Original Article

HIV: The invisible epidemic of the United States healthcare system

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Abstract   We argue that the HIV epidemic in the United States is considerably more widespread than is officially reported. The occasional reports of outbreaks in cities like Washington DC, comparison with other countries in the developed world and our mathematical models, all point to the conclusion that the number of people living with HIV, but not AIDS, in the United States is more than four times larger than the current estimate. Although there are many reasons that HIV-positive individuals may not be aware of their serostatus, we argue that the United States healthcare system provides an additional pressure that simultaneously discriminates against and ignores the very people it should be targeting most.
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Introduction

Although HIV infection presents initial symptoms, such symptoms are often mild and mistaken for influenza or other temporary infections; consequently, few people go to the doctor for these symptoms and fewer still get tested for HIV as a result. This effect is compounded within a user-pay system, or where patients have limited or no access to health care; the Centers for Disease Control (CDC) estimate that fewer than half of all US adults have ever been tested for HIV (Gerberding, 2003). Other reasons that individuals do not determine their HIV status during the long asymptomatic period between infection and the onset of AIDS may include lack of awareness of HIV risk, disinterest, good

health, dislike of doctors/hospitals, stigmatisation of the HIV test, relationship between infection and criminal activity or fear of consequences (such as travel/ visa restrictions) for an HIV-positive result (Watney, 1989; Danziger, 1994; Rogers, 1997; Valdiserri *et al*, 1999). However, we argue that there are further factors that may have an impact on the lack of asymptomatic HIV cases known to the United States healthcare system in particular. These include insurance status, race, gender, and socioeconomic status, as well as their intersection.

Because of such factors, large numbers of HIV-positive people remain unknown to the medical establishment. Such numbers are usually larger in poor societies, such as sub-Saharan Africa and South East Asia. There are no reliable methods of estimating HIV prevalence in such situations. An example recently occurred in India where, before 2006, HIV prevalence was estimated by the World Health Organisation (WHO) and the National Aids Control Organisation of India (NACO) to be at least six million. One of us wrote a research paper in 2006 estimating that HIV prevalence in India, at the end of 2004, could not be more than 2.5 million (Aggarwala, 2006 a) . Later, after a careful survey in 2006, NACO came to the same conclusion. This shows that mathematical models can provide useful guidance in such situations, and that field observations may give a very misleading picture of HIV prevalence in a society.

Unlike primary infection, end-stage HIV status corresponds to a failure of the immune system and the onset of AIDS. At this point, infected individuals present severe symptoms, including persistent generalised lymphadenopathy, persistent or recurrent fever, progressive weight loss or poor weight gain, chronic diarrhoea, skin manifestations, persistent cough and oral candidiasis (Emodi and Okafor, 1998). It thus seems reasonable to assume that the majority of AIDS cases enter the medical system in both the United States and Canada.

The Burden of Health Care

The United States healthcare system is the largest in the world, with an economy as large as the entire economy of France (Aaron, 2003). Per-capita spending in 2000 was US$4631, more than double the $1983 per capita spending in 30 other OECD countries (Anderson *et al*, 2003). The US system is based on a competitive model, with subscribers able to choose between different private health insurers, often with a user co-pay and linked to employment (Urbach *et al*, 2005). However, the system suffers from massive overadministration, duplication of services among rival healthcare providers and overall poor health care (Woolhandler *et al*, 2003). Deaths from medical errors are the third leading cause of death in the United States, after heart disease and cancer, accounting for more than 225 000 deaths per year (Starfield, 2000).

The US healthcare system leads the world in technological advances; yet, it yields health outcomes comparable to those of countries with much lower spending (Blendon *et al*, 2003). For-profit hospitals accounted for $6 billion of waste in 2001, with a CEO to minimum wage worker pay ratio of 180:1, compared with government and not-for-profit healthcare institution ratio of 20:1 (Woolhandler and Himmelstein, 2004). The US ranked twelfth out of thirteen in overall health care of its population, in a survey of industrialised countries, and thirteenth out of thirteen for years of potential life lost, excluding deaths from violence and motor vehicles (Starfield, 2000). An estimated 18 per cent of the population (approximately 46 million people) have no insurance (National Coalition on Health Care, 2009), primarily among the socioeconomically disadvantaged and racial and ethnic minorities (Valdiserri *et al*, 1999), categories that of course overlap. The infant death rate for African Americans in the United States exceeds that of Costa Rica, Cuba and Singapore as well as most industrialised countries (Roberts, 1997).

