the same drug use habit. In the majority of our interviews it came across that their family knew about their drug consumption. When the users had children, they knew about their parents past habits (assuming this as a past habit indeed, usually linked to the notion that they had been in treatment). The nuclear family usually rejected the consumption habit with attitudes that ranged from "pissed off" or "worry" to "pain". In any case, they would try to make or force the user to get into some type of rehabilitation treatment.

A very particular group is the so called "consumption friends", that for obvious reasons know about the habit,

will talk about it, accept it and understand it. They are referred to in past tense, and in some cases with a discourse that would not judge them but still describe them in negative terms. This was a way to “avoid” those who were still consuming drugs and distancing themselves from the group, to “change paths”. Some members of this group became an important network of support, especially for rehabilitating drug users and/or people living with HIV and/or Hepatitis C, just because they shared the experience of rejection from others due to their past life of drug consumption and “out of control” behavior. From this group they emerge not only friends, but also potential life partners with a drug consumption past, or HIV. These network of users and former users – just like the networks of gay people – became an important tool to make life easier for people living with HIV: to gain access to support groups, information and more amicable health professional, and to get practical advice. Furthermore, in the drug users case –just like for gays– the personal diagnosis of HIV/AIDS and Hepatitis C – different from the gays– was not a surprise, since all of them had loved ones or member of their close circles that were infected, sick, or had died from either HIV or Hepatitis.

In the workplace generally the information about drug use was not communicated to others, except in work environments related to rehabilitation (addictions counselors, the director of an institution that worked with addicts, and a person that worked in HIV prevention). It was very unusual to share their past as drug users. In a few cases it was shared with just a few close people or a trustworthy person (very similar to homosexuality), although there was not enough information about the criteria to decide to share it or not. In some cases there was a suspicion that their co-workers already knew of their past with drugs.

Finally, there was not enough information or significant patterns that could clarify what happened in terms of sharing information with their significant other. Some of our interviewees had partners while others did not. Some couples shared their habits, or they got to know their partners in the new network of socialization. Sometimes the information was shared with those who appeared in the post addiction time. Sometimes just part of the information was shared (like the fact they injected drugs). An HIV diagnosis could trigger the communication about having been an injection drug user.

People Living with HIV/AIDS and/or Hepatitis C as Patients

A diagnosis and a life with a chronic illness had a great impact in every aspect of the daily lives of people, depending on the type of pathology (Hepatitis C, AIDS) and also depending on the previous or present support networks, usually linked to those same pathologies. Most of our

interviewees mentioned they could count on a family member in terms of who was by their side in moments when they needed to talk about personal things, or when they needed any type of help to deal with the illness. This bond was in constant transformation during the life of the interviewee when dealing with the infection/illness. In some cases, the interviewees could not find support from a close family member. Some participants with a past of drug use mentioned that the infection did not change the dynamics of their families towards them. They recalled their relationship with their family as problematic anyhow. These individuals then tried to find support in friends and professionals. Close friends were identified as very important support networks at the moment of looking for emotional help, in other instances of dealing with the illness, and when they just “need to be listened”. Most of our participants said they were emotionally supported, but in few cases they mentioned receiving any material support.

The stigma that comes along with an illness considered “deadly” or “terminal” carries with it the person’s obliteration of their future, and the inability to foresee long term projects (Davis, 1997). When asked about this, our interviewees stated the following typical experiences. First, projects were perceived as professional/work ventures, mainly about economical stabilization: start/end careers or studies, continue growing as professionals, buy a new apartment, go back to school, and get/keep a job. Particularly, they mentioned the difficulties in terms of the pre-hiring tests – or inversely – to be denied access to public health services if they decide to get a job. Second, suspended projects, or projects that before were considered impossible to achieve, reappeared such as getting and keeping a partner and having children. This last statement surprised us at the beginning of the interviews but we found it was a repeated fact in our following interviews and in other studies about people living with HIV. They felt fine and they explicitly talked about life giving them a “second chance”. This “second chance” was perceived even when they were totally conscious of the risk of prenatal infection, or to pass the virus to their HIV negative girlfriend, as in one of our case studies. Third, and this only refers to HIV/AIDS (not Hepatitis C), homosexuality, and drugs use, some of our interviewees stated that after they received the impact of their diagnosis, they had readjusted their lives, and they even found a way of socio-professional reinsertion in fields related to their pathologies: training and work as operators of self-help telephone lines, as voluntaries, militants, in NGO’s, and in health services. Finally, there were the escaping projects: leaving the country in search of better treatments, and radical changes that would give meaning to their lives. Escaping projects were found in the testimonies of four interviewees.

Health Professionals and People Living with HIV and/or Hepatitis C

When analyzing the role HIV/AIDS and/or Hepatitis C stigma according to the experiences with health professionals working with people living with these infections, we should take into consideration at least two elements: the position of physicians in the stigmatization process, and their role as stigmatizing subjects. The important role of health services professionals has been studied by Goffman: "physicians are the best ones to inform patients of their future situation" (Goffman, 1998, p. 49). Physicians are the first persons to demonstrate to patients how stigmatized they will become to the rest of the society (because of the infection). The diagnosis is usually announced by a physician, and becomes a central social event in the definition of stigma. From this moment on, the individual will become a chronic illness patient, and together with the acquisition of strategies to deal with the infection (regular tests, treatments, dealing with the health system) they will also develop abilities to continue with their daily lives (information control techniques, secret management, and in some cases public/political positioning).

To most of the patients getting to know their diagnosis, the bond between them and their doctor is crucial to understand the social meanings of the infection. In these cases doctors and other health professionals are the only persons with the knowledge about how to deal with stigma. The social learning, with exclusive guidance of the doctor/health professional, will coexist later on with bonds made through out the process with other people living with the illness, with other types of health services (changing the physician), and in some cases with family or friends support networks (depending on how the patient is managing information). This widening of the links that connect the patient with the social meanings of having the infection is part of the very important expertise process, described later.

The health professional interviewed mentioned how patients with HIV and/or Hepatitis C tended to protect themselves through secrecy or by telling half truths. This harmonizes with the slow pace at which information is released. In a lot of cases, patients with both viruses, use Hepatitis C to conceal HIV, as a way of protecting themselves with a disease that it is not as stigmatized by society. Since Hepatitis C has a lesser social weight than HIV, the moment of communicating the infection to family members was simpler. As a result, fewer possibilities of rejection were expected, making the concealment of information less important.

The majority of the interviewed health professionals associated the diffusion of the information with the "quality" of the patients' social surroundings. From this perspective, it is more probable that the patients shared their information with closer people with who they could open up, people they trusted and from whom did not expect discriminatory attitudes, or because they were experiencing the same

situation themselves: living with one or both viruses. As a result, according to the interviewed health professionals, the majority of the patients first told their significant other, who in most cases was also living with one or both viruses. They shared this information if they were a steady couple, if they felt they could trust them about what was happening in their lives. At the same time their significant others were the only ones the doctors pressured the patient to tell for reasons of risk of contagion. Meanwhile, in terms of revealing the diagnosis to anybody else, our interviewees thought it was a patient's personal choice, since it was part of their private lives.

Many times, fear of discrimination lead the patients to not reveal their infection to anybody, fearing they might be excluded, or even fearing losing their jobs. Not revealing this information to other significant social relations made the physician and health professionals the only ones they talked about the infection (sharing this exclusivity with the media and any other information about the virus they can find by themselves). This entailed a very restricted social learning about the meanings of the infection in our society. In the other hand, to reveal the information can get the patient access to a series of social interactions that we had described.

As health professionals and specialists in the treatment of these illnesses, they become part of the social space (in a more or less organized way) of people living with the infections. They become part of the patient's social surroundings as empathic figures (people that know "how it feels") (Goffman, 1994). In many cases, this empathic figure role leaves the scene at the moment of closing the health center, but in many other cases their insertion in the social space of people living with these illnesses is framed in their "commitment with the cause", getting involved not only with the clinical treatments, but also with the life conditions and sustainability of their patients. In some occasions, and in extremes cases, this commitment can make health professionals assume the "representation" of the patients. In any case, the insertion of these professionals from a general medical field, occurs after their participation in the social space configured by people living with the illness, so to speak, they embodied another social space configured by specialist in HIV and/or HCV, and then the rest of the paraphernalia it involves (congresses, journals, publications, researches, clinical essays, travels, economical profit, professional links).

A second element to consider when analyzing the role of stigma associated to these illnesses among health professionals is their role as stigmatizing subjects. In our study, we found that few health professionals and health center employees had direct stigmatizing attitudes towards those living with one or both viruses. The stigmatization process was built, as we pointed out before, over other social stigmas like those regarding behavior practices that

were considered risky (IDU's), sexual identities (gays, transgenders), and lifestyles. Previous studies in Argentina (Grimberg, 2002; Komblit, Giménez, Méndez Diz, Petracci, & Vujosevich, 1997) have also found that the construction of HIV/AIDS from a biomedical perspective in the health system has created stigmatizing categories, linked to groups and practices perceived as "risky" (homo/bisexuality, drugs use, sex work) categories that would appear as responsible of the emergence and diffusion of the illness. This marks the appearance of a scale of values in which drugs users—especially injection drug users—were the most stigmatized by the health system, followed by transgenders, and men who have sex with men. This leaves heterosexual patients that do not use drugs and that might get infected with HIV or Hepatitis C by sexual contact or by a blood transfusion at the other extreme of the scale. This is the testimony of a female infectious diseases physician:

"Drugs addicts are like the worst in the health system... I am telling you what doctors say: "Dude, the junkie is yours, you see him". Who's next? Transgenders come next in the scale, generally they come in group, they make noise... they revolutionize the waiting room because they are treated in the men's ward but they are girls... girls that want to be treated in the women's ward. It is a festival dance over there, a brothel.... Then you come up in the scale if you're gay."

Interviewer: -"There is also rejection towards gays?"
"Yes"

Interviewer: -"So, we can say that it is ideal to be heterosexual and not use drugs to go get health services?"

"That's the way they teach you at medicine school, the faculty is very conservative."

It was interesting to make synchronic analysis on each and every one of the interviews and to find how some health professionals can detect discriminatory attitudes in other professionals, not realizing their own discourses are also contaminated with the same attitudes.

Analyzing the testimonies from health professionals and health center employees, we found differences in treatment and conception of the patients living with HIV/AIDS and those only infected with Hepatitis C. Our interviewees didn't talk that much about Hepatitis C, giving priority to comments related to HIV/AIDS. This silence is evidence of a double invisibility, first they don't talk about the C virus, and secondly they don't realize they don't talk about it. In other words, there is a double movement by which the importance of a chronic illness (of increasing epidemiology relevance like Hepatitis C) is denied in the biomedical environment. When asked about HIV/AIDS—an illness they are constantly talking about—some health professionals manifested that even when it was true that patients were treated better than before, there was greater discrimination and prejudice against them than against people living only with Hepatitis C.

In terms of secrecy and/or publicity of issues as patient's homosexuality and drug use, most of the participants demonstrated being uncomfortable and said that these issues were part of the patient's private life which regularly came up at the physician interview, but generally was not addressed directly. This may cause problems because the fact that a patient is gay might be related to specific diseases, so if the physician does not know about the patient's sexual activities he would not be able to prevent or to early diagnosis these diseases. Drug users could have a similar situation because if the primary physician ignores these practices there could be inconveniences for Hepatitis C patients.

In terms of the stigma related to other individual characteristics, we found that most of the interviewees perceived IDU's as difficult patients, aggressive, and causing trouble for health professionals. Some stated that they need help treating these patients so they could deal exclusively with the clinical issues and they understood that the patient's drug use presented other challenges. Drug users were seen as "bad patients" that do not adhere to treatment and cannot commit to a long term treatment. The patient's disobedience was perceived as a challenge to their authority. This negative perception was presented by the participants regarding their colleagues and themselves. They showed a desire to help patients quit drug use but the generalized attitude was rejection of drug users and a profound ignorance about people who engage in these practices.

For health professionals these patients had difficulties adhering to the treatment regimen which made them fail the treatment making more obscure their future perspectives (Pecheny, 2004). However, analyzing the interviews of participants living in drug abuse situations we found self-care strategies and care for others, which made possible their adherence to treatment. The interviews also presented a clear difference between types of drug used.

There were not definitive positions of rejection towards homosexuals as there were for drug users. It was clear that the politically correct discourse was not to discriminate against homosexuals, so none of the participants openly acknowledged rejection for this population. Even though most stated that they did not feel rejection among other professionals, a considerable group did identify rejection from colleagues. Contrary to the perception of IDU's, homosexual patients were perceived as good patients, complying with treatment, responsible, and with a positive attitude towards the fact of living with the disease. This demonstrates that complying with treatment norms is a key element in the construction of good and bad patients; norms that are not established by the patients and that reflect the authority of professionals.

Homosexuality, as long as it was not explicit, did not bother physicians who could talk to their patients in a neutral way without directly addressing the issue. Some female

physicians recognized that beyond the argument of the private life of the patient, it was culturally difficult to address issues of sexuality, harder if it was prohibited. In this situation instead of addressing sexual practices, physicians talked in general terms about issues of transmission focusing exclusively on medical terms and prevention, excluding a social point of view.

Health professionals also had a negative view of transgenders. Professionals considered them to be conflictive patients, not only because of their behavior, but because of their sexual identity. When the "information" about their sexuality cannot be disguised, as in the case of transgenders, a tense situation at the physician's office and treatment centers was developed and professionals did not know how to react. The physician calls a patient for treatment with a male name and a female figure appears. Issues related to how to address these patients and where to place them for hospital treatment presented difficulties for health professionals. This situation confused them and made them react by making jokes and openly discriminating transgenders. It is important to state that even with this differentiation between homosexuals and transgenders, discrimination and stigmatization still persisted towards both groups among health professionals, regularly disguised by the need to show a politically correct attitude towards these populations. Transgenders appeared to be the highest group exposed to mocking which underlines the strong rejection against them that still exists in society.

In summary, by analyzing the role of stigma related to HIV/AIDS and/or Hepatitis C, as presented by health professionals treating people living with this conditions, we must take in consideration their role in the stigmatization process as their role as stigmatizing subjects. Health professionals in general presented a low predisposition to stigmatize their patients in basis of their disease, however stigma shifted to other behaviors, personal characteristics or life styles. This influenced the quality of care, and particularly patient's human rights.

Patients as Experts

Patient-doctor relation influences the "patient capital". This capital of information and autonomy is greater among those that come from or integrate themselves to social networks of people directly or indirectly affected by the disease, for example networks of gay people, former drug users or current users, and people living with the disease. The "expertization" of people living with a chronic disease is a phenomenon that we feel important to highlight. By this term we designate the process by which these patients acquire a determined level of knowledge, specifically in medical terms, that separates them from lay people; bringing them near to those with the legitimate knowledge in the matter, the professionals. This body of knowledge can be discursive (it can be express in words) or practical (the know-how).

As the field of the body of knowledge in HIV/AIDS and Hepatitis C is not homogenous and does not have all the answers, the knowledge of the patients becomes a legitimate

competitor with the state of the art knowledge. It is also possible to analyze up to what point the context of medical "not-knowing" and "no-power" delineated a type of patient-doctor relation characterized by asymmetry and less distance than traditionally attributed to this relation.

Being an expert basically implies an increase of knowledge of the disease by the one who suffers it. As we said, the people that we interviewed initially had some HIV/AIDS knowledge, more or less precise, more or less correct, at the same time that almost none knew what Hepatitis C was or its implications, generally confusing it with "common" Hepatitis A or B. This lack of knowledge changed immediately at the moment of diagnosis and knowledge increased through months and years of living with the disease. Knowing about the etiology and transmission modes allowed the person to formulate hypothesis on how and when they got the infection. Some people expressed knowing exactly how it was, others had a somewhat correct hypothesis, and some did not know because they could not identify in their life history any risky situation (particularly in Hepatitis C).

In the personal discourses of these people the issue of "how" was not presented with high concern at the moment of the interview maybe due to the time passed, their fatalism or as not to add guilt to an already difficult situation. By contrast, almost all participants expressed feeling that others did present them with questions about "how", which made social interaction difficult based on the stigmatizing supposition that there were "innocent victims" and people who "looked for it".

In the cases which occupies us here, the subjective way of living the disease in loneliness determined the relations with significant others and in different social spaces. In this sense the interviews showed the existence of a positive or negative feedback between the subjective living with the disease and the social link with others. In this way the normalization of the subjective impact goes hand and hand with the level of trust towards close people or, to the contrary, with "new" or unrelated people. They did this following a trial and error process: you develop trust in yourself, trust others; you evaluate how it was and this positively or negatively feedback the process. Most participants expressed having had fear in trusting information about their disease to others at the same time that they did not find rejecting attitudes, but some indifference, from family, friends, and colleagues.

The learning developed by these people about these diseases included several aspects related to symptoms, treatment, medication, medical terminology, clinical tests, reactions from others including health professionals, and developing the ability to access places or specialized professionals. Learning to read the signs provided by the body is one of the fundamental issues in these patients' trajectory. Learning to correctly read the signs and to act in

consequence is particularly critical for people living with HIV and Hepatitis C because of their undefined asymptomatic period and rollercoaster evolution of the infection. In both cases there are expected and feared signs that could predict serious complications and eventually rush decision making for the beginning or change of treatment modalities. Reading laboratory reports was one of the indispensable knowledge that patients acquired with time, which validated or rectified their corporal experience. The knowledge of treatments and regimens included information on medical terms, risk and side effects, and the technical ability to follow the treatment. Some participants that used to be drug users expressed their ability for drug injection applied to the use of injected treatment. At the same time others expressed that using injections for treatment reminded them of their previous cocaine use.

The knowledge on medications was related to the quality, its effects, counter indications, ingestion procedures, prices, and ways of acquiring them without having to pay. The use of medical terms was incorporated to their daily language, including among people or family who are generally outside the scope of the subject. Sometimes medical terms were reformulated and included in daily life, not always with fidelity to its medical origin or by ways of elliptic figures. For example, Susana (38 years, low income, HIV/HCV+) said:

"I have been undetectable for two years, I have 777 CD4... Cannot transmit the bug by sexual relations, I could transmit it by blood but not through sexual relations."

Evidently, the undetected are her antibodies or virus, not herself.

As we can see, an important issue is the anticipation of others' reactions, related to discrimination or support, including health professionals. Anticipation allowed determining to whom and how to trust the information about their infection or their children's. This knowledge was crucial and doubt and uncertainty constituted one of the major agents of anguish for people affected. For example, this happened to mothers of children in kindergarten or at a summer camp. In the same manner, people try their surroundings with the objective of knowing who will be of support. This trial and error provided valuable information that reduced uncertainty because "someone who suffers a chronic disease that 'waits too much' or 'makes too much demands' probably will be more rejected by others. This means that the person who is sick must continuously evaluate the possibility of expressing their demand to others" (Nettleton, 1995, p. 69). Subjects become experts in knowing people, environments, and more or less amicable relations in respect to their health condition which is crucial for the success of their treatment and for keeping their quality of life.

The ability to get access to treatment and medications is another essential knowledge to increase their quality of life. Studies on daily life of chronic patients show a trait found in our interviews in terms of the variable of time: the longer the

time living with the infection, less fear of developing the disease, less fear of near and inexorable death, and less uncertainty (Pierret 1998, p. 66).

It is interesting to note the relation between becoming an expert and the existence of networks of people living with the disease or peer networks (e.g. gay men, drugs users) at the same time that we examine the role of the non-governmental organizations (NGO). In this sense, we found mostly through the testimonies of gay men and some former drug users, that NOG's and self-help groups had an important role in their process of becoming experts and learning to live with the disease. This process was mostly identified from the initial diagnosis up to the normalization of their infection several months later. Becoming an expert was more evident in families with multiple people with the disease. We found several of these cases, for example one female participant mentioned that her partner, sister, brother in law, one of her children, and her brother's mother in law, all lived with HIV/AIDS or HIV/AIDS and Hepatitis C. Other cases showed partners living with the same disease either simultaneously or not.

Discussion

The participants established a hierarchy of motives for stigma in their rejection scale. Among former drug users what is most rejected was their previous drug use, secondly the fact of living with HIV/AIDS, and finally the Hepatitis C diagnosis. HIV was sometime perceived as a simple consequence of drug use and sometimes could be seen as positive in terms that HIV make them 'reach the bottom' and abandon another disease, drug addiction. In several cases Hepatitis C infection was seen as a lesser evil compared to HIV, as perceived by those with the co-infection or those only with Hepatitis because of the feeling of 'escaping the HIV even if they have been injecting'. The perspective of having HIV was different for gay men for whom homosexuality was not something to reject or regret. They acknowledged the stigma but did not blame themselves. For this reason, in their rejection scale the first (and probable, the only one) place was occupied by HIV.

Social and family discrimination due to AIDS, real or anticipated, had a notable effectiveness: the perception or fear of rejection from their social and emotional environment acted as a self-exclusion factor. The situation was more difficult when the revelation of serostatus came with the revelation of non-public behaviors, particularly homosexuality or drug use. In this line, several testimonies presented the fear of reactions due to lack of information ("they don't understand", "they discriminate", "they hurt you", "its shocking", etc.) and, in particular fear of discrimination from their personal environment (specially family) and "other undetermined" people for which the individual cared for ("the society").

Through out this paper we traced similarities, differences, and articulations in terms of the management of the

information on homosexual identity, being drug users, and living with HIV/AIDS and Hepatitis C. We analyzed these issues as non-evident traits of discreditable individuals, which allowed a relative concealment and fears of revealing their secrets. So much as these issues were motives for stigma; discreditable individuals would want to carefully conceal them from determinate people. "Even in the case that someone could keep a secret, a concealed stigma will reveal that social relations ratified in our society by mutual confession of concealed defects, will make them to reveal their situation to their close friends or to feel guilty if they don't" (Goffman, 2001a, p. 92). In our analysis the increments and the differentiated strategies, context and time, taking in consideration that the person who hides will pay attention to social situations that others assume without much care or special calculations (Goffman 2001a). Many of the different reactions between the communications of both issues come from the obvious differences that separate a sexual identity from a disease, although both may act as motives for stigma and are socially perceived as related.

Now, in terms of personal trajectories people living with HIV/AIDS usually changed from anger and fear, to fighting against the disease. This feeling of "being in charge" of their own lives generally implied a change in social network participation; change that provided for other personal ties in terms of management of the information about sexual orientation and living with HIV. This was so at least in two senses, first letting others know about their HIV infection status could contribute to revealing a more or less discreet life of homosexuality – revelation that would imply a redefinition of ties with others non-homosexuals, which could reaffirm friendships and family bonds or separate them. Second, for many homosexuals their HIV diagnosis led them to finally define their gay identity and to develop strong ties with peers and others living with HIV/AIDS.

The AIDS epidemic produced a forced 'coming out of the closet' for many homosexuals whose sexuality was protected by the limits of their intimate space. This individual phenomenon became a social issue because homosexuality since the AIDS epidemic became an everyday topic in the media and governmental instances. Paradoxically, the AIDS experience accelerated the inclusion of the subject of discrimination and the human rights of sexual minorities in the public scene, allowing a redefinition of the subordinate status of homosexuality as a stigmatized practice relegated to the private sphere of discretion.

However, this optimistic panorama with regards to occidental societies has its limits for many of our participants who had not modified their criteria for revelation of their information even after knowing their HIV diagnosis. Some fears (from family's failure to understand, to loss of employment capability) made them conceal their serologic status or their sexual identity. The origin of these fears is precisely the fact that the perception of society is that homosexuality and HIV/AIDS are mechanically linked.

Family, friends, labor, and sexual/affective relations of people living with HIV/AIDS were conditioned on a daily

basis by this control on the information (or secret) in a profoundly homophobic society, which rejects drug use and discriminates against HIV. As reminded by Gabroe (VIH+/HCV+):

"If there are people that I don't want by any means to know that I have HIV...? This is complicated, because many times I proposed myself to keep anonymous so it does not... it does not harm me that others know... because of the fear of discrimination, but it is stronger than me... and sometimes it comes out, you see. Because I... I am not ashamed that people know, really it does not bother me, if it bothers others it is their problem..."

As Goffman (2001a) states, if something from the past or present of the individual is discreditable, his precarious position seems to vary directly with the amount of people that are involved in the secret. As more know about the obscure side, more treacherous the situation will be (p. 96). The tension of the secret as a constitutive element of interpersonal relations acted as a life condition of the participants in our study. We tried here to elaborate only some of the consequences associated with such a tension in daily life in the expectations of other studies that could address and critically examine the tension of secret as a life condition for people living with HIV/AIDS.

This analysis makes us reflect on the different forms of the experience of the disease: in each individual and in the relation of each individual with his/her vision of the social image of their disease. In terms of AIDS, as more accepting is the individual vision (from himself or from what he perceives from society), the closer the HIV/AIDS experience comes to that of Hepatitis C, to the banality of daily live, and the authorization for future vital projects including having children. Inversely, the graver the perception of Hepatitis C, that is, the less it is associated to Hepatitis A, the stronger the vision of living with an infection becomes, and the experiences of uncertainty will be similar to those related to HIV/AIDS.

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Living with HIV in the Dominican Republic

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Abstract

This is a qualitative study based on the testimony of directors of organizations addressing HIV/AIDS and people living with HIV/AIDS in the Dominican Republic. Although the manifestations of stigma and discrimination related to HIV/AIDS have decreased in the Dominican Republic in comparison to past decades, ignorance and lack of supervision from government authorities foster that people with HIV do not receive adequate health services and the protection of their right to employment. Some groups are more affected than others as a product of the reinforcement of existing prejudices in the Dominican society, such as antihaitianism. Facing the changes in the spread of the epidemic I propose some reflections on gender and HIV, and suggest how to reinforce existing positive initiatives and the adoption of new ones.

Keywords: Acquired Immune Deficiency Syndrome; stigma; Dominican Republic.

Viviendo con VIH en la República Dominicana

Compendio

Este es un estudio de carácter cualitativo, basado en testimonios de dirigentes de instituciones dedicadas a la prevención del VIH y personas viviendo con VIH en la República Dominicana. Aunque la manifestación del estigma y discriminación ha mejorado en la República Dominicana respecto a décadas anteriores, la ignorancia junto con la falta de supervisión de las autoridades hace que a muchas personas portadoras se les prive todavía de la adecuada atención en salud y el derecho al empleo. Unos grupos son más afectados que otros como producto del reforzamiento de los prejuicios existentes en la sociedad dominicana, tales como el antihaitianismo. Ante los cambios de las vías de expansión de la epidemia planteo algunas reflexiones sobre género y VIH, y sugiero cómo reforzar las iniciativas positivas existentes y adoptar nuevas soluciones.

Palabras Clave: Síndrome de Inmunodeficiencia Adquirida; estigma; República Dominicana.

“The only way of accomplishing any progress is to substitute shame with solidarity, and fear with hope”
(Peter Tiot, UNAIDS, 2002)

In any effort being made to prevent the spread of HIV/AIDS it is evident that stigma and the associated discrimination are obstacles for prevention programs. The United Nation has stated so very clearly, when declaring that the third phase of the epidemic is indeed stigma and discrimination. In fact, this disease has undressed fears and prejudices society has concerning sexuality, pain, death, immigrants and poverty. Those fears are directly connected with ignorance about HIV and how it is spread. This ignorance makes people believe HIV carriers are a threat to society. Stigma is a way to identify and pointing out “threatening people” so they can be met with rejection, reclusion and elimination. Rejection has prevented HIV positive people from receiving basic rights, like health care and employment, so people with HIV hide their condition and stop going to health care centers and looking for jobs. HIV stigma and discrimination are a constant reason for

pain and sadness for HIV positive people and they contribute to silence, and as a consequence, the expansion of the epidemic.

Some Facts about the Dominican Republic

Dominican Republic shares two thirds of the island of Hispaniola with Haiti. It has a population of just a little more than 8 and a half million people, with an economy mainly based on tourism, duty free industries, and the money sent by Dominicans living outside the Island, for the most part in USA or Spain, an increasing population estimated in more than a million people. Even when the economy has had a notable growth in this past decade, superior to any other country in the region, the past ten years have also witnessed a huge banking sector crisis in which economic indicators have decreased, while inflation and unemployment increased (Rathe, Lora, & Rathe, 2004).

After Haiti, the Dominican Republic has the highest numbers in HIV prevalence in the Caribbean and Latin American region. According to the demographic and health survey of 2002 carried out by ENDESA (Spanish acronym for the Demographic and Health Survey), HIV prevalence is of 1% between the ages of 15-49. This percentage increases to 5% in populations living in *bateyes*, or sugar cane areas, generally a Dominican-Haitian zone. Geographically speaking, tourist oriented counties report higher numbers than others. The expansion of HIV has been increasing

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² This paper is based in research on HIV/AIDS stigma and discrimination conducted in the Dominican Republic by the author in 2004 for Family Health International/Project Conecta/USAID. It was translated by Verónica Toro Ruiz..

among women due to unprotected heterosexual contact. In 2003, retroviral therapy started very timidly with the support of international organizations like Global Found, the Clinton Foundation, and Columbia University. This effort has reached less than 400 persons, in comparison to the 8,000 persons who were supposed to start the treatment (Rathe et al., 2004). It is this scenario in which this study was carried out to explore manifestations of AIDS stigma from the perspective of key personnel in the HIV/AIDS related community.

Method

This was a qualitative study and information was collected through interviews conducted by the author to key members of the community. The goal of the interviews was to record their perception of stigma and discrimination associated to HIV/AIDS in the Dominican Republic. The interview intended to explore differences in the manifestation of this phenomenon among population groups, and the expressions of rejection and discrimination in different situations, from individuals who internalize society rejections, to its impact in couple relationships and family, and the most hurtful form of stigma: discrimination in health services and employment.

Eight key members of the community were interviewed. They were selected according to their personal relationship with HIV issues, either they were themselves infected or impacted by people from different population groups living with HIV in their workspace. Specifically, there were two persons living with HIV, a man and a woman, both connected to the *Red de personas viviendo con VIH* (REDOVIH - Network of People Living with HIV) and members of support groups. The rest of the informants were people very close to the HIV issues that worked in institutions that offer services or some kind of support to HIV positive individuals. Their testimonies talk about their daily life experiences including:

- a. A female pediatrician in charge of the HIV/AIDS Program in a pediatric hospital, that also offers services in a shelter for orphans infected with the virus. She provided first hand information about the situation of HIV/AIDS among children in our country.
- b. The director of a non-governmental organization (NGO) situated in an intercultural community (different from bateyes) in which Dominicans live together with temporary Haitian immigrants. She gave us information about the immigrant Haitian population infected with HIV who lives outside the bateyes. There is a lack of documentation about this specific population.
- c. The director of the only NGO that provides support to the homosexual community of males. He is a source of information about stigma and discrimination associated to HIV/AIDS in this population.

- d. The director of a NGO that provides in prevention of HIV in a tourist oriented city. He gave us specific information about discrimination against people living with HIV/AIDS in hotels and the tourism sectors.
- e. A pastoral agent from an Episcopal Church gave us her testimony on the positive and solidarity-based approach that her church uses to develop HIV prevention strategies, and to work with people living with HIV/AIDS.
- f. Finally, we recorded the opinions of the country's representative to an international organization that works with HIV/AIDS, and who is responsible for developing health related policies.

The interview intended to explore in depth each of the informant's appreciations of stigma and discrimination associated with HIV/AIDS. It also dwelled into their experiences with these manifestations among different population groups, including differences between women and men. Through the interview I also explored the perceptions on how rejection and discrimination impacts private and public life. The interviewees were asked to make recommendations to deal with this problem.

We explained the purpose and nature of the study to all participants and their confidentiality was guaranteed. The interviewees who did not live with HIV mentioned they had no problems with including their names, and the names of the organizations they represented in the study. Every interview was recorded and then transcribed in order to analyze them according to established guidelines. A qualitative content analysis was carried out with all interviews in order to find patterns in the data associated to the objectives of the study.

Results

The results reported here are widely confirmed by other researches. The Human Rights Watch report of 2004, confirms the status of Dominican women and the discrimination they are submitted to in employment and health services

Stigma Associated to HIV/AIDS does not Affect Every Group Equally

Rejection and discrimination does not manifest itself equally among all impacted groups. Stigma associated to HIV/AIDS reinforces already existing prejudices and rejection towards certain groups of people. HIV/AIDS strengthens stigmas and multiplies rejection, it also catalyses and leaves out in the open every existing prejudice in society. Some authors have stated, basing their opinions on the work of Foucault (1977), that stigmas deepen social inequalities making them seem reasonable (Aggleton & Parker, 2002).

Departing from what the interviewees said, we could establish a group scale for stigma associated with HIV in the

Dominican Republic. The most stigmatized groups are: Haitians, homosexual males, and sex workers. On the contrary, children can be put at the other side of the scale, being the less stigmatized group, but not exempt of discrimination. Within this scale metaphor, women from every particular population group are the most rejected by generic discrimination.

“If the person who has AIDS is a famous artist, white and blonde, there will be a wave of compassion and everyone would want to help him. But if she is a poor Haitian worker with skin ulcers... I think that this is like pulling up the curtain that hides existent strong prejudices. This situation strengthens what you already have inside”.

(Director of a NGO against racism and discrimination)

Haitian Immigrants - Racism and xenophobia are basic components in the construction of HIV stigma and discrimination (ONUSIDA, 2002), like any other stigma, where the rejected subject appears to be foreign. In the Dominican Republic xenophobia is regularly expressed in combination with racism primarily against the Haitian immigrant population. The Haitian immigration is widely used in the country as cheap labor force, a condition that makes them subject to constant violations of their rights, including the condition of illegal aliens. This fact is documented in the periodical reports on Dominican Republic from the International Commission of Human Rights, among other reports by various authors (see the excellent work on Haitian immigrants by Wooding & Moseley-Williams, 2004).

One participant pointed out the anti-Haitian prejudice which is combined with HIV/AIDS stigma held against this population, but there seem to be no solutions to their health needs:

“This is a country where there is a lot of prejudice against Haitians, a country full of racism. It is not only anti-Haitian, it is racist. You can imagine what it means when you can hear people saying Haitians have AIDS besides being black, besides being illiterate, besides being Satanist and Voodooist... The problem is that AIDS is spreading among this population, and we are doing nothing to prevent it, because we don't offer them health services”.

(Director of a NGO against racism and discrimination)

Men who have Sex with Men (MSM) - Homophobia, so rooted in our society, strengthens rejection towards HIV positive MSM. With only the suspicion that a patient is a MSM, the doctor orders an HIV test. The pastoral agent we interviewed compares the situation in the Dominican Republic to what she has seen in other countries:

“Here in the Dominican Republic... they are discriminated against because they are homosexuals, but also because they are positive. Then the drama is worse, because what we have seen in New York or France is that there is acceptance. Discrimination against homosexuals in those countries is not like here, here is seriously homophobic, so here the weight is more unbearable”.

(Pastoral Agent)

Children - There is no data on the specific number of HIV infected children in the Dominican Republic. Since 2000,

vertical transmission has been reduced significantly, but not completely, when most hospitals implemented *Nevirapin* treatment for HIV positive pregnant women.

According to testimonies recorded, children are the least blamed group since most of them got infected via vertical transmission. There are certain cases that in the testimonies come across as making references to children born out of a rape, or due to prostitutes' relationships with foreigners (Arregui, 2004). Nobody blames them, but they are still rejected.

The pediatrician, through her experience with her patients knows exactly what happens in this field:

“At schools, if they say they are HIV positive they are forbidden entrance, maybe by ignorance of some professors and directors. They say it is because if other children know they all will leave, especially in private schools. It goes as far as not wanting the HIV positive kid to play with other kids, etc”.

(Pediatrician)

She also narrated how some family members don't want to take care of children when they become orphans, because they find out they are infected with HIV:

“(With children) it is more difficult to see rejection, it is very rare to see someone rejecting a baby. The manifestation comes when the parents die, or at least one of them. The baby goes to live with a grandmother, or an aunt, a cousin, or neighbor, and they stop helping saying they don't have money to take care of him/her... That's the excuse: 'I don't have any money'. If he or she wasn't infected, they would”.

(Pediatrician)

There is more to the rejection than just fear of being infected, as the doctors points out, it is very difficult for poor people to take care of the young infected kids. In most cases they are grandmothers in poverty, who realize the special needs of their “sick” grandchildren and know they will spend a lot in health care. These grandmothers also think the help they can provide will be useless in the future if they become teenagers. The State or private institutions are no good in taken care of these HIV positive children. Therefore, families are forced to take care of the children. As poor as they already are, they have to take them into their homes. Báez (2003) documents the dramatic situation lived by these orphan HIV positive children in the Dominican Republic.

A woman living with HIV gave us her testimony, as she narrated how stigma not only affects people living with HIV/AIDS, but also their children. Her son, who is HIV negative, has been rejected at school because she is HIV positive:

“Kids, neighbors... the other mothers tell their kids: 'don't play with him, because his mom has AIDS'. That's very traumatic. My son has had a lot of problems because of that”.

(Woman living with HIV)

Women - Power relations between women and men are an important factor that puts women in a very vulnerable position in terms of risk of infection, because they feel they cannot refuse to have unwanted and unprotected sex.

Women are the most blamed if they get infected, and they suffer more discrimination than men. This situation becomes more serious when the number of women infected by their heterosexual partner is increasing.

“Women have to deal with accusations of being prostitutes, unfaithful, and other things that our chauvinistic society permits to men”. (Medical director of a NGO in a tourist area)

“With all the moral precepts that we impose on women, it is more difficult to accept that she is infected, moreover if she is a young woman. Everything that a woman did is being judged, her life, if she is married or not, and how she was infected. That’s what’s less accepted”. (Director of a NGO against racism and discrimination)

Manifestations of Stigma and Discrimination Associated to HIV

People living with HIV witness how their whole life, private and public, is affected. Rejection and discrimination are manifested, first as internalized stigma and in their significant other relationship, then among family relations, community, schools, and, above all, health centers and the workplace.

