

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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