Unlike the United States, Canada has a universal heathcare system, which allows equal access for all citizens and residents, funded through provincial taxes (Urbach *et al*, 2005). Canada's healthcare system has consistently been ranked in the top tier of such systems worldwide (Starfield, 2000). Despite the apparent disparities in the two systems, the US government nevertheless pays more per capita to prop up the private health industry than Canada's government does for universal coverage (Woolhandler and Himmelstein, 2004); this is done through the explicitly public-funded Medicaid, but also through health benefits for middle-class government workers and tax subsidies that flow to the affluent (Woolhandler and Himmelstein, 2002). Canada's per-capita healthcare spending is almost half that of the United States, at $2535, but delivers a higher acute bed density and greater number of acute care hospital days per capita (Anderson *et al*, 2003). Furthermore, Canada has a commitment to preventive healthcare (Rogers, 1997), which has improved the overall health of the average Canadian (Starfield, 2000). It has been shown that, with universal health care, the poor make the most use of the system (Roos and Mustard, 1997).

HIV Prevalence in the United States and Canada

The total number of AIDS cases in the United States is 468 577 (CDC Report, 2007). Estimates based on back-calculation methods to account for undiagnosed HIV-positive individuals and multiple diagnoses have placed the prevalence of PLWHA (people living with HIV/AIDS) at 1 039 000–1 185 000 (Glynn *et al*, 2007), in agreement with other estimates (McQuillan *et al*, 2006; UNAIDS,

2006). Subtracting the number of AIDS cases from this upper limit suggests a maximum of 716 423 people living with HIV, but not AIDS, in the United States.

The Public Health Agency of Canada has also used back-calculation methods, accounting for undiagnosed and multiply diagnosed individuals, to estimate the Canadian prevalence at 48 000–68 000 PLWHA at the end of 2005 (Boulos *et al*, 2006). The number of AIDS diagnoses in Canada from 1998 to 2004 was 19 468 at the end of 2006 (UNAIDS, 2006). Thus, a minimum estimate for the number of people living with HIV, but not AIDS, in Canada is 28 500 (taking the lower prevalence estimate and subtracting the number of AIDS diagnoses). In a recent publication (Aggarwala, 2006 b), we have argued that HIV prevalence in Canada should be towards the lower limit of the UNAIDS estimates, rather than the estimate of Health Canada, which is towards the middle limit (Boulos *et al*, 2006).

It seems reasonable to assume that the number of people diagnosed as HIV positive should be roughly the same in proportion to the number of people who are AIDS patients. HIV-positive people progress to AIDS at roughly the same rate in Canada and in the United States. Thus, if one percent of the HIV-positive people have AIDS in one society, then approximately one percent of HIV-positive people should have AIDS in the other society.

The number of people who were diagnosed with AIDS in the United States during the years 2001–2005 was 38 079, 38 408, 39 666, 39 524 and 40 608, respectively, giving an average of 39 527 per year. Also the number of AIDS deaths was 16 980, 16 641, 17 404, 17 453 and 16 316 giving an average of 16 958.8 per year during these years. In Canada, the corresponding numbers were 416, 404, 383, 318 and 318 giving an average of 367.8 per year for AIDS cases and 201, 144, 152, 78 and 72 giving an average of 129.4 for AIDS deaths during the same years. The corresponding ratios work out to 106.735 for AIDS cases (between the United States and Canada) and 131.057 for AIDS deaths. It follows that the number of HIV-positive people in the United States should be roughly one hundred times the number in Canada. From the lower limit of Canadian people living with HIV, but not AIDS, we estimate the corresponding prevalence of people living with HIV, but not AIDS, in the United States to be 2.85 million. This is significantly higher than the official estimate of 0.7 million. It follows that the number of HIV-positive cases may have been underestimated by a factor of four.

This is also the conclusion we have reached through our mathematical models. Assuming that the actual number of HIV-positive people is α times the 'official' number, our mathematical models concluded that the likely values of α are 1.22 for Canada and 4.25 for the United States (Aggarwala, 2004), implying that, while 22 per cent of HIV-positive people are unknown to the medical

system in Canada, 76.5 per cent of HIV-positive people are unknown in the United States.

In simple terms, there are a similar number of AIDS cases per capita in the United States and Canada. However, the ratio of HIV to AIDS cases is significantly higher in Canada than the United States. This suggests that the number of HIV cases in the United States neither matches the number in Canada, nor the number of AIDS cases in the United States. It follows that the number of HIV cases in the United States must be severely underestimated.

Reasons for the Disparity

So, where are all the HIV-positive people in the United States unknown to the medical system? HIV targets many of the touchstones of cultural identity that western countries have traditionally shied away from: homosexuality, race, gender, the socioeconomically disadvantaged and promiscuity (Treichler, 1999). When the United States finally recognised the AIDS epidemic as a healthcare problem, responsibility for federal public education was made the sole responsibility of a small private company in Connecticut (Treichler, 1999). Fears that the US health system might collapse under the strain of the epidemic reflect the originating mythology of 'African AIDS', rather than prior structural inadequacies of American healthcare provisions (Watney, 1989). Before 1996, long-term residents of the United States, even if they were undocumented, received limited public healthcare services; subsequently, health-related services to undocumented immigrants were cut off and being HIV positive became cause for deportation (Mukherjea, 2006).