Self-Hatred: The first scenario affected by rejection and stigmatization associated to HIV/AIDS is the self image. An HIV positive person first reflects every prejudice and rejection learned in society onto himself/herself. He or she is flooded with rational and irrational fears. Fear and silence take control over the life of the person recently diagnosed with HIV. Fears clouds over the possibility of being recognized as an infected person, so he or she tries to hide what others don’t know. The person is silent and afraid to tell others about what is happening. Sometimes they keep the secret even from their significant other. They experience suffering that could be mitigated if HIV/AIDS was socially approached differently as a health condition and not as a shameful and terminal illness.

“I cloistered myself, I wasn’t even going out for groceries, and I cleaned around a little, and then went back to confinement. I became very timid. I would go to my mother’s, sit down, and then go back home, and seclude myself from everything”. (Women living with HIV)

Stigma has a corrosive power upon people living with HIV/AIDS. It is well known that emotional depression deteriorates physical health reducing immunity (ONUSIDA, 2002). For people living with HIV/AIDS, fears and silence also have effects on their emotional and physical health. A woman living with HIV gives an excellent explanation of the dangerous effects of discrimination in the health of patients:

“I think that what really kills a patient is discrimination... The opportunistic illnesses come because of the sadness ones suffers, that decreases the CD4, and increases the viral load up to a million”. (Woman living with HIV)

The reactions of Haitian immigrants deserves special attention:

“They deny it and say “that’s not true...that’s the Dominicans willing to say we Haitians are infected with

AIDS, I will go to Haiti and they will give me a homemade cure, that’s a voodoo job someone sent me...”. They have a series of taboos, of strong resistance to accept it and understand it. When symptoms start to appear and they become really sick, then they accept it, they go through a resignation phase, of suffering, they never complain too much. I would say that around 10% accept and understand clearly what’s happening to them”. (Director of a NGO against racism and discrimination)

The interviewee talked about a particular Haitian population, who are poor and illiterate and come to the country as cheap labor force. The denial of the illness isn’t exclusive of HIV/AIDS or Haitians immigrants. We humans tend to believe that ill fate and illness are things that can’t happen to us. In the case of AIDS, denial and rejection to people living with HIV/AIDS trigger this type of reaction.

Alternatives to Fight Fear and Silence

In the interviews it became evident that counseling strategies, like support networks for people living with HIV/AIDS, are powerful weapons to destroy fear and silence. When a positive diagnosis is obtained together with information about the virus, how it can be transmitted, how it works and behaves, and when it is possible to receive that information from an HIV positive person as well, the newly diagnosed will also understand that the world has not come to an end. Counseling helps to decrease fears of death and prevents seclusion and confinement. This is the testimony of a HIV positive man in counseling:

“I took it easy when I got the results. The ideas of committing suicide and disappearing were gone. I went on with my normal life”. (Man living with HIV)

Support groups, where people living with HIV and their families openly talk about AIDS, along with the existence of networks for people living with HIV that are not afraid to go public and talk about their condition and fight for their rights, have a huge impact on the lives of HIV positive people.

“She told me: ‘welcome, welcome to the family’ and I went in. They welcomed me with a lot of love... I kind of thought that HIV... ok, it is an illness, but there were so many people more or less like me, that were very happy. Why couldn’t I be as happy too? I can continue my life being very happy”. (Woman living with HIV)

The Couple: Reflections from a Gender Perspective

Rejection due to HIV also can be seen in couple relationships, where power dynamics are already in struggle. Aggleton and Parker (2002) have documented differentiated attitudes due to gender in developing countries.

Once a positive diagnose is announced, it is suggested to the patient that he or she talk to their partner, in order for them to be tested also, since in most cases the virus has been transmitted sexually. Our interviews show that both women and men are resistant to be tested. In the case when both partners are positive, frequently they start blaming each other because of

who is primarily responsible. Fear of being blamed, or even losing the partner makes seropositive people remain in silence, and not to talk to their partners about it. On this matter the pediatrician we interviewed said:

“If a woman comes to me, I advise her to ask her husband to be tested...but she never gives him the message. She is always afraid, “if I tell him he will kill me”. I say: “If you haven’t had any other relationships, then he did”. “Yes, but you know, he is too aggressive...” There are worst cases. Women get married knowing they are infected. There are a couple of cases in which the husband dies or they get divorce and soon after she starts a relationship with someone else. She gets married again without telling the new husband she is infected”. (Pediatrician)

This testimony states a very important and fundamental topic in the knowledge of how the virus is transmitted. In one hand, it makes evident a behavior others authors have described (Báez, 2003) as *sequenced polygamy*, referring to the multiple relationships that people establish, especially in the popular or lower classes. This behavior, rooted very deeply in our societies, constitutes a very important risk factor in the transmission of HIV. On the other hand, it makes women vulnerability even more obvious: “It is typical in our countries that if a poor woman gets divorced, she will not remain alone for long. Daily survival is very difficult, since in most cases husbands play a role of authority and principal money provider, although this last one is more symbolical than real. Husbands do the same: one woman after another...and it is also typical in our country that a man, while having a more or less stable relationship with a woman, still goes out and has sexual relationships with other women more or less continuously. Most of the time not using condoms” (Báez, 2003, p. 50).

The power inequality among women and men is traduced as a higher vulnerability risk for women getting infected by HIV. There are authors that have established that most of the women get infected not as results of their own risky behavior, but those of their partners (Brofmann & Herrera, 2002). Recent studies in the Dominican Republic about women and the use of condoms show the difficulty women have to introduce condoms in their sexual relationships with their “trustful partner” because they don’t want to make them mad. The demonstration of “love” toward their partner comes first than the responsibility of protecting themselves (Báez, Félix, & Martínez, 2004).

In cases where only one of the partners is infected, we could see different gender related reactions. In heterosexual couples, the behavioral pattern that comes across the interviews is like this: if the woman turns out positive and the man negative, he leaves her while accusing her of unfaithfulness and prostitution. If the man is the one positive, she will remain with him and provide care without abandoning him.

“We say that being a poor woman in the Dominican Republic is a risk on its own, without any other conditions.

Dominican women are very submissive in a couple relationship... women are very dependant, economically, mentally and emotionally, and even more so if there are kids, it’s very difficult then for them to leave the relationship. In the reverse case, if she is the one that is sick, and the man is not, he would leave her and accuse her of prostitution and all the thinks imaginable”. (Physician and director of a NGO in a tourist zone)

This behavioral pattern, worsened by poverty, is seen in both poor Haitian and Dominican communities:

“If women shows symptoms first, and if it is a Haitian family, the man notices the woman is getting sick – sometimes he does not even know it’s AIDS- and starts saying the woman is “hazardous”, that she makes him spend too much money in medicines and she doesn’t get well...and then he leaves. Sometimes even pregnant and or with a couple of kids. But, if the woman discovers that her husband is sick, she stays and works like crazy seeking money to give him his medicine, until his death. A lot of times when the man dies, she would go back to Haiti”. (Director of NGO against racism and discrimination)

“In the Dominican couple, it’s the same. At the end it is how it works in every couple. He is the one who gets his wife infected – at least this is what happens here- and then it is the woman who forgives everything one way or the other. Furthermore, she would have an attitude of continuous help for him, keep serving him, making him her reason to live”. (Director of NGO against racism and discrimination)

What is happening in my country makes me wonder. It is the man the one that “carries the virus”? At least that is how people around here refer to it, and how international surveys insinuate. The social conditions influenced by gender tolerate and encourage men to have extramarital relationships, and also repress them of having open men to men sexual relations. This contributes to concealed homosexual relations and as a result we are seeing more and more men becoming infected, and then carrying the infection to their wives. The social gender conditions imposed on women are also important in this equation, since women are being infected by their husbands or significant others. Women will tolerate infidelities that can place them at risk, and they don’t protect themselves sexually. At the rate women are being infected, there will be more women living with HIV/AIDS without a partner everyday.

The speed at which the virus is spreading among Dominican women shows the need to pay attention to the cultural and economical elements that influence their vulnerability to infection. The possible measures to control the transmission of the virus confront questioning from predominant patterns of masculinity, and women empowerment at different levels.

Family: From Rejection to Solidarity

In most cases, family members of the person with HIV/AIDS are also targets of social rejection, facing the same discriminatory attitudes. According to our interviewees the

situation has changed in comparison to past years when families did not even receive them, and patients would die on the streets after being rejected from hospitals and homes:

“One of the reasons (for which our institution was founded) was because gay people were being rejected... a lot of gay men were dying on the streets of Santo Domingo because they were rejected at the hospitals, and they were kicked out of their homes. Rejection has been decreasing comparing it to past years...but, the fact that families have become more responsible in taking care of AIDS patients, doesn't mean stigma inside the house has been erased. Stigma prevails when the patient is isolated in a separate room, regularly in the back room, and when they are not allowed to have visitors so that people don't notice that he/she has AIDS”. (Director of an NGO supporting MSM population)

When a family accepts to take care of its infected family member, women show more comprehension and tolerance. They are usually the ones in charge of the ill. Interviews show cases in which a family supports and protects its family member emotionally and economically. This was the testimony of a man that receives money from his brother who lives overseas:

“I am lucky to have brother overseas. He never forgets about me, and he once told me “you just have to call me, I will solve any problem”. In that sense I am all right. He said to me “don't you worry, you will have my help until you find something”. (Man living with HIV)

Community

The shameful mark that still prevails upon HIV is clearly seen in the relationships inside communities, urban or rural. The smaller the community the less possible it is to be anonymous. Therefore there is a greater possibility that the HIV positive person is identified and stigmatized. An informant working among the Haitian community explains the rejection toward certain people:

“We had a case, a woman that returned to Haiti. She was a symbol of stigma. I mean, HIV positive, poor and female... she really had to leave places. After being a couple of months in a place, when they figured out or even insinuated that she might be ill, she had to go. Here they rent washing machines so people can use them at home. She couldn't rent them, people just didn't rent them to her”. (Director of a NGO against racism and discrimination)

Solidarity from Churches

The work done in some churches is worth mentioning. It is prevention work in which HIV positive people get involved so they can give out information about the virus and how it is transmitted. They also prepare the general community to help them accept and welcome people living with HIV/AIDS inside the community:

“When the community learns more about the virus, and they get to know about the suffering of the people that already have the virus, then we ask them: “What is God

telling us with this experience, with those human beings?”

When the workshops are over, people are more sensitive, and when they have to deal with a person living with HIV/AIDS, they deal with them in a normal manner, because they no longer fear them. That's the issue, fear, we have to make fear to go away”. (Pastoral Agent)

This pastoral work, based on compassion instead of damnation offers hope in efforts to eliminate stigma. The different churches that exist today are very influential in our society. Their messages are well received and accepted by a great portion of the population. In the same way that other religious discourses get through to people from the pulpit, making them believe that HIV is a punishment from God, and that people living with HIV/AIDS are suspicious of deviant sexual behavior, this compassionate religious approach can contribute and encourage acceptance of the ill and the HIV positive. Furthermore, this approach has a deeper biblical foundation than that of the damnation since compassion mimics Jesus's behavior towards the Samaritan (Jn 4), the adulterous (Jn 8, 1-11), the leprous (Lc 17, 11), and other stigmatized people of His time.

Having HIV/AIDS and Going to a Hospital

In order to explore how discrimination manifest itself in health centers across our country, we asked the interviewees about their knowledge on the matter, either by personal experiences or stories told to them by people living with HIV/AIDS. According to them, discrimination associated to HIV/AIDS among the health sector has decreased significantly in comparison to past years. But, still today, either in public or private health centers, there are clear discriminatory practices that prevail even when they are well known violations to basic human rights of people living with HIV/AIDS, or when they go against the laws or the international agreements signed by the Dominican government. Discrimination at hospitals, along with rejection of employment, is the greatest expression of stigma and discrimination associated to HIV/AIDS according to our key informants. The testimonies we present here, are widely supported by other reports like the *Human Rights Watch* (2004), and Báez's (2003) report on children's vulnerability to HIV, both previously quoted.

A summary of the most common expressions of discrimination described by our informants are the following:

a. Open rejection, or excuses from health professional to reject clients.

“In specific departments, like neurosurgery, otorhinolaryngology and thoracic surgery they won't treat these kinds of children... we still don't have a professional willing to perform a bronchoscopy. They always say there is no bronchoscope, or that it is broken... That is the experience in every hospital, not only here. Also in intensive care... in order for them to accept a patient there, they do it with resentment; they would say:

“sidosos”, that’s the diminishing word they would use: “why would you even treat ‘sidosos’, they are going to die anyway”. (Pediatric Doctor)

“From the moment they know a patient is HIV positive, their attitudes change, even when there are capable health professionals to take care of these patients. It changes during labor... if a caesarean is necessary, the gynecologist disappears, nobody wants to deal with a patient like that”.

(Doctor and director of an NGO in a tourist zone)

We suppose these attitudes are individual behaviors and not hospital policies, in which case they would be in open violation of Law 53-93. In any case, these attitudes toward HIV positive individuals are tolerated by the hospital administration, that are not supposed to ignore this type of rejection that does not save lives that could be treated with antibiotics, or that prevent the patient from being tested further so they can receive a better diagnosis.

b. Subtle forms of rejection included placing patients in wards where there are other contagious patients and when health professional are extremely precautious because they found out they are dealing with an HIV patient. The woman living with HIV gave us a dramatic testimony.

“One time I was poisoned by seafood, I was taken to a public hospital. Because I am a conscious person, I saw that the doctor who was going to inject a serum in me wasn’t protecting herself that much, so I told her: “Listen I am HIV positive, wear gloves, protect yourself a little”. Ah! The doctor wore three gloves. She put me in a stretcher far away, where there was a hepatitis patient that was completely yellow. To my other side there was a tuberculosis patient that couldn’t breath. I felt so bad that I didn’t let her give me the serum. I told her ‘doctor... why don’t you bring a bottle of turpentine, find a needle and inject me 10cc of it... the way you are discriminating against me, you are killing me. I feel I am dying inside”.

(Woman living with HIV)

This woman compares discrimination with death in a very lucid way. The way she was treated was worse than being injected with turpentine. She even had the courage to express how she felt to the doctor who was treating her badly. These attitudes demonstrate how health professionals’ lack of information fosters the perspective of the patient’s condition as a death threat, and blames the positive person for any risk of contagion making the patient feel like they are “dying inside”.

c. Some health professionals order HIV test to be performed on patients without their consent, even when Law 53-93 prohibits it. This is a common practice when the physician assumes the patient is homosexual, a group already stigmatized in relation to HIV.

d. Hospital personnel do not respect the confidentiality of the test results:

“We have testimonies from communities... in which for example, the person running the test makes comments like ‘Such and Such is infected, or Such and Such is taken’. Then there is fear in that community... they rather go to

the capital, or to San Pedro de Macoris to be tested for HIV, instead of being tested in XXX because there is no warranty of confidentiality whatsoever”. (Director NGO in support of MSM)

This same informant mentioned:

“Frequently we receive people that get to know about their positive diagnoses because the laboratory gave the results to their parents”. (Director NGO in support of MSM)

The lack of confidentiality in laboratories and from health professionals prevents anyone from following any recommendation given by the Pan-American Health Organization who encourages people to get tested for HIV (Organización Panamericana de la Salud [OPS], 2003).

e. Lack of access to antiretroviral treatment for most of the population is an urgent problem. The fact that most of the population has no access to antiretroviral therapies that have changed the lives of many, drastically reducing the number of deaths associated with AIDS, is also a form of discrimination. The antiretroviral (ARV) program originated in 2003 has a very limited reach, and it is mostly funded by international sources.

f. Heightened discrimination in hospitals towards several groups is common. Although every person living with HIV/AIDS can be an object of discrimination at health centers, some groups are more vulnerable than others. Hence, poor people are subject to greater rejection, along with more stigmatized groups like Haitians immigrants, prostitutes and homosexual men. This stigma is manifested even when health professionals only suspect they belong to one of these groups. The most dramatic situation is lived by Haitian immigrants. Some NGOs and religious institutions have developed programs like “Solidarity Companionship”³ to accompany HIV positive persons when they have to go to a health centers and ask for services. For population groups as discriminated as Haitian immigrants, whose situation is worsened due to the language barrier, most of the times these programs are the only way people living with HIV/AIDS are actually treated at health centers.

“In XXX Hospital, if they go on their own it gets very difficult. The thing is that we have relationships with international organizations, with projects; we are capable to denounce it. If we go with them, especially in that hospital, they get served. Some people do treat them just because, other do it because we accompany them”.

(Director of an NGO against racism and discrimination)

The way they discriminate against people living with HIV/AIDS in some Dominican hospitals is a clear violation of their human rights. Discrimination is responsible for the death of many patients due to opportunistic diseases that could have been treated with the proper medicine. At the

³ This is the name of an NGO program that accompanies people living with HIV/AIDS to health centers.

same time, it also causes patients to decide not to go to health centers to ask for treatment so they won't be exposed to humiliation from health professionals.

Still, not all is lost. There are many testimonies that account for positive experiences at health centers. Many health professionals, in public or private hospitals, are sensitive to the needs of people living with HIV/AIDS, a fact that is well recognized by some patients who go health professionals who are friends of family members as an alternative to prevent discrimination.

Having HIV and Looking for a Job: Employment Discrimination.

Employment discrimination due to HIV is not an exclusive phenomenon happening in our country (Aggleton & Parker, 2002; Organización Internacional del Trabajo [OIT], 2001). It is a complex phenomenon in which economic and social implications are interconnected with AIDS stigma. Employers fear an increase of their health insurance coverage policy, and the alleged decrease of employees' performance in the workplace. This is added to the lack of information on HIV that leads to believe that clients and other workers at the workplace are at risk of getting infected by the person living with HIV. People living with HIV are not only being fired from their jobs, but they also have problems accessing new jobs because of discrimination against them. Both situations are part of the context of a country in development in which there is more work force than jobs, a context in which violations of labor laws are frequent.

When asked, our key informants reported about their own experiences in the workplace, or that of others. Their testimonies were impressive. Stigma and discrimination associated with HIV/AIDS in the Dominican Republic have a direct effect on the employment status of people living with HIV/AIDS, especially those without skills. Paying jobs are denied to people with HIV, and therefore their economic and emotional situation is worsened.

Stigma manifestations are obvious when employers illegally ask their employees, and those applying for jobs, to get tested for HIV. As a result, positive employees are fired, and new jobs are denied to those who apply for them. The testimonies we recorded make open references to the tourist and manufacturing industries, the last one called manufacturing zone.

"I only knew how to sow in a manufacturing zone...but they ask you for a complete blood count, and there they run the HIV test. From the moment they see you have tested positive to HIV they tell you 'we are not going to need you'. That is very depressing... You can't get a job anywhere". (Woman living with HIV)

Testimonies recorded account for employers that do not tell their employees the results of the HIV tests, because that would entail accepting that they are proceeding against the laws of consent. In these cases, employers have a

mechanism that could prevent other people from getting infected. Still, they don't use it because they are more interested in their economic profit and their intention is to get rid of these employees that could cause them economic losses and low performance rates.

"The Law 55-93 is broken. In hotels and in manufacturing zones, everywhere, they test their employees and then they don't tell them the results. If an employee is HIV positive they wait for the first mistake they do to fire them. Employers from different workplaces exchange the list of names of HIV positive employees. That's how, HIV positive workers can't get jobs anywhere". (Physician and director of an NGO in a manufacturing zone)

"We have a lot of dancers that have been fired from the tourist industry, from hotels in Bávaro, in Juan Dolio, in Puerto Plata...most of the times they are from small towns, from rural areas, sadly enough these guys have to go back there to die". (Director of a NGO in support of the MSM population)

When labor laws are broken and human rights are violated like this, the impact in the lives of people living with HIV/AIDS is enormous: poverty and emotional distress. Many of them lose their job, and therefore lose their only source of money. Báez (2005) states that the relationship between HIV and poverty is very clear. Bronfman & Herrera (2002) concluded that: "A household impacted by HIV/AIDS, where one or more of its members are infected, lives not only a great human tragedy, but also an economic crisis. The cost of health care expenses increases very rapidly" (p. 75).

This situation is worsened when we assess the alternatives to deal with employment discrimination. In this context, contrary to the access to health care services where there are some centers or health professionals willing to give quality services to people living with HIV/AIDS, there are almost no alternatives in the workplace. When confronted with the lack of employment, some take very risky exits:

"We worry for the transvestites that have to become prostitutes. For a gay man living with HIV, sometimes there is no other solution to unemployment than prostitution. They can't find a job anywhere else, so they are out there selling sex, and we are not sure what is their level of protection". (Director of an NGO that supports the MSM population)

The lack of community efforts to fight for their rights of the marginalized leave employers unpunished. Still, our key informants reported that sometimes suing them, or even threatening them with suing, has made employers reinstate employees fired because they were HIV positive. This could make us think that in the fight against discrimination associated to HIV/AIDS, we need to get more involved with the judicial branch of the governmental system, especially to deal with employment issues. We can't forget that in order for a person to go to court to fight for his/her rights, they have to go public about their condition, a decision that people living with HIV/AIDS might not be empowered to make.

In order to prevent that employment discrimination goes unpunished in the country, state officials have to be more vigilant of the implementation of labor laws. Strategies must be developed to make employers, and the media, more aware and sensible to this issue. This should be done in collaboration with the networks of people living with HIV/AIDS, so they can continue defending their rights. All this is needed so discrimination in the workplace can be eliminated.

Conclusions: Some Suggestions to Fight Stigma and Discrimination

Although many of our interviewees stated the situation is better in comparison to years past, they also mentioned that stigma and discrimination associated to HIV is still very predominant in the Dominican society. According to key informants, this is a situation that deeply affects the quality of life of HIV positive individuals, becoming an obstacle to the prevention of the epidemic.

Interviewees gave us several suggestions of actions to take in order to change the current situation. The mentioned strategies could very well be the foundation for a national HIV prevention plan:

Our key informants *asked for political willingness from state officials in order to stop the spread of the virus*. Some of the interviewees asked politicians to talk openly about HIV and AIDS, in order to fight the silence that minimizes and conceals the real situation of the disease.

Unanimously, the interviewees *reclaimed that state officials should become alert about the situation so that in every public health center people with HIV/AIDS can receive quality services*. It is urgent that health professionals have updated information about the virus, and that discriminatory practices are censored and supervised. They also asked for the availability of more treatment therapies, such as antiretroviral treatment:

“Although there have been changes, the true changes are going to come when access to treatment becomes the norm, when people get cured, when people get treated, when they see it is possible to live with HIV”. (International Organization Director)

The interviewees unanimously stated the need to *increase HIV/AIDS educational campaigns* with information on facts on transmission methods and services for people living with HIV/AIDS. These campaigns must reach every sector of the population, including Haitians immigrants. Information should get to far away places where television and electricity is still unavailable.

They mentioned the need to fight employment discrimination that makes people living with HIV/AIDS lose their only source of income. It is very important that state officials impose the current labor laws and international agreements upon employers. It is equally important to

develop strategies to make those employers more sensitive to HIV issues, and to empower networks of people living with HIV/AIDS so they can give support to those affected by discrimination and keep fighting for their rights. It is very convenient to spread the word on successful stories of people living with HIV/AIDS, so they can serve as examples for employers and even other HIV positive individuals.

Interviewees also mentioned the need to foster a gender perspective on the matter. The increasing rate of women infected with HIV requires approaches from different perspectives in order to develop prevention strategies that take gender inequalities into consideration. It is particularly important to build strategies based on the empowerment of women in their relationship with men, and also encourage them to be economically independent.

Active participation of people living with HIV/AIDS in the search for better solutions was also an important topic mentioned. Some people suggested the integration of people living with HIV/AIDS to the policy making process as “part of the solution” (UNAIDS, 2002). This suggestion also included inserting them in health center committees, and being the main advocacy groups to support their rights:

“I think that everyone working with HIV, every counselor working with HIV, has to be positive, so they know. Because that person is living with HIV too, and can give better advice, and increase self esteem in other HIV positive persons...There should be at least one HIV positive person working in every hospital...it hasn't been done yet”. (Woman living with HIV)

Finally, the need to replace judgment and damnation in the church with solidarity and compassion was also mentioned. Interviewees made a special call to churches so they can raise their voices and take a stand on HIV/AIDS issues with a pastoral approach that encourages solidarity and compassion towards HIV positive individuals. This should replace discourses that describe HIV as a punishment from God, and condemn people for their sexual behaviors.

There is much to be done to eradicate the stigma surrounding HIV/AIDS in the Dominican Republic. I hope the verbalizations of the key informants in this study shed light on the potential roads of action to achieve a stigma free society.

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AIDS Stigma in the Puerto Rican Community: An Expression of Other Stigma Phenomenon in Puerto Rican Culture

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Abstract

Puerto Ricans have been disproportionately affected by the AIDS epidemic in the United States (CDC, 2000). Although the Puerto Rican community is known to be family-centered, often their infected members have had to face their illness without family and community support. A central assumption in this paper is that a compelling cultural phenomenon exists in the Puerto Rican community when it is faced with HIV/AIDS. It is strongly linked to the culture's deep religious and spiritual roots that seem to take hold within the context of the meaning Puerto Ricans give to HIV/AIDS. These roots have pushed the HIV and AIDS illness into the realm of sin and evil. This culture's inability to condone the shameful and sinful behaviors associated with HIV/AIDS, the fear of casual transmission, and the fear of bochinche (malicious gossip) have driven many infected persons to keep their diagnosis secret in order to avoid the inevitable rejection from family and community.

Keywords: Acquired Immune Deficiency Syndrome; stigma; culture; family; Puerto Rico.

El Estigma del SIDA en la Comunidad Puertorriqueña: Una Expresión de otro Fenómeno de Estigma en la Cultura de Puerto Rico

Compendio

La comunidad puertorriqueña en los Estados Unidos ha sido desproporcionadamente afectada por la epidemia del SIDA (CDC, 2000). Aunque es una cultura centrada en la familia, frecuentemente sus miembros infectados enfrentan su enfermedad sin apoyo de la familia o la comunidad. Una idea central de este trabajo es que existe un fenómeno cultural importante en la comunidad puertorriqueña al enfrentar el VIH/SIDA. Está fuertemente atado con las raíces culturales basadas en la religión y la espiritualidad que parecen controlar los significados asociados al VIH/SIDA. Estas raíces han empujado al VIH/SIDA al reino del pecado y la maldad. La inhabilidad de esta cultura de aceptar las conductas catalogadas como bochornosas y pecaminosas, el miedo al contagio, y el miedo al bochinche (chisme malicioso) han hecho que muchas personas mantengan su diagnóstico en secreto para evitar el rechazo de la familia y la comunidad.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; cultura; familia; Puerto Rico.

Although Hispanics comprise 14% of the United States population, they account for 19% of AIDS cases diagnosed since the beginning of the epidemic (Office of HIV/AIDS Surveillance, 2004). Among Hispanics, Puerto Ricans are at risk several times greater than whites and other Hispanics throughout the country (Center for Disease Control [CDC], 2000). This data suggest that Puerto Ricans have been disproportionately affected by the AIDS epidemic and are experiencing a profound impact in their communities throughout the country. One study shows that the Puerto Rican infected person often struggles with the challenges of his/her illness without the support of family and community (Roldán, 2003). These figures also indicate that current AIDS prevention programs are not reaching this community. In order to help and serve this population, we need to understand the cultural attitudes, values and beliefs

that influence the Puerto Rican community's view of HIV/AIDS and how these may affect the community's response to a member with AIDS.

Background

This paper is based on findings from a qualitative study conducted with Puerto Rican people living with HIV/AIDS (PWHAs) in Chicago. The sample included 16 PWHAs adults and 3 PWHAs partners (six females and thirteen males). Because some participants only spoke Spanish, the informed consent was provided in both English and Spanish. Special consideration was given to the possibility that the interviews could evoke discomfort or anxiety in some participants. In the event this occurred, additional support and/or intervention were offered. Interviews were semi-structured and tape recorded. I was the primary interviewer which necessitated a high degree of interaction with participants. General questions during the interviews with participants focused not only on their experience with HIV/AIDS, but also how they experienced their family's response to their

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illness. Cultural attitudes, beliefs and values, and self-perceived acculturation levels were examined through topics such as attitudes about homosexuality, drug use, premarital and extramarital sexual relations; beliefs about HIV transmission; attitudes about gender roles (machismo² vs. marianismo³); and level of interaction with others outside of their culture. Data were collected, organized, and analyzed according to the grounded theory method for qualitative research detailed in Straus and Corbin (1998).

While the number of participants in this study is small and represents a limited geographical area in Chicago, this research aimed to capture depth and richness rather than broad representation. This sample also represented the population most at risk for HIV/AIDS in Puerto Rican communities – the injection drug user. The findings provide important knowledge about the experiences of the sample participants.⁴

Although this paper illustrates the psychological transformation in Puerto Rican HIV/AIDS individuals previously documented by Shelby (1992, 1995), it focuses primarily on the cultural context within which this transformation occurs. These individuals fiercely avoid the effects of the stigma attached to their illness by keeping their diagnosis secret. In my study, I found that often Puerto Rican PWHA experience rejection and isolation by family and community. The data suggests that there is an interaction between Puerto Rican cultural values and belief systems and the stigma Puerto Rican people attribute to HIV/AIDS. This interaction is at the root of the breakdown of the family system.

Flaskerud and Ruiz-Calvillo (1991) suggest that traditional beliefs about the prevention, cause and treatment of illness often attributed to peoples of Spanish, Mediterranean, and Hispanic origins are those influenced by the Hippocratic doctrine of humoral balance. The theory of humoral balance proposes that health is a state of balance among body humors causing the body not to be excessively dry, wet, hot, or cold. Religion, having faith, regular confession, penance, and devotion to God, the Virgin, and the Saints are believed to result in both spiritual and physical well-being and good health. Hispanics place a high value on spiritual matters. Therefore, classifying the causes of illness into natural and supernatural categories is common in their community. Natural illnesses are those caused by exposure to cold, damp, and impurities, lowered resistance,

and improper diet. Supernatural approaches to health promote beliefs such as sinful acts can cause diseases, and miracles performed by God can cure them. Pares-Avila and Montano-Lopez (1994) caution that the accuracy of these generalizations about cultural beliefs and values may vary as a result of the acculturation process, individual personality differences, or subgroups variations. In my clinical experience, however, Hispanics who are more acculturated tend to retreat to this way of thinking when under stress or facing serious illness.

I also caution the accuracy of the following generalizations about Puerto Ricans but believe some understanding of the Puerto Rican family is necessary to fully appreciate the lived experience of the Puerto Rican PWHA. Providing the cultural context is crucial because one cannot begin to understand the contradictions observed in the Puerto Rican community when it comes to HIV/AIDS without exploring the Puerto Rican's reality of HIV/AIDS and their explanatory model for this illness.

Puerto Rican families are characterized as people who, in times of stress, turn to their families (Garcia-Preto, 1982; Morales & Bok, 1992). The Puerto Rican family is described as loving, caring, and nurturing. Family members are expected to come to the aid of those members experiencing a crisis. In terms of cohesion and adaptability, Puerto Rican families encourage interdependence with emphasis on the group rather than the individual. Families value unity, family ties, and intense relationships. The family ensures safety, protection, and caretaking for life *as long as the person remains within the cultural norms*. Therefore, separations are experienced with profound grief and reunions are cause for celebration (Garcia-Preto, 1982). Typically, Puerto Ricans are also moralistic and traditional in family values. These characteristics have endured despite family disruptions caused by poverty, dislocations from rural to urban settings, and migration between the United States and Puerto Rico.

Although the majority of Puerto Ricans in Puerto Rico and the United States are Roman Catholics, spiritism is a widespread belief system in Puerto Rican communities. Often the beliefs regarding health and illness have roots in the world of spirits and humors (Flaskerud & Ruiz-Calvillo, 1991; Harwood, 1977; Hohmann, et al., 1990). Spiritism is a belief system that serves as a religion which posits that the world is inhabited by both good and evil spirits. Good spirits are responsible for good luck and health. Evil spirits are responsible for sickness and suffering (Delgado, 1979). Illness and suffering may also be attributed to evil influences exacting punishment to those who engage in sinful acts.

Morales and Bok (1992) and Garcia-Preto (1982) emphasize that Puerto Ricans PWHA constitute a distinct ethnic group. They also suggest that individuals who engage in behaviors that put themselves at risk of contracting HIV/AIDS such as drug abuse, prostitution, and

² Machismo: System belief that men are superior and must always be in control in all situations, including family life and sexuality.

³ Marianismo: System belief that women should be in a submissive position and like the virgin Mary, always suffering and unselfish.

⁴ A more detailed description of the study's methodology can be found in Roldán, 2003.

homosexuality are ostracized within the Puerto Rican community (Ayala & Diaz, 2001). The negative attitude toward these behaviors often leads to social denial, which these authors believe makes prevention of at-risk behaviors more difficult. Most importantly, the culture's condemnation of these behaviors forces the Puerto Rican person to keep his/her diagnosis secret from family and community.

For the Puerto Rican PWHA, the HIV/AIDS experience has its own distinct characteristics and qualities which are unique to this culture. As mentioned earlier, Puerto Ricans have been experiencing the devastating effects of the AIDS epidemic for almost twenty years. Many have suffered multiple losses going back at least two generations. The primary mode of transmission of HIV/AIDS "I've been surrounded by drugs since I was 16 years old. My older brothers used and were dealing." "I started doing drugs when I was 9 years old. I used to go to shooting galleries to get high. I'm 40 years old now." "I've been an addict for 20 years. I have gone through several rehab programs, too. I've tried to get off this stuff". In this community has been through injection drug use. In the mostly poor urban Puerto Rican communities throughout the United States, the pervasiveness of drugs and drug use appears to be tolerated and accepted as a way of life. Several participants stated: Families often express compassion toward the drug abuser in their family and community.

Although HIV/AIDS has also become pervasive in their communities, Puerto Ricans are responding in a way that runs contrary to this culture's strong values of close family ties, unity, and intense relationships. Although families of injection drug users have experienced much disappointment, worry, and frustration with their drug addicted members, they tend not to withdraw their support. Not until family members contract HIV/AIDS does the family support become threatened.

Roland (1988) describes a different organization of the self which helps to illustrate how the experiential sense of self is of a "we-self." Self-esteem would be closely linked to strong identifications with the reputation and honor of the family and other groups. It is called the familial self. According to Roland (1988), the familial self is a basic inner psychological organization that allows women and men to function well within the intimacy relationships of the extended family and community. It involves intensely emotional intimacy relationships where emotional connectedness and interdependence is emphasized.

Given that the Puerto Rican family develops from a relationship-centered culture, the HIV/AIDS crisis then has transformed the relationship-centered culture dramatically. It has left their infected members with extreme feelings of disconnectedness, rejection and abandonment. PWHA are

then faced with a developmental challenge which is an anomaly in their culture. They are, perhaps for the first time, pushed into more autonomous, independent functioning. They have to face HIV/AIDS alone without the safety and security of the family.

Development of the Theoretical Proposition

In the case of HIV/AIDS, the culture's strong religious and spiritual roots seem to take hold within the context of the meaning Puerto Ricans give to this illness. These religious and spiritual roots seem to have pushed the HIV and AIDS illness into the realm of sin and evil and underlie the stigmatization of the HIV/AIDS illness in this community. The inability to condone the shameful and sinful behaviors associated with HIV/AIDS and the fear of casual transmission have driven many of these families to push away their infected members. I contend that the family's and the community's negative response to their infected member is due to the culture's condemnation of behaviors associated with HIV/AIDS.

Therefore, immense psychological stress is experienced when someone in the Puerto Rican community is diagnosed with HIV/AIDS. Risking the loss of family support puts the Puerto Rican PWHA in a despairing situation. Feeling vulnerable, frightened, confused, and ashamed, the infected person wishes and expects to be surrounded by the safety and security of the family. This wish only gives rise to angry and resentful feelings because the Puerto Rican PWHA, expecting to be judged and rejected by both family and community, is subjected to suffering in silence.

As a result, living with HIV/AIDS makes unusually tough demands on the Puerto Rican PWHA. Many are fending off depressive, angry feelings which they believe can only debilitate them further. "When you're sick, it is necessary to maintain a state of peace. Tension and stress makes one depressed and affects the immune system." In addition, the mental energy that is required to defend against these feelings is often overpowering. In their daily lives they must cope with their mortality and their fantasies about death without losing hope and giving into feelings of despair. For most participants, beliefs about death were rooted in their Catholic upbringing, and they often expressed a loss of hope for redemption because of their sinful acts. PWHA will not only face death alone and die in secret; they will also be condemned to burn in hell (Roldán, 2003).

Because Puerto Rican PWHA cannot depend on the customary support of the family, their support system may just include his/her partner. It may or may not include children, parents, or siblings. The fear of rejection and humiliation has forced PWHA, and sometimes his/her nuclear family, to separate from extended family. They feel forced

to function more autonomously in order to protect themselves and their families from the stigma associated with the HIV/AIDS illness. Thus, keeping the secret is of paramount importance.

Due to the Puerto Rican community's attitude toward HIV/AIDS, facing the reality of their illness is complicated by a very strong code of secrecy. Underlying this code of secrecy is the fear of *bochinche* (malicious gossip). *Bochinche* is perceived as harmful, intrusive, and destructive; yet it is a part of the social fabric of the Puerto Rican community. It is often fueled and driven by misinformation and fear. Statements common among participants were: "They find out somebody is HIV and they start talking." "They have nothing good to say." "Shit, you're still human."