In response, the onset of the disease provided an opportunity for those initially infected to organise politically. ACT UP (AIDS coalition to unleash power) formed a coalition to fight US government inaction on AIDS, including needle exchange and prison projects (Cohen, 1997). Needle exchange programs proved to have a measurable benefit in reducing the sharing of needles (Jaffe, 2004), and prison projects fought for awareness that the government was the same source of power in denying both wealthy gay men and incarcerated men's and women's access to drugs and conditions needed to combat HIV and AIDS (Cohen, 1997). Organisations such as ACT UP formed coalitions that crossed boundaries of sexuality, race and income to challenge the dominant constructions of who deserved care (Cohen, 1997). However, more recently, the burden of the epidemic in the United States has shifted from a 'gay disease' to a 'straight, black woman's disease', with a resulting shift from the visible to the invisible (Globe and Mail, 2007). For groups that were maginalised relative to

the state, AIDS provided a context for further discrimination against the distasteful – and now diseased – other.

Since the advent of antiretroviral drugs, the disease burden has largely moved from an organised, white, male, middle-class gay population to poor African American and Hispanic residents of inner cities and the rural South (Jaffe, 2004). The US CDC has stated that, among those infected with HIV, the majority of young men who have sex with men, 90 per cent of African Americans, 70 per cent of Hispanics and 60 per cent of whites did not know that they had the disease (*The Financial Times*, 2003). The majority of injecting drug users have little contact with the medical system (Celentano *et al*, 1998), unless they present two or more HIV-related symptoms (Solomon *et al*, 1991). Many US state laws restrict the sale of syringes, criminalise their possession and refuse to support needle exchange programmes, despite studies demonstrating their effectiveness; nevertheless, injecting drug users still account for 25 per cent of newly reported AIDS cases (Jaffe, 2004). Many young people who get tested do not return to find out their serostatus (Valdiserri *et al*, 1999).

Understanding that many of these categories overlap is critical to determining the status of the epidemic (Crenshaw, 1991). Because of hierarchies of oppression, African American lesbian women and heterosexual African American men may have much less access to healthcare than do white gay men. HIV infection among American college students (generally perceived as not at high risk for HIV infection) has been projected as the next wave of the epidemic (Hightow *et al*, 2005). It is difficult to track HIV prevalence in college communities because of their transient nature. Unlike prisons, or other stable populations that have traditionally been used as barometers for the epidemic, the prevalence of HIV in college students may not be easy to measure. Despite college-student access to healthcare, many barriers to testing remain; these include questions of confidentiality, perceptions that testing is only done within a physician's office and lack of information about testing sites (Payne *et al*, 2006). Furthermore, even if HIV positive, most students are unlikely to exhibit end-stage symptoms during their time in tertiary education.

However, there are a number of indicators that suggest that college campuses are likely to be hard hit by the epidemic. Co-indicating diseases are a useful measure of prevalence; surrounding high schools that have a high incidence of syphilis or Chlamydia are useful, stable populations that may be more easily tracked. In particular, high schools that have a large proportions of high-risk students (students of colour, students who have same-sex relationships and intersections therein) would be useful sites to study the progress of the disease into colleges.

If HIV disproportionately affects people who are poor, racialised or outside the heterosexual norm, then those satisfying more than one of these

descriptions may have different outcomes than those who only fit one category (Crenshaw, 1991). Such outcomes are not necessarily cumulative, however. African American men who have sex with men may be able to draw on information available to the gay community that eludes heterosexual African Americans. Many narratives of the disease have sought to collapse 'gayness' with 'Africanness' (Watney, 1989), equating the diseased 'other' as something foreign to right-thinking (western) societies and hence a matter to be comfortably ignored as someone else's problem. Similarly, race often functions as a displaced or surrogate class system (Brantlinger, 1985), whereas AIDS prevalence in Africa has been attributed to 'othered' behaviour, such as bestiality, cannibalism, violent sex and so on, rather than heterosexual transmission (Treichler, 1999). It follows that the complexity of identity must be understood in relation to the prevalence and spread of the disease, as well as accounting for factors relating to the invisibility of the epidemic.