Avoiding *bochinche* requires one to expend much psychic energy because of the fear of being subjected to the humiliation, shame, and rejection of others. In many ways, fear of *bochinche* seemed to organize the lives of the participants in my study as they continually struggled to maintain their diagnosis secret from loved ones and community. It is a daily preoccupation and worry about what others may think or say. Keeping the diagnosis secret functions as a self-protective measure against the destructive forces of *bochinche*. As one participant stated, "My family thinks he has cancer. I will keep his secret until he dies. I will bury his secret with him." In addition, there is the fear that the family will become the target of *bochinche*. This is the driving force behind keeping the HIV/AIDS diagnosis secret. A participant stated, "My parents don't know. Don't want to unnecessarily cause them trauma." This concern overrides any anxiety PWA has about himself/herself and is the source of much distress in this community. For instance, one participant declared, "You know Puerto Ricans; they're bochinchosos (gossipers). Make a mountain out of a mole hill." Another participant stated, "We don't tell anyone [about being infected] to avoid *bochinche* and have people drag us through the mud."

Bochinche appears to be a necessary evil in the Puerto Rican community in Chicago and on the island as well. It symbolizes the intense social interactions this population enjoys and dreads. *Bochinche* seems to be a form of communication which keeps people involved with one another. There is a sharing of life's joys and sorrows with others in the community. As a result, people respond by offering help and comfort. *Bochinche* also seems to be experienced as something invisible with supernatural qualities and powers. Everyone fears it. Yet, everyone does it. It is feared because in matters that are considered evil, *bochinche* rears its malevolent head. It brings with it destruction and shame

Bernal y Del Rio (1982), a psychoanalyst practicing in Puerto Rico, attempts to dynamically explain *bochinche*. He suggests that the geographical closeness, the extended family, and the intense social contacts of the Puerto Rican people are what make the psychoanalytic situation special in Puerto Rico. Given these features, he reports that any of his analysands "can get for the asking a more-or-less benevolent but thorough biography of mine" (Bernal y Del Rio, 1982). However, when it comes to HIV/AIDS, PWA and his family struggle with the fear that a malevolent biography (*bochinche*) would be spread throughout the community. The fear is rooted in the inescapable shame and humiliation *bochinche* will bring to PWA and his/her family should the diagnosis become public knowledge. It is also the motive behind the collective secrecy in the community (Roldán, 2003). Fimbres (1993) refers to how the Hispanic family's fear of not only what the neighbors will say and even do often prevents them from acknowledging a member has died due to HIV complications. *Bochinche* then becomes a metaphor for the AIDS illness. It is almost as if the greater fear is of becoming infected with *bochinche*.

There is a sense that one is helpless from the onslaught of *bochinche*. PWA express anger and frustration about having to keep their illness a secret. They overwhelmingly blame an external source for their community's struggle with the disease. *Bochinche* is also blamed as the source of the Puerto Rican community's ignorance regarding HIV/AIDS. Although there is much available information about AIDS, the Puerto Rican community is still greatly misinformed. Because misinformation is fueled by *bochinche*, when it comes to HIV/AIDS the Puerto Rican community reacts with fear and panic. Therefore, PWA feels helpless when faced with the possibility of someone finding out his/her secret.

PWA experience their family's revulsion and fear but do not feel these feelings can be openly expressed. They cannot tell their families how it feels to be treated "like a leper". Another participant lamented, "They say and do stupid things. They're still afraid of contracting the disease. I have seen a lot of ignorance when it comes to AIDS. People turn away. It's sad". There seems to be some great prohibition about speaking and expressing these feelings to family members. In fact, there is evidence of a giant collusion among family members. Perhaps this is due to cultural inhibitions regarding taboo subjects such as sex or behaviors considered sinful (Marin, 2003). Also, open communication related to topics such as feelings of loss and shame seems to be discouraged. Bardach (1995) similarly found that when confronted with the illness of AIDS, open communication within the Hispanic family seems

to break down and instead a “conspiracy of silence” is adopted.

This lack of communication often leaves PWHA feeling isolated and abandoned. Although families do not cut off all contact with the infected person, interactions tend to change dramatically. Many participants interviewed have been subjected to countless painful experiences of rejection by immediate family, friends, and strangers. One participant stated, “*They don’t know the facts about the disease, so I don’t know if they’re going to have a separate glass or plate for me.*” Another infected participant added, “*Since I found out I had the virus, I isolate myself. I don’t visit family or friends like I used to.*” The intense connection and intimacy PWHA enjoyed within the family prior to disclosing his/her HIV/AIDS diagnosis no longer exists. PWHA feels his/her family’s anxiety and fear when in their presence. Even customary ways of greeting one another are modified. No longer can they enjoy the physical contact so casually offered to other members of the family. These experiences lead to feeling very vulnerable, and in order to protect themselves from further hurt, PWHA often choose to distance themselves from their family. Although my study data (Roldán, 2003) suggest that participants did not experience out-right rejection by family, these experiences invariably left them feeling unwanted.

Conclusion

Rolland (1994) suggests that a family characteristic which is generally viewed as dysfunctional under certain circumstances can be adaptive during a health crisis. Systems theory also views a family’s response to stressors or crises in terms of its coping and adaptation abilities. A balance between cohesion and adaptability allows family members to manage and resolve hardships without losing their sense of independence and connection to their families (Walsh, 1982).

There is an assumption in the statement above which alludes to the Western value of maintaining independence while remaining connected to family. This statement does not reflect a unitary Hispanic family systems model or unitary Puerto Rican family systems model. However, it is helpful to look at how some of the family systems concepts compare to what I found in my study. Looking at the Puerto Rican family from a systems perspective, one can identify a characteristic which could enhance their ability to cope with a health crisis. That characteristic is cohesion. Rolland (1994) also suggests that family adaptability is a crucial characteristic for well-functioning family systems. Family adaptability or flexibility is essential in facing the challenges of the more progressive, relapsing illnesses such as AIDS.

However, when it comes to HIV/AIDS, the Puerto Rican family is lower in both cohesion and adaptability making it more vulnerable when facing HIV/AIDS.

The Family Systems-Illness Model that Rolland (1994) developed also suggests that a cohesive family is more likely to be able to cope and adapt in a health crisis. This model views illness as dynamic and with specific phases. Each phase has its own psychosocial demands and developmental tasks which present the family with different challenges. Rolland (1994) suggests that not solving the phase-related tasks of the three major phases (crisis, chronic, and terminal) can jeopardize the coping process of the family. According to this model, the crisis phase begins before the actual diagnosis. The individual or family has a sense something is wrong. This is where the Puerto Rican family remains trapped. Although Puerto Rican PWHA transition onto the other phases and tasks of living with HIV/AIDS, their families do not.

According to Rolland (1994), in the crisis phase proper, there is a sense of the family pulling together. The family group effort is at a premium during this phase. However, the Puerto Rican family seems not to enter into this experience. My data suggest that the Puerto Rican family may not be able to enter into “the pulling together” experience because of their beliefs about the causes of HIV/AIDS. Rolland (1994) found that a family’s belief about the causes of the illness also organizes their experience and mirrors their belief system. These core beliefs shape the family’s reaction, response and coping strategies.

Similarly, the Puerto Rican family’s core beliefs about the causes of HIV/AIDS and illness in general shape their reaction and give rise to the complicated feelings and fantasies which are culturally derived. These beliefs are what drive the Puerto Rican family to act uncharacteristically distant and un-nurturing when faced with HIV/AIDS. The shame associated with the HIV/AIDS illness interferes with the Puerto Rican family’s ability to face the crisis phase developmental tasks that pull the family together. Using this model to understand the Puerto Rican family’s response to HIV/AIDS, one might say that the Puerto Rican family’s unfinished business from the crisis phase blocks their movement onto the other phases. Since many Puerto Rican PWHA do not disclose their diagnosis to their families, their families remain stuck in the stage where everyone has a sense something is wrong but no one is talking about it.

In addition, the Puerto Rican community’s strong anti-homosexual attitudes affect the family’s response to PWHA. These attitudes have religious roots which are connected to behaviors considered sinful. They are also connected to the gender roles and social scripts ascribed to men [machismo] and women [marianismo] in the Puerto Rican

culture. Machismo is a complex phenomenon which emphasizes male superiority and the need for the man to present as masculine and dominant. Men are responsible for the family's safety, well-being and the defender of its dignity and honor. It also involves cultural values such as courage and fearlessness. This machismo code makes it difficult for men to accept help or demonstrate vulnerability. Marianismo is the female counterpart of machismo. It is based on the worship of Mary who is both virgin and Madonna in the Catholic religion. The term connotes the chaste and submissive female whose purpose is to bear children and be self-sacrificing, especially when it comes to her husband and family.

Consequently, behaviors associated with HIV/AIDS such as homosexuality and prostitution tend to be viewed as impure, sinful and evil. Therefore, HIV/AIDS is viewed as a punishment from God for sexual transgressions. This belief would undoubtedly affect how others respond to PWHA. As mentioned earlier, culturally based beliefs regarding health and illness have roots in the world of spirits and humors. If sickness and suffering is believed to come to those who engage in sinful acts, HIV/AIDS then afflicts those who have been sinful and impure. Not so explicit is the fear that PWHA is judged homosexual. Becoming the target of *bochinche* could then put one at risk of being seen as homosexual, especially since homosexual behaviors are still thought to be strongly linked to HIV/AIDS. Thus, the drug user living with HIV/AIDS and his family struggle to keep his/her illness secret for fear of being thought of as homosexual. In the Puerto Rican community, being perceived as homosexual is far more shameful than having HIV/AIDS. "Sharing needles, that's how I got it. I'm not a fag. God, people talk." Another participant stated, "Families worry about what others will say. Before you know it, the whole 'barrio' has judged you, diagnosed you and buried you."

The religious and spiritual beliefs which are central to the Puerto Rican individual's reality strongly influence the Puerto Rican's attitude towards prostitution, homosexual activity, and HIV/AIDS. These religious and spiritual beliefs often stimulate PWHA's fantasies about retribution. It is as if HIV/AIDS represents the guilt and shame of all past sins. The fear is that *bochinche* will seal their damnation because this time they have gone too far. HIV/AIDS is the stamp on "the ticket to hell". They are beyond redemption. An uninfected participant who cared for her mother living with AIDS described this painful and conflicting experience, "My grandmother would be angry with my mom for being infected and call it the Demon's disease. She's very Catholic. Maybe that's where that demon stuff came from. But it would break my mother's heart to hear that." Rejection is

understood in terms of retribution. Another participant stated, "They reject us because the Bible says this or that. It's a sin."

It is also believed that an imbalance of body humors can cause illness. This imbalance can occur when impurities enter the body. These impurities can be transmitted through body excretions, saliva, and coughing. In the case of HIV/AIDS, what seems to be coughed or expelled is not a germ. It is instead something impure which seems to be equated with bad or evil. Therefore, if PWHA are viewed as evil, full of impurities, and culpable, one can begin to understand the intense fear this community has of HIV/AIDS. One can also understand why families continue to deny a member has been afflicted with HIV/AIDS. More significantly, we can appreciate the tremendous psychological stress experienced by the infected person as he/she faces the fear of being rejected and abandoned by others.

As PWHA reflect on their future and the prospect of facing death, they experience a combination of resignation, anger and fear. Sadness also emerges as they look back at the people they have lost. Loss of potential, poor choices, shameful acts, and death before fulfillment give rise to much regret for PWHA. "It hurts me when I think about all the people I've hurt." They also live with a sense of impending doom. "For us [Puerto Ricans] if you have HIV/AIDS you're going to die. It's a matter of time." Consequently, there is a wish to avoid talking about the future; yet intrusive thoughts about death and dying are a daily psychic battle. Death means not knowing until Judgment Day if one's sins will be forgiven or if one will be condemned to hell. Therefore, suffering does not end with death. Living in fear of dying a horrific death only to be also punished after death triggers angry and helpless feelings which often result in fantasies about suicide as a way of ending this life's suffering. One participant despaired, "Before it gets me I will take an overdose." Another participant stated, "My brother gets upset when I tell him that when the time comes I'll take my life." It is important to note that what is underlying the anger is the fear of dying alone without family support and comfort. Added to that is the shame associated with the wish to have others take care of them.

Turning to religion appears to free some PWHA from the despair of not knowing what will happen in the end. While not necessarily religious, the belief in a higher power and life after death are strongly held beliefs by most of the PWHA in my study (Roldán, 2003). For many participants, drugs were a way to escape the painful realities of their lives. Although some PWHA did turn

back to drugs as way of coping with fear and anxiety, some turned to their faith to ask for forgiveness in the hope they will be redeemed as they face the painful realities of their illness.

Also, fear of *bochinche* has had a profound impact on the way Puerto Rican families are responding to HIV/AIDS. Fear and *bochinche* are inextricably connected. Beliefs about the causes of HIV/AIDS fuel the fear of *bochinche* which drives the family and PWHAs away from each other. Fear of *bochinche* is a cultural phenomenon which functions as a metaphor for the HIV/AIDS illness in the Puerto Rican community. The greater fear is of becoming infected with *bochinche* which will destroy PWHAs and his family should his/her diagnosis be disclosed. Fear of *bochinche* also serves another function. It pushes the HIV/AIDS illness into the supernatural world that is malevolent and helps to explain the contradictions among cultural standards (Harwood, 1977). *Bochinche* allows family members and the community to distance themselves from the problem. As one participant said, "They are in the dark – ignorant."

In summary, a central assumption in this article is that a compelling cultural phenomenon exists in the Puerto Rican community underlying the stigmatization of HIV/AIDS. It is strongly linked to the culture's deep religious and spiritual roots that seem to take hold within the context of the meaning Puerto Ricans give to the HIV/AIDS illness. These roots have pushed the HIV and AIDS illness into the realm of sin and evil. This culture's inability to condone the shameful and sinful behaviors associated with HIV/AIDS, the fear of casual transmission, and the fear of *bochinche* have driven many PWHAs to keep their diagnosis secret.

Most still believe that HIV/AIDS is easily transmitted, that it is contracted when one engages in sinful behaviors such as homosexuality or prostitution, and that it is a death sentence. Because there is enormous shame and dishonor associated with the HIV/AIDS illness, families tend to respond uncharacteristically toward their infected member. Families who ordinarily value family ties, unity and intense relationships break down. They reject their infected member because now this member has crossed the threshold of what is acceptable and tolerated in this culture.

If HIV/AIDS is viewed as a punishment from God for sexual transgressions, the devastating effects of the stigma attached to HIV/AIDS in this community put PWHAs and his family at high risk of being ostracized, rejected and humiliated should their illness be disclosed to the broader community (*bochinche*). Given that the

Puerto Rican community serves as an extended family to most Puerto Rican immigrants and that many rarely come in social contact with communities outside of their own, feeling accepted and respected in one's community is a matter of survival.

Lastly, I assert that HIV/AIDS prevention programs have failed the Puerto Rican community because they have not tailored interventions that are consistent with the Puerto Rican culture's values and beliefs. Programs must validate Puerto Rican PWHAs' cultural experience and encourage behavioral and attitudinal changes within that context. That is, families cannot pull together and respond in a typical way if they are afraid for their own physical and emotional well being. Recognizing and addressing this community's strong anti-homosexual attitudes, beliefs about health and illness and the roots to the stigma attached to HIV/AIDS is critical to any effective HIV/AIDS prevention program in the Puerto Rican community.

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AIDS-Related Stigma and Health Professionals in Puerto Rico

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Abstract

This study addresses an important issue in the AIDS epidemic in Puerto Rico: AIDS stigma among health professionals and health profession students. AIDS stigma has been documented among health services providers such as doctors, nurses, psychologists, and social workers. It has detrimental effects of the services provided and the lives of people living with HIV/AIDS (PLWHA). The main objective of this study was to explore AIDS stigma manifestations among a sample composed of eighty health professionals and health profession students who participated in in-depth qualitative interviews. Four thematic categories stemmed from the data analysis process. These addressed the following subjects: social manifestations of stigma, stigma manifestations in the workplace, use of sensitive information to control PLWHA, and surveillance of PLWHA. Participants manifested instances of stigmatization they had witnessed in their work and training scenarios. Furthermore, they elaborated on the need to place effective surveillance mechanism on PLWHA in order to control the epidemic.

Keywords: Acquired Immune Deficiency Syndrome; stigma; health professionals; Puerto Rico.

El Estigma Relacionado al SIDA y los Profesionales de la Salud en Puerto Rico

Compendio

Este estudio aborda un tema de importancia en la epidemia del VIH/SIDA en Puerto Rico: el estigma que emana de profesionales de la salud y estudiantes de dichas profesiones. El estigma relacionado al VIH/SIDA se ha documentado entre profesionales de la salud de la medicina, enfermería, psicología y trabajo social. El mismo tiene efectos detrimentales en los servicios provistos y las vidas de las personas que viven con VIH/SIDA (PVVS). El objetivo principal de este estudio fue explorar las manifestaciones del estigma relacionado al VIH/SIDA en una muestra de ochenta profesionales de la salud y estudiantes de profesiones de la salud que participaron en entrevistas cualitativas a profundidad. Cuatro ejes temáticos emanaron del análisis de las entrevistas. Estos abordaron los siguientes temas: manifestaciones sociales de estigma, manifestaciones de estigma en sus escenarios de trabajo, uso de información sensible para controlar a las PVVS, y la vigilancia de las PVVS. Las personas participantes describieron manifestaciones de estigma que habían presenciado en sus escenarios de trabajo y adiestramiento. Además, proveyeron descripciones elaboradas sobre la necesidad de implantar sistemas efectivos de vigilancia sobre las PVVS para controlar la epidemia.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; profesionales de la salud; Puerto Rico.

The Island of Puerto Rico is located in the Caribbean, between the Caribbean Sea and the North Atlantic Ocean, and to the east of the Dominican Republic. For centuries it was inhabited by aboriginal people and in 1493 it was claimed by the Spanish Crown following Christopher Columbus' second trip to the Americas. In 1898, after 400 years of colonial rule that saw the indigenous population nearly exterminated and the inclusion of African slave labor introduced, Puerto Rico was conceded to the United States as a result of the Spanish-American War. Puerto Ricans were granted American citizenship in 1917, and popularly elected governors have served since 1948. In 1952, a constitution was enacted providing for internal self-government while the Island remains a commonwealth associated with the United States of America and subject to federal law (Central Intelligence Agency, 2004). Puerto Rico's population is 3,808,610 as of the US Census carried out in 2000 (US Census Bureau,

2000). It is in this context that the HIV/AIDS epidemic plays out. A country with strong Latin American roots, enmeshed in the social and cultural context of the United States of America.

Puerto Rico and the HIV/AIDS Epidemic

Although Hispanics comprised just 13.7% of the US population in 2003, they accounted for 20.3% of new AIDS cases reported that year, a proportion that has remained steady over the past five years. Hispanics represented 19.9% of people living with AIDS at the end of 2003 (Health Resources and Services Administration [HRSA], 2005). These numbers evidence how hard the epidemic has hit the Hispanic population, Puerto Ricans included.

As of today, there are an estimated 2.1 million PLWHA in Latin America and the Caribbean. Around 300,000 people contracted HIV in 2004, and at least 130,000 died of AIDS in the same year. The Caribbean has the second highest rate of HIV infection in the world after sub-Saharan Africa, with 440,000 PLWHA (International HIV/AIDS Alliance, n.d.). In Puerto Rico itself, the numbers are alarming. Almost 30,000 cases of AIDS were confirmed as of March, 2004 (PASET, 2004). Of those cases, 18,370 have died. The most common means of transmission

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among male adults are needle sharing for drug use (54%), unprotected homosexual activity (21%), and unprotected heterosexual activity (14%). Among females the main means of transmission are unprotected heterosexual activity (60%) and needle sharing for drug use (37%). In total, the most common adult/adolescent means of transmission were needles sharing (50%), unprotected heterosexual activity (24%), and unprotected homosexual activity (17%).

These numbers are important because they show the epidemiological face of the disease. Puerto Rico lives on the boundaries on Latin America and the United States. On the one hand it lies in the second most affected geographical region of the world (the Caribbean), and on the other it is home to many of the most disproportionately affected minority groups of the United States (Hispanics). Still, the social implications of living with the disease reveal a more human side of the epidemic that surpasses numbers. HIV/AIDS continues to negatively impact the lives of those who live with the disease and makes daily life even harder. One of the main obstacles that PLWHA face is the existing manifestations of AIDS-related stigma which is very present in Puerto Rican society (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2004).

What is Stigma?

The concept of stigma appears in Ancient Greece, where it was used to describe a mark in the body or a tattoo on the skin of a person. This was evidence of the person's participation in a negative action and the identification of a person that needed to be avoided (Crawford, 1996). It has also been defined as a mark printed in a supernatural way on the bodies of saints, an imposed mark with incandescent iron as a symbol of a penalty or slavery, and as evidence of a bad reputation (Real Academia Española, 1992). Stigma is also defined as a social construction associated to the recognition of a difference that is based on a characteristic or a mark and the subsequent unworthiness of the person that has it (Dovido, Major, & Crocker, 2000). These definitions reflect the basic concepts of the notion of stigma. These are: 1) stigma implies a mark or body delimitation with a negative meaning; 2) these marks reflect a non desirable aspect of the person that have them; and 3) stigma has negative implications for the person that has it (Varas-Díaz et al., 2004).

It is also vital to address Erving Goffman's (1963) ideas about stigma, since his work is widely credited with providing the theoretical underpinnings that frame most stigma research (HRSA, 2003). For Goffman, stigma is an attribute that is deeply discrediting within particular social interactions. Due to this negative mark that fosters stigma, the stigmatized is considered almost inhuman. Goffman identified three types of stigma: 1) body abominations; 2) individual blemishes of character; and 3) the tribal stigmas. Body abominations are based on physical deformation of a particular person. For example, people that lack any part of their body can suffer this type of stigma. Individual blemishes of character are related to the way a person is or how he/she behaves. For

example, people that have mental disorders, are imprisoned, or have drug and/or alcohol addictions can suffer from this type of stigma. Finally, tribal stigmas are transmitted through lineage by being part of a racial, ethnic, national, religious, or other groups.

In their work, Varas-Díaz et al. (2004) summarize some of the most important characteristics of the concept of stigma. These are: 1) the stigma is a negative mark with an important bodily component; 2) stigma is related to the interpretation of both the stigmatized and the stigmatizer; 3) when stigmas are developed, ideas regarding the devalued nature of that person are fostered; 4) the stigmatizing process has primarily negative consequences; and 5) there are generalized ideas about stigmatized people in our society. These definitions have served to develop a better understanding of the stigma surrounding HIV/AIDS.

AIDS-Related Stigma

The HIV/AIDS epidemic has fostered several responses in society which include prejudice, fear, and even in some occasions, hysteria (Kelly, St. Lawrence, Smith, Hood, & Cook 1987). The negative interpretations of HIV/AIDS and PLWHA have been coined as AIDS-Related Stigma. This term reflects the magnitude of the stigma associated to HIV/AIDS (Herek & Glunt, 1988). This type of stigma is directed towards people that are perceived to be infected with HIV, without taking into consideration if they really are infected or if they manifest AIDS symptoms (Herek & Glunt, 1988). Therefore, people associated to HIV/AIDS by work or family relations can be stigmatized, even when they are not PLWHA (Snyder, Omoto, & Crain, 1999). Herek and Glunt (1988) discuss two major sources of this stigma: the identification of AIDS as a deadly disease and the association of AIDS with already stigmatized groups, especially gay men.

Diseases associated with the highest degrees of stigma share common attributes: 1) the person with the disease is seen as responsible for having it; 2) the disease is both progressive and incurable; 3) the disease is not well understood among the public; and 4) the symptoms cannot be concealed. HIV infection fits this profile (HRSA, 2003). People infected with HIV are often blamed for their condition. Second, although HIV is treatable, it is nevertheless an incurable and progressive disease. Third, HIV transmission is not well understood by many in the general population. Finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related may not be. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction (HRSA, 2003).

The Consequences of AIDS-related Stigma

AIDS-related stigma poses threats to the physical and psychological well-being of PLWHA. AIDS-related stigma has multiple consequences (HRSA, 2003). These are: 1) the deterioration of interpersonal relationships; 2) the manifestation of negative emotions; 3) adverse effects to health as a consequence of the rejection of the HIV antibody test; 4) anxiety; 5) depression; 6) guilt; 7) loss of support; 8) isolation; 9) difficulties with family dynamics; 10) emotional or physical violence, and (11) the deterioration of relations with health care providers. Other negative consequences of

AIDS stigma include: 1) the development of new infections as a consequence of people deciding not inform others of their condition; 2) loss of health insurances; 3) social discrimination; 4) loss of employment; 5) problems accessing health services; 6) stress related to hiding the condition; and 7) the development of discriminatory policies by governments (Herek, 1999; Leary & Schreindorfer, 1998; Varas-Díaz et al., 2004).

The consequences of AIDS stigma are worsened when it emanates from sectors of the population that are of vital importance to PLWHA. One such case is AIDS-related stigma manifested by health professionals which can limit access to services that are essential for the quality of life of PLWHA.

AIDS-related Stigma and Health Professionals

Having access to health care services can be a problem for PLWHA because health scenarios themselves can be a source of stigma. Research from early on in the epidemic evidenced that health care providers' fear of contagion and death had negative effects on their attitudes toward and treatment of PLWHA (HRSA, 2003). These attitudes were largely based on worries related to their vulnerability to the infection (All & Sullivan, 1997). Researchers have attributed stigmatizing attitudes among health professionals to lack of contact with PLWHA, fear of infection, and anxiety related to death (Weinberger, Conover, Samsa, & Greenberg, 1992). Fear of infection has been documented even among providers that are aware of universal precautions to avoid infection in the workplace (Wallack, 1989). These attitudes can lead to denial of services and condemnation of sexual activity and drug use (McCann, 1999).

Still today, some health professionals avoid treating PLWHA and evidence of stigma continues to emerge from survey research and anecdotal reports. As part of the community in general, these professionals are susceptible to a lot of the stereotypes and biases that characterize the rest of the society (All & Sullivan, 1997; Kelly et al., 1987). The stigmatizing attitudes towards PLWHA among health professionals are unfortunate because it is to these professionals that they frequently reveal their positive status (Sowell, Lowenstein, Moneyham, Demi, Mizuno, & Seals, 1997). AIDS stigma affects the well-being of PLWHA and influences their personal choices about disclosing their serostatus to others (Herek, 1999). These attitudes and stigmatizing situations are also problematic and have negative consequences in the services that PLWHA receive. For example, some studies have documented the unavailability of health services providers to treat PLWHA (Varas-Díaz et al., 2004). In light of these potentially negative consequences the main objective of this study was to explore AIDS stigma manifestations among a sample composed of health professionals and health profession students in Puerto Rico.

Method

In order to achieve the proposed objective of the study we developed and implemented an exploratory design using a qualitative technique. This was done through the

implementation qualitative in-depth interviews with health professionals and health profession students.

Participants

The total sample of the study was composed of 80 participants. We interviewed 80 participants (40 health professionals and 40 health profession students) equally divided among the following disciplines: medicine ($n=20$), nursing ($n=20$), psychology ($n=20$), and social work ($n=20$). The inclusion criteria for the health professionals were: 1) that they were older than 21 years of age; 2) that they voluntarily participated in the study; and 3) being active practitioners of their profession at the moment of the interview; and 4) that they worked in health institutions in which PLWHA could receive services (*e.g.* public hospitals, community based organizations, etc). We developed these inclusion criteria in order to ensure that the professionals could legally consent to participate, that they did so without being coerced, that they could talk about their past and recent work experiences, and that these experiences were in scenarios in which PLWHA receive or could receive health services.

The inclusion criteria for the health profession students were: 1) that they were older than 21 years of age; 2) that they voluntarily participated in the study; 3) that they were health profession students at the moment of the interview; and 4) they had completed at least one practice in a health care institution at the moment of the interview as part of their training. These inclusion criteria ensured that students could legally consent to participate, that they did so without being coerced, and that they could talk about their past and recent training experiences. Students from the fields of medicine and psychology were recruited at a graduate level (MA, PhD or PsyD) since these degrees are required in Puerto Rico to practice each profession. Students from social work and nursing were recruited from both graduate and undergraduate levels since both professions can practice with such degrees.

The demographic data from participants can be seen in Table 1. Most of the sample was composed of females as in most of these health professions (psychology, nursing and social work) they outnumber men. Half had received some kind of HIV related training and had provided services to PLWHA at some time. Seventy five percent of participants knew someone living with HIV/AIDS. The mean age for the sample was 32. The most common range for income was between \$20,000 and \$30,000 $n=47$ (59%).

Selection and Screening

The research team recruited participants in several scenarios which included the following: government agencies, public housing projects, public hospitals, public schools, and public and private universities. The initial steps for the recruitment were telephone calls to the directors of these institutions to explain the purpose of the study and to request permission to

Table 1
Demographic Data for all Participants in the Study

Variable	Stage 1 (Qualitative interviews)	
	F	%
N	80	100
Gender	Male	30
	Female	70
HIV training	41	51
Services to PLWHA	39	49
Knew PLWHA	60	75

Note: * Only 228 participants answered this question.

invite employees and students to participate in the study. After we obtained permission, the research team personally identified potential participants in order to ensure that they did not feel obliged by supervisors or teachers to participate in the study.

We explained to each potential participant the purpose of the study and we invited them to participate. Those that wanted to take part completed a consent form explaining the nature of the study, their participation, and the measures in place to ensure their confidentiality. The consent form also mentioned the following issues: 1) the benefits and risks of their participation, 2) the time that their participation required, 3) the possibility of ending their participation at any time, 4) the possibility of requesting psychological services if they needed them due to their involvement in the study, and 5) the right to receive the results of the study.

Instruments

We developed several instruments as part of the study which are described here. These were the following: screening form, socio demographic data questionnaire and the qualitative in-depth interview guide.

Screening form - This screening form served as a guide for recruiters to ensure that all participants met the inclusion criteria previously described. Each form included a question for each of the criteria and contact information (in the case of the qualitative interviews). This form was completed with participants for both the qualitative and quantitative stages.

Socio demographic data questionnaire - This self-administered questionnaire included 30 questions addressing variables such as gender, age, sexual orientation, marital status, area of residence, employment status, professional training, and income. The questionnaire version completed by health profession students also included questions related to their current training scenario.

In-depth interview guide (Varas Díaz, 2005) - This interview guide served to maintain a minimum level of uniformity in the subjects that were explored during the interviews. This guide was composed of questions addressing seven subject areas: 1) training and work experiences related to HIV/AIDS; 2) definitions of illness; 3) personal perception of the HIV/AIDS epidemic in Puerto Rico; 4) potential contributions of health professionals

and students in issues related to the lives of PLWHA; 5) perception on society's opinions regarding PLWHA; 6) health professionals' opinions regarding PLWHA; and 7) the bodily dimensions of the HIV/AIDS epidemic. The guide included specific instructions for the person interviewing to follow.

The guide of the interview was evaluated by a panel of six judges that included researchers in the area of HIV/AIDS and a PLWHA in order to establish ensure the appropriateness of its content. After incorporating their feed back we carried out a pilot study with eight people (four professionals and four students). The results of the pilot study evidenced that the participants understood the questions and they were able to answer them without difficulties.

Procedures

As an initial step for the implementation of the interviews, interviewers participated in formal training sessions on the following subjects: 1) AIDS stigma definitions; 2) the role of stigma in the HIV/AIDS epidemic; 3) ways in which stigma is manifested among health professionals; 4) ethical dimensions of the study; 4) adequate forms of recruitment; and 5) implementation of the interview, specifically the phrasing of the questions and the use of follow up questions when needed.

When the participants were recruited, a date for the interview was scheduled in a place of the participant's choosing. That place needed to meet the following requirements: 1) be a private place; 2) without interruptions; and 3) in which the person that was interviewed felt comfortable. At the moment of the interview the interviewer explained once again the purpose of the study and the nature of their participation. After the person agreed to participate, they signed the consent form, completed the socio demographic data questionnaire, and proceeded to participate in the interview. The interviews lasted on average an hour and a half. When the interviews were completed, they were transcribed by people already trained and submitted to a qualitative analysis.

Analysis

The information gathered through the in-depth interviews was subjected to a qualitative analysis. It was our interest to understand how the participating health professionals and students perceived PLWHA. In order to achieve this goal the interviews were transcribed through a supervised

process to ensure fidelity (Poland, 2002). The research team met on a weekly basis to identify themes or patterns in the data related to our objectives. Once those themes were identified the research team searched for texts that evidenced them. All selected texts were discussed to ensure that they were in accordance with the themes they were associated to (Phillips & Ardí, 2002). Once these texts were selected they were coded with the use of qualitative analysis computer software (Nudist Nvivo V.1.). All themes were finally discussed by the research team and descriptions of each were generated.

Results

We organized the participants' verbalizations into four categories that evidenced several forms of stigmatization of PLWHA. In Table 2 we describe each of these categories. In this section, we present verbalizations from the interviews that encompass each of the categories. In order to identify the presented texts we use the following codes: PM (Professional Medicine); PP (Professional Psychology); PSW (Professional Social Work); PN (Professional Nursing); SM (Student Medicine); SP (Student Psychology); SSW (Student Social Work); and SN (Student Nursing). We also used M to represent males and F to represent females, I for interviewers and P for participants.

Social Manifestations of Stigma

In this category we included verbalizations addressing participants' perceptions of society's stigmatizing opinions towards PLWHA. Participants understood that Puerto Rican society has overall negative opinions towards PLWHA. They indicated that society's stigma manifestations occurred as a consequence of lack of education and information. They also mentioned that stigma manifestations are related to the association of HIV to homosexuality, drug use, promiscuity, divine punishment, fear of contagion, and the influence of the

media. These were answers to the question: What do you think is society's general opinion about PLWHA?

P: "...that they are people that are ill. People that have the potential to keep infecting others. People that got infected because they were doing things that they shouldn't be doing... and that they are going to die". (PSW/F)

P: "This woman lived with her son. Her son was an HIV patient. When she discovered it, she put plastics on all the furniture. She gave him plastic dishes to eat out of, with plastic utensils, and plastic cups. When her grandchildren came to visit her he couldn't be in the house or had to stay in his bedroom. I understand this is total ignorance to what HIV is. In the public housing project where I work I saw one of the clients have a fight with another girl. The other girl yelled "Go away. You are putrid". Those are comments that you see and there is still a lot of discrimination, a lot of rejection from the community and family". (PSW/F)

P: "...A lot of them think that they have that illness because they were asking for it, because they did not protect themselves. That they wanted to do whatever they wanted without being careful. A person that is ill cannot be touched... it is like having them isolated. That is what most people think". (SN/F)

P: "...that they are depraved, that they are promiscuous, that they are people that haven't done good in their life. That they are drug users or that they are gay.

I: And why do you think opinions are like this? Why do people think this way?

P: I think that the press and the media, maybe due to sensationalism, they focus on characteristics associated to the patients that are not necessarily the ones that respond to a reality". (PP/F)

I: "Have you witnessed first hand an event that you understand was prejudiced for a PLWHA?"

P: "Yes, a person that worked at Burger King that had HIV and worked making hamburgers. Someone from the hospital went and saw him. The person told the manager, or something

Table 2.
Description the Categories of Analysis

Category	Description
Social manifestations of stigma	In this category we included verbalizations addressing participants' perceptions of society's stigmatizing opinions towards PLWHA.
Stigma manifestations in the workplace	In this category we included verbalizations addressing participants' descriptions of events in which stigma was manifested in their work or practice scenarios.
Use of sensitive information to control PLWHA	In this category we included verbalizations where participants described the need to collect sensitive information from PLWHA in order to control them and the epidemic.
Surveillance of PLWHA	In this category we included verbalizations where participants described the need to establish surveillance over PLWHA in order to stop the epidemic.

like that, and the manager put him to work cleaning. The wages were the same, everything was the same, but he did not want to... This is a true story, something that someone told me last week. The person felt so bad that he took the first weeks mopping the floor and the next week he resigned from his position". (SP/F)

Stigma Manifestations in the Workplace

In this category we included verbalizations addressing participants' descriptions of events in which stigma was manifested in their work or practice scenarios. Participants made reference to examples to evidence the stigma manifestations that can be seen in health scenarios such as hospitals and clinics. During the interview they mentioned feeling resistant to mention these examples since they were compromising the professional ethics of their workplaces, as well as their colleagues' conduct. Even while facing this difficulty during the interview, the majority of the participants agreed that discrimination exists in health scenarios. The examples provided by participants were related to discriminatory acts and opinions of other health professionals, and not themselves. They made reference to how stigma is manifested by lack of training and by isolating patients.

I: "How do you think these attitudes manifest themselves in the work scenarios?"

P: "They feel fear. If they get pricked (with a needle). I had a case like that happen to me personally. I needed some blood tests and the lady got pricked with the needle she used to take my blood. She pricked herself and she said to me: 'You don't have HIV/AIDS right?' And I said to her: 'Well... there are my blood tests if you want to analyze them'. I mean, there are professionals like that". (PSW/F)

I: "Do you think that health profession students should receive specialized training in HIV?"

P: "Yes. Because sometimes when you say 'I have an HIV patient in the floor' then they all get crazy. It is the same when you have a tuberculosis patient. Everyone gets crazy with the tuberculosis patients". (SM/M)

I: "Do you think that discrimination does not exist in the health scenarios or is it just hard to spot?"

P: "I know that there are people that have said... they go to a public hospital or to an office and since they know that the person is HIV positive, a drug user, or lives in public housing, they make the person wait until the end of the day. When people arrive they get served at the end of the day, to see if the person gets tired and leaves. This can be a form of discrimination". (PM/M)

I: "Have you been in situations where discrimination is evident in health scenarios?"

P: "Yes. People that are drug addicts or drug users sometimes arrive and they are left to the side. I have seen doctors that do not provide services for them. They say 'I am not going to serve them' and do not do it". (SP/F)

P: "...we also have two isolation rooms that are used when there are no beds in medicine.... For me it is a condition that it is seen as very threatening. Even though we have the

preparation and know how to protect ourselves of the illness, there is a lot of fear. It is something, I would, say emotional. For example, in the morning I come and they tell me that I have been assigned from rooms 25 to something. Well... in that bedroom is isolation and there is an AIDS patient. Well... it is like, I preferred not to have it. It is not that I am rejecting the person, but I would prefer not to have to intervene". (PN/F)

Use of Sensitive Information to Control PLWHA

In this category we included verbalizations where participants described the need to collect sensitive information from PLWHA in order to control them and the epidemic. Unlike both categories previously described in which stigma emanating from others was mentioned, in this category instances of personal stigmatizing perspectives are evidenced.

The participants suggested the need to collect information regarding: age, sex, mean of infection, time that the person has lived with the illness, full name, address, social security number, medical regime, work scenarios and level of education. Participants mentioned that information could be used for prevention efforts, to provide medicines and measure their effectiveness, and to keep updated for statistics regarding the epidemic. They also mentioned the need to use this information as part of a census mechanism to understand if the epidemic has improved or worsened. Although described as information that would be used for beneficial purposes, participants recognized that it would entail in some cases interfering with the right to privacy of PLWHA. What was most evident in all the verbalizations was the perceived need to create a detailed data bank with the profiles of PLWHA as a way to control the epidemic.

I: "Do you think that the Health Department should create a register of the new cases and of the cases that already exist in the country?"

P: "I think so, yes. I also think that the basic information of the person should be collected: name, address, social security, and etcetera. I would say it is important to know how that person got the virus because that will give us information that we need to try to prevent it in the future". (PSW/F)

I: "Do you think it is important to ask that person their name and the address?"

P: "Yes. Because that way if by coincidence it is necessary to go to their houses you have the address to go to. Because you are not going to a municipality (town) to say 'X person' is like this: 'this hair color, this skin color...'" (PN/F)

I: "If a man goes to have the test, what information do you think is important to gather from his history?"

P: "...if he is married, what is his sexual preference, if he has a partner, if he has tattoos, with how many partners he has been with in the last years, if he knows who he has been with. The most information possible".

I: "Why do you think it is important to know his sexual preference?"

P: "...Because that way, I mean, if this is for a prevention plan, to be able to control. One will be able to guide people that are involved with that human being". (PP/F)

Surveillance of PLWHA

In this category we included verbalizations where participants described the need to establish surveillance over PLWHA in order to stop the epidemic. Participants indicated different ways of supervising PLWHA in order to control their behaviors so they do not infect other people. For example, this surveillance would be useful to determine if PLWHA could adopt a child, regulate the sexuality of PLWHA, address the issue of children with HIV in schools, and to determine types of work that they could engage in. One participant went as far as to recommend mandatory HIV testing for all people who are going to get married.

I: "In some cases PLWHA want to adopt children and raise them. What do you think the Family Department should do with these cases of adoption?"

P: "To investigate both parts, the place where they live, how they live, what they do, their occupation, all of that because if they are going to give a child to this family, it has to be a responsible family, that are oriented about their illness. So they do not... a baby that is not guilty of anything... that he gets infected. But mostly to investigate the place, how they live". (SN/F)

I: "Even though there are fewer cases of children that live with HIV/AIDS, let's imagine that you have a son or a daughter and that you know that in the same school there is another boy that has HIV. Would you be worried about the security of your son?"

P: "...I don't think he will be infected with AIDS only for sharing with another boy."

I: "Would you say something to him to protect himself?"

P: "Let us suppose beforehand that I know that the kid has AIDS and my son doesn't know it. I would not tell him because then my son, for example, would fear the kid. But I would explain about the illness and about the precautions, etc. But I do not think it would create a danger to share with him because he is a school peer".

I: "Would you recommend something to the school? Would you recommend something to the teacher?"

P: "Yes, because I would be very attentive because... suppose they fight or there is physical contact that involves cuts and wounds. In that sense, they should have supervision". (SP/F)

I: "Do you think a person that is HIV+ should avoid having sex?"

P: "...doesn't have to avoid them, because the right that they have as human beings cannot be avoided. But, having the precautions... First they have to reveal it to the person that has the sexual relationship and use protection, and take precautions. The maximum of protection they can have... try to have the same partner". (SM/F)

I: "Do you have any another comments before we finish the interview?"

P: "Yes. I think that the Health Department should work with making the HIV tests compulsory for people that are going to get married". (PM/F)

Discussion

We would like to begin our discussion of the findings by addressing one methodological issue of importance. These interviews were hard to carry out. Social desirability was evident during the process as participants did not want to be identified as stigmatizers of PLWHA. Still, we feel that we were able to assess manifestations of stigma by implementing detailed and in-depth interviews. Taking this fact into consideration it is understandable that the first two categories of the analysis were related to opinions and actions that "other people" manifest. For example, in the first category we can see how participants were mostly concerned and fluently described how they perceive "society" stigmatizes PLWHA. In the second category, they were able to be more detailed and express instances of AIDS stigma they had witnessed in their work scenarios. Still, this transition from society to health professionals was difficult for participants and interviewers, as the first expressed feeling that they were reporting inappropriate information about colleagues of their work or training scenarios.

As we dwelled deeper into personal opinions regarding PLWHA we were able to examine two specific instances related to AIDS stigma. These were related to the supervision and surveillance of PLWHA. Information seems to be a major concern for the interviewed sample. Specifically, gathering personal information from PLWHA. Although some of this information is currently gathered in Puerto Rico as part of the Health Department's surveillance system (mean of infection, age, gender), other information suggested went far beyond what is collected today, and would potentially infringe on the privacy of PLWHA. This included names, addresses, social security numbers and even levels of education. Although participants described that the information would be used for prevention efforts, the potential use of such data is worrisome.

This worry regarding the use of sensitive data from PLWHA was corroborated when participants manifested the need to supervise and regulate those living with the virus. Instances from work scenarios to sexual activity were described as areas that needed to be regulated with the use of the gathered information in order to stop PLWHA from infecting others. The use of sensitive information, in light of these attitudes towards surveillance of the sick, poses a major challenge for PLWHA and a fertile ground for AIDS stigma. Participants seemed to agree that PLWHA were responsible for the spread of the epidemic and that proper surveillance of their activities would be an essential prevention effort. These views on prevention regularly violate the rights of PLWHA and foster stigma.

These findings must be understood in light of the ongoing discussions, or lack thereof, regarding the HIV/AIDS epidemic in Puerto Rico. Two main issues stand out: 1) government officials have publicly stated that the epidemic is currently under control, and 2) funding for HIV medication is provided by the United States under the Ryan White Care act. These two facts have fostered little public discussion regarding the ever-growing

nature of the epidemic in the Island. Furthermore, the availability of medicine with relative ease (in comparison to other Latin American countries) has promoted complacency among many that seem to think that the worst part of the epidemic is far behind us. Within an epidemic that is perceived as being under control and with the alleged "main necessity" of PLWHA financed by the United States, it seems evident to participants that the only real need left would be to control those that already have HIV in order to completely stop the epidemic. It is in this rationale that surveillance efforts are a manifestation of stigma in the Puerto Rican context.

As health care service providers and as future professionals it is important to reflect upon issues like the ones presented in this study. As professionals, we have a responsibility towards those that need our services. Due to the growing number of HIV/AIDS cases in Puerto Rico and the world it is imperative to develop strategies to eradicate AIDS stigma. This is particularly important among health professionals and students, since they interact on a daily basis with PLWHA and are expected to provide quality health services. These manifestations of stigma represent an obstacle to the services that they offer. We must continue exploring the different manifestations of AIDS stigma among health professionals to develop culturally embedded interventions that are relevant to their concerns, fears, and stigmatizing attitudes.

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Stigma and Discrimination for HIV/AIDS in the Health Sector: A Polish Perspective

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Abstract

The manifestations of the HIV/AIDS epidemic in Poland, as in other countries, have been received with stigma and discrimination towards those living with the disease. The social implications of stigma are worsened when they hinder the provision of effective treatment by members of the health sector. One such limitation is the perceived need for mandatory HIV testing among hospital patients. This practice can violate the rights of the patient and foster stigmatization. This quantitative study had as its main objectives to survey: 1) the degree of fear of acquiring HIV at work among surgeons and surgical nurses, and 2) the impact of HIV/AIDS training and practical experience with HIV patients on support for a testing policy of admitted patient and those who would undergo surgery among the same sample. Results evidence support for HIV testing of all inpatient admissions in hospitals and pre-operative testing among both nurses and surgeons. Training on HIV matters can be an important factor for lowering support for mandatory testing.

Keywords: HIV; Acquired Immune Deficiency Syndrome; stigma; health care service; hospitalized patients; Poland.

Estigma y Discriminación por VIH/SIDA en el Sector Salud: Una Perspectiva Polaca

Compendio

Las manifestaciones de la epidemia del VIH/SIDA en Polonia, al igual que en otros países, han sido recibidas con estigmatización y discriminación hacia las personas que viven con la enfermedad. Las implicaciones de este estigma empeoran cuando afectan negativamente el ofrecimiento de servicios por miembros del sector salud. Una de estas limitaciones es la necesidad percibida de llevar a cabo pruebas de VIH mandatorias entre pacientes hospitalizados. Esta práctica puede violar los derechos de los pacientes y fomentar estigmatización. Este estudio cuantitativo tuvo como objetivos principales explorar: 1) el nivel de miedo de adquirir VIH en escenarios de trabajo entre profesionales de la cirugía y enfermería, y 2) el impacto del adiestramiento sobre VIH/SIDA y experiencias prácticas con pacientes en el apoyo a políticas de pruebas de VIH compulsorias en pacientes en hospitales y de condición pre-operativa. Los resultados evidencian apoyo a pruebas de VIH en ambos tipos de pacientes entre profesionales de enfermería y cirugía. El adiestramiento sobre temas relacionados al VIH puede ser un factor importante al reducir el apoyo a estas pruebas mandatorias.

Palabras clave: VIH; Síndrome de Inmunodeficiencia Adquirida; estigma; servicios de salud; pacientes hospitalizados; Polonia.

HIV/AIDS became an urgent medical and social problem in the early 1980s. It has been spreading rapidly because of its characteristics and has become a health threat and the most devastating disease humankind has ever faced. HIV spreads making no distinctions by religion, language, ethnic origin, sex, or country base.

Research investigating the psychological experience of people living with HIV/AIDS (PLWHA) indicates that these patients do not suffer only from the physical disease process. They experience emotional agony not only because there is no cure for AIDS, but also because of a public frenzy that ends in blaming the victim. The social stigma attached to HIV and AIDS leads to social rejection of patients. Sontag (1988) pointed out that diseases of unknown cause and ineffective treatment evoke fear and revulsion, and that in North American culture cancer was once the disease of fear and shame. Nowadays, AIDS has replaced cancer, and the experiences of many PLWHA parallel those of cancer patients. Cherry and Smith (1993) have stated

that the literature of social knowledge that explains cancer as a dreaded disease has been transferred to HIV. Such phenomena have been observed in many countries all over the world, among them Poland. HIV is currently a metaphor of "sinful" and "evil", discrediting an individual's claim to be a "moral character" and "one of us".

Stigma and discrimination fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimization (Taylor, 2001). This has an effect on PLWHA as individuals, and on their illnesses, behavior and perception of the health care they receive. In Europe and North America HIV/AIDS is most prevalent in populations that have been disenfranchised by society, including homosexual men and intravenous drug users. Health care workers (HCWs), being human, bring to their medical work their foibles, anxieties, and deficiencies that characterize the human species. Unfortunately, there is no requirement in the medical school of any nation that the physician be sensitive to the problems of disenfranchised groups. When members of these groups acquire an illness related to their behavior, which is frowned upon by many HCWs, it becomes easier for such HCWs to behave in a discriminatory manner (Shapiro, Hayward, Guillemot, & Jayle, 1992).

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An essential question to ask is the degree to which societal prejudices and stigmatization, linking the illness to one or another “specific lifestyle” and “sexual behavior”, influence the health sector. The answer is crucial, because of the power of health professionals in their role of establishing the physical and emotional welfare of PLWHA.

HIV/AIDS in Poland *Epidemiological Situation*

The first report of an AIDS case in Poland was made in 1986. The history of AIDS in Poland began with a homosexual. As a result, the disease was immediately stigmatized by its association with socially disapproved sexual behavior. Since that time, the number of newly registered HIV cases has stabilized at 500-600 persons per year. Data from the National Institute of Hygiene (2005) showed 9 new infections in 1986, 59 in 1988, 809 in 1990, 539 in 1995, 579 in 1997, 527 in 1999, 559 in 2001, and 574 in 2003. By the end of September 2005, there were reported to be 9659 HIV infected people in Poland. Many experts indicate that this figure is far from reality, due to the long asymptomatic period for HIV. Another factor affecting reporting is that individuals who may be infected with HIV avoid screening because they believe that self-disclosure will result in stigmatization. HIV infection is linked in many people's minds with homosexuality, injection drug use, sexual activity, and commercial sex – behaviors that not only make people feel uncomfortable, but also challenge attitudes and values. To disclose that they are sero-positive is difficult for people with HIV/AIDS, because they believe that society will isolate them and their social milieu will threaten them.

About three-thirds of those currently living with HIV/AIDS in Poland are males. The majority of newly detected HIV carriers are men aged 20-29. The main route of transmission is use of injectable drugs; 55% of PLWHA were infected in this way. Unfortunately, the main mechanism of transmission is unknown for about 25%.

A rapid increase in HIV-infected persons in neighboring countries, including Russia, Belarus, and the Ukraine, as well as the rise in importance of heterosexual intercourse as a means of spread, may become threats to the health of the Polish population (National Institute of Hygiene, 2005; Rosińska & Werbińska, 2004).

Myths and Facts

HIV/AIDS is a topic that has unleashed a flood of opinions. Unfortunately, these opinions are often based upon an insufficient knowledge about such a sensitive topic. As a result, people tend to develop unscientific explanations or myths. A major function of a myth is to reduce peoples' fears of personal vulnerability by implying that such events happen only to “other” kinds of people. Myths also provide convenient and over-simplified explanations of complex social issues. When repeated often enough, myths become “conventional wisdom” and may pass for well-established facts. Myths about HIV/AIDS have been particularly hard to dispel (Juszczak & Gładysz, 1999; Sobeyko, 2003).

The arrival of HIV/AIDS in Poland was sufficiently delayed to allow time to prepare society to face the threat. The earliest initiative in prevention came from the Ministry of Health just after the first AIDS case was diagnosed. According to one of their circulars, HIV/AIDS is accepted as a contagious disease and should be so declared. The National AIDS Center as well as programs such as The National Program for HIV – Infection Prevention, and Care of People Living with HIV and AIDS was created to coordinate efforts to combat the infection. Interventions included widespread distribution of condoms, free needle-exchange programs, an anonymous HIV-testing system, and public information about the infection. In recent years, a number of governmental and non-governmental organizations (NGOs) have done much to try to change social attitudes towards PLWHA (Sobeyko, 2003).

At the beginning of the epidemic, HIV/AIDS education was introduced at Polish schools. This education was provided by various organizations outside the Department of Education, including sanitary-epidemiological centers and NGOs, and was financed by the Ministry of Health. At the end of the 1990s, schools implemented HIV/AIDS topics into their own curriculum. Students 13-15 years of age are given one hour of teaching per academic year on “STD/AIDS”, and there is a second hour for older youth on the topic of “Immune Deficiency”. Such educational interventions were associated with some positive changes. Surveys in Poland during 1990 to 2002 showed a significant increase in tolerance towards PLWHA among 15 and 17-year-olds (Gańczak, Boroń-Kaczmarska, Leszczyszyn-Pynka, & Szych, 2005; Woynarowska, Szymańska, & Mazur, 1999).

Nonetheless, AIDS is still a serious social and psychological problem in Poland. Numerous campaigns have concentrated mainly on improving the knowledge of particular social groups, such as youth, persons vulnerable to infection, and medical staff. Unfortunately, adults who have already completed or dropped out of school have not yet been selected as a target population for HIV/AIDS educational campaigns. Furthermore, media, an important potential source of HIV/AIDS information, are reluctant to lead educational actions, and prefer to seek more sensational topics (Izdebski, 2003).

The lack of information and education on HIV/AIDS influences people's attitudes towards the infected. Surveys were conducted in Poland during 1997-1998 on randomly selected, representative groups. It was found that although nearly 90% knew the main routes of HIV transmission, less than 5% knew the prevalence of PLWHA in the community. There was a significant age-difference in the proportion of individuals willing to take care of a relative with AIDS, with almost 66% of 15-17-year-olds willing to do so, compared with only 33% of adults.

Nearly 50% of youth, but only 27% of adults, agreed that there is nothing wrong with homosexuality (Izdebski, 2000). This difference could perhaps be interpreted as

evidence that education early in the school curriculum may lead to change of some homophobic attitudes. On the other hand, there is a general taboo against discussing homosexuality in society, and conservative forces such as the Roman Catholic Church actively oppose more open debate. Although the gay movement has gained a higher profile in some parts of the country, an evident change of social and public attitudes towards sexual minorities has not yet appeared, especially among adults (Staugard, 2000). Homophobic attitudes remain widespread among Poland and are major factor in HIV/AIDS-related discrimination. In illustration, doctors and nurses from all over Poland were surveyed in 1997-1998, and were found to believe that homosexuality is a "social pathology", like drug addiction, alcoholism, and Satanism (Ciastoń-Przeclawska, 2001). In another 1997 survey, 70% of Poles aged 17-59 treated homosexuality as a disease and wanted such persons to be cured. Homophobic attitudes among political leaders are also widely reported. In November 2005, the former head of state Lech Walesa said: "I believe homosexuals need medical treatment". When asked whether homosexuality should be condemned, Polish Prime Minister Kazimierz Marcinkiewicz stated: "It's unnatural. The family is natural and the state must stand guard over the family. If a person tries to 'infect' others with their homosexuality, then the state must intervene in this violation of freedom" (LifeSite, 2005, line 7). Lack of tolerance for homosexuality is not only a Polish phenomenon. A decade earlier, 25% of young people in the United States agreed with the statement that gay men "deserve to get AIDS" (Imperato, 1996).

Health Sector and HIV/AIDS Stigma Legislation

In Poland the right to medical care is guaranteed by article 68 of the Polish Constitution (1997). This means equal access to all publicly financed health institutions. The Charter of Patients Rights cites this article of the constitution as the basis of the right to medical care (Minister of Health and Social Welfare, 1998). The charter has no legal powers and was created simply to inform patients about their rights.

According to Article 30 of the Polish Act on Physician's Profession (1996), the right to medical care means the right to competent care, and that every physician must help a patient whenever she/he requests. It also adds that this obligation is in force when delay could result in death, grievous body harm, health disorder, or in other cases of emergency. This clause could allow a health provider to refuse to treat a patient in the absence of such conditions. Nevertheless, another clause was included to help avoid leaving patients being left without care. If a physician wants to discontinue treatment for a patient, he/she must inform the patient in a timely manner how to obtain care from another physician or health facility.

The Code of Medical Ethics (1993) also imposes the duty of helping any person who asks for it; however, the code also states that where justifiable, the physician is not forced to provide care, except in emergencies. Nevertheless,

the physician must inform his patient about other possibilities for obtaining treatment.

Some physicians refuse to help PLWHA, without consequence. A fragment of a letter by a 30-year-old HIV-infected drug user sent to the United Nations Development Program Office in Warsaw stated: "I had a serious sinusitis, doctors were considering purulent meningitis as a consequence of the basic disease. But they left me without any help, not willing to mess up their hands" (Malinowska-Sempruch, 1997).

Patient autonomy means that a patient has the right to decide about his/her treatment and can refuse consent for any medical intervention. This includes HIV screening. The physician's duty to obtain informed, freely given consent is an obligation established by national and international law.

According to international guidelines for HIV/AIDS and Human Rights, an individual's interest in protecting her/his privacy is "particularly compelling in the context of HIV/AIDS". This is for two reasons: first - mandatory HIV test is invasive, and, second, disclosure of HIV status leads to stigma and discrimination from loss of privacy and confidentiality.

Article 17 of the International Covenant on Civil and Human Rights protects privacy and forbids lawless interference in somebody's private or domestic life, home, or correspondence, as well as lawless attempts on somebody's honor and good name. The Covenant also says that everyone has the right to such protection. Article 8 of the European Convention for Protection of Human Rights and Fundamental Freedoms states that everyone has a right to respect of her/his private and family life, home, and correspondence. Granting these rights means that PLWHA do not have to reveal their infection. These rights also imply the patient's right to anonymous screening for HIV.

Article 47 of the Polish Constitution guarantees the protection of private and domestic life, honor, good name and the right of deciding about personal life. This right is of great importance to PLWHA as it implies many rights for patients and many obligations for medical staff. For the first time informed consent was created in the Polish legal system by the act on Medical Care Centers (1997), article 19.1.3, which states that a patient has the right to consent or to refuse, after obtaining proper information. The Ministry of Health, in Recommendations for Medical Staff (1997), creates more specific requirements for HIV infection, stating that the patient must be fully informed about any plans to screen for HIV and about the nature of HIV infection itself. The physician must obtain the patient's informed consent for such screening and prepare the patient psychologically in the event there might be a positive result. The patient has a right to anonymous screening.

As mentioned above the number of PLWHA is increasing in Poland and all over the world. Many need surgical treatment and the risk of complications after surgery in HIV infected patients is shown to be lower than initially feared (Gerberding, Lewis, & Schecter, 1995). As the consequences of acquiring

HIV infection are so great, most surgeons and nurses working at the surgical suit, where blood exposures are so common, understandably fear acquiring infection. As a result many support controversial policies such as universal preoperative HIV testing, and indeed many support testing of all inpatients (Chapman, Meadows, Catalan, & Gazzard, 1995; Danziger, Abel, Goddard, McGrouther, & Pawson, 1996; Joint Working Party of the Hospital Infection Society and the Surgical Infection Study Group, 1992).

There has been vehement debate surrounding the question of preoperative HIV testing of patients. Opponents, represented by people who are professionally involved in HIV/AIDS problem, state that routine HIV antibody testing of patients is not recommended. The testing is opposed by many because of the civil rights implications of a positive test result and the fear that HIV-positive patients would receive sub-optimal treatment. Testing should be undertaken only on the basis of clinical assessment or where it is in the interest of both: patients and HCWs. The provision of patient's confidentiality and privacy, as well as informed consent for testing is essential. Any argument that more stringent precautions would be put in place for those who are tested as HIV positive would fly in the face of universal precautions, which are meant to prevent the transmission of known and not-known blood-borne pathogens in all instances (Dammani, 2003; World Health Organization [WHO], 2000). On the other hand, medical personnel believes that, dealing with the patient, they have the right to know whether they are at risk for acquiring a potentially fatal infection after exposure to patient's blood. The routine HIV antibody testing would help them to prevent such an infection. They suggest that the knowledge that one of their patients is sero-positive would cause them to use special procedures during operations which would decrease the risk of acquiring HIV infection. According to this view, it is difficult to practice these precautions at the 100% level, 100% of the time (Shanson, 1991; Tyndall & Schechter, 2000).

HIV-antibody testing was implemented in Poland in 1985, just few months after such tests had been required in the rest of Europe. However, regarding this issue, the practice presently existing in Polish hospitals only theoretically fulfils requirements set by legal provisions. Lot of hospitals have implemented HIV testing concerning patients admitted to the surgical wards or admitted for diagnostic procedures. Although there are no requirements or standard protocols for pre-operative and universal testing of all admissions, surgeons often implement their own screening programs, some other permanently review the possibility. Most often the patient is informed about the character of surgical intervention (and about the consent) directly before it starts, usually in very hermetic professional language not understandable for the average person. The consent is given during preparation to the intervention so the patient rarely carefully reads what is to be signed. Regarding how stressed he/she is, it is not fair to call such consent "informed". The

patient is not able to estimate any information given rapidly by the medical staff, often even not by the physician (Sobeyko, 2003). It must be said that such testing is illegal, simply because is not used to make a diagnosis. It appears that the information about serological status of the patient is "indispensable to a hospital" (Juszczak, 1995). It is important to point out that routine screening of all patients admitted to the hospital is an easy way to destroy the patient's life and that is not the purpose of HCW's.

In light of these challenges and difficulties, the main objective of this study was to survey: 1) the degree of fear of acquiring HIV at work among surgeons and surgical nurses from the same surgical wards, and 2) the impact of HIV/AIDS training and practical experience with HIV patients on support for a testing policy of admitted patient and those who would undergo surgery among the same sample.

Method

A descriptive and analytical survey was conducted among doctors (2001) and nurses (2003) from the same wards representing surgical specialities at 4 hospitals located in the city of Szczecin (2 academic, 2 municipal), as well as 4 situated in the County of Western Pomerania. This region of north-western Poland borders Germany and the Baltic Sea and is close to Berlin. Hospitals were selected from a Health Department list using a random-number table. At the selected hospitals, all surgical wards participated.

Data Collection

An anonymous questionnaire was developed for the survey, using guidelines from a study in New York (Lowenfels, Wormster, & Jain, 1989). The survey covered the following areas:

- Part 1: Age and sex of doctor/nurse, type of hospital.
- Part 2: Number of HIV patients treated, attendance to HIV/AIDS training, level of concern of acquiring HIV infection at work, and number of sharps injuries per year.
- Part 3: Opinions about HIV testing of patients, and whether it should be mandatory.

Questionnaires were mailed to hospital administrators between May 2001 and March 2003. The purpose of the survey was explained to respondents and they were assured of anonymity. All doctors and nurses present in the ward on the day when the questionnaire was administered completed it. Each subject was asked to respond independently. No doctor or nurse present at the time of survey refused to participate. The final sample included 132 doctors and 383 nurses. Questionnaires were stored in a locked cabinet and computer data password-protected.

Data Analysis

Data analysis was performed with the use of STATISTICA PL software. Categorical data were analyzed by chi square, chi square test with Yates correction, Fisher exact test (two-side test), chi-square Mc Nemar test, and chi square for trend for more than two categories, with significance at $p < 0.05$. For the

purposes of comparing doctors and nurses with and without training and experience, all doctors/nurses who had had one or more courses together were grouped as having experienced the intervention, and all doctors/nurses with occupational experience of one or more known HIV patients were grouped as positive for that "intervention".

Results

Composition of Sample

The sample included doctors with a median of age 39 years (range 26-73) and nurses 20 to 58 years old, with a median of 36 years. The vast majority of doctors were males ($n=106$; 80%) and 99% ($n=379$) of nurses were female. Eighty per cent of participants were recruited from urban teaching hospitals, 15% from urban non-teaching, and 5% from rural. Location of work included general surgical wards (51%), ob/gyn wards (29%), orthopaedic wards (12%), urology (4%) and otolaryngology (4%).

Training, Experience, History of Injury

One or more sessions of HIV/AIDS training was reported by 49% of doctors ($n=65$) and 77% ($n=296$) of nurses, one or more occupational experiences caring for a known HIV patients was reported by 55% ($n=72$) of doctors and 30% ($n=116$) of nurses. At least one percutaneous injury had been sustained in the preceding year by 98% ($n=129$) of doctors and 46% ($n=177$) of nurses. One per cent of doctors ($n=1$) and 17% ($n=65$) of active nursing staff did not regularly use gloves while in contact with potentially infected material. All doctors and 374 nurses answered the question regarding fear of contracting HIV infection at the workplace. HIV concern was admitted by 96% ($n=127$) of doctors and 95% of nurses ($n=355$) (Figure 1).

Attitudes towards HIV Testing

HIV testing of *all inpatient admissions* was supported by 58% ($n=76$; 95% CI 49-66%) of 132 doctors and 65% ($n=247$; 95% CI 59-69%) of 383 nurses ($p>0.15$) and pre-operative testing of all surgical admissions by 90% of doctors ($n=119$; 95% CI 84-

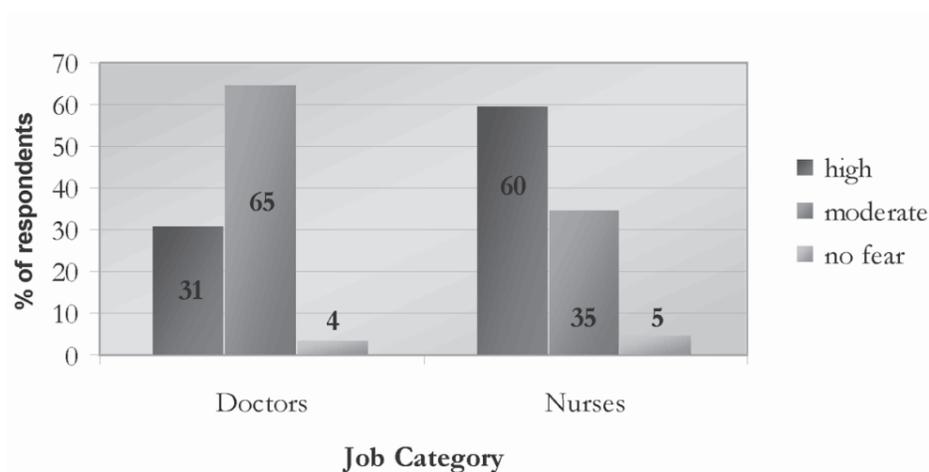


Figure 1. Surgeons ($n=132$) and surgical nurses ($n=374$) by fear of occupationally contracte HIV west Pomerania, Poland 2001-3

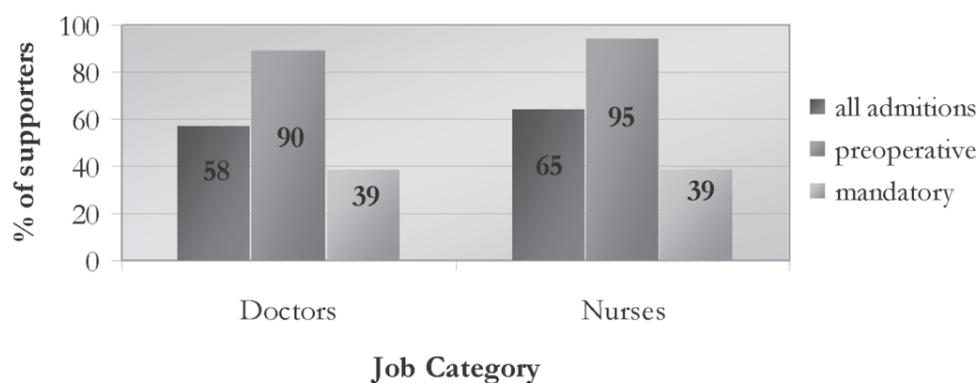


Figure 2. Surgeons ($n=132$) and surgical nurses ($n=383$) by support for HIV testing of all admissions & pre-operatively, west Pomerania, Poland 2001-3

94%) and 95% ($n=365$; 95% CI 92-96%) of nurses - $p<0.04$ (Figure 2). There were statistically significant differences between numbers of doctors/nurses supporting HIV testing of all admissions and pre-operative testing ($p<0.001$) (Figure 2).

Regarding both job-categories (doctors and nurses), there were no differences in support of testing of all admissions by age (doctors: $p>0.07$, nurses: $p>0.26$), number of injuries in the past year (doctors: $p>0.27$; nurses: $p>0.85$). Among doctors there were no differences in support of testing of all admissions by type of hospital ($p>0.99$). Nurses from municipal hospitals were opting less for such testing than nurses from university and rural hospitals ($p<0.002$).

There were no differences in support of pre-operative testing by age (doctors: $p>0.48$; nurses: $p>0.33$), or by number of injuries in the past year (doctors: $p>0.85$; nurses: $p>0.52$), and type of hospital (doctors: $p>0.79$; nurses: $p>0.58$).

Mandatory Imposition of HIV testing

Of all respondents 39% doctors ($n=51$; 95% CI 31-48%) and 39% nurses ($n=150$; 95% CI 35-44%) thought HIV tests for all admissions should be mandatory. There was no differences in support of such testing by age (doctors: $p>0.21$, nurses: $p>0.24$), number of injuries (doctors: $p>0.72$), and type of hospital (doctors: $p>0.75$, nurses: $p>0.05$). Nurses who did not sustain

percutaneous injury in the past year were less supportive for mandatory testing than nurses who reported such injury ($p<0.02$).

HIV Training, HIV Experience, & Attitudes to HIV Testing

Doctors - There was less support of mandatory testing of all admissions by doctors with HIV/AIDS training ($p<0.04$). Less doctors (34%) with experience with at least one patient supported mandatory HIV testing than doctors without such an experience (41%), but the difference was not statistically significant ($p>0.38$). The support for mandatory testing was less among doctors with both training and experience, than among doctors with neither training nor experience (chi square for linear trend comparing doctors with neither intervention to either training or experience, or to both training and experience: 4.040, $p<0.04$) (Figure 3). Confidence intervals included: No intervention - 46% (95% CI 30-62%), experience only - 34% (95% CI 24-46%), training only - 29% (95% CI 19-41%; both training and experience - 24% (95% CI 16-43%) (note: CI were wide for this group, since the sample sizes were relatively small). There was no difference in support of testing of all admissions and pre-operative HIV testing between doctors with and without either or both HIV training or experience (Table 1).

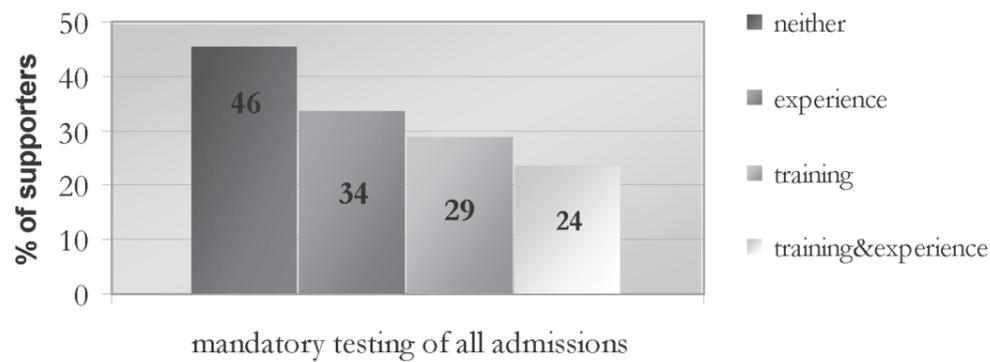


Figure 3. Support by surgeons for mandatory HIV testing of all admissions by HIV training & experience ($n=132$) west Pomerania, Poland 2001-3

Table 1

Support of Various Types of HIV Testing (%) Between Doctors ($n=132$) and Nurses ($n=383$) with and without either or both HIV Training or Experience

Intervention	All admissions		Mandatory		Preoperative	
	Doctors	Nurses* (Or)	Doctors** (Or)	Nurses	Doctors	Nurses
Experience & Training	67	56 (1.00)	24 (1.00)	46	94	97
Experience	57	59 (1.15)	34 (1.33)	42	90	96
Training	60	60 (1.21)	29 (1.68)	39	92	95
Neither	71	79 (2.95)	46 (2.69)	43	95	97

Notes: * chi square for trend $p<0.02$

** chi square for trend $p<0.04$

Nurses - Although support for HIV testing of *all admissions* was relatively high in both groups, there was significantly less support by nurses with HIV/AIDS training ($p < 0.01$). Less nurses (59%) with experience with at least one patient supported such HIV testing than without such an experience (66%), but the difference was not statistically significant ($p > 0.16$). The support for such testing was less among nurses with both: training and experience, than among nurses with neither training, nor experience (chi square for trend: 5.323, $p < 0.02$) (Figure 4). Confidence intervals included: No intervention - 79% (95% CI 66-88%), training only - 60% (95% CI 55-66%), experience only - 59% (95% CI 50-68%), and both training and experience - 56% (95% CI 45-66%) (Figure 4). There was no difference in support of pre-operative HIV testing neither mandatory testing of all admissions between nurses with and without either or both HIV training or experience (Table 1).

Discussion

The most notable feature of this study lies in the divergence between official policy as stated by WHO and Polish regulations (Recommendation for Medical Staff, 1997; WHO, 2000,) and the views (although maybe not the practices) of surgeons and surgical nurses. In our survey, the vast majority of respondents favoured pre-operative HIV antibody testing and a large majority also supported universal HIV testing for all admissions. Concerning surgeons, HIV/AIDS training and practical experience with HIV patients decreased support only for mandatory imposition of HIV testing but not for the idea of testing of all admissions neither for pre-operative testing. The combined impact of training and experience was significantly greater in decreasing support for testing than a single intervention. Regarding nurses, HIV/AIDS training and practical experience with HIV patients decreased support only for testing of all admissions but not for pre-operative testing. Again, the combined impact of training and experience was significantly greater in decreasing support for testing than a single intervention.