Dealing with a Discriminatory Healthcare System

Of the 46 million people without insurance in the United States, the majority are poor, disenfranchised or from an ethnic minority (Weinick *et al*, 2000). Front-end fees result in patients, especially those in low-income brackets, foregoing needed care (Blendon *et al*, 2002); thus, it is little surprise that 'non-essential' preventive care, such as HIV testing, would fall by the wayside. However, the US healthcare system has been shown to disproportionately discriminate against non-white patients, even when socioeconomic status, insurance coverage, stage or severity of disease, type and availability of healthcare services and patient preferences are excluded (Mayberry *et al*, 2000). African Americans have been reported more likely to refuse testing, to report not having been tested in the past and fail to return for their test results if they are tested, when compared with white clients (Valdiserri *et al*, 1999). Even when on treatment, African Americans have been shown to be 41–73 per cent less likely than whites to receive particular drug agents (Moore and Hepworth, 1994), even when age, sex, mode of HIV transmission, insurance, residence, income and education are excluded (Graham *et al*, 1994). The results are similar for the Hispanic population (Shapiro *et al*, 1999), some of whom are undocumented immigrants, with little access to health care or English-only services (Crenshaw, 1991). Both African American and Hispanic youth and adults were less likely than whites to have any contact with a physician in the past year, even after accounting for income and health status (Bartman *et al*, 1997). It is highly likely, then, that there is a distrust of the healthcare system among

African Americans, Hispanics and other ethnic minorities in the United States, whether insured or uninsured.

Furthermore, the United States has a history of medical criminalisation of people on welfare, especially women with children, who have received negative attention as so-called 'welfare mothers' (Roberts, 1997). Policies of sterilisation of Puerto Ricans, Tuskegee syphilis experiments in African American men or the court-ordered implanting of Norplant (an intravenous birth control method that can only be inserted and removed by doctors) in women on welfare has led to considerable distrust of the medical system by poor, racialised women (Roberts, 1997). Women are less likely to receive care from an HIV specialty provider or antiretroviral therapy, initiate therapy later than men and have a lower likelihood of achieving undetectable levels of HIV (Turner *et al*, 2003). A substantial proportion of women at risk of HIV infection have not been tested, delay seeking testing and fail to obtain results if they were tested (Valdiserri *et al*, 1999).

Thus, HIV disproportionately affects the same people who fall through the cracks of a for-profit healthcare system; issues of class, race, gender, drug use and sexuality are intrinsically tied to both risk factors for HIV infection and to limited or non-use of health care. The 'invisible epidemic' of HIV is most likely to be rife within the groups who have least access to the care and preventive education they need.

It should be noted that many of the discriminatory biases present in the US healthcare system are also present in the Canadian public health system, which is by no means perfect. Health care in aboriginal communities, in particular, is severely limited; HIV-positive aboriginal people in British Columbia, Canada, are more likely to die without ever initiating antiretroviral therapy than their non-aboriginal counterparts, even when such treatment is made available free of charge (Miller *et al*, 2006). However, we argue that such biases provide less pressure upon already-pressured populations within a system of universal health care than within a private or semiprivate system that leaves the most vulnerable groups out of the system altogether.

Recommendations

Consequently, we make the following recommendations as a minimum. Voluntary HIV screening should be instituted in accordance with regular physician visits, as part of general wellness; although not comprehensive, it has been estimated that even a voluntary screening programme would locate significant numbers of HIV-positive individuals and be cost-effective (Sanders *et al*, 2005). Free, anonymous, mobile HIV-testing vans that have been deployed in areas frequented

by men who have sex with men should be implemented in other high-risk communities. Public-health awareness campaigns should be increased; in particular, 'safe sex' should be reinterpreted to mean that one should assume that everyone is HIV positive, unless proven otherwise. HIV testing should be understood to be a preventive tool, rather than a diagnostic one (Danziger, 1998). The benefits of early diagnosis of HIV should be promoted (Valdiserri *et al*, 1999). Further studies are needed to estimate the true prevalence of HIV in communities most at risk. All these recommendations should include cultural sensitivity and specificity in their messages; it has been shown that physicians who receive culturally specific training are vastly more effective in minority communities (Wade and Bernstein, 1991), whereas culturally relevant videotape messages have more impact on AIDS information in minority communities than standard public-health messages (Kalichman *et al*, 1993).

Areas of Washington DC already have HIV levels that are similar to those of sub-Saharan Africa (US News, 2003). College campuses in these areas may be similarly at high risk. The time to act is now. If the 'invisible epidemic' is not identified, understood and contained, it will spread, both through the current disadvantaged populations and subsequently through the rest of society. This will have severe ramifications, not only for public health, but also economic development and sustainability.

What is urgently needed is an understanding and awareness that issues of class, race, gender and sexuality cannot simply be swept under the carpet. The impact of HIV on societies has the potential to be devastating. A healthcare system that systemically ignores or discriminates against the very people most at risk of contracting HIV only serves to hasten the progression of the disease. This ultimately makes the 'invisible epidemic' all too visible.

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