Occupational Risk & Fear of HIV transmission

In the current context in Poland, the results indicate that for most surgical doctors and nurses there is a substantial difference between real and perceived levels of risk for occupational HIV infection. Mathematical estimates of the chances of transmission of HIV to the surgeon vary from 0.1% to up to 10% over a 30-year period. The actual risk depends mainly on the prevalence of HIV infection amongst the surgical patients operated on (Shanson, 1991). The prevalence of HIV carrier state in Poland is relatively low (1.5 for 100,000) comparing to many other countries worldwide, so the risk of contacting infection while working at surgical suite is lower (Rosińska & Werbińska, 2004). Accordingly the less fear should be felt by Polish medical professionals, fewer should advocate for HIV screening of patients. Surveys of HCWs generally show that despite the seroprevalence in the population, a concern of contracting HIV at the surgical suit remains on the same level: 95-96% of Nigerian surgical specialists, 96% of practicing American general surgeons, and Polish orthopaedic surgeons and neurosurgeons reported such a concern (no data is available regarding surgical nurses) (Gańczak & Szych, 2004; Obi, Waboso, & Ozumba, 2005; Owotade, Ogunbodede, & Sowande, 2003; Patterson, Novak, & Mac-kinnon, 1998). What differs among surgical personnel worldwide are the numbers of preoperative HIV testing opponents and advocates. In contrast to Poland, in many countries opinions are usually balanced, or testing advocates are only in a small majority (Danziger, et al., 1996; Hoffman-Terry, Rhodes, & Reed, 1992; Wright, Young, & Stephens, 1995).

The degree of risk of occupational HIV infection among surgical nurses as compared with surgeons is greater among the first. Surgeons' injuries are likely to be caused by suture needles, which are believed to be less efficient in transmitting infection than hollow-bore needles. Surgeons also may be more likely to be wearing gloves when the exposure occurs. Wearing gloves may reduce the volume of blood introduced through the injury by more than half (Geberding, et al., 1995; Joint Working Party of the Hospital Infection Society

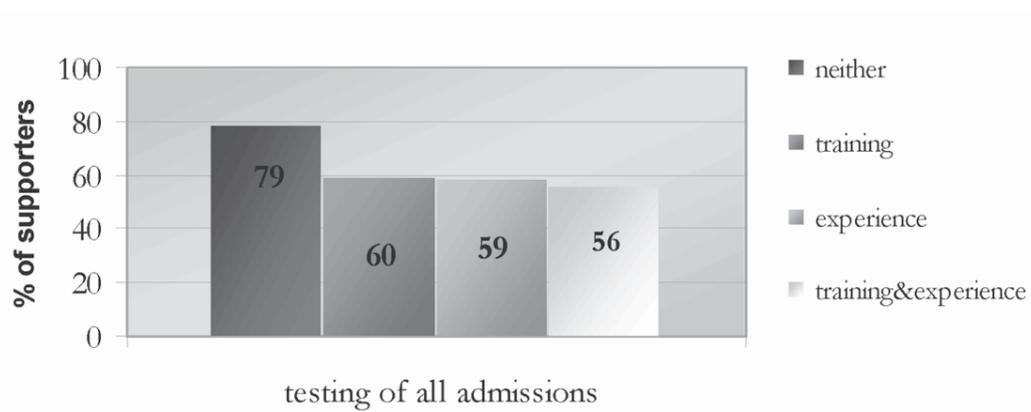


Figure 4. Support by nurses for HIV testing of all admissions by HIV training & experience ($n=383$) west Pomerania, Poland 2001-3

and the Surgical Infection Study Group, 1992; Wright & Mc Geer, 1993). Although the risk of acquiring the occupational HIV infection is small, surgical nurses perceive it as greater comparing to the surgeons, and they fear more. Among the American surgeons, moderate concern was reported by 88%, extreme concern by 8% and no concern by 4% (Patterson, et al., 1998). Among Polish surgeons from this survey slight/moderate fear was expressed by 65%, high fear by 31%, and no fear by 4%. The majority of nurses (60%) reported a high degree of fear of occupational HIV, while moderate degree of fear was perceived only by 35%. The higher degree of fear is probably the main reason why nurses more often than surgeons opt for screening of patients.

Knowledge of Risk of Infection & Personal Experience

According to Brown, Macintyre and Trujillo (2003) there are two kinds of fear: the unfounded fear of casual contagion which can be dispelled through accurate information in appropriate training and the "healthy" fear of the real but low risk of infection from occupational exposures. The authors also agree that not training alone, but a combination of appropriate training and experience with HIV infected patients is necessary to reduce fear levels to a degree where the HCW would not feel the need to test all admissions or all pre-operative patients for HIV.

Currently at Polish hospitals it is not routine to offer regular education regarding blood-borne pathogens. It is usually a one-time or infrequent event, with voluntary attendance. And indeed, 50% of surgeons and 23% of nurses had never attended HIV/AIDS training. There is a lack of regulations regarding such education, as well as a shortage of licensed medical staff and facilities to provide it (Gańczak, Milona, & Szych, in press). The lack of knowledge among doctors and nurses about their actual risk of infection and about pre- and post-exposure prophylaxis could be the main reason for an "unhealthy" degree of fear resulting in the high number of preoperative HIV testing advocates (Gallop, Lancee, & Taerk, 1991; Highriter, Tessaro, & Randall-David, 1995; van Wiessen & Woodman, 1994).

There could be also another explanation of a large number of preoperative HIV testing advocates in surgical suites in Poland, where the HIV/AIDS is rare. Generally, HCWs there are unfamiliar with appropriate management techniques, which may influence discriminating attitudes (Foreman, Lyra, & Breinbauer, 2003).

According to our data 45% of surgeons and 70% of surgical nurses have never had professional contact with HIV infected patient. Contact with such a patient means that medical professionals are more able to develop personal relations (Foreman, et al., 2003). As has been pointed in some other studies conducted among medical personnel such personal experience could also reduce the high degree of fear we found among surgical doctors and nurses (Oerman & Gignac, 1991; Rea, Brown & Calder, 1992; van Wiessen & Woodman, 1994). Since even the best theoretical knowledge cannot replace insight gained by real occupational experiences with infected persons, training

with HIV infected patients should be implemented in Polish hospitals, but in a structured educational setting, which would be expected to be more effective than any experience, as reported in this survey.

Disadvantages of Preoperative HIV Screening

The most frequently used HIV tests detect antibodies to HIV, not the virus itself. False negative antibody results that occur in the window period are also possible. In such situations personnel may feel an unjustified sense of security, and relinquish universal precautions. Another issue is that asking a patient about to undergo surgery to submit to an HIV test may generate unnecessary anxiety at an already stressful time, and that a positive result, if it appears, may come as a great shock for an unprepared patient. It is also said that any directive that increases the number of people tested who are at extremely low or now risk will lead to increased numbers of false-positive results. How to deal with false positives, however small they might be? The confirmation is possible only days or weeks later with the Western Blot test at designated reference laboratories. The anxiety to the patient and HCW in the intervening period cannot be doubted. The disadvantage is also the extraordinary expense and difficult logistics inherent in a program of universal testing. How often to retest patients and what is the cost of doing that? Another legitimate argument against universal preoperative HIV testing is in relation to emergency surgery. It should generally be accepted that for all forms of such type of surgery it is safest and most practicable to assume that the patient is HIV antibody positive without the need to perform screening antibody test. The last but not least argument of the pointlessness of preoperative HIV screening comes from the issue of proper counselling and informed consent. It is universally agreed that HIV testing must be accompanied by proper counselling before and after testing. The feasibility of providing proper pre-test counselling to the hundreds of patients before all invasive procedures is dubious in the extreme (Chapman, et al., 1995; Danziger, et al., 1996; Geberding, et al., 1995; Juszczak, 1995; Shanson, 1991; Tyndall & Schechter, 2000).

Many surgeons and surgical nurses think they would take greater care in the operating room when operating on a high risk patient and believe this justifies screening. A study from San Francisco in a hospital experienced with AIDS patients and in which standard precautions were implemented showed that knowing the HIV status of the patient made no difference on the incidence of sharps injury (Gerberding, Littell, & Tarkington, 1990).

In considering possible implementation of obligatory HIV testing, we should not forget an obligation for doctors. According to the Polish Medical Code of Ethics of 1993 and Polish Doctors' Law of 1996, every doctor should keep secret information about his patient obtained during professional work, including prevention and control. This need is deeply justified by the fear of denying access not only to medical care, but also to employment, education, or religious affiliation. Unfortunately, at the average Polish hospital, keeping information from HIV

test confidential is very difficult. Reassuring patients that confidentiality will not be breached does not result in implementing appropriate systems to keep the information secret. It has been found out that that the obligation of confidentiality is some sort of fiction that everybody declares but nobody respects (Gładysz, Juszczak, & Dubik, 1999).

In this study, more doctors and nurses favoured preoperative HIV antibody testing than testing of all admissions. The difference suggests that for some of them it was unimportant to define the serological status of a non-surgical patient. It is unclear whether surgical personnel perceived other HCW's to be at lower risk, or whether they were simply more concerned about their personal risk than for other HCWs.

Limitations

An anonymous self-reported questionnaire based on recall of events has limitations. In particular, recall may be inaccurate. However, the questionnaires were completed anonymously, which is conducive to obtaining unconstrained opinions. Additionally, the large variety of hospitals was selected for random sampling and 100% response rate was achieved, so doctors and nurses in this report are likely to be representative of other surgical staff in the study area. Secondly, what people say and what they do may be different, so discriminating attitudes resulting in a large numbers of surgical staff supporting preoperative HIV testing of patients may not be translated into discriminatory behaviour. Thirdly, limitations include the small sample size of doctors which may influence the precision of the estimates.

Finally, these results may not be generalized to doctors and nurses from non-surgical wards. The extent to which the results of this study may apply to other parts of the country has to be considered. The West Pomeranian region is characterized by a higher incidence of HIV infection (2.2 per 100,000 population per year) than for Poland as a whole (Rosińska & Werbińska, 2004). This may influence Pomeranian doctors' and nurses' perception of their risk for acquiring HIV at work. Thus, desire for preoperative HIV testing may be stronger than in some other regions of Poland.

Recommendations

HIV/AIDS training programmes and practical experience working with known HIV patient positively influenced doctors' attitudes toward mandatory HIV testing and nurses' attitudes toward testing of all admissions, and the combined effect was greater than either alone. Therefore, it is recommended that both effective training in methods to minimise the risk of occupational HIV infection and practical experience working with known HIV patients should be designed and implemented for the surgical staff in the aim of eliminating inappropriate uses of HIV testing.

On the other hand, even many of the trained and experienced doctors and nurses in this survey had not changed their attitudes towards preoperative testing. So, probably, existing education for blood-borne infections should be improved as training and hospital policies may overestimate the real risk for contracting

HIV infection in the surgical suite, and the differences between HIV/AIDS and other blood-borne infections may be over-emphasized. It appears that an important component of future educational efforts in this area should be also discussions of ignorance, professional ethics and responsibilities. Information sessions need to be coordinated by the different providers, who can share their personnel and resources to ensure that information is evidence-based. The level of support for pre-operative testing reported in this study was so high among nearly all surgeons and surgical nurses, that even a modest improvement is urgently needed.

For this to occur, hospitals must design properly documented training programmes with appropriate examinations. Such training should be initial and continued, since short-term education does not change values and behaviours (Green & Kreuter, 1991). Both lectures and workshops are needed to help surgical staff see the problem of infection from the perspective of PLWHA. Furthermore, the wider implementation of infection control procedures, as wearing gloves for every procedure involving contact with blood, should be more effective in reducing occupational risk of HIV than routine testing. In eight hospitals surveyed in this study, 17% of active nursing staff did not regularly use gloves.

HCWs have to understand that care of people infected with HIV and suffering from AIDS means not only the need for medical treatment, but must also include approaching patients with respect for their right to autonomy and to decide for themselves, their right to privacy, and their right to not be discriminated against. The stigmatizing character of this disease makes these requirements very important.

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HIV/AIDS Stigma and Discrimination among Nurses in Suriname

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Abstract

The more civilized a society becomes the more subtle the stigma and discrimination gets. Suriname is a country known for its folklore, hospitality, and social control. In the last decennia a new trend of cultural diffusion has led to greater recognition of formerly classed deviant practices of behavior. Under the influence of this kind of exposure our norms, values, and beliefs now cater for modern day perspectives of liberal thinking that encompass acceptance of one another on the basis of perceived differences of culture and appearance. Yet still, stigma and discrimination play a part in our day to day experiences of religion, poverty, independence, freedom of choice, social strata, disease prevention and even political ferment.

Keywords: HIV; Acquired Immune Deficiency Syndrome; stigma; discrimination; nursing; Suriname.

Estigma y Discriminación por VIH/SIDA en el Personal de Enfermería en Surinam

Compendio

Mientras más civilizada viene a ser una sociedad el estigma y la discriminación se hacen más sutiles. Surinam es un país conocido por su folklore, hospitalidad y el control social. En el pasado decenio la nueva tendencia de difusión cultural ha llevado al reconocimiento de conductas previamente consideradas como prácticas desviadas. Bajo la influencia de ese tipo de exposición nuestras normas, valores y creencias se encaminan hacia perspectivas modernas de pensamiento liberal que conlleva la aceptación mutua en el contexto de las diferencias percibidas de apariencia y cultura. Sin embargo el estigma y la discriminación juegan una parte en nuestra experiencia cotidiana de la religión, la pobreza, la independencia, libertad de selección, estrato social, la prevención de enfermedades y hasta el fermento político.

Palabras clave: VIH; Síndrome de Inmunodeficiencia Adquirida; estigma; discriminación; enfermería; Surinam.

It is remarkable to see the dynamics of cultural diversity in a country with such closely knitted ethnic societies blend into one people that have a sense of patriotism and a prevailing hope for stability and peaceful progress. Suriname's current incidences of stigma and discrimination are resolved in a cautious, but peaceful manner. Explanation for this phenomenon can be traced back to the development of our perspectives of survival and contentment and an even laid back attitude which we sometimes demonstrate.

Defining Stigma and Discrimination

To some, stigma and discrimination is demarcated by the measurement of its opposite in our existence. Others see it as a mere notion of suppressed ego and unfulfilled maturation into adulthood. Even more common is the understanding that these two unpleasant attributes go together hand in hand. Therefore one does not talk about stigma without mentioning discrimination. There are those that have even developed a sequence for their occurrence by stating that people first stigmatize and then discriminate.

The Encarta dictionary employs the following definition for discrimination:

"Discrimination, any situation in which a group or individual is treated differently based on something other than individual reason, usually their membership in a socially distinct group or category. Such categories would include ethnicity, sex, religion, age, or disability. Discrimination can be viewed as favorable or unfavorable, depending on whether a person receives favors or opportunities, or is denied them... However, in modern usage, "discrimination" is usually considered unfavorable". (Microsoft® Encarta® Encyclopedia 2000)

Martin Luther King Jr. once said that we fear that which we do not know. If this is true then the unknown may not only become the object of our interest, but also the goal of our intellectual curiosity in our efforts to alleviate our fears. More so, we may start calculating our fears on the basis of that which we do not know. If this is the yardstick of our conviction then our problem is made worse, since it is only by confrontation that we realize that which we do not know.

The problem with stigma and discrimination is that it is often a derivative of our instinct to live and protect life. Our tendency to survive has made us filter out the dangers that can cause us not to survive. Sadly enough, this sort of instinctive behavior leads us to stigmatize and discriminate against those that we perceive as causing danger to our existence. In the case of HIV/AIDS this tendency is prolonged because of the fact that we know the detriment

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resulting from this disease and the shame and taboo that surrounds it in our small Caribbean States where social control prevails.

Stigma and discrimination are often seen as deriving from a lack of knowledge and understanding of a person, situation, characteristic, personality trait and even emotion. In doing so it is often dismissed as a subtle sense of bias, which can be dispelled as soon as more information is made available to us about the given person or situation. This may be the reason why so many HIV/AIDS advocacy programs focus on information sharing tactics, while hoping that prevention and acceptance are wrought through one singular effort of advocating the do's and don'ts of sexual exploits and habitual living traits.

Since the eighties we have come to realize that stigma and discrimination for HIV/AIDS is as cunning as the mutation of the Human Immunodeficiency Virus and often leaves us with a sense of helplessness, anger, and frustration when we encounter it. The progression of AIDS as a medical disease is similar to the havoc caused by societal stigma and discrimination of HIV and AIDS.

Background on Suriname

Historic, Geographic and Demographic Characteristics of Suriname

Suriname is a country situated at the northern coast of South America. It is surrounded by French Guyana in the East, Guyana in the West, Brazil in the South and the Atlantic Ocean in the North. The country is a former Dutch colony, but gained independence in 1975 after approximately 300 years of Dutch dominion. Since the abolition of slavery in 1863 a series of indentureships occurred which brought together people from India, China, Java and Indonesia into one conglomerate culture that existed among descendants of African slaves (primarily from the west coast of Africa), descendants of former colonizers and plantation owners (primarily Dutch), and indigenous Amerindian tribes (mainly Arowaks and Caribs). Due to the geographical size of the country (162,000m²), it was still then possible to keep ethnic groups separated.

Initially the separation was a result of the fact that in most mainland territories of the Caribbean, colonizers and *conquistadors* only settled in the coastal areas where trade of humans and goods was taking place. Later the separation was used as a tactic to keep the various ethnic groups and or politically strategic groups segregated from one another. This form of dominance has been called Divide and Rule politics (Caprino, 1995) which dates back to separate peace talks, which were held with tribes of maroons (*Aucaners*, *Aloekoes en Saramaccaners* the tree different tribes of maroons) in the 1760's. The term maroon was coined as a group of slaves that had fled from plantations during slavery. Because of the activities such as rebellion and plundering

of plantations, the government deemed it necessary to sign peace treaties with them. These peace treaties were set with such cunning and distinctive terms that the then existing white population kept dominion of all others. Though the population ratio of Negro to Caucasian in Suriname was 20:1 at that time, the treaties signed and tactics used by the Dutch governing colonizers prohibited fraternization among various groups of maroons and slaves. Two of the tenets of the peace treaties signed in 1760 and 1762 between the Dutch colonizing government and the *Aucaners* (1760) and then the *Saramaccaners* (1762), specifically stated that:

The maroons would not go to town or the plantation without permission. The maroons would not take new runaway slaves in their tribes, but they should return the runaways for which they would get a reward. (Caprino, 1995, p. 119)

Ironically enough maroon tribes were formed by runaway slaves from plantations. Forcing this limitation on the maroons, as part of peace talks, meant forcing them to limit themselves and fellow slaves in their quest for freedom and existence. The incentive created in this regard was one of the known tactics used to prevent cultural diffusion and geared towards ethnocentric tendencies among those that were in maroon tribes and those that wished to join. This was one of the institutionalized mechanisms that perpetuated and in some cases harnessed an instilled notion of superiority among people of similar origin, language, culture and even physical distinctions in Suriname.

Geopolitical Transitions Since 1975

On February 25, 1980 Suriname experienced a military coup. Many say that this type of insurgence was the result of discontentment among a group of sixteen militaries led by Desi Bouterse. The fact is that for the first time in our history we experienced such a takeover of government by citizens of the country registered in the armed forces. As a result of this coup there were changes made to the political structure and hierarchy of power in the country. The military appointed leaders for the country and the existing climate of democracy and freedom of expression was censored (Hoogbergen & Kruijt, 2004). There were no elections until 1987 and the main form of government was more autocratic than democratic. Insurgence was dealt with in a military way.

In 1986, there was a guerrilla upheaval led by Ronnie Brunswijk. Mr. Brunswijk was an ex-military commando who gathered together a group of fellow maroon descendents to fight against the protective armed forces of the country. Due to this guerilla war, blood of innocent people was shed and great numbers of persons migrated from Albina, Moengo and other villages in the East in addition to migration from the district Brokopondo and Sipaliwini to Paramaribo, the capital of Suriname. One of the major demographic results of this migration was the increase of maroon descendents in neighborhoods such as

Latour, Abbra Broki and Wintie Wai. Since the infrastructure of these urban outskirts of Paramaribo did not cater for such a sudden increase of population, living conditions in these areas became hazardous and led to newly formed villages such as *Sunny Point*. In instances such as the case with Sunny Point, housing development areas of the government were cracked by squatters in search of a place to stay.

Sociological Background of Stigma and Discrimination in Suriname

Suriname is not unknown to the gruesome practices of slavery. For more than three hundred years we have been a colony in transition to a society of neo-colonial influence. Due to different colonizers we have been left with a folklore that reveals a spectrum of various cultures of the world. The most common of languages is Taki – Taki (Sranan Tongo) and has a blend of dialects traced back to the west coast of Africa, with a mixture of Dutch, Spanish and English. This blend is the result of the need of colonizers to communicate with their slaves. Along with the urge to communicate, there was also an urge to segregate, since the dominant culture of the colonizers was only practiced by whites, who were far less in numbers than the slaves.

In some cases the segregation was voluntary, since slaves chose to flee from the plantations to the jungle in search of freedom. Tribes that were formed in this manner were called “maroon tribes” and were primarily found in Suriname and Jamaica (the vast geographical landscape and geographical relief of both territories afforded the slave a chance to run away). The word “maroon”, however, is a derivative of the word *Cimarones*, which loosely translated means runaway animal. Similarly in our *lengua franca*, a strong connotation existed for the word *marron*. The word *marron*, (*Cimarones*) did not just signify a slave

that had runaway and was out of bondage, but more so the fact that by calling a slave a *marron*, runaways were seen as runaway animals. And these “animals” had to be persecuted; punished or mutilated to instill fear in others that had similar intentions.

Society, Sex and Sexuality

In Suriname, just like lots of other parts of the Caribbean, an open discussion on sex, sexuality, and sexual preferences has not yet become part of street corner conversations. There is an inclination towards secrecy and taboo when matters concerning sex are discussed and it is believed that in some subcultures of the country love making and sex education are not seen as part of childrearing.

There is a change of sexual acceptance and openness of sexual expression that has taken place in the last 15 years. What was termed as rudeness and disgusting has now found a place in class discussion and television programs in Suriname. There is an even greater structural change taking place that marks the beginning of a free flow of information on sex and sexuality in our educational system, which is monitored and orchestrated by the Basic Life Skills Program (local counterpart of Health Facts for Live Education).

HIV/AIDS Statistics for Suriname

The first reported case of HIV/AIDS in Suriname dates back to 1983 (Prohealth, 2004). As a result of the then newly discovered disease a National AIDS Commission was created in 1986. This commission consisted of medical doctors which were working in the field of HIV/AIDS. In 1988, the Ministry of Health created the National STI/HIV/AIDS Program. The main purpose of this program was to reduce the spread of HIV/AIDS in Suriname and to work as the executing arm of programs that would mitigate the spread and impact of HIV/AIDS in Suriname. Since HIV/AIDS is known to have a geometric progression, its prevalence increased over the years as seen in Figure 1.

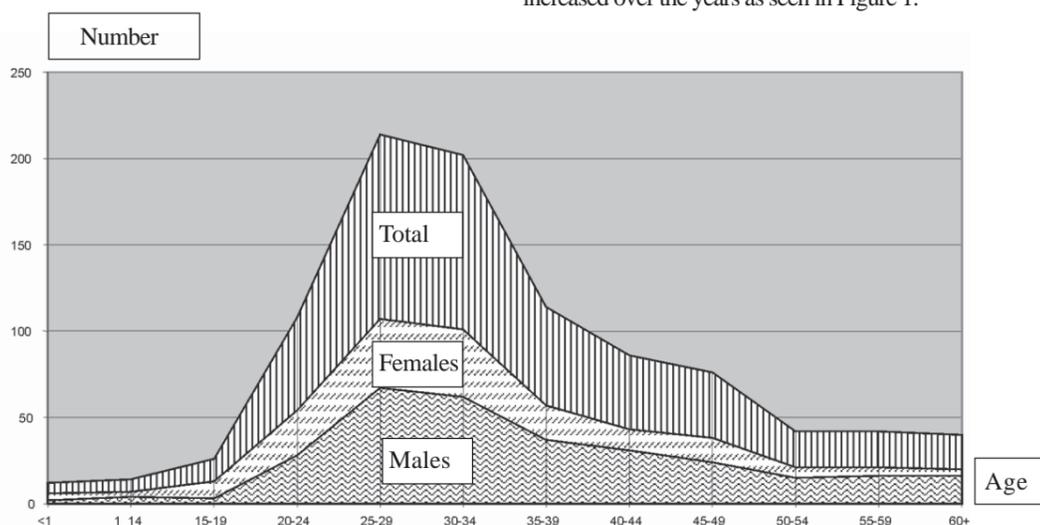


Figure 1. HIV/AIDS index of new cases by gender for the period Jan. 1983 - Sept. 1995 for Suriname
Source: Statistics Department Dermatology Services Suriname, 2000

WINSTON ROSEVAL

Table 1
Preliminary Test Data at Dermatology, Dec. 2, 2005 – Feb. 2, 2006

Gender	# tested	# positive tests	% of positive tests by gender total
Male	359	17	4.74
Female	641	23	3.59
Total	1000	40	

Note: Source - Mr. Mahesh Algoe, Chief of Laboratory at Dermatology.

Just like all other countries of the Caribbean, the progression of HIV is most prevalent in the age group 15 – 49. This occurrence is generally associated with the age of the people in the labor force of a country and as such gives evidence why the effects of HIV/AIDS are correlated to productivity. On a macro economic scale HIV/AIDS affects the Gross Domestic Product (GDP) of countries in the Caribbean. Reports of UNICEF indicate that with the current progression of HIV/AIDS in the Caribbean, there will be a decline of GDP by the year 2010 (Senaapa, 2002). Even more startling is the fact that the ages between 15 and 49 are also considered to be the years of sexual reproductivity. Current trends of test results of HIV/AIDS at the Dermatology Department at the Ministry of Health reveal 2082 HIV cases from 2000-2005.

Since November 2005 there has been a “know your status campaign” that encourages people to get tested voluntarily in conjunction with safer sexual practices and availability of Antiretroviral Therapy (ART). This campaign has resulted in a number of test sites being erected throughout the country. A preliminary analysis of sample data from Dermatology, one of the major test sites is shown in Table 1.

Though this rudimentary data still has to be scrutinized and placed in macro statistical context, it confirms suspicion that prevalence ratios in Suriname may be higher than indicated by reported cases of HIV/AIDS, such as confirmed in the Situation and Response Analysis on HIV/AIDS Report (Prohealth, 2002)

Incidences of Stigma and Discrimination

Recorded Stigma and Discrimination

De Ware Tijd, one of Suriname’s local newspaper reports the following incident of stigma and discrimination: this is not how you should die? This can also happen to me said Randjiet Dewnarain, a friend that accompanied 29 year old AIDS patient Pran Mahadew, to Academisch Hospital Paramaribo (Local Hospital). Mahadew died yesterday afternoon in the Office of Maxi Linder due to an infection of the lungs. He was refused treatment at the Emergency Medical Facilities of the Academisch Hospital Paramaribo. (Aviankoi & Irion, 2006, p. 1)

The article continues by pointing out that one of the residing physicians of the Emergency Room at Academisch Hospital blatantly indicated that Pran Mahadew would not

be treated because he was an AIDS patient and that he should be sent to St. Maxi Linder, an HIV/AIDS non governmental organization, specializing in Street Based Commercial Sex Workers. Pran was almost thirty and had been HIV positive for ten years. He was a street commercial sex worker and did not have a social security card. His mother says that they were in the process of getting one as the incident occurred. He was referred to the hospital by a general physician that saw the seriousness of his illness. An attending nurse, who did not wish his identity to be known, said that Pran was not refused treatment. “We took a photo of his Lungs and did not see any need to keep him in the hospital” (Aviankoi & Irion, 2006, p. 4).

This incident did not only shock me, but my colleagues as well. It is not the first, but the most recent of account that I have heard regarding the treatment of people living with AIDS (PLWA) in hospitals. I should rush to say that not all accounts show discriminative treatment of PLWA, but we hope to bring these startling accounts to minimal and scarce occurrence.

Reports of Stigma and Discrimination among Healthcare Workers

In Suriname a fairly reasonable amount of research has been done on HIV/AIDS. What is evident, however, is the fact that this research does not particularly address HIV/AIDS stigma and discrimination. In recent years researchers have acknowledged this gap and have endeavored to focus on the so called “softer” side of science when doing research on HIV/AIDS. Two important investigations were done to cover possible existence and/or the nature of HIV/AIDS stigma and discrimination in Suriname in the past two years. The first was done by a Working Group on the Reduction of Stigma and Discrimination (2004) and the second was done by me in 2005 and completed in 2006. The Working Group on Stigma and Discrimination consisted of representation of CAREC/PAHO, Maxi Linder Foundation, Mamio Namen Project, Claudia A Foundation, The Regional Health Services, The Medical Mission, and the National STI/HIV/AIDS Program Suriname. I was fortunate enough to represent the National STI/HIV/AIDS Program Suriname in this group of researchers. All of the mentioned organizations work with HIV/AIDS and as such have specialized task and responsibilities in the execution of their services. The

Table 2
Organizations Participating in Stigma and Discrimination Research

Organization	Service/Responsibility in Suriname
CAREC	HIV/AIDS research, compilation of data, treatment, care and support
Maxi Linder Foundation	Counseling and testing, prevention research and support of street commercial sex workers
Mamio Namen Project	Counseling, prevention, care and support of PLWHA* (focal point and core group for PLWHA)
Claudia A Foundation	Counseling, prevention, care and support, shelter to those infected and affected by HIV/AIDS
The Regional Health Services	Counseling and testing, treatment, prevention
Medical Mission	Counseling and testing, treatment, prevention
National Aids Program Suriname	Counseling and testing, treatment, care and support, data compilation, prevention

Note: * PLWHA is an abbreviation for People Living With HIV/AIDS

specific responsibilities from these organizations are listed in Table 2.

There are countries that place Counseling and Testing under Prevention, but I choose to list it particularly in this Table 2 since it is the crosscutting service that all these agencies provide. The research that resulted from this joint venture of agencies was geared towards the detection of HIV/AIDS stigma and discrimination among health care workers by focusing on PLHWA.

In my research on stigma and discrimination (2005/2006) I also focused on student nurses and qualified nurses working in hospitals, clinics and private institutions. My focus was distinct in the sense that it used a deductive approach of behavior traits and attitude to determine the modus operandi from those nurses working in hospitals and clinics and private institutions, while being part of a wider society. As such there were four distinct sub-categories in my research, revealing:

- Personal data: Identification to prevent duplication in my investigation.
- Knowledge data: Area that showed familiarity with HIV/AIDS.
- Attitude data: Area showing their beliefs and thoughts with regards to HIV/AIDS.
- Personal and social health beliefs: Area giving possible motivation of such beliefs and thoughts by personalizing HIV/AIDS in their family relations.

Research Methodology and Background

This research was carried out among nursing students and qualified nurses studying at COVAB Foundation. The COVAB Foundation is one of two primary agencies responsible for the preparation of student nurses to become nurses. In addition to these services, it also trains nursing assistants and tailors special training courses for qualified professional nurses. The institution has both fulltime and part time lecturers and provides students with housing

facilities. Over a period of four years, student nurses receive both theoretical and practical training as will be shown in the results. In the test phase of the survey a group of thirty (30) final year nursing students were used as a pilot group to establish accuracy of logic and scope of the survey. After participation, I carefully mapped out the methodology used to acquire data through this survey after which I divided the students in three groups of ten (10) students. As a pilot group, they were asked to comment on logic flow, accuracy, relevance and difficulty levels of the questions from the survey. Ninety percent (90%) of these pilot participants indicated that the approach used was fresh and dynamic and some of them even wanted to use the research scheme as an example for their final research report. From the 10% that remained, one pilot participant was undecided and two reiterated the fact that such a survey should not be done among first year nursing students, since they may not have enough nursing experience to back up their perspectives. Afterwards, these pilot participants were to become field assistants in the sense that they had to carry out the research in the other selected populations.

The survey was to be carried out concurrently in three selected groups in a class setting, thus preventing participants from discussing survey questions with one another. This was done in an attempt to let each participant give his/her own, unbridled, uninfluenced and unchallenged opinion of the questions asked. The remaining group was surveyed immediately after in a different section of the compound. Each group was given an organizational division with specific responsibilities given to each group member. This aided in accurate execution of the survey.

A total of five (5) groups of nurses were sampled, namely: one (1) group of registered nurses in training to become diabetic nurses, three (3) groups of third year nursing students and one (1) group of nurses in their final year. The total number of participants was 112. The total number of survey forms returned was 112. Two (2) of the forms had

double answers and had to be discarded. The remaining 110 returned forms were considered as the total number of participants (n). The survey was carried out in the third week of January, 2006. Survey data shows that 14% of participants were males and 86% females.

The participants in this research were not selected because of gender distinctions. The groups of nurses were selected on the basis of the year group that they were in and the class that they attended at the time the survey was conducted. Male/female division of this survey is also representative of the gender ratio of nurses in Suriname. Although the division is not a numeric or direct representation of the ratio male/female, it is reflective of the fact that there are more female than male nurses in Suriname. The age of the participants can be seen in Figure 2.

The majority of the nurses in this survey were older than 25 years. Considering the fact that only 17.27% of participants were qualified nurses and they were all over the age of twenty five, it is evident that the remaining 31.73% of nurses over the age of twenty five were still in training. Furthermore, the basic assumption that can be drawn is that the majority of the participants have reached an age of maturity in addition to having acquired life and academic experience that should enable them to form opinions on issues surrounding HIV/AIDS in Suriname.

The assumption can be confirmed when analyzing the results of the question on work experience in the hospital. Almost 45% of the nurses had close to 4 years of experience working in the hospital, followed by 23.6% who had more than six (6) years of experience working in the hospital. The reason why so many nurses had around four and more than six years work experience is because a number of them had already completed the nursing assistant program and had worked in hospitals and clinics. The nursing degree is an additional degree that they were pursuing, but they already had experience working in hospital wards.

Participants' Proximity with HIV/AIDS

The majority of the participants (95.45%) came from hospitals and had direct contact with people living with HIV/AIDS. This placed them in a vocational setting with potential direct physical contact with HIV/AIDS. Those excluded from this category had other means of contact with HIV/AIDS. Contact points were measured in various degrees in an attempt to understand how HIV/AIDS evolved in and around the lives of the participants. There were several stations at which this form of contact was probed. The first was the question: "Do you know someone with HIV/AIDS?". Results to this response demonstrated that 82% knew someone, and 96% had taken care of someone living with HIV/AIDS.

Intrinsic to this question is the notion that HIV/AIDS can only be detected through testing. Knowing the status of a patient means knowing their test result. In the case of taking care of people living with HIV/AIDS in a hospital, of whom knowledge is available on their status, it simply means that they were tested and the information on their status was shared among nursing professionals. This deduction is confirmed when 70% of participants reported that they have told a colleague at work that a patient is HIV positive.

This statement shows that the majority of nurses participating in this research had passed information about patients' positive HIV status. This result made me think whether this is a means of caring and protection of others or whether this is a stigmatization process by which PLWA are identified and his or her health condition is shared without authorization among healthcare workers. This sharing of information seemed to be prevalent among colleagues. Closely related to this deduction is the fact that 47.27% of the participants had received HIV/AIDS training. As HIV training provides better management of the disease, it gives way to the fact that training has provided tools on prevention

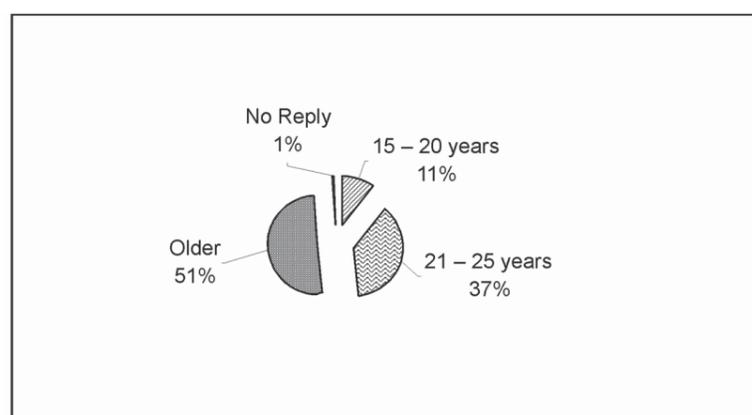


Figure 2. Age distribution of research participants

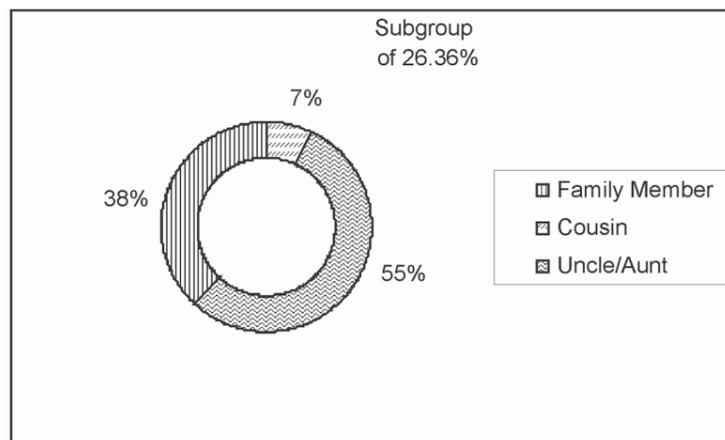


Figure 3. Family relations of nurses to HIV positive persons

and that the general training of nurses incorporates disease prevention tactics and measurements of general and specific hygiene as indicated in an interview with Ms. M. Vreugd, Coordinator of the Nursing Program at COVAB (Vreugd, 2006; personal communication). So, there is no need to know the specific sero-status of a patient as long as universal precautions are implemented.

Attitudes and Family Health Beliefs

In this section questions focused on blood relations and situation at home. 26% of the participants reported having had an HIV positive family member. The percentage of participants with a relative that was HIV positive was further specified by type of blood relation. It appears that from the group of participants that had a relative which was HIV positive, 55% had a cousin and 38% an uncle or aunt, as presented in Figure 3.

What was also striking about this particular subgroup is that only four had actually lived in the same house with someone that was HIV positive. When asked if they knew how the person got infected, 15.45% from the total participants responded affirmatively. When asked if they passed this information to others only 8.18% did, while 62.73% did not reply to this question. It appears that unlike the situation that exists in the hospital, nurses in this study are not likely to pass information on the positive HIV status of relatives, whether they live in the same household or not.

The question on sharing the same household with someone that is HIV positive tried to establish whether immediate contact with such a person might have changed the attitude towards those infected. From current information it is somewhat difficult to interpolate, whether nurses would pass on information of the status of HIV positive relatives to their colleagues at the hospital, once these relatives are admitted to their hospital. A strong tendency of care and compassion for those infected with HIV/AIDS seems to emerge from the results of the remaining questions of the survey. When asked if people that are HIV

positive had to be taken care of in a special way in the hospital, 49.10% said yes, while 45.45% said no and the remaining 5.45% did not know. Drawing from earlier answers it can be concluded that even though 47.27% of the participants had specific training in HIV/AIDS, combined with the information they had of HIV/AIDS as confirmed by interview with Ms. Vreugd, there still existed a sense of singling out HIV/AIDS from other diseases in the hospital.

I do not think that this notion is a direct result of the virulence of the Human Immune deficiency Virus, since there are other diseases with similar if not more aggressive forms of physical, physiological and mental regression. I believe that this type of uncertainty indicates that the fear instilled by HIV/AIDS as a disease can only be mitigated if nurses convince themselves that though exposed to HIV/AIDS at their work place they will not be infected. They are surrounded by information and it seems the trend is not due to a lack of information, but to other obstacles that prevent this information from maturing to practice.

In the last part of the survey the focus was given to opinion formulation regarding people living with HIV/AIDS. Two main questions were asked to establish a perspective on infected persons. The first was "What can best be done with HIV positive persons?" and the results are presented in Table 3.

The main mode of transmission of HIV in Suriname is through heterosexual contact. Given these findings, it seems participants acknowledge that even though transmission might have occurred through sexual contact, the fact that people have become positive should not prevent them from

Table 3
What can Best Be Done with HIV Positive Persons?

Answer	Percentage
Provide them with condoms	72.73
Find work for them	21.82
Give them financial assistance	30.91

having intercourse. It might also explain the liberal thinking that exists among participants on the right for a person to have intercourse, but more so the right for HIV infected persons to enjoy intercourse and still be responsible enough to protect themselves and others. Nurses recognizing patients' right to a healthy sexual life might be confronted with their own interest in protecting public health as they might believe that PLWA are responsible for the current spread of the infection.

A second conclusion from these results is that there is some agreement in the perception that HIV infected persons may be in a precarious financial situation due to loss of work and/or financial resources. This is the reason why more than 50% of the participants saw a relation between a positive HIV status and lack of financial resources. Furthermore, the subcategory of participants that stated that we need to find work for positive persons, also acknowledged that these persons were fit for work. In a broader sense it shows that even if positive persons do not have jobs, we should not only help them find one but also find no reason to prevent them from working.

From the perspective of economic deprivation due to HIV we end up with a view of family relation that indicates that nurses as parents have two things that stand out when their child comes home stating that he/she has contracted HIV. Most participants (81.82%) indicated that they thought that they would have to find a solution if their child told them that they had contracted HIV. Subsequently 64% of the participants indicated that they thought that their child did not listen to them. Those that indicated that they would look for a solution may regard HIV as a problem which can be solved. It can also indicate acceptance of HIV, which to me seems a rather levelheaded approach to a hypothetical situation.

Conclusion

From historic and present day appearances it seems like Suriname has been blessed with a people that don't strive

for vengeance but rather try to accept and adhere to culture, beliefs, norms and values of their fellowmen. In the case of HIV/AIDS, people living with HIV/AIDS may be at risk of having their status revealed to others by those they trusted because of their professional code of conduct. There is no excuse for such attitudes and behavior, but we try to understand such practices by focusing on the fact that HIV/AIDS may still be impersonal and distant to some of us.

Finger pointing and name calling are some of the effects wrought by a breach of confidence and trust once someone's status has been revealed. This does not foster the atmosphere for those living with the disease to have a fulfilling live. It also does not give them the chance to cope with their own struggles, but rather adds to the pangs caused by social and emotional deprivation.

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Methods for Understanding the Stigma of AIDS in the United States: A Review and Future Directions

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Abstract

Since AIDS was first diagnosed in the United States in 1982, people with AIDS have been severely stigmatized. In this article, we explore the origin of the AIDS stigma and offer an explanation for why individuals with AIDS are stigmatized. Then, we review studies that exemplify how the stigma of AIDS in the United States is typically investigated. Finally, we outline future research directions for studying the stigma of AIDS. Specifically, we argue that future research should disentangle the stigmas of homosexuality, IV drug use, and the stigma of AIDS; address the implications of the AIDS stigma in the workplace; and consider strategies for remediating the stigma.

Keywords: Acquired Immune Deficiency Syndrome; stigma; United States; research.

Métodos para Entender el Estigma del SIDA en los Estados Unidos: Una Revisión y Direcciones Futuras

Compendio

Desde el primer diagnóstico de SIDA en los Estados Unidos en 1982, las personas con SIDA han sido severamente estigmatizadas. En este artículo exploramos el origen del estigma asociado al SIDA y ofrecemos una explicación de las razones por las cuales se estigmatiza a las personas con SIDA. Entonces, revisamos estudios que ejemplifican cómo el estigma del SIDA ha sido típicamente estudiado en los Estados Unidos. Finalmente, esbozamos futuras direcciones de investigación para el estudio del estigma del SIDA. Específicamente, argumentamos que las futuras investigaciones deben explorar las combinaciones de los estigmas sobre la homosexualidad, el uso de drogas inyectables y el SIDA; abordar las implicaciones del estigma del SIDA en los escenarios de trabajo; y considerar estrategias para reducir el estigma.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida; estigma; Estados Unidos; investigación.

Since the HIV virus was first diagnosed in the United States in 1982, an estimated 929,985 individuals have been infected with the virus (Centers for Disease Control [CDC], 2004). In 2003 alone there were 43,171 diagnoses of AIDS, including 31,614 men, 11,498 women, and 59 children under the age of 13 (CDC, 2004). It is estimated that 524,060 individuals in the United States have died from the virus (CDC, 2004). Unfortunately, it is difficult to report the full scope of both incidence and deaths due to AIDS. The Center for Disease Control (CDC) estimates an additional 180,000 to 280,000 people have HIV and do not know they have the disease or are hesitant about seeking medical assistance. This hesitancy may be a product of the persistent stigma

associated with AIDS in the United States. That is, despite the increasing number of Americans affected by the disease, individuals associated with AIDS are subject to negative stereotypes, social rejection, and discrimination (Crocker, Major, & Steele, 1998). Consequently, the purpose of this chapter is threefold: to review the foundations of the stigma associated with HIV/AIDS, to review the methods that are typically used in U.S. based investigations, and to offer suggestions for future research in this area.

The Nature of Stigma

Goffman (1963) ignited research on the topic of stigmas, and provided a framework for their examination, when he defined a stigma as an attribute that is discrediting and prevents full social acceptance for the stigmatized individual. His early research identified two classes of stigma, the "discredited" stigmas (or those that are known to others) and "discreditable" stigmas (or those that can be concealed).

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Jones et al. (1984) also identified the communicability of stigma as an important dimension along which reactions to stigmatized individuals may vary. More recently Crocker et al. (1998) defined stigma as “devaluation by being the target of negative stereotypes, being rejected socially, being discriminated against, and being economically disadvantaged” (p. 505). For the purpose of this chapter, we concentrate on the three factors that past researchers postulated as definitive for stigma: controllability, concealability, and contagion.

First, controllability is defined by the perception of how much control an individual has over their condition. Weiner, Perry and Magnusson (1988) suggested that the more a stigma is perceived to be controllable, the more negative is its stereotype. The perception that AIDS is a gay-related disease is still prevalent in the United States. Therefore, it is possible that many Americans believe that those individuals who have AIDS had some control over their infection. The second leading cause of AIDS is through the use of IV drugs. Since 1982, intravenous drug (IV) drug use has been blamed for 26.5% of all AIDS cases (CDC, 2004). Given that IV drug use is a chosen behavior (Cooney, 1997), it is easy to see why its link with AIDS strengthens perceptions of AIDS being highly controllable.

Second, a stigma that is concealable (e.g., alcoholism) gives rise to very different considerations than a stigma that is not concealable (e.g., obesity). When an individual’s stigma is not obvious to observers, they face the difficult decision of whether to disclose their stigmatized status. The “disclosure dilemma” is often researched from the perspective of gay and lesbian individuals who “come out of the closet” or reveal their sexual orientation (e.g., Griffith & Hebl, 2002; King, Reilly, Hebl, & Griffith, 2005). A similar dilemma might apply to individuals who are in the early stages of HIV, but who have no visible signs of the AIDS disease. Such individuals must decide whether, how, when, and to whom they should reveal their HIV status. However, the final stages of AIDS may be very identifiable to others. Herek (1999) suggested that the nature of the advanced stages of AIDS makes the disease readily apparent to observers, and these visual cues may cause distress to potential interactants. Thus, the progression of the disease creates a stigma that varies along the concealability spectrum and has very divergent consequences.

Third, the stigma of AIDS is affected by the fact that it is a potentially contagious disease (see Herek, 2002). Simply put, many people wish to avoid all contact with those who have HIV or AIDS because they fear being infected. In fact, a study by Rozin, Markwith and McCauley (1994) showed that people were even reluctant to try on sweaters previously worn by individuals with AIDS. Thus, added to the

controllability and concealability descriptions of the AIDS stigma, interactants may respond with negative affective and avoidant reactions in an attempt to ostensibly protect themselves from what is largely misperceived as a highly communicable disease. Consistent with this explanation, despite far-reaching advances in its treatment, the majority of Americans continue to believe that the disease is fatal and highly contagious (Herek, 2002).

In defining stigma, it is also important to understand that these three factors- controllability, concealability, and contagion- are negotiated within the social interaction. That is, stigma is a socially constructed phenomenon. We next turn our attention to describing the social constructivist nature of stigma and present a specific look at how it has been negotiated within the context of the U.S. military.

The Social Construction of AIDS

To better comprehend the nature of this stigma, it is necessary to also understand the history of the HIV virus. One method for investigating the historical basis for AIDS stigma is through a social constructionist framework. Social construction refers to the process society uses to give meaning to some type of phenomenon. These meanings may be experienced differently across various cultures (Cooney, 1997). As Rushing (1995) points out, one example of such social construction occurred in the 14th century when the “Black Death” became an epidemic in Europe and Asia. At that time, the world was largely divided along religious lines and medical knowledge was limited. A lack of scientific knowledge, coupled with the dominance of religion and the magnitude of the epidemic, led the survivors to the same interpretation: mankind was being punished by God for its sins (Cooney, 1997). In other words, the plague was attributed to the perceived sinful conduct rather than the poor sanitation conditions and diseased vermin. The Plague came to symbolize sinful conduct and embodied existing religious differences. Rushing (1995) also suggested that, Jewish individuals were primary targets of stigmatization and bore the brunt of the blame for the epidemic.

The social construction of AIDS shares a similar historical evolution. In 1981, 108 cases of a *Pneumocystis Carinii* (a rare form of pneumonia), and Kaposi’s Sarcoma (a rare form of cancer) were diagnosed (Shroff, 1991). When those cases were first reported, medical personnel were unable to explain the nature of the illness. When it was discovered that ninety-five percent of the diagnosed individuals were homosexual, it was assumed that some aspect of homosexual behavior was responsible. That assumption led to the original label of the disease, “Gay Related Infectious Disease” (GRID). Perhaps even more

important to the evolution of the AIDS stigma was the unofficial name given to this new disease, the “Wrath of God Syndrome” (WOGS) (Shroff, 1991).

Both the official name of GRID and the unofficial label of WOGS have had an important impact on the AIDS stigma. The initial construction of AIDS as a gay-related disease led the American public to associate homosexual behavior with a very frightening new disease. The media assisted in the propagation that the disease was in fact a manifestation of homosexual behavior by referring to AIDS as a “gay disease”, “gay cancer”, or even “gay plague” (see Herek, 1999). It is not surprising that one explanation of the persistence of the moral interpretation of AIDS rested in the fact that the most commonly infected individuals were gay men, an already highly stigmatized group (Rushing, 1995). It was not until 1982, when AIDS began to be diagnosed in heterosexuals at higher rates, that the syndrome was relabeled Acquired Immune Deficiency Syndrome (AIDS) (Rushing 1995; Shroff 1991). However, the framework for AIDS stigma had already taken hold and would persist for years.

Thus, AIDS stigma could be closely aligned with the homosexual population based merely on the fact that the disease first showed up in gay men. In 1988, the Center for Disease Control (CDC) reported that 63% of adults diagnosed with AIDS in the United States were men infected through homosexual behavior (CDC, 1988). The CDC reported that the second most common method of AIDS transmission was through the use of illegal drugs (19%). Since 1988, the avenue by which AIDS is transmitted has changed. As of 2003, only 48% of all AIDS cases since 1981 were attributed to male-male sexual contact. In fact, in 2003 only 41% of all new AIDS cases were attributed exclusively to male-male sexual contact. The next highest group, constituting 31% of all new reported AIDS cases, were individuals who contracted AIDS through heterosexual contact (CDC, 2004). Despite the decreasing incidence of male-male sexual contact as the primary method for HIV acquisition, AIDS stigma is still very much associated with homosexual men. In fact, Pryor, Reeder and McManus (1991) found that people with negative attitudes toward gay men were less likely to want to interact with an AIDS patient than those who had more positive attitudes. One reason for this persistence could be the early work of some conservative religious organizations. At the onset of the AIDS epidemic, political conservatives attacked homosexual behavior and used AIDS as part of their rhetoric (Herek, 1999). For example, in a 1987 column Patrick Buchanan wrote:

There is one, only one, cause of the AIDS crisis—the willful refusal of homosexuals to cease indulging in the immoral, unnatural, unsanitary, unhealthy, and suicidal

practice of anal intercourse, which is the primary means by which the AIDS virus is being spread through the ‘gay’ community, and, thence, into the needles of IV drug abusers, the transfusions of hemophiliacs, and the bloodstreams of unsuspecting health workers, prostitutes, lovers, wives, and children. (Herek & Capitanio, 1999, p. 1131)

It was not uncommon for articles to espouse such views of AIDS and homosexuality during the first decade of the disease as some conservative groups were eager to attack the “gay lifestyle”. AIDS stigma was propagated through the inflammatory rhetoric of special interest groups trying to demoralize the gay rights movement.

Of particular importance in the evolution of AIDS stigma is the spread of the disease to “innocent” individuals. When the disease began to spread to the heterosexual population, the dominant group began to blame those whom society considered deviant, namely homosexuals, drug users, and prostitutes (Cooney, 1997). It is through this social construction that one can truly understand the origin and persistence of the stigma associated with AIDS in the United States.

A Case Study of Social Construction: AIDS and the U.S. Military

One striking example of the social construction of AIDS comes from the United States military. When AIDS was first identified among military members, the initial inclination was to medically disqualify those individuals from serving in the armed forces (Cooney, 1997). While reaction has been modified, as we shall explain there are still policies in place that legally discriminate against individuals with AIDS in the U.S. military. Although some people might prefer that military members with AIDS be expelled from the military, the Department of Defense (DoD) policy has formally stripped many of the moral implications from AIDS and focused solely on the ability to complete duties expected. The DoD encompasses all of the military arms of the United States (Army, Air Force, Navy, Marines and Coast Guard) and is the driving force for creating and implementing policies that affect all DoD employees. There are two facets of the DoD policy that are important in regards to how AIDS has been socially constructed: testing and disposition (ability to perform required job tasks) of those who have AIDS.

The first component of the DoD policy on AIDS concerns testing for AIDS prior to service. According to DoD Directive 6485.1 (Department of Defense [DoD], 1991), which applies to all military branches, all military applicants are screened for exposure to HIV. For those hoping to enlist, this means testing prior to being accepted to serve in the military. Applicants must test positive for the HIV virus on three separate tests to be disqualified from service (DoD,

1991). Those in officer training programs such as the Reserve Officer Training Corps (ROTC) or the service academies who test positive for HIV are also denied appointment and discharged from service (Burrelli, 1992). This means that anyone who is HIV positive and currently enrolled in a commissioning program (e.g., U.S. Military Academy or U.S. Air Force Academy) will be disenrolled and prohibited from serving in the military.

Finally, each active duty soldier (officer and enlisted) is tested on a regular basis, approximately once every two years (Burrelli, 1992; DoD, 1991). When an individual on active duty tests positive for HIV, several procedural consequences follow. To begin, the soldier is given a medical examination to determine fitness for duty (i.e., disposition). If an individual is still mentally and physically able to perform their military duties, they are retained in the service until such time that they can no longer accomplish their duties. At that time, they are medically retired and guaranteed continued medical coverage for themselves and their dependents (Towell, 1996). In other words, military personnel are not discharged when they test positive for HIV.

However, active duty personnel that are HIV-infected are placed under certain restrictions. First, they are permitted to serve only within the United States. Many host countries have policies that prohibit the stationing of HIV-infected soldiers within their territories and access to necessary medical treatment overseas may be limited. Second, they are not permitted to perform in combat, largely due to the increased potential for fluid (i.e., blood) transmission (All of you, out, 1996). Third, they are usually given a written order to inform any sexual partner of the fact that they are HIV-positive and to use protective measures, such as condoms, should they engage in sexual intercourse (Miller, 1991).

Despite the generally equitable policies toward active duty HIV positive soldiers, its socially constructed association with homosexuality complicates the actual attitudes and behaviors encountered. Homosexual behavior is expressively forbidden in the military environment (Cooney, 1997). A recent study of HIV infected Army personnel revealed that the risk behaviors that most increased a soldier's chance of becoming infected were same-gender sex and, among heterosexuals, sex with casual or anonymous partners (Levin et al. 1995). The military's HIV screening process can also be understood from the perspective of the social construction of the AIDS stigma. By prohibiting HIV positive individuals from serving, the military guards against introducing homosexuals with AIDS into a predominantly heterosexual population.

Beyond the effects of DoD policies, a soldier identified as being HIV-positive is stigmatized by other soldiers as a

function of the socially constructed perceptions of AIDS and its transmission. While efforts are certainly made to protect the identity and status of infected soldiers, the information is not classified and may easily leak out to others. The combination of restriction of assignment, duty time lost for medical appointments, loss of a security clearance, and notification of sexual partners may provide clues to nonstigmatized perceivers. The consequences of societal perceptions of AIDS in the context of the U.S. military highlight the need to promote research and a more accurate understanding of the AIDS stigma. This understanding should be based on findings of past AIDS stigma research carried out in the United States.

Past Research

Fortunately, a sizeable amount of medical research has given people with AIDS a better quality and quantity of life over the past twenty years. However, what is less encouraging is the scarce amount of research concerning the psychological factors associated with AIDS and its stigma. The remainder of this chapter will offer examples of research that has been conducted in the United States regarding the stigma of AIDS. We will also identify what we believe are fruitful areas for future research.

Perceptions of AIDS

Much of the stigma-related research conducted in the United States since AIDS was first discovered has been focused on the perceptions and attitudes toward people with AIDS. Early studies showed that there was widespread fear of the disease and inaccurate information regarding how the disease was contracted and the extent of contagiousness of the disease. There have been many anecdotal stories of how horribly people with AIDS were treated in the 1980's. For instance, Herek and Glunt (1988) reported that such treatment ran the spectrum from a mail carrier refusing to deliver mail to an AIDS Task Force office for fear of catching the disease to a family's house being burned down after three brothers tested positive for the HIV.

Misperceptions surrounding the contagiousness of AIDS fueled much of the early research into AIDS stigma. Sheehan, Lennon and McDevitt (1987) investigated employees' attitudes toward working with a coworker who had AIDS. Employees read short vignettes with endings differing in the type of illness a team member had (either AIDS, cancer, or hepatitis) and the perceived control over each of these diseases (either controllable or not controllable). Thus, the individuals with AIDS either contracted it through homosexual behavior or a blood

transfusion, the individual with cancer either had lung cancer from smoking or pancreatic cancer, and the individual with hepatitis either was a drug user or acquired the disease through a blood transfusion. The results showed that participants indicated less willingness to interact with a coworker with AIDS than coworkers who had cancer or hepatitis. In addition, the controllability perception influenced evaluations of coworkers with cancer and hepatitis but did not affect ratings of the individual with AIDS. It is possible that the overwhelmingly negative reaction to the stigma trumped any factors that might mitigate reactions (e.g., controllability perceptions).

In another study showing the dramatically negative effects of the AIDS stigma, Rozin et al. (1994) investigated the impact of "indirect" contact with other people, including people with AIDS. In their study, participants were given a survey intended to measure participants' willingness to wear a sweater, drive a car, or sleep in a hotel bed that had been previously used by a healthy male, a man with Tuberculosis (TB), a man who had been convicted of murder, a man who had lost a leg in an uncontrollable automobile accident, a man who was homosexual, a man who was homosexual and had AIDS, and a man who had AIDS from a blood transfusion. The results indicated that participants were less willing to wear a sweater, drive a car, and sleep in a hotel bed if the man was homosexual than if the man were not. Furthermore, participants were even less willing to engage in those activities if the man had AIDS (regardless of the source of transmission) (Rozin et al., 1994). This suggests that despite attempts to educate the American public on the transmission of HIV, there still exists a perception that people with AIDS should be feared and that AIDS can be spread not only through direct contact, but also through vicarious contact with inanimate objects.

Unfortunately, these attitudes and beliefs persist today. Such discrimination is evident in more recent events, including the fact that an eight-year-old girl with HIV was unable to find a Girl Scout troop that would allow her to be a member after she disclosed her infection. That act of discrimination occurred in 1998, more than 15 years after the disease was first diagnosed in the United States (HIV positive girl..., 1998). In light of the fact that negative feelings continue to persist regarding AIDS, it is imperative that further research investigates more of the consequences of the AIDS stigma.

Dual-Process Frameworks

Most social psychological research on the incidence and processes involved in stigmatization examine two simultaneous systems. For example, Pryor, Reeder, Yeadon

and Hesson-McInnis (2004) proposed that there are two psychological systems involved in people's reactions to stigma. The first system is reflexive, evolutionary in nature, and requires little conscious decision making processes. The second system is reflective and uses cognitive processes to determine the correct response for the situation. Pryor et al.'s model is based on the idea that people control their prejudicial attitudes based on two factors: internal and external motivations (Plant & Devine, 1998). People control their attitudes because of internal factors such as their belief that being prejudiced is wrong. Similarly, there is an external factor for controlling prejudice that includes the belief that other people would not approve of their attitudes. This dual process theory of stigma was applied to understanding reactions to individuals with HIV. That is, Pryor, Reeder and Landau (1999) suggested that people have automatic and controlled reactions to an individual perceived to have HIV. First, people first have an impulsive reaction to a person with HIV such as disgust or fear. Second, people experience a reaction that is more controlled. Although they might feel fear or disgust, they are able to control how their external behavior based on their belief that a measured response is expected. This cognitive portion of the dual process theory is similar to the external motivation that Plant and Devine (1998) suggested. Simply stated, people will control their reaction to a person with AIDS because society requires empathy rather than disgust.

Pryor et al. (2004) expanded their original model by suggesting that the two processes can be labeled as "reflexive" and "rule based." They believe that reflexive systems involve instinctive reactions or spontaneous reactions that have developed through learning and do not possess a cognitive element. Following this rationale, AIDS provokes an instinctive avoidance reaction due to the perceived danger that HIV projects. However, rather than openly show fear when confronted with somebody with AIDS, the rule based process might cause an individual to purposefully act in such a way that conforms to society's rules by actively engaging the person with AIDS rather than avoiding the perceived danger. This element of the model involves a cognitive element of thoughtful reaction and deliberation (Pryor et al., 2004). In an empirical test of this rationale, Pryor et al. (1999) investigated whether rule-based processes could lead to emotional reactions against the stigma of HIV. They hypothesized that pity might be the reaction when an individual is not considered responsible for their stigma. Conversely, anger or irritation might be the reaction when the stigma is considered controllable by the individual inflicted. Specifically, they predicted that participants would display more positive reactions to a

person with an uncontrollable stigma if given time to respond than they would if required to give an immediate response. They found that if given 15 seconds to respond, participants rated having lunch in the company of a little girl with AIDS (an uncontrollable stigma) more positively than those participants who were required to respond immediately. When the researchers asked participants to react to having lunch with somebody with a drug addiction (a controllable stigma) the 15-second delay did not have an effect on participants' reactions. Thus, it seems that the rule-based process may take longer to dictate a response when the stigma is perceived as controllable.

Building from these findings, Pryor et al. (2004) studied the moment-by-moment reaction to the AIDS stigma in a computer simulation paradigm. Participants used a computer to indicate the distance they would like to be from three different people (someone with HIV from a blood transfusion, someone with a criminal past, and an honors student). Consistent with their theory, the researchers predicted that participants would avoid the person with HIV and the person with a criminal past. Conversely, it was expected that participants would be more likely to move their cursor (i.e., feel positively) toward the honor student. Participants also completed a survey after their computer work that measured their attitudes toward homosexuality using the Heterosexual's Attitudes Toward Homosexuality (HATH; Larsen, Reed, & Hoffman, 1980) as well as a questionnaire to measure their motivation to control prejudice (Motivation to Control Prejudice Scale) (MTCP) (Pryor et al., 1999).

The results indicated that participants with negative attitudes toward homosexuality kept a greater distance from the person with AIDS in the first few seconds of their response. In other words, their reflexive response was to avoid the individual with AIDS, while their rule-based response motivated participants to move toward the person with AIDS. Additionally, the results were interpreted to suggest that perceived controllability attenuated initial responses. Although participants' first reaction was not positive toward those with AIDS, after cognitively assessing the situation their behavior was modified. It is possible that they changed their opinion of the individual with HIV as a function of the fact that HIV was contracted from a blood transfusion.

Contact Frameworks

In addition to considering the position of the AIDS stigma within dual-process frameworks, research has also focused on the stigma as a function of direct and vicarious contact. Herek and Capitanio (1997) investigated the relationships

between the AIDS stigma and direct contact with people with AIDS (e.g., a friend, family member or acquaintance) as well as vicarious contact (e.g., a public figure through the media who has AIDS). They randomly selected interview participants from the 48 contiguous states using a Computer-Assisted Telephone Interviewing (CATI) system. Survey questions assessed respondents' attitudes regarding coercive policies, perceived blame for persons with AIDS (e.g., "people who got AIDS through sex or drug use have gotten what they deserve"), avoidant behaviors (e.g., having a close relative with AIDS, having a child attend a school where another student has AIDS, working with a male coworker who has AIDS, and discovering that the owner of a neighborhood grocery store had AIDS), and beliefs of how AIDS is acquired (e.g., by drinking glass or use of public toilets). In addition, participants were asked whether they had any direct contact with an individual with AIDS. Vicarious contact was measured using opinion measures on the influence of public figures with AIDS (e.g., Magic Johnson) on their own opinions. Finally, participants' attitudes towards gay men were measured using a 3-item Attitudes Toward Gay Men (ATG) scale (Herek & Capitanio, 1997).

The results of this survey suggest that direct contact does affect the AIDS stigma. Respondents who indicated that they had experienced direct contact with a person with AIDS reported that the contact had influenced their attitudes some (30%) or a great deal (40%) (Herek & Capitanio, 1997). Furthermore, those individuals reported significantly lower stigma scores than the participants without direct contact. Conversely, of respondents who had heard of Magic Johnson's HIV announcement, only half indicated that their attitudes toward individuals with AIDS were influenced some (29.5%) or a great deal (24%). A separate study confirmed that individuals made negative attributions for Magic Johnson's illness, blaming internal and controllable, rather than external and uncontrollable, factors (Graham, Weiner, Giuliano, & Williams, 1993). This indicates that although vicarious contact might reduce the stigma of AIDS, it is through direct contact with people who have AIDS that most negative perceptions of AIDS are dispelled.

Herek and Capitanio (1997) also studied various demographic issues and how they relate to the AIDS stigma. The responses were broken down by race, political ideology and socio-economic status (SES). They found that the Black participants were more likely than members of the rest of the sample to know a person with AIDS, and that their perception of people with AIDS was highly influenced by that contact; 71% reported it affected their attitudes a great deal and another 14% reported that it affected their attitudes

some (Herek & Capitano, 1997). Similarly, Blacks who had experienced direct contact with an individual with AIDS demonstrated less severe stigmatization than those without contact with regard to their attitudes toward coercive policies, blame, and avoidance.

Perhaps the most disheartening conclusion of these surveys is the amount of support for policies that would ostracize, discriminate, and severely restrict individuals with AIDS. Herek (1999) reported that a "significant minority" of the United States public reports negative feelings towards people with AIDS. Those feelings can have tremendously negative consequences for people with AIDS. Herek, Capitano, and Widaman (2003) investigated support for HIV surveillance policies as well as how the stigma of AIDS could affect people's willingness to seek medical treatment if they suspect they could have AIDS. In another telephone survey of respondents from the original survey ($n = 666$) and new, randomly selected respondents ($n = 669$) participants were interviewed on four separate measures: perceptions of HIV stigma (the researchers asked respondents their opinion on how much people with AIDS had been unfairly persecuted), the social risk and HIV testing (had respondents ever been tested for AIDS and what their perceptions of their treatment would be if they were diagnosed with AIDS), their attitudes toward HIV surveillance procedures (should AIDS reporting be mandatory), and their attitudes toward people with AIDS and other stigmatized groups. The results indicate that the majority of respondents did believe that people with HIV are a continued target of persecution. Consistent with the fact that most individuals reported being concerned about being stigmatized if they should test positive in the future (39% very concerned, 29% somewhat concerned and 15% a little concerned), only 52% of respondents indicated that they had been tested for HIV. This indicates that there is a possibility that the stigma of having AIDS could be an impediment for people being tested. The possibility of facing the stigma of AIDS and the adverse outcome of having AIDS could fuel the continuation of the stigma as well as serve as an impediment toward people seeking treatment for AIDS. A plethora of research has identified that there is a stigma, and further research has identified the cognitive processes involved in the AIDS stigma, but many questions regarding the stigma of AIDS remain unanswered.

Future Directions

There are innumerable directions that AIDS stigma research could take with regard to the research content and methodology. In particular, we suggest that researchers consider the independent and associated effects of the

stigmas of AIDS and homosexuality, the workplace implications of the AIDS stigma, the targets of stigma, and strategies for remediation. We also suggest that research continue to utilize experimental and field methodologies, and to incorporate social interaction and behavioral paradigms.

Potential Content of Future Research

Homosexuality and AIDS Stigmas - One particularly important question for future research is the association of the stigma of AIDS and the stigma of homosexuality. Survey research has indicated that there is a strong association between the stigma associated with AIDS and the stigma associated with homosexuality (Bouton et al., 1989). Although there is good evidence to suggest that both stigmas are perceived to be controllable (Graham et al., 1993; Herek, 2000) research is still needed to disentangle the independent effects of AIDS and homosexuality stigmas. In other words, is AIDS stigmatized primarily because the onset of the disease was associated with homosexual activity? Rozin et al. (1994) found that people do not differentiate between individuals who had AIDS from transfusions and those who had AIDS from homosexual contact in relation to perceived interpersonal contagion. In addition, research should consider the associations between sexual activity, another controllable behavior, and the AIDS stigma. Unsafe, promiscuous behavior may increase an individual's likelihood of contracting AIDS. Consistent with gender stereotypes and the social construction of expectations for sexual behavior across genders, these behaviors may be perceived more negatively for women than for men.

In addition to considering these aspects of the perceived controllability of AIDS, future research should also examine the unique dilemmas that are associated with the initial concealability of the disease in its early stages and its visibility later in the disease progression. The initial stages should be tested in comparison to the experiences of gay and lesbian individuals who decide whether or not to make public or disclose their sexual orientation (i.e., "come out of the closet"). A new framework is needed to understand the experiences of individuals with AIDS as it begins to manifest visibly, the potentially changing nature of the stigma, and the best strategies for coping with this progression. It is likely that perceptions of the communicability of the disease will be influenced by its visibility; that is, as visible symptoms emerge, people may fear that the disease is more highly contagious. Thus, it may be particularly important to increase education and awareness efforts regarding later stages of

HIV-AIDS. Future research should examine these yet untested issues.

AIDS at Work - One context in which these questions should be given particular attention is the workplace. The topic of AIDS at work has an enormous amount of potential for future research. Although some research has been dedicated to investigating the effects of being openly gay in the workplace (Ragins & Cornwell, 2001), the topic of being HIV-positive in the workplace has only recently begun to gain attention. In one study, Timmons and Lynch (2004) studied the importance of employment for individuals with AIDS. They conducted four separate focus groups with 29 participants who had AIDS. The results indicated that employment was an important source not only of economic security, but also self-respect, fulfillment, and well-being for people with AIDS (Timmons & Lynch, 2004). The same group of participants identified two employment-related concerns: health benefits and fear of discrimination. Participants were concerned that their jobs would not provide the necessary health benefits that AIDS requires and that their social security benefits would be revoked upon employment. Additionally, participants were very concerned that they would face discrimination when they disclosed their condition at work. In fact, the majority of participants indicated that they would leave their job rather than disclose their condition at work.

One framework that may be helpful for investigations of the stigma of AIDS is a recently proposed multi-level, dual perspective approach to understanding the nature of stigma in the workplace (Hebl, King, & Knight, 2005). This model explores the possibility that stigma in the workplace can be viewed from multiple levels and perspectives. That is, research should investigate the antecedents, consequences, and manifestations of stigmatization at the individual, group, and organizational levels of analysis. In the case of the stigma of AIDS, what organizational actions enhance the AIDS stigma (e.g., refusal to institute benefit plans)? What are the outcomes of stigmatizing individuals with AIDS? Is a workgroup stigmatized as a function of one member's HIV status?

In addition to offering a framework for answering these questions, Hebl et al. (2005) model advocates consideration of the experience of the target of stigmatization. In other words, the authors argue that it isn't enough to simply study why individuals with AIDS are stigmatized in the workplace, or even what consequence that might have on workplace outcomes. It is also necessary to investigate the outcomes of such stigmatization on all three levels of analysis: the individual level (e.g., self-esteem and feelings of worth), the group level (e.g., task cohesion and group performance)

and the organizational level (e.g., the traditionally thought of outcomes studied such as workplace violence, attrition and job satisfaction). Many questions can be understood within this framework, and this type of research could provide a wealth of information that has not yet been available.

For example, at the individual level of analysis, one area that is of particular importance would be in the manifestation of discrimination toward individuals with AIDS. Although it is illegal to discriminate against a person with AIDS under the Americans with Disabilities Act, it is possible that people with AIDS are still discriminated against in the workplace. Hebl, Foster, Mannix and Dovidio (2002) developed a taxonomy to distinguish between "formal" and "interpersonal" discrimination. Formal discrimination encompasses behavior that is typically considered illegal (e.g., firing somebody because they have AIDS). Conversely, interpersonal discrimination would describe behavior that is not illegal such as nonverbal behavior. This discrimination could take place in very subtle ways that have not received sufficient research. It is possible that although an organization might not overtly discriminate against anyone with AIDS, their actions and behaviors might inadvertently cause adverse impact. For example, a supervisor might not feel completely comfortable traveling to conferences or conventions with an individual with AIDS. Therefore, the supervisor might select other employees for traveling to conferences, thereby building a relationship that might enhance the perceived promotability of the non-stigmatized individual. Meanwhile, the person with AIDS did not have that interpersonal exposure with the supervisor and may be penalized by being overlooked for a promotion in the future. Subtle instances of discrimination may accumulate over time and create large discrepancies and disadvantages for stigmatized individuals (Valian, 1998).

These subtle forms of discrimination have been documented for openly gay employees. Ragins and Cornwell (2001) found that gay employees who reported being discriminated against received fewer promotions than employees who did not report discrimination at work. Conversely, those employees that reported discrimination did not report a significant difference in compensation from those employees that did not report discrimination. They propose that since compensation is a highly visible method of discrimination and easily documented, that it was used less than the subtle form of promotions and awards. Furthermore, they postulate that promotions are due to selective grooming, mentoring and networking, and that

gay employees report being excluded from such mentoring relationships. Similarly, Hebl and colleagues (Hebl et al., 2002) found that gay and lesbian individuals were hired at similar rates as heterosexual individuals, but received more negative interpersonal treatment. This type of research should be conducted for employees with AIDS to determine how discrimination is manifested toward this stigmatized group.

Targets of Stigma - The influence of the perceived controllability, concealability, and contagion of AIDS should be examined across many populations. However, the individuals targeted by the majority of research in this area is limited. For example, little research has investigated the effects of stigmatization on the group being stigmatized. Most research, to date, regarding the stigma of AIDS has been focused on how individuals with AIDS are stigmatized, and how that stigma has changed over the years. However, the effects of being stigmatized on the targets of the stigma have received very little attention (see Swim & Stangor, 1998). This is another direction that we believe should be investigated more thoroughly. The stigma of AIDS might negatively impact self-esteem, self-efficacy, and ultimately health outcomes. In addition, it would be valuable to investigate how the stigma of AIDS impacts interpersonal relationships and family dynamics. Mason et al. (1995) investigated stigma disclosure and found that Spanish-speaking Latinos were less likely to disclose their condition to significant others (including family members) than English-speaking Latinos and whites. Furthermore, when asked for reasons for withholding disclosure, Latino men were more likely than white men to withhold disclosure of their condition for "other-focused" reasons. In other words, they did not disclose their condition for fear of hurting those close to them (Mason et al., 1995). This points to the importance of considering ethnic differences in the decision to disclose AIDS to family members and the experience of the AIDS stigma.

One of the most neglected aspects of the AIDS stigma involves an often ignored segment of the homosexual population: female-female sexual relationships. Since the HIV epidemic began, research has focused on male-male sex, but has virtually ignored lesbian, bisexual and transgender individuals. While it may be true that male-male sex and heterosexual sex account for the vast majority of AIDS cases, research still should address the stigma attached to HIV for female-female sexual relationships. This oversight has severe consequences, including a failure to include gay women in the education and prevention of AIDS (Morrow, 1995).

Another often-ignored population that should be given more consideration for future research is parents of individuals with HIV-AIDS, as well as parents who have AIDS themselves. Letteney and LaPorte (2004) studied how the stigma of AIDS affects the extent to which mothers with AIDS disclosed their illness. Those participants who felt devalued and discriminated against because of AIDS were significantly more likely to hide their illness from their children. This secrecy could have unintended consequences such as disease transmission, lack of medical treatment, and lack of proper planning for the care of children. More research should address the unique concerns of parents with AIDS and how the stigma affects not only the parents, but also the consequences for surviving partners and children.

Coping Strategies - Although past research has effectively identified and described the stigma of AIDS, there is a lack of research aimed at remediating the stigma of AIDS. In other words, what should be done to combat the stigma of AIDS? Herek and Capitanio (1997) studied how direct and vicarious exposure to a person with AIDS affects attitudes and found that such contact can alleviate the stigma of AIDS. However, it is not feasible to believe such a method could effectively eliminate the stigma. Future research should address the possibility that current methods for educating the public on AIDS might not be as effective as hoped, and even more importantly, what can be done to further eliminate the stigma associated with AIDS.

Several remediation strategies have been tested in social psychological research studies that may direct investigations of the remediation of the stigma of AIDS. For example, Hebl and Skorinko (2005) found that acknowledgment of one's stigma early in an interaction can improve interaction outcomes. However, this study focused on the stigma of disability, which is typically perceived to be uncontrollable. In cases, such as AIDS, where stigmas are perceived to be controllable, different strategies may be more effective. For example, stigmatized group members who provide individuating information about themselves may be able to separate their identity from the stigmatized characteristic. An individual who is HIV positive may inform interaction partners about their hobbies, community service projects, or other activities and information that can help them be perceived to be more than just a person who is HIV positive. In addition to these personal strategies, organizations and government agencies might remediate the stigma of AIDS by instituting protective legislation, policies, or training programs. The relative effectiveness of each of these

strategies in remediating the stigma of AIDS and its consequences should be thoroughly tested in empirical research.

Methods of Future Research

Future research should examine many of the questions discussed previously with a myriad of methodological approaches, including vignette studies, computer simulations, and social interaction paradigms. One method that has been used, but could be expanded on is the use of vignettes to study participant reaction to interacting with a person with AIDS. That type of research strategy could address many of the questions regarding AIDS in the workplace. For example, researchers could use vignettes to establish how participants would feel working in a variety of workplace conditions (i.e., jobs that require strong task cohesion, jobs that require travel, jobs that require personal contact, etc.) with people who have AIDS.

The use of vignettes could also be used to study situations that would be virtually impossible to study using behavioral strategies. For example, suppose researchers are interested in determining how jobs requiring very close personal contact (i.e. a dental hygienist working with a dentist) are affected by an individual who discloses being HIV positive. It might be important to determine if employees are affected by the knowledge that their coworker has AIDS. However, it would be ethically irresponsible to develop an experimental strategy that deceives participants who might fear for their own health. In such cases the use of vignettes could determine if there is a relationship without causing mental anguish.

Another method that should be used more extensively in future research is the use of computer simulations. Pryor et al. (2004) used computer simulation to study the moment-by-moment reactions to individuals who have AIDS. That type of research could be used in a variety of research strategies. For example, researchers could use computer simulations in which participants react to an interactive computer-based scenario. The scenario could involve what a participant might be expected to encounter in everyday life. As the participant changes their behavior in the simulation, the computer program changes the situation. For example, a participant might be requested to interact as part of a simulated group with a specific work related goal. The participant would be required to make decisions on how they would interact with members of the group, including one group member who is identified as having AIDS (either controllable or uncontrollable). The manner in

which the participant interacts with members of the group dictates what is achieved.

Finally, we strongly advocate the use of social interaction paradigms in studying the stigma of AIDS, as they will provide some of the richest data for studying the AIDS stigma. What individuals indicate their response would be through the use of vignettes or computer simulations could be vastly different from how individuals actually respond when confronted with a real situation. For example, participants might vary their response to a vignette because they fear they will seem closed minded or mean. However, when faced with a real-life situation, their reaction might be completely different. For example, suppose a participant indicates a willingness to drink out of the same glass as a coworker with AIDS through the use of computer simulation. That participant might be influenced by their expectations of social norms and how they appear to the researcher, and may adjust their response to seem more empathetic or unconcerned. However, it is possible that the same individual would be unwilling to actually drink out of the same glass as a person who has AIDS if placed in a situation where they actually have to make that decision. Rozin et. al. (1994) found that people would be less willing to wear a sweater if somebody who had AIDS had previously worn the sweater, drive a car if the car had previously been driven by somebody with AIDS and sleep in the same hotel bed that had been slept in the previous night by an individual with AIDS, even if these things were clean. The results of their study indicate an unwillingness to have vicarious contact with inanimate objects that had been used by people with AIDS. Future research should study how people will act in what they perceive as a real-life situation. It would be valuable to determine if behavior now is similar to attitudes expressed over ten years ago.

A triangulation of methodologies may be the best approach to maximize internal and external validity and develop a comprehensive understanding of the processes involved in the stigma of AIDS. As an example of such a design consistent with previous stigma research, a researcher could develop a study using an experimental field paradigm to determine how AIDS affects employment selection. Confederate researchers could participate in job interviews in which they either disclose HIV positive status or do not. Interpersonal, subtle behaviors and hiring decisions could be assessed to determine the contemporary manifestation of discrimination toward individuals with HIV/AIDS. Furthermore, research must address the perceptions of the stigmatized group. Experiences of those individuals who are stigmatized should be investigated further. Although

qualitative in nature, such information would be invaluable for determining future research directions.

In summary, there exists enormous potential for studying the stigma of AIDS in work and social contexts in the United States. Much of the stigma of AIDS research has investigated the nature of the stigma, while very little research has addressed the potential impact of the stigma of AIDS on its targets. Future research should consider the impact of the stigma of homosexuality on the AIDS stigma, the dynamics of the stigma of AIDS in organizational contexts, and strategies by which the stigma may be reduced or avoided. By thoroughly integrating behavioral and applied scientific approaches, we may begin to fully understand the problem of the stigma of AIDS and to identify and implement its solution.

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Rights Matter: Structural Interventions and Vulnerable Communities

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Abstract

This contribution includes a lecture delivered by Dr. Dennis Altman at the International AIDS Conference held in Bangkok, Thailand during the summer of 2004. Its main goal was to recognize Jonathan Mann for his commitment to the struggle against HIV/AIDS.

Jonathan Mann is probably best known for his work with the World Health Organization and the publication of the two volume book entitled AIDS in the World. In this address the concept of vulnerability is critically addressed in order to expose how risk behaviours are intimately linked to the environment in which they are manifested. Therefore, structural interventions that take into consideration this context are urgently needed. These structural interventions can serve to reduce the stigma surrounding HIV/AIDS and address the future of the epidemic without blaming those living with the virus.

Keywords: Acquired Immune Deficiency Syndrome; stigma; structural interventions; vulnerability.

Los Derechos Importan: Intervenciones Estructurales y las Comunidades Vulnerables

Compendio

Esta contribución incluye un mensaje hecho por el Dr. Dennis Altman en la Conferencia Internacional del SIDA llevada a cabo en Bangkok, Tailandia en el verano del 2004. Su objetivo principal fue reconocer a Jonathan Mann y su compromiso con la lucha contra el VIH/SIDA. Jonathan Mann es probablemente mejor conocido por su trabajo en la Organización Mundial de la Salud y la publicación de su libro de dos volúmenes titulado SIDA en el Mundo. En este mensaje el concepto de vulnerabilidad es críticamente abordado para exponer cómo las conductas de riesgo están íntimamente ligadas a los contextos en los cuales se manifiestan. Por lo tanto, intervenciones estructurales que tomen en consideración este contexto son urgentemente necesarias. Estas intervenciones estructurales pueden servir para reducir el estigma que rodea al VIH/SIDA y abordar el futuro de la epidemia sin culpar a las personas que viven con el virus.

Palabras clave: Síndrome Inmunodeficiencia Adquirida; estigma; intervenciones estructurales; vulnerabilidad.

The Context of this Contribution: An Editorial Perspective

It will be evident to the reader that this contribution is significantly different than the others in this special issue. It does not concentrate on theoretical implications or specific research findings. Still, we understood it to be an invaluable asset to this journal due to its content and context. This contribution includes a lecture delivered by Dr. Dennis Altman at the International AIDS Conference held in Bangkok, Thailand during the summer of 2004. Its main goal was to recognize a man who committed his life to the struggle against HIV/AIDS.

Jonathan Mann is probably best known for his work with the World Health Organization and the publication

of the two volume book entitled AIDS in the World. Probably his most important work on a global perspective was speaking out loud about the implications of this epidemic. In his eyes HIV/AIDS was not only a biological threat, but a social epidemic of meaning. He called this the "third epidemic" which would cause of marginalization, poverty, discrimination and oppression of many who were already at a disadvantage in social hierarchies. Mann was clearly referring to AIDS stigma.

In this lecture, Dennis Altman focuses on the implications of Mann's perspectives and ideas for the development of interventions to address this "third epidemic". Structural interventions are an effective way of understanding the implications of HIV/AIDS from a perspective that does not blame or stigmatize those that are living with the virus. Due to the importance of Jonathan Mann's work for AIDS stigma, and the importance of developing structural interventions to address this epidemic, we have included this lecture in the special issue, and hope that it generates even more reflections on the topic of stigma eradication.

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² This lecture has been published with permission of the author and the Journal Health and Human Rights (2005).

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Jonathan Mann Memorial Lecture (Bangkok, Thailand. July 14, 2004)

My original invitation to deliver this address specifically spoke of interventions for ‘MSM⁴, IDU’s⁵ and sex workers’, leading one friend, a veteran activist, to dub this the perverts’ plenary. The very framing of this topic shows both the strengths and the limits of the current international language of HIV prevention. It is highly important both to emphasize prevention and to recognise that some groups, because of particular behaviours, are particularly vulnerable to HIV infection. But this assertion makes two problematic assumptions. One is that we assume people can be neatly divided by behaviour into discrete and identifiable groups. The second is that everyone has the knowledge and the resources to make free choices, whether this be the choice for sexual abstinence and refusal of drugs, or alternatively the choice to always use condoms or clean needles.

Interestingly both conservatives and liberals place great emphasis on choice: the advice to “just say no” is equivalent in some ways to the advice to always follow safer sex and injecting practices. Yet this ignores the harsh reality that before we have choice, or what social scientists like to term ‘agency’, we need both knowledge and the means to act on that knowledge. Estimates from most parts of the poor world suggest a continuing ignorance about HIV and the basic measures to control it: one survey in Orissa, in eastern India, suggested 60% of women have never heard of AIDS (AIDS in India, 2004).

If there is one comment which sums up the legacy of Jonathan Mann it is his assertion that: “We must protect human rights because we want to effectively control AIDS as well as protecting rights for their own sake” (Mann, 1988). As the founding director of the Global Program on AIDS, Mann led us to understanding the link between health and human rights. His work lives on through the journal, *Health & Human Rights*, through the Boisrouvray Centre at Harvard University and through the words of leaders such as South Africa’s Nelson Mandela and Burma’s Aung San Suu Kyi, whose absence from this conference reminds us of the indivisibility of human rights. Jonathan was willing to offend when doing so would confront people with the consequences of their actions, or, equally important, their inactions. His is a model I shall follow.

Given the gravity of the epidemic, we need go beyond a legalistic emphasis on covenants and policies to a genuine understanding of the moral and pragmatic priority of human rights. Our shared work grows out of respect

for human life and dignity, which is both a religious and a secular tradition. It is closely related to the basic concept of human security, and the worst excesses of the past decades (eg. Rwanda/Cambodia/Bosnia) remind us that without respect for human life there can be no security. In much of sub-Saharan Africa today societies face the literal possibility of total collapse and disintegration due to the ravages of HIV. If unchecked, HIV will undermine societies as surely as will the bombs of terrorists. Yet the resources provided to check HIV/AIDS are miniscule in comparison to those being put into fighting terror.

Who are Vulnerable?

Let us be careful, as we focus on youth and women, today’s theme, that legitimate outrage at the treatment of many women does not mean we forget that poverty, racism, war and oppression also limit choices for men. Indeed, the very term ‘men’ is itself problematic, as is clear if we think about the diverse ways in which gender is expressed. The rich transgender heritage of groups such as *kathoey*, *waria*, *hijra* (eg. Boellstorff, 2002; Jackson, 1997), to take three examples from this part of the world (Asia), remind us there are many ways of acting out ‘maleness’. Men who deviate from the conventional assumptions of masculinity are often likely to be particularly vulnerable to HIV.

There is a parallel danger in assuming all women are equally vulnerable. Such a view can too easily paint all women as inherently powerless, depicting them as either Madonnas or whores. This can further stigmatise the most dispossessed, and increase their vulnerability. In general the more socially and economically marginalised a population the greater its vulnerability to infection, and there are many groups who might also have been discussed in today’s session: refugees, migrant workers, prisoners and indigenous and tribal populations.

Access to prevention is as significant as access to treatments, and an equally political demand, for it is about our right as healthy citizens rather than as unhealthy dependents. We need not choose between allocating resources to prevention rather than treatment, for strengthening one can only strengthen the other. This argument is developed in a paper that the AIDS Society of Asia and the Pacific will release later today (McNally, 2004). Unlike failure to access treatment, it is hard to blame the rich world in general or pharmaceutical companies in particular, for failures in prevention. Even poor countries can afford to support good prevention efforts, as Uganda and Cambodia remind us.

The greatest tragedy of HIV/AIDS is that we know how to stop its spread, and yet in most parts of the world we are failing to do so. The literature tends to emphasize immediate problems—lack of condoms or clean needles,

⁴ MSM = Men who have sex with men.

⁵ IDU’s = Intravenous drug users.

safe sex fatigue, unwillingness to interfere with the immediate gratification of sex or drugs. There is less emphasis on the political barriers that are accelerating the epidemic—the deliberate neglect by governments, the unwillingness to speak openly of HIV and its risks, the hypocrisy with which simple measures of prevention are forestalled in the name of culture, religion and tradition.

What do We Mean by 'Structural Interventions'?

Put simply, structural interventions involve policies that recognise vulnerability to HIV goes far beyond individual choices and behaviours, acknowledging that such behaviours are products of larger environmental factors (Parker, 2002). Structural interventions can be as ambitious as reducing economic inequalities to give people better housing and clean water, but they can also describe specific programs such as needle exchanges or the provision of condoms to sex workers and prisoners. In most cases they will involve governments, either through their own policies or at least by not blocking programs undertaken by NGOs and community groups.

Imagine a child, living on the streets in the slums of Rio, Dacca, Lagos or Kiev, forced to survive through prostitution and petty crime, often turning to drugs to numb the pain, the fear, the hunger and the cold of everyday survival. Telling such a child to use condoms or not to share needles to ward off an illness that may strike many years hence is meaningless. Imagine a young woman, forced by family and community pressure, to marry at thirteen and have sexual relations with a man older than her father, whom she has never properly met, and the possibility of her insisting on his using a condom—if, indeed, she even knows the dangers of unprotected intercourse. Imagine a young man, forced into an army or militia, having to flee his family and home to survive, perhaps in prison or a make shift camp, introduced to drugs as a means of escape, and then imagine the chances that he will have the means or the incentive to reject the short term euphoria of a hit because the needle may not be clean.

Yet for millions of people in the world today struggle for immediate survival is the reality of their everyday life. As Paul Farmer has written:

“For many...choices both large and small are limited by racism, sexism, political violence and grinding poverty... Both HIV transmission and human rights abuses are social processes and are embedded, most often, in the inegalitarian social structures I have called structural violence.” (Farmer, 2003, pp. 40)

Unfortunately there are more examples of political interference that have hampered sensible HIV prevention

programs than have supported them. Too many governments have applied sanctions, punishment and repression, ignoring the reality that humans will seek both pleasure and survival in ways that often confront the traditional norms to which social, religious and political leaders pay lip service.

Identity Versus Behaviour

There is a double vulnerability involved in HIV: both economic and social factors are crucial. Someone who sells sexual services in order to survive is likely to be more vulnerable to HIV, and this is a result both of the specific behaviour and of the poverty and despair that underlies that behaviour. There is a critical difference between concepts of ‘risk’ and ‘vulnerability’ (Aggleton, Chase, & Rivers, 2004), but also between behavior and identity. In discussing the latter we need be aware of oppression that results both from material inequality and from prejudice and discrimination based on identity. Here I draw on Nancy Fraser’s very useful distinction between “injustices of distribution and injustices of recognition”, both of which she claims have material consequences and both of which need be countered to achieve social justice (Fraser, 1996).

There is a problem in talking of ‘vulnerable populations’, as if they are discrete and their boundaries are known. Most people who engage in the behaviours I have been asked to address do not necessarily identify themselves in these terms. Sometimes we need name groups—and empower them. At other times we need understand that most people do not necessarily accept the terms of the HIV world and that they may be reached through other approaches (eg. through outreach to women or to street kids or to unemployed youth).

The fear of stigmatising homosexual men by linking them too closely to HIV, a concern for some gay men in the early stages of the epidemic, has been replaced by a frightening silence, whereby most national and international organizations working on HIV/AIDS are unwilling to even acknowledge homosexuality. In Japan there is much talk of ‘young people’ at risk of HIV, but little acknowledgement that many of these are young homosexual men. To always speak of HIV transmission through heterosexual intercourse without recognising that many men will engage in sex with each other is to send the very dangerous message that homosexual intercourse is without risk. The Hong Kong Advisory Council on AIDS has recognised the need to address silence about homosexuality in schools, health care settings and within government as an integral part of HIV prevention (Smith, 2001).

In the west, gay communities pioneered responses to HIV, particularly the development of safer sex programs that are still relevant to most societies and populations today. Equally, as one Australian drug worker pointed out:

“It was us, individually and collectively through our organizations, who developed the educational messages, trained the peer educators, taught each other safe injecting techniques, and passed on the equipment and information from person to person.” (Stafford, 2004, p. 2)

This does not mean that we can speak of all vulnerable groups as if they resembled gay men or users in rich western cities. There is a political and conceptual problem in lumping together very different groups into category of “vulnerable populations”. Where people can organise around particular identities this can be the most powerful force for prevention and action against stigma. The history of AIDS demonstrates this was true for gay men and haemophiliacs in western countries, for sex workers in groups across the developing world, for people living with or close to those with HIV, in major social movements like TASO in Uganda or South Africa’s TAC.

Some of the greatest bravery in this epidemic has come from people who have confronted the double stigma of their identity and their seropositivity, creating the community organisations without which many of you would not be at this Conference. Today their legacy is carried on in groups like Global Network of People living with HIV/AIDS (GNP+) and the International Community of Women Living with HIV/AIDS (ICW), in organizations of sex workers, homosexual and transgender men and drug users, who through asserting their basic human dignity and right to expression are also creating models for HIV work. As we were organising the last regional AIDS in Asia & the Pacific Congress (ICAAP) in Melbourne in 2001—a conference held in the shadow of 9/11—we were inspired by the bravery of young homosexual men in Lucknow, India, who were harassed and imprisoned by local authorities as they sought to provide basic information and resources for safe sex to homosexual men in Uttar Pradesh. Also in India, is the extraordinary sex worker cooperative known as the Durbar Mahila Samanwaya Committee, which seeks to empower sex workers to protect themselves and their dependents from HIV infection (Thekaekara, 2004). There are examples of great bravery from people who have set up needle exchanges and done outreach work for drug users on the streets of cities ranging from New York to Beijing, risking police and government persecution and intimidation.

Just prior to the International AIDS Conference there was a regional ministerial meeting in Bangkok devoted to AIDS, at which there was only very token participation by representatives of affected and infected communities, and

that only after considerable pressure on the organisers. The lessons from countries as far apart as Brazil and Uganda, that policy work demands the full participation of infected and affected communities, seems to have been forgotten by our governments.

What are Good Structural Interventions?

Good structural interventions include legal and social regulations that take as their starting point improving the quality of life, health and citizenship for all. As in other areas of HIV/AIDS, Brazil stands out, with its combination of governmental and non-governmental programs aimed at linking treatment and prevention, its willingness to promote condoms and clean needles, and the launching of a government sponsored plan called *Brazil Without Homophobia*. Earlier Brazil proposed a resolution at the United Nations Commission on Human Rights — unfortunately postponed—against discrimination based on sexuality.

There is growing tension between evidence based public health and denial of that evidence, fuelled by a bizarre combination of religious and ideological pressures, which often see the United States and some of its bitterest opponents unite in their support of repressive legislation. This is clearest in the area of drug use. Countries such as Switzerland, the Netherlands and Australia contained spread of HIV by intravenous drug use (IDU) through the early introduction of needle exchange and harm reduction. Yet this lesson is still disputed by the United States and most Asian governments, with the result that IDU in parts of Asia and Eastern Europe is fuelling the epidemic in alarming proportions. Even here in Thailand, a country many of us have long admired for its responses to HIV, the recent crackdown on drugs has greatly increased vulnerability of users to HIV. I congratulate the Prime Minister for his opening remarks, which came close to acknowledging this. Thailand might look to Portugal, which has moved to remove users from the criminal justice system, itself one of the greatest factors for harm, and has registered a corresponding decline in needle-related HIV infections (Van Beusekom, Van Het Loo, & Kahan, 2002).

In most countries there are ongoing restrictions on the discussion and promotion of condoms, on sex education in schools, on recognition that homosexuality and sex for money are realities in every complex human society. Often the most significant structural interventions possible are those that remove barriers to honest discussion of human behaviour. If the choice is between maintaining the demands of ancient religious superstitions—and with them the power of male clergy—and proving the information and the

resources to protect young women and men from infection with a potentially lethal and painful virus, can anyone who seriously believes in a just God, or a system of ethical standards, seriously doubt the answer?

Good interventions support genuine choice and protect people in the choices they make. In the case of sex work this means action against the enforced recruitment of women and children into prostitution, often with the involvement of government, business and military officials. Sex workers need genuine alternatives to prostitution as a means of livelihood, while simultaneously protecting those who survive through working in the sex industry. Extending workers rights, as is the case in some European countries and has been proposed recently by a Thai Senate committee, might be the most significant structural intervention in some cases. So too are 100% condom programs, but only when they involve sex workers themselves, as has been claimed of several projects in the Dominican Republic (Kerrigan et al., 2003).

Good structural interventions will acknowledge the presence and human dignity of people who live outside conventional expectations. Often this involves the provision of safe spaces for people whose behaviours put them at risk from both state and unofficial violence. Such policies would include the provision of safe spaces for injectors, as exist in Switzerland; safe street areas for prostitution; or community drop-in centres for those who identify as homosexual, as provided by the Humsafar Trust, with city and state support, in Mumbai.

Because effective interventions empower and remove stigma, effective interventions uphold human rights. Further, they increase the likelihood that people will do what they can to protect themselves. An empowered sex worker or drug user is more likely to find alternatives than one who is criminalized and stigmatised.

We need think imaginatively and act boldly. In countries like the United States and Russia, where prisons are incubators for HIV, reducing the number of people imprisoned would be a very effective way to reduce the spread of HIV. In many parts of the world only a radical shift by organised religion, and a willingness to accept that safeguarding life is more important than preserving antiquated moral precepts, will bring the resources and the messages about safer sex to those who are most vulnerable. Moves to remove the criminal sanctions against and persecution of homosexuals and sex workers are crucial to achieving the goals of slowing HIV infection. In most of Britain's former colonies in South and Southeast Asia, in

Africa and the Caribbean, homosexuality is criminalized because of British laws, which have been retained on the books by governments who boast of their opposition to colonialism.

Theoretical discussion is relevant to finding empirical solutions: how we think about and frame the questions will help determine the answers. Not nearly enough attention is paid at these Conferences to analysing the barriers that religion, politics and human hypocrisy erect against effective programs of HIV prevention. In the end the great issues that demand research and action are political questions, in that they involve issues of power, control and ideology.

As the epidemic grows we have many reasons to be angry, particularly at the hypocrisies of most governments and most religious leaders. Indeed, we are so unwilling to confront these issues that we fall back on platitudes about "communities of faith", ignoring the ways in which fundamentalists of all faiths perpetuate the gender and sexual inequalities that fuel the epidemic. We constantly hear rhetoric about leadership, rather than analysing what it is we want leaders to do. But anger that is not supported by analysis, and that does not lead to action, is wasted and self-indulgent. As the world becomes more dangerous and uncertain, and political attention is increasingly focused on war and terror, how we respond to the challenge of halting the spread of HIV is a central test of human decency and human solidarity.

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HIV/AIDS Stigma and Discrimination: A Canadian Perspective and Call to Action

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Abstract

Canada as a nation is committed to addressing HIV/AIDS stigma and discrimination. The federal government has recently announced that funding for HIV prevention, care and treatment will double by 2009, from a current \$42.2 million to \$84.4 million. While the prevalence of HIV/AIDS in Canada is relatively low, experiences of HIV/AIDS stigma and discrimination are common. In response to this situation, the Canadian HIV/AIDS Legal Network has recently released a report outlining a series of goals and actions designed to prevent, reduce and eliminate HIV/AIDS stigma and discrimination. By promoting tolerance and understanding through research, legislation and community level action we can diminish the overarching epidemic of stigma and discrimination and decrease the extent of the HIV epidemic in Canada.

Keywords: HIV; Acquired Immune Deficiency Syndrome; stigma; law; Canada.

El Estigma y la Discriminación del VIH/SIDA: Una Perspectiva Canadiense y una Llamada a la Acción

Compendio

Canadá es una nación comprometida con abordar el estigma asociado al VIH/SIDA. El gobierno federal ha informado recientemente que el financiamiento para la prevención de VIH, el cuidado y tratamiento se duplicará para el año 2009, de la cifra actual de \$42.2 millones a \$84.4 millones. Aún cuando la prevalencia del VIH/SIDA en Canadá es relativamente baja, las experiencias del estigma y discriminación relacionadas al VIH/SIDA son comunes. En respuesta a esta situación, la Red Legal sobre VIH/SIDA de Canadá ha publicado recientemente un reporte delimitando una serie de metas y acciones diseñadas para prevenir, reducir y eliminar el estigma y la discriminación relacionada al VIH/SIDA. A través de la promoción de la tolerancia y el entendimiento mediante la investigación, legislación y acción comunitaria, podemos disminuir la amplia epidemia de estigma y discriminación, a la vez que reducimos la epidemia del VIH en Canadá.

Palabras clave: VIH; Síndrome de Inmunodeficiencia Adquirida; estigma; ley; Canadá.

December 1st, 2003 marked the 15th Annual World AIDS Day. In an unprecedented move, the 2003 theme, *Stigma and Discrimination*, was a repeat of the theme used the previous year (AVERT.org, 2003). From the beginning of the HIV/AIDS epidemic, stigma has been a crucial issue (Goldin, 1994; McGrath, 1992; Treichler, 1999). In North America, a slow public health response was the result of the epidemic initially being located in a population labelled as deviant (homosexual men). Moral critics blamed the victims believing them to be responsible for their own infection because of their immoral lifestyles. As the epidemic spread, it moved into other stigmatized populations such as injecting drug users (IDUs), sex trade workers, and migrants. The public health response was equally as slow and the moral outrage became amplified. It was not until the disease began appearing in the more general population via the blood supply that the public health alarm bells began to ring (Gilmore & Somerville, 1994; Shilts, 1987; Treichler, 1999).

It is unfortunate that two decades into what is poised to become the worst catastrophe in recorded human history (Foster, 2002; Haseline, 1993) we are still battling the stigma associated with HIV/AIDS. We are now armed with a tremendous amount of knowledge about this disease and

know that social deviance is neither a necessary nor a sufficient explanation for the rapid spread of the virus. In Canada, the initial public hysteria about the *gay plague* has been replaced by a general state of apathy among the public at large (Canadian HIV/AIDS Legal Network, 1999). The initial response was not consistent with the actual risk of contracting the disease and the current response is incongruent with the increasing severity of the epidemic and its accompanying social and economic problems.

Globally, the social costs of this epidemic have been high: An estimated 34 million dead by the end of 2004; An estimated 40 million currently infected, many of them unable to access healthcare or afford life-preserving medications; Five million new infections in 2004 alone (Joint United Nations Programme on HIV/AIDS, 2004). The economic costs have also been high, and are set to skyrocket. Already the economies of several developing nations are on the brink of disaster even as healthcare systems in more developed nations strain under the burden (World Health Organization [WHO], 2003).

In Canada, the overall prevalence of HIV/AIDS is relatively low—an estimated 0.3% at the end of 2003 (Joint United Nations Programme on AIDS, 2004). The incidence of HIV was steadily declining until 1995. However, since 2000, this trend has reversed, the number of newly reported HIV infections are increasing. Officials suggest that this

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increase may be partly due to improved surveillance and reporting which, in most provinces and territories, also includes immigrants who are now faced with mandatory testing. By the end of June 2004, there were a total of 56,523 positive HIV test reports, and 19,468 reported AIDS cases (all ages included). The use of highly active anti-retroviral therapy (HAART) has been widespread in Canada since 1996, and this has resulted in an overall decline in AIDS diagnoses and deaths but a corresponding decline in HIV infections has not been evident (Public Health Agency of Canada, 2004a).

Between 1985 and 1997, women accounted for about 12% of all newly diagnosed HIV infections. Since 2000, that proportion has doubled—25% of new infections are reported among women. Similarly, the number of women diagnosed with AIDS has increased from about 7% prior to 1994, to 25% at the end of 2003—almost a four-fold increase. Canadian women between 15 and 29 years of age have been particularly hard hit by HIV/AIDS. Prior to 1995, women in this age group accounted for just fewer than 10% of AIDS cases; by 2003 this group accounted for 41% of AIDS diagnoses. Perhaps even more disconcerting, at the end of 2003, women between the ages of 15 and 29 accounted for 42.5% of all newly reported HIV infections amongst this age group. While injection drug use has some influence on infections amongst women, particularly those participating in the sex trade, heterosexual contact is believed to be the driving force (Public Health Agency of Canada, 2004a).

Up until 1988, the overwhelming majority (91%) of HIV/AIDS cases in Canada (where ethnicity was reported) were diagnosed amongst Caucasians. By 2003, almost half of new cases were diagnosed amongst ethnic minorities. Aboriginal and Black Canadians are now over-represented in Canadian HIV/AIDS statistics. In 2001, Aboriginals accounted for roughly 3.3% of the Canadian population, Blacks 2.2%. At that same time they accounted for 5.9% and 15.6% (respectively) of AIDS cases with known ethnicity. By the end of 2003, those proportions had increased to 14.4% and 20.7%, respectively. It is believed that injection drug use is driving the epidemic amongst Aboriginals, while heterosexual contact is driving the epidemic amongst Blacks (Public Health Agency of Canada, 2004a).

As elsewhere, in Canada many of those who are infected with HIV/AIDS are afraid to come forward for care and support. People who may be infected are afraid to come forward for testing and counselling. Therefore, those who are at risk are afraid to learn about and adopt new behaviours because this may imply infection. These fears are fuelled by the potential for stigmatization and discrimination. Many of those infected, affected, and at risk fear the stigma associated with HIV/AIDS, and thus, avoid being identified. The isolation of persons from the larger community is troublesome enough from a humanitarian standpoint, but the dissociation of persons from the realities of the disease is an epidemiological nightmare.

Throughout history, stigma has divided the world, defining *us* and *them*. Whether the mark was a physical, mental, social, or spiritual characteristic, those who did not fit the social ideal of the time (or at least come close to it) were shunned, dishonoured, and scorned (Ainlay, Becker, & Coleman, 1986; Goffman, 1963; Heatherton, Kleck, Hebl, & Hull, 2000; Jones et al., 1984; Katz, 1981). Social ostracism reduces one's *life chances* (access to jobs, earnings, education, housing, etc.) and seriously jeopardizes health (Gilmore & Somerville, 1994; Link & Phelan, 2001). HIV, initially marked by its association with homosexuality and with other individuals and groups who were already stigmatized, has proven to be a most difficult public health challenge (Joint United Nations Programme on HIV/AIDS, 2003; McGrath, 1992; PANOS Institute, 1990; WHO, 2003).

The World Health Organization (WHO) has recognized the importance of a concentrated effort to avert the HIV/AIDS pandemic and is currently scaling-up its '3 by 5' plan aimed at supplying 3 million people in developing nations with anti-retroviral drugs by the end of 2005 (WHO, 2005, 2003). While the plan is behind schedule, it is expected that mainstreaming the provision of medication will significantly reduce social costs by extending life and productivity, will stabilize healthcare costs through prevention and decreased morbidity and mortality, and reduce HIV/AIDS stigma and discrimination.

The US National Institutes of Health has also recognized the importance of addressing stigma and recently announced funding to nineteen new research projects under the auspices of the *Stigma and Global Health Research Program*. The support is for both domestic and international collaborations which will study the role of stigma in global health (National Institutes of Health [NIH], 2003).

In Canada, the Canadian HIV/AIDS Legal Network has recently published *A Plan of Action for Canada to Reduce HIV/AIDS Stigma and Discrimination* (de Bruyn, 2005) which nicely complements the initiatives of the World Health Organization and the US National Institutes of Health. The plan outlines eighteen stigma and discrimination-related concerns that the Canadian government will need to address in order for the *Canadian Strategy on HIV/AIDS* to be effective (de Bruyn, 2005). Of primary importance is respecting, protecting and fulfilling the human rights of all individuals. By promoting tolerance and understanding through research, legislation and community-level action there is a good chance of diminishing the overarching epidemic of stigma and discrimination which will help decrease the extent of the HIV epidemic in Canada and elsewhere.

I begin this chapter with a general discussion of the history stigma, including a biocultural framework that does much to explain the origins of stigmatization and discrimination. From there, I move to a general review of what we know about the progression of epidemics, biologically and socially appropriate responses to infectious

disease, the social construction of illness, and how this knowledge may be applied to the HIV/AIDS epidemic. I then outline the recommendations put forth by the Canadian HIV/AIDS Legal Network (de Bruyn, 2005) which are designed to effectively address HIV/AIDS stigma and discrimination in Canada.

The History of Stigma

Several branches of various disciplines within the social sciences have investigated numerous aspects of the personal, situational, cultural, and historical antecedents and consequences of stigmatization. Many of the theories related to identity, attribution, prejudice, stereotyping, group dynamics, and social movements are relevant to a discussion of stigma, as are many other aspects of human interaction. As well, cross-cultural and historical contexts need to be considered given that stigmas which are significant in a particular society and/or at a particular time in history may be relatively insignificant in another society and/or at another time in history (Neuberg, Smith, & Asher, 2000; Reingold & Krishnan, 2001).

The word stigma originated with the Greeks who were known to apply physical markers (e.g., scars and brands) to identify various deviant members of society such as slaves and thieves. The original meaning shifted in later Christian times and the word took on a two-fold meaning: Stigma could refer either to a physical indicator of holy grace (*stigmata*) or to a physical manifestation that signalled a spiritual fall from grace (Goffman, 1963). The grace/disgrace dichotomy was a reflection of religious beliefs of the time which taught that spiritual morality or immorality would be rendered visible to others and that physical disfigurements, disorders, or diseases were God's punishment for immoral behaviour (Goffman, 1963; Reingold & Krishnan, 2001). Goffman (1963) suggested that the word stigma is currently "used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it" (p. 2).

I might argue that, in North American society, the metaphorical interpretation of stigma as a physical manifestation of immoral conduct is still the tendency of many on the religious right, particularly in the case of sexually transmitted infections and especially in regards to HIV/AIDS because of its association with homosexuality and promiscuity. In the context of a grace/disgrace dichotomy (regardless of bodily evidence of displeasing the gods), heuristic attribution processes coupled with justifying ideologies (Crandall, 2000) promote *us vs. them* thinking (Gilmore & Somerville, 1994; Link & Phelan, 2001). The marked individual is devalued and thereby viewed as someone less than fully human, possibly someone to be discounted and hence stigmatized (Goffman, 1963).

Later researchers suggested that the characteristics of stigmatized individuals may be a necessary but not sufficient

explanation of the stigmatization process (Ainlay et al., 1986; Heatherton et al., 2000; Jones et al., 1984; Katz, 1981; Link & Phelan, 2001). It was proposed that stigma could be further understood in the context of the characteristics of relationships between Goffman's (1963) *deviants* and *normals* or what Jones et al. (1984) refer to as the *marked* and the *markers*. It has been suggested that disruptive emotional, cognitive, and behavioural processes taint these relationships and because everyone is marked as deviant to some extent in the eyes of others we can all imagine the feelings associated with being labelled negatively (Jones et al., 1984).

Answers to the more fundamental question of where stigma originates have the potential to explain why some attributes, such as infection with HIV/AIDS, are universally stigmatizing, while others vary across cultures and time (Mann & Tarantola, 1996). These are issues that have not been sufficiently explained by individual-level theorizing that locates the mechanisms of, and responses to, stigmatization somewhere inside the stigmatizer and the stigmatized (Dovidio, Major, & Crocker, 2000; Stangor & Crandell, 2000; Link & Phelan, 2001).

A comprehensive theory of stigmatization must account for shared beliefs as well as cross-cultural similarities and variances in perceptions of stigma. An extrapolation of theories from the prejudice and stereotype literature does much to explain the formation of shared beliefs and cross-cultural similarities and differences (Stangor & Crandell, 2000). In general, prejudice refers to attitudes held by individuals, which inform cognitive representations (stereotypes) of other individuals or groups of individuals merely because they occupy a specific social position (Biernat & Dovidio, 2000). In general, stereotypes are oversimplified cognitive conceptions or beliefs about individuals who belong to a particular social group or category. They tend to be rigid caricaturizations that often have little basis in reality (Dovidio et al., 2000).

Based on reviews of the stereotype and prejudice literature it has been suggested that:

Stigma develops out of an initial, universally held motivation to avoid danger, followed by an (often exaggerated) perception of characteristics that promote threat, accompanied by a social sharing of these perceptions with others. Moreover... stigmas exist primarily in the minds of stigmatizers and stigmatized individuals as cultural social constructions, rather than as universally stigmatized physical features. (Stangor & Crandall, 2000, pp. 62-63)

A Biocultural Framework of Stigma

The idea that stigma is a function of deep-seated fear is congruent with a biocultural framework of stigmatization, which proposes that stigmatization "represents one end of the continuum of the process of assigning positive or negative labels to those we come across, and then valuing or devaluing them as their labels warrant" (Neuberg et al.,

2000, p. 31). As a potential explanation of the origins of stigma, a biocultural framework appears promising.

Anthropological evidence strongly suggests that humans living within highly interdependent, cooperative groups had an evolutionary advantage. Forming and maintaining functional groups (generally based on kinships) is believed to have become a primary human survival strategy for maintaining reproductive health and well-being. The functionality of a given group, and hence its evolutionary advantage, depended to a large degree on sharing, cooperation, mutual investment, and trust that others would do the same. Group functionality would be especially important during times when resources were scarce, and reciprocal prosocial behaviour would enhance health and thus, improve the chances for survival (Neuberg et al., 2000).

The evolutionary advantage afforded by reciprocal prosocial behaviour suggests that such behaviour would become normative within groups. According to a biocultural model, the processes and consequences of stigmatization within groups begin with violations of these group standards. Actions (or inactions) judged to weaken the evolutionary advantage gained by group living would be frowned upon or actively challenged. Physical disability or blatant disregard for group standards of reciprocity, for instance in the form of thievery, are two examples of stigmatizing forms of non-reciprocation although the latter is an active anti-social choice and breach of trust. It is suggested that the perceived threat to survival presented by dysfunctional group members predicated stigmatization (albeit often to greatly differing degrees) (Neuberg et al., 2000).

In most cultures, at most times, the physically and mentally infirm have depended upon the goodwill of others for survival. In times of plenty, goodwill was abundant. During times of scarcity, those who were unable to reciprocate likely depended upon the prosociality of key affiliates for continued existence. It appears that historically, non-reciprocation based on disability was stigmatized, but generally to a lesser degree than non-reciprocation that appeared to be the result of purposive disregard for group norms. The deliberate exploitation of others for personal gain tended to be more highly stigmatized than a failure to reciprocate predicated on inability (Neuberg et al., 2000).

Problematically, by their very nature, prosocial acts are ripe for exploitation. The exploitation of another's goodwill without reciprocation increases the chances for individual survival. For example, an individual who benefits from a share of the food provided by the group without sharing his/her own resources would have a greater chance of maintaining fitness (at least until such time as the group discovered the deception). It has been suggested that the potential benefits gained by exploiting group norms would be tempting to many individuals, and as a result social sanctions against such behaviours were incorporated (Neuberg et al., 2000).

Within a biocultural framework, it is proposed that groups are built upon a foundation of trust and breaches of trust are perceived as threats to survival. Group members are socialized to uphold group norms of trust and reciprocity and risk being labelled as a threat to social order if they deviate from these norms. Liars, cheaters, thieves, and traitors are stigmatized to a greater degree because individuals actively exploiting the norms of trust and reciprocity are seen to pose a significantly greater threat to survival. At many times, in many cultures, those caught abusing trust, if not subject to the death penalty were/are subject to public exposure of their transgressions. Often this public exposure was in the form of various physical markings, for example, brands and tattoos were popular among the ancient Greeks, amputations are popular among the Taliban (Goffman, 1963; Neuberg et al., 2000). More recently, at least in Western culture, criminal records, jail time, and/or the stripping of professional licenses and credentials mark breaches of trust. Individuals bearing such marks are to be discredited, scorned, and avoided.

Individual group members can pose threats to the group in other ways. Groups thrive when members appreciate and adhere to the social rules and scripts that allow "coordinated social action and interaction" (Neuberg et al., 2000, p. 47). Additionally, the survival of the group depends on the reproductive fitness of group members. Individuals exhibiting defects marking genetic weakness, behaviours that threaten effective group reproduction (such as homosexuality) and those exhibiting symptoms of contagious disease tend to be stigmatized. Groups have a collective need to maintain fitness and to function effectively. Within-group members who present a threat to fitness, functionality, or both (whether the threat is tangible or intangible) are at great risk of stigmatization. As well, other outside groups can present threats.

At the risk of oversimplifying a very complex field of study, the fundamental differences between in-groups and out-groups can be understood by examining the quality of interactions among and between group members. Interaction within groups tends to be characterized by co-operative behaviour, whereas interaction between members from different groups tends to be characterized by competitive behaviour. While group cooperation affords an evolutionary advantage to all members of the group, between group competition affords that advantage to only one group or the other. The threat presented by competing groups tends to set in motion the mechanisms of stigmatization again; this time based more on group membership than on individual behaviours and physical characteristics (Neuberg et al., 2000).

To summarize, in an evolutionary context, the health and well-being of a social group depends upon trust, sharing, cooperation, and mutual investment in the form of reciprocation and prosociality. The functionality and reproductive fitness of groups also depends on members

conforming to social roles and expectations. Those unable or unwilling to meet these demands pose threats to survival and are thus stigmatized. In addition, competing groups which pose threats to survival are also stigmatized. This is not without reason when viewed from an evolutionary standpoint. However, this is not to say that stigmatization is biologically determined, nor that what was adaptive or even natural from an evolutionary standpoint is right or justifiable, especially on the context of contemporary society (Neuberg et al., 2000).

The Nature of Epidemics

I will now turn my attention to what we understand about the progression of epidemics, biologically and socially appropriate responses to infectious disease, and the social construction of illness. Applying this knowledge to the current HIV/AIDS epidemic has the potential to improve population health in Canada and elsewhere.

Predicting the Size and Shape of an Epidemic

We typically think of a new epidemic in a "virgin" population as something that arises suddenly, sweeps through the population in a few months, and then wanes and disappears. (Anderson, 1996, p. 71)

The prevalence of an infectious agent may be referred to as endemic, epidemic or pandemic. At an endemic level there is a relatively low but constant presence of the disease in a specific geographic area or population group. At the epidemic level, more cases of a disease occur than are expected in a given area or group. The term pandemic is used when an epidemic affects large proportions of a population and spans a wide area (several countries or continents). For example, while HIV/AIDS may at one time have been endemic to a specific region it is currently a full-fledged epidemic, and the global distribution of infections gives it pandemic status (Anderson, 1996).

Human pathogens may be classified based on mode of transmission (although some pathogens such as HIV have more than one mode of transmission). Vector-borne diseases are those which are transmitted to humans via non-human hosts (vectors). Mosquitoes, lice, and fleas are common vectors and can transmit various diseases such as West Nile, malaria, typhus, and bubonic plague to humans. Given a disease carrying vector, a susceptible human host, and adequate contact for disease transmission between the two, the transmission of disease is probable (adequate contact varies by pathogen). Other diseases, such as measles, influenza, syphilis, and chickenpox are the result of direct contact between human hosts with no intervening vector. Transmission routes include respiration, fecal-oral contact, or sexual contact. Given a susceptible human host, an infected human host, and adequate contact between the two, the transmission of disease is likely. Still other diseases such as cholera, typhoid, and salmonella are the result of environmental contamination. Transmission of these

diseases is likely to occur when a susceptible human host comes in contact with a pathogen living in the environment via food, water, air, or items such as contaminated needles or clothing (McGrath, 1991).

The development of an epidemic depends on the effective reproduction of infection (case reproduction). With most contagious diseases, for example respiratory or intestinal tract infections caused by viral or bacterial agents, the classical epidemic curve is bell-shaped. The steepness of the slope of the curve reflects how rapidly secondary cases are generated from primary infections (a measure of contagion or infectivity) and the length of the curve describes the duration of the epidemic. The degree to which secondary cases are generated from primary cases depends on the transmission efficiency of the infectious agent. Transmission efficiency is an expression of the probability that an uninfected, susceptible individual will come in contact with an infected individual, multiplied by the possibility that transmission will occur during such contact (Anderson, 1996).

In the case of highly infectious diseases such as measles, which have a relatively short period of infectiousness (generally 2 weeks), the duration of an epidemic is also relatively short (typically 6 months to a year) (Anderson, 1996). In comparison, the genital herpes virus (HSV-2) has an intermittent period of infectivity (Steben & Sacks, 1997), while HIV has an extended period of infectiousness (Anderson, 1996). HSV-2 can be transmitted during times of viral shedding (which are unpredictable and often undetectable) over the course of a normal lifespan, while the HIV virus may be transmitted at any time after initial infection until death, a time span of up to a decade or more (Anderson, 1996; Steben & Sacks, 1997). These lengthy periods of infectivity suggest that these epidemics could endure over a number of generations. It has been predicted that the HIV epidemic will be marked by an elongated epidemic curve showing several distinct peaks rather than a classical bell-shaped curve (Anderson, 1996). This prediction has been borne out in Canada, with the first peak occurring amongst homosexual men, the second amongst injection drug users, and more recently with a third wave beginning to peak amongst heterosexuals, particularly young women (Public Health Agency of Canada, 2004a).

The transmission of infectious agents depends upon the successful exploitation of physiological and anatomical vulnerabilities. The probability of transmission of infectious agents is also influenced by behavioural and social risk factors. When biological vulnerabilities are lessened by appropriate behavioural or social change, the natural course of an epidemic can be disrupted (McGrath, 1991; Anderson, 1996).

Biologically and Socially Appropriate Responses to Disease

According to McGrath (1991), there are four conditions that limit disease transmission: 1) Elimination of the source of

infection, including vector populations, pathogenic organisms, or sources of environmental contaminants; 2) Elimination of adequate contact between sources of infection and susceptible hosts or susceptible vectors; 3) Reducing infectivity of vectors, hosts, or environments, and; 4) Reducing host susceptibility. "The biological appropriateness of a given response is evaluated in terms of how effectively it fulfills one or more of these four conditions" (McGrath, 1991, p. 415). If none of the four conditions are met, the response will fail to affect the epidemic and the transmission of disease will continue. However, if a response eliminates the source of infection, eliminates contact with the source, decreases infectivity, and/or decreases susceptibility; the response will decrease the incidence of disease and hence, is biologically appropriate (McGrath, 1991).

"Disease is the result of a complex interaction of host, pathogen, and environment" (McGrath, 1991, p. 407) and concomitant social responses to disease may or may not be biologically appropriate. Social responses which severely alter the normal functioning of a social system, thereby causing a high degree of social disruption have the potential to increase the biological impact of an epidemic by increasing incidence of the disease and therefore may not be biologically appropriate. In her 1991 review of ethnographic reports of social responses to epidemics, McGrath outlined the most common social responses to epidemics, many of which have considerable potential for social disruption.

Social responses to disease can take the form of direct or indirect action and responses often hinge on the type of disease. The most commonly reported response to highly contagious, acute disease is *flight*, whereby those who are able, flee the area. This direct response can be highly disruptive to social systems in that the young, elderly, and impoverished are often left without adequate means to care for or heal themselves. In addition, some of those who flee may be carriers or incubators of disease and thereby cause further spread.

The next most common response (which is also a direct response) is the adoption of extraordinary preventative or therapeutic measures to break the chain of transmission (previously untried or unproven methods of disease control). Extraordinary measures may include special medications, rituals, or quarantines aimed at or adopted by individuals or groups. Such measures can be socially disruptive in that they require special adaptation (McGrath, 1991).

The third most commonly reported response, and most common indirect response to epidemics is scapegoating, whereby blame is ascribed to individuals, groups or classes of individuals (as has been done in Canada), or to religious or governmental authorities. The scapegoats are often those who are already marginalized and hence deemed blameworthy. The scapegoating process reinforces prevailing social prejudices and may result in resignation or acceptance of the inevitability of morbidity and mortality among the population that is scapegoated and does little or nothing to reduce disease transmission (Gilmore & Somerville, 1994; McGrath, 1991).

Ostracism of those infected or those at risk of infection often accompanies scapegoating. The practice of social ostracism is qualitatively different from the public health practice of quarantine. Ostracism implies a moral or value judgment about the individual afflicted with a disease rather than a medical judgment about the disease itself. The attachment of a stigma to an illness does little to eliminate contact with contagions, although this can provide an artificial boundary between *us* and *them*. While this response may be psychologically satisfying for the stigmatizer, it can cause a great deal of social disruption for the ill, and now stigmatized, individual (Gilmore & Somerville, 1994; McGrath, 1991). As well, the social disruption caused by stigmatization can extend to include those perceived to be at risk based on their associations and behaviours. Intragroup conflicts about who or what is to blame for the epidemic can also produce social disruption (to the point of social disintegration), especially if the conflict threatens the fundamental organization of the group (e.g., the rejection of government authority) (McGrath, 1991).

McGrath (1991) suggests that the social responses to epidemiological threats follow a predictable sequence over time: "At the outset of an epidemic, therapeutic and/or preventative measure are implemented based on the healthcare system in place at the time ('familiar responses')" (p. 412). If these measures work, the epidemic ends. If these measures fail, extraordinary measures such as quarantines and the development of new drugs will be tried. Once again, if these measures work the epidemic ends. If extraordinary measures fail, the chances for social disintegration increase because flight, rejection of authorities, and/or resignation and acceptance of the inevitability of morbidity and mortality ensue. Each of these last three responses can lead to intragroup conflicts, which further erode social systems (McGrath, 1991).

The Social Construction of Illness

Just as people are labelled and given social identities, health conditions are labelled and given social meaning, and the symptoms of ill health become social facts with specific consequences (Brown, 1998; Waxler, 1998). The definition of health conditions and the associated social expectations depend greatly upon society and culture, often more so than on the biological characteristics of the condition. The adaptation to chronic disease requires the ill individual to fall in line with the cultural expectations and roles that society dictates are appropriate for such social deviants (see Talcott Parsons 1902/1979 for review of the *sick role*) and any deviation from this social role is discouraged (Goffman, 1963).

Societies attach meanings to illness based on three important factors: the *ill* individual, who provides the social circumstance; the *other* who provides a social reaction; and, a moral judgment made by the other about the *ill* individual (Brown, 1998). If the other judges an illness to be the result of morally reprehensible behaviour, as has been done in many cases with HIV in Canada, the ill individual will tend to be stigmatized, especially if that individual is already socially

marginalized due to lifestyle or group association/s. Often, as is the case with HIV/AIDS, the social reaction to a stigmatized disease (avoidance, hostility, or ostracism) is out of proportion with the pathology of the disease (Inhorn, 1998; Waxler, 1998), as seems to be the case with HIV, a pathogen which is relatively easy to avoid. Attaching stigma to a medical health condition does little to reduce transmission, and may even increase transmission probability (McGrath, 1991, 1992).

Waxler (1998) examined the social construction of illness in the context of a cross-cultural comparison of the stigma attached to leprosy (Hansen's disease). Her findings suggest that the social responses to leprosy are not universal and hence the degree of stigma attached to the disease is dependent upon cultural context. While the stigmatization of HIV appears to be universal (Mann & Tarantola, 1996) it has also been suggested that the stigma associated with the condition has not been constant across time and place (Busza, 1999). In the case of leprosy, the degree of stigma appears to increase in societies with strongly hierarchical organization such as in India, where social classes, or castes, are used to organize society (Waxler, 1998). The degree of stigmatization associated with HIV has also been reported to differ with prevalence of infection. In areas like Canada, with low HIV prevalence where few communities or families are affected, the illness tends to be highly stigmatized. Conversely, in high prevalence areas where many are infected and affected the disease may become *normalized*, a process which appears to reduce stigmatization (Busza, 1999).

Both leprosy and genital herpes provide examples of diseases which are, in many cultures, demonized out of proportion with their biological consequences. In the case of leprosy, "a disease of biblical proportions" (Waxler, 1998, p. 147), early diagnosis and treatment of the disease renders it relatively benign and the progressive degeneration and associated disfigurement can be avoided (Waxler, 1998). However, even while medical science has disproved the *disease of the unclean* theory and shown that the *mycobacterium* that causes Hansen's disease is not highly contagious, the social reaction to lepers continues to feature fear and disgust. In the case of genital herpes, the discomfort and potential for transmission during an outbreak is cause for concern, but the virus itself, while annoying to those afflicted, is again relatively benign (Inhorn, 1998). Throughout the world, sexually transmitted infections have been, and still are, frequently stigmatized because they are thought to reflect the immorality of the patient (Brown, 1998). Perhaps, HIV/AIDS provides the most poignant illustration of this.

In some senses, AIDS has become the new leprosy. HIV/AIDS, like Hansen's disease, has a known cause, an effective treatment, and no known cure. Thus, there is a predictable outcome. Like lepers, HIV/AIDS patients are often feared, shunned, refused care, rejected, exiled, and in many cases routine treatment is neither offered nor received. The medical facts of both diseases are also similar. Initially, the effects of infection with the *mycobacterium* or the human immunodeficiency virus are mild and unremarkable, and this frequently results in late

diagnosis and treatment. With early diagnosis and treatment both of these two diseases can be arrested, symptoms disappear leaving no visible signs of infection and the infected individual is able to lead a relatively normal life (Waxler, 1998). However, it is important to note that with HIV/AIDS, the interruption of the progression of the illness is usually temporary and the need to take large amounts of anti-retroviral drugs makes the disease more obvious when the patient is undergoing treatment (Canadian HIV/AIDS Legal Network, 1999). Later, both Hansen's disease and HIV/AIDS result in serious and visible medical consequences (Waxler, 1998).

Deviance and Immorality

Historically, sexually transmitted diseases (STDs) have been stigmatized due to their connection with behaviours judged to be deviant and/or immoral (Gilmore & Somerville, 1994; Goldin, 1994). Moral judgments about the means of acquisition of STDs often result in the labelling of individuals as *guilty*, *innocent* or *defenceless victims* based on their perceived responsibility for infection. Those individuals or groups whose lifestyles are presumed to have led them to infection are pronounced guilty, their naïve partners as innocent, and children of innocents are the defenceless victims (Busza, 1999). These moral judgments often serve to isolate afflicted individuals because a diagnosis has the potential to devalue them and thus set them apart from normal society. Unfortunately, these fears of stigmatization and discrimination can preclude health-preserving behaviours and increase the probability of transmission thereby accelerating an epidemic.

This potential is amplified in the case of HIV because the stigma of the illness may be layered upon pre-existing stigmas associated with homosexuality, drug use, or sex-trade work (de Bruyn, 2005; WHO, 2003). The layering of stigma upon stigma has great potential for disrupting social systems which would normally support prevention and care.

Reducing Stigma, Improving Public Health

Upon review of the mechanisms of stigmatization and the interventions necessary to prevent the spread of contagious disease, it is clear that the social construction of HIV does not encourage interventions that are, at the same time, both biologically and socially appropriate. Biologically appropriate interventions must eliminate the source of infection or contact with the source of infection, or decrease infectivity or susceptibility to the pathogen. Socially appropriate interventions should not result in undue social disruption and should promote stability along the prevention/care continuum (McGrath, 1992).

While elimination of the source of infection *may* be biologically appropriate with nonhuman hosts (e.g., mosquitoes), and *some* might argue that genocide of the group infected with HIV would be advantageous from an evolutionary standpoint, the social disruption caused by this response would ultimately lead to complete social disintegration. Therefore, elimination of the source of infection must be abandoned as an option because it is *not* socially appropriate.

The three biologically and socially appropriate keys to disrupting case reproduction rates for HIV are measures aimed at: 1) eliminating exposure to the virus through the use of universal precautions when handling bodily fluids; 2) reducing infectivity through the use of anti-retroviral medications, and; 3) reducing ones susceptibility to the virus through the use of vaccines (when they become available) or, as recommended by Foster (2002), through the use of nutritional supplements (i.e., selenium). However, without a concentrated focus on reducing stigma and discrimination, these means of averting the epidemic will continue to fail (Canadian HIV/AIDS Legal Network, 1999; Joint United Nations Programme on HIV/AIDS, 2003; NIH, 2003; WHO, 2003). The fear of experiencing stigma and discrimination prompts many who are infected to avoid accessing treatment and care which could reduce infectivity or susceptibility, and may encourage those infected or those at risk of infection to avoid or neglect the behaviours which eliminate adequate contact with the virus (Busza, 1999; Malcolm et al., 1998; McGrath, 1992).

In recognition of the impact of HIV-related stigma and discrimination on the health and well-being of HIV-positive persons and those vulnerable to infection, and through extensive research and consultation with various stakeholders, the Canadian HIV/AIDS Legal Network (de Bruyn, 2005) has developed a series of goals designed to help prevent, reduce and eliminate HIV-related stigma and discrimination. They call upon the Canadian government to take action to respect, protect and fulfil human rights obligations in the context of HIV/AIDS and these goals nicely complement the initiatives of the World Health Organization and the US National Institutes of Health.

More specifically, the goals contained in the Canadian plan of action centre on five broader themes. The first, and perhaps most important focus, is to ensure that those living with HIV/AIDS and those vulnerable to infection are included in policy and program planning. It is recommended that government and non-governmental organizations make every effort to involve HIV-positive persons and those at risk of infection in all aspects of program design, planning, implementation, and evaluation. Further to this it is recommended that the Canadian government provide adequate, long-term funding for education and advocacy.

The second focus is to actively challenge public attitudes which stigmatize HIV-positive persons and those vulnerable to infection. It is suggested that officials from all levels of government and religious and other community leaders must speak out in support of HIV-positive persons and other marginalized groups who are at risk of infection (e.g., ethnic and sexual minorities, the mentally ill, injection drug users, and sex trade workers). Additionally, the preparation of packages for the media which clearly articulate the critical issues concerning HIV/AIDS in local communities to promote non-stigmatizing, informed media coverage, and sufficient funding for peer education are recommended.

The third focus is on bringing greater attention to human rights issues in the context of HIV/AIDS by advocating for the rights of HIV-positive persons and those vulnerable to infection.

Recommendations include the strengthening of community-based education and advocacy programs, promoting greater awareness of human rights, increasing access to legal information and services for those infected or at risk, and working with human right commissions to ensure proper representation for those experiencing HIV/AIDS-related discrimination.

The fourth focus is on ensuring that HIV-positive persons and those vulnerable to infection have access to programs, services, housing and employment, all of which help improve an individual's life chances. The provision of more targeted and culturally appropriate HIV/AIDS education and prevention programs, the provision of client-centred health services by workers who are sensitive to the social and psychological impact of HIV/AIDS, and the provision of affordable, accessible and adequate housing are recommended. Governments, employers and trade unions are called upon to renew efforts designed to protect the rights of workers in the context of HIV/AIDS. It is also recommended that culturally sensitive, age-appropriate, comprehensive sexuality education programs for youth which provide factual information and which support the acquisition of the behavioural skills necessary to prevent HIV (e.g., condom-use and interpersonal negotiations skills) be instituted on a nationwide level and that outreach services be provided for those no longer engaged in the school system. Further to this, it is recommended that HIV infected immigrants and refugees wishing to enter Canada not be arbitrarily refused entrance based on their serostatus and that the Canadian government cooperate with international initiatives designed to increase access to HIV prevention, care and treatment through active participation and by providing leadership and funding for such initiatives.

Lastly, the Canadian HIV/AIDS Legal Network (de Bruyn, 2005) emphasizes the importance of strengthening existing research and evaluation initiatives in regards to HIV/AIDS stigma and discrimination. It recommends that the Canadian government generously fund community-based participatory research and rigorous evaluations of prevention, care and treatment interventions, especially those aimed at reducing stigma and discrimination.

This series of recommendations are based on extensive research and consultation with various stakeholders and outline the goals that must be met to prevent, reduce and eliminate HIV/AIDS stigma and discrimination in Canada, as well as the actions necessary to meet those goals. The Canadian HIV/AIDS Legal Network points out that "under international law, governments are *obliged* to respect, protect, and fulfill the human rights guarantees enjoyed by all people" (de Bruyn, 2005, p. 11). Most fortunately, in May 2004, the Canadian government committed to strengthening federal action on HIV/AIDS by announcing substantial funding increases for HIV/AIDS prevention, care and treatment. Federal funding will double from \$42.4 million in the 2003-2004 fiscal year to \$84.4 million by 2008-2009 (Public Health Agency of Canada, 2004b). It is hoped that the forthcoming federal government report *Leading Together: An HIV/AIDS Action Plan for of All Canada* will address the issues of HIV/AIDS stigma and discrimination and with integrate the

many valuable recommendations proffered by the Canadian HIV/AIDS Legal Network (de Bruyn, 2005). With the increase in funding, it is likely that many of the goals identified by the Canadian HIV/AIDS Legal Network can become reality, and that Canada will become a leader in addressing HIV/AIDS stigma and discrimination.

Conclusions

In an 1988 study, May and Anderson (1988) developed a mathematical model which was used to predict future HIV infection rates based on known AIDS cases. The prediction was a "slow but continuous development of the AIDS epidemic over many decades... where the numbers of cases of HIV infection (and hence AIDS) increase faster as time goes on, in compound interest fashion" (Anderson & May, 1992, p. 58). Using this mathematical model and assuming "exponential growth, with a doubling time of, say, three years, it would take 30 years for the prevalence of HIV infection to change from a thousandth of a percent to a detectable level of one percent, but only three years to change from 10 to 20 percent" (Anderson & May, 1992, p. 59). In 1998, it was noted that the global epidemic was spreading at twice the initial predicted rate (Balter, 1998) and much of this has since been attributed to the negative influences of stigma and discrimination. While the situation in Canada is less dire than in many other nations, rates of HIV infection continue to increase (Public Health Agency of Canada, 2004a) and stigma and discrimination continue to thwart HIV/AIDS prevention, care and treatment initiatives.

As we have seen, with sexually transmitted infections, limiting exposure to a pathogen is not as straightforward as it is in limiting exposure to less stigmatizing diseases (Gilmore & Somerville, 1994; McGrath, 1992; Malcolm et al., 1998). In North America, including Canada, HIV was initially ignored due to its discovery and early transmission amongst already stigmatized groups (homosexual men, IDUs, sex trade workers and migrants). As the epidemic spread to the more general population and traditional and modern medicine failed, new drugs were developed and other extraordinary measures were instituted at legislative and community levels (Joint United Nations Programme on HIV/AIDS, 2003). Many of these responses also promoted stigma and discrimination which have further fuelled the HIV pandemic (Busza, 1999; Goldin, 1994; Malcolm et al., 1998; Link & Phelan, 2001).

The enormous public health challenges presented by the HIV/AIDS epidemic will require special consideration given that this is a *fatal* disease which is primarily *sexually* transmitted. Prevention has been hindered because individuals fearing stigmatization and discrimination disassociate themselves from supposed risk groups, avoid testing and counselling, fail to access health care, and resist behaviour change. All things being equal, the incidence of HIV will increase under these circumstances (McGrath, 1991).

For all intents and purposes, public health responses designed to limit exposure to STDs such as HIV/AIDS which

include education, skills programmes, counselling, testing, and access to latex barriers should motivate biologically appropriate behaviour change. Yet, social acceptance is lacking, and stigma and discrimination have been identified as the cause. Discovering and evaluating new ways to make biologically and socially appropriate public health responses more socially acceptable is a necessary next step (Link & Phelan, 2001).

The World Health Organization's *3 by 5 Plan* (2005) will do much to reduce HIV/AIDS stigma and discrimination on a global level, as will the international research on stigma and discrimination being funded by the US National Institutes of Health. Additionally, incorporating the recommendations presented by the Canadian HIV/AIDS Legal Network (de Bruyn, 2005) for reducing stigma and discrimination into the *Canadian Strategy on HIV/AIDS* can do much to address the problems here in Canada. Overall, the Canadian recommendations are designed to promote a social movement towards normalizing HIV/AIDS prevention, care and treatment at both the legislative and community level by supporting responses which are at the same time both biologically and socially appropriate.

When responding to the HIV/AIDS epidemic, we must be ever mindful of the urge to separate *us* and *them* based on a few (often irrational) attributions (Blascovich, Mendes, Hunter, & Lickel, 2000; Link & Phelan, 2001). Our hardwired fear of death is an over-reaction to a pathogen that is relatively easy to avoid (Gilmore & Somerville, 1994). Our propensity to blame others for public health threats (McGrath, 1991) is illogical when we have the capacity to eliminate risk of exposure, reduce infectivity, and potentially reduce susceptibility through the use of nutritional supplements (Foster, 2001) or future vaccines. HIV/AIDS poses a great threat to humanity and if we are to survive, we must adapt. If the pandemic is to be halted, the overarching epidemic of stigma and discrimination that obstructs prevention, care, and treatment for those infected and affected by HIV must be challenged publicly and politically, because *we are them* (Gilmore & Somerville, 1994). Canada, as a nation, is committed to furthering these ideals.

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Instrucciones a los Autores

Categorías de Artículos

Los manuscritos aceptados caen dentro de tres categorías:

Artículos (no más de **20 páginas** incluyendo referencias, tablas y diagramas) que pueden incluir informes sobre estudios empíricos tanto cualitativos como cuantitativos, desarrollos teóricos, revisiones integrativas o críticas de la literatura y contribuciones metodológicas.

Informes breves (no más de **10 págs.** incluyendo referencias, tablas y diagramas) que pueden incluir experiencias profesionales novedosas, asuntos de política y adiestramiento relacionados con la profesión, o datos obtenidos en estudios preliminares, y

Reseñas de libros (usualmente por invitación; no pueden exceder **5 págs.**). Debe considerar los méritos del libro y su aportación a la psicología de las Américas.

Además de estos, la RIP publicará los trabajos que han sido destacados con el Premio Estudiantil de Investigación de la SIP (tanto de pre como de post-grado) y los Premios Interamericanos que no se publiquen en las Memorias de los Congresos. También publicará ediciones o secciones especiales. Las guías para someter este tipo de publicación pueden solicitarse a la Editora.

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Los manuscritos deben ser inéditos y no pueden haberse sometido a la consideración para publicación de ninguna otra revista profesional o académica. Tampoco pueden haberse publicado en su totalidad o parcialmente en ninguna otra revista.

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En cuanto a estilo deben ceñirse **estrictamente** al Manual de Publicaciones de la *American Psychological Association* (5ta Edición, 2001).

1. El artículo debe estar acompañado por dos compendios (125 palabras) uno en el idioma del artículo y otro en uno de los cuatro idiomas oficiales de la SIP (español, inglés, francés, portugués).
2. La página de título debe incluir una nota al calce con información de cómo comunicarse con el autor o autora, si al lector o lectora así le interesa. Esta información al igual que el nombre de todos los autores o autoras no debe aparecer en ninguna otra página.
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Redacción

En cuanto a redacción la RIP fomenta el uso de un lenguaje inclusivo por género, raza, edad, origen nacional, orientación sexual, impedimento y otras características sociodemográficas.

La Editora sugiere el uso del término 'participantes' en sustitución del término 'sujetos' de la investigación. Además, requiere se especifique en los artículos el procedimiento utilizado para obtener consentimiento informado de las personas participantes. La descripción de las características socio-demográficas de las personas participantes debe ser lo más explícita posible.

La Editora invita a los autores a redactar sus artículos utilizando la primera persona singular, excepto en casos de dos o más autores. De esta manera se reduce la ambigüedad de las opiniones personales y se evade el uso excesivo del "nosotros".

La Editora sugiere que los autores utilicen preferentemente la voz activa en tiempo presente. En la medida de lo posible deben evitar el uso de regionalismos o tecnicismos.

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En cuanto a presentación, los autores deben enviar cuatro copias de los manuscritos en papel tamaño carta (22 x 28 cms) a doble espacio y por una sola cara a la Editora (Dra. Silvia Koller, Cep-Rua/Instituto de Psicología/UFRGS, Caixa Postal 9001, CEP 90040-970, Porto Alegre, RS, Brasil). Debe incluir una versión electrónica con este primer envío.

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104 **Instructions to Authors****Categories of Manuscripts**

Accepted manuscripts fall into three categories:

Articles (no more than **20 pages** including references, tables and diagrams), which can include research reports of qualitative or quantitative data, theoretical developments, integrative and critical literature reviews and methodological contributions.

Brief Reports (no more than **10 pages** including references, tables and diagrams) which may include innovative professional experiences, policy issues, training, or data from preliminary or pilot studies, and

Book reviews (usually by invitation; no more than **5 pages**). They should consider the book's merits and its contributions to psychology in the Americas.

The Journal will also publish articles, which have received the Student Research Prize of the SIP (both at the undergraduate and graduate levels) and the presentations of Interamerican Prize awardees, which are not published in the Congress Proceedings. It will also publish Special Issues and Special Sections. Guidelines for these should be requested from the Editor.

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The RIP will **strictly** follow the guidelines of the American Psychological Association Publication Manual (5th Edition, 2001).

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2. The title page must include a footnote containing information about how the reader may communicate with the author/s. **This information, as well as the author's name should not appear in any other page of the manuscript.**
3. The title length should be around 12 words.
4. The use of footnotes is not encouraged.
5. All sources cited in the manuscript should be included in the reference list and vice-versa.

6. The title page should include 3-5 keywords that will allow the article to be indexed in databases.

Writing Style

The RIP encourages the use of inclusive language in terms of gender, ethnicity, age, national origin, sexual orientation, disability and other sociodemographic characteristics.

The Editor suggests the use of the term 'participants' instead of 'subjects'. The procedures used to obtain informed consent from participants should be described. Their sociodemographic characteristics should be presented as explicitly as possible.

The Editor invites manuscripts in first person singular except in the case of two or more authors. In this manner ambiguity regarding personal opinions is diminished and the excessive use of "we" is eliminated. The Editor invites, also, the use of the active voice in the present tense.

Regional and technical terms should be avoided.

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The authors should send their manuscript in US letter size paper (22 x 28 cms), double-spaced and on one typeface to the Editor (Dr. Silvia Koller, Cep-Rua/ Instituto de Psicologia/UFRGS, Caixa Postal 9001, CEP 90040-970, Porto Alegre, RS, Brazil). The author should include an electronic version with the first submission.

The author will be informed immediately about the reception of the manuscript and provided with information relating to the manuscript's disposition. To facilitate this process the authors should provide mailing address (for regular and express mail), phone number, fax number and e-mail.

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Instructions pour les auteurs

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Rapports Brefs (pas plus de 10 pages comprenant des références, des tables et des figurés) qui peuvent inclure des expériences professionnelles inédites, des affaires de politique et d'entraînement liées à la profession.

Comptes Rendus de Livres (usuellement par invitation, ils ne peuvent pas excéder 5 pages). Ils doivent considérer les mérites du livre et sa contribution à la psychologie des Amériques.

Outre cela, la RIP publiera les travaux qui se sont distingués avec le Prix Étudiantin d'Investigation de la SIP (tant de pré que de post-grade) et les Prix Interaméricains. Elle publiera aussi les éditions ou les sections spéciales. Vous pouvez solliciter à l'Éditrice les guides pour soumettre ce genre de publication.

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1. L'article doit être accompagné de deux abrégés (125 mots), l'un dans la langue de l'article et l'autre dans un des quatre langues officielles de la SIP (espagnol, anglais, français, portugais).
2. La page du titre doit inclure une note en bas de page avec des renseignements pour joindre l'auteur au cas où le lecteur ou la lectrice voudrait ainsi faire. Ces renseignements, de même que le nom des auteurs, ne doivent pas apparaître dans aucune autre page.
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Rédaction

Quant à la rédaction la RIP encourage l'utilisation d'un langage inclusif de genre, race, âge, origine nationale, orientation sexuelle, désavantage et d'autres caractéristiques sociodémographiques.

L'Éditrice suggère l'utilisation du terme "participants" au lieu de terme "sujets" de l'investigation. En outre, elle requiert qu'il soit spécifié dans les articles la procédure utilisée afin d'obtenir le consentement informé des personnes participants. La description des caractéristiques sociodémographiques des personnes participants doit être aussi explicite que possible.

L'Éditrice invite les auteurs à rédiger leurs articles en utilisant la première personne singulière, sauf lorsqu'il y a deux auteurs ou plus. De cette manière l'ambiguïté des opinions personnelles est réduite et l'usage excessif de "nous" est évadé.

L'Éditrice suggère aux auteurs d'utiliser de préférence la voix active au présent de l'indicatif.

Dans la mesure du possible évitez l'utilisation des régionalismes et des termes techniques.

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Quant à la présentation, l'auteur doit envoyer quatre copies des manuscrits en papier à lettres (22 x 28 cms) à double interligne et d'une seule face à l'Éditrice (Dr. Silvia Koller, Cep-Rua/Instituto de Psicologia/UFRGS, Caixa Postal 9001, CEP 90040-970. Porto Alegre, RS, Brasil). Et une version électronique sur disquette 3 pouces 1/2 en Word pour IBM.

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