HIV/AIDS as a transnational health care issue: migrants in the European Union

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Nearly 25 years into the global AIDS pandemic, the number of people living with the human immunodeficiency virus (HIV) has topped 40 million. Five million people were newly infected last year, over half of them young people between the ages of 15-24 years (Piot 2005). Women have now gained approximate equality in HIV statistics. Despite the efforts of many national governments, international organizations and grassroots groups which have driven down local rates of infection through community-oriented interventions around the world, HIV/AIDS remains a persistent and endemic global problem. The high incidence of HIV/AIDS in many regions contributes to international instability through the socio-economic consequences of local communities disintegrating under the weight of death, illness and distress. Although all people are at risk of infection with HIV, the epidemiology of the pandemic clearly demonstrates the fact that certain social, economic, and identity groups in specific geographical areas are indeed more vulnerable than others. The challenges of fighting the AIDS pandemic are thus intimately entwined with questions of health as a human right, empowerment and social justice.

The AIDS pandemic and health as a human right

The body of human rights developed in the period after the Second World War represents a set of aspirations by the international community to overcome the scourges of war, pestilence, and poverty. In the 1946 Constitution of the World Health Organization, the notion of health is conceived broadly: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

This definition emphasizes a holistic and collective vision of health that places the preconditions for disease prevention and well-being as the cornerstones for individual welfare. The WHO conception also draws clear connections between health and the impact of poverty and social exclusion, and underlines the intrinsically collective nature of public health. States also have an obligation, according to the body of international law, to create conditions that are favorable to the achievement and maintenance of the highest possible level of health (Hendricks 1998, 389). These conditions and rights are not limited solely to citizens, but are a fundamental human right of all people.

Health issues have not often been discussed in terms of human rights. The increasingly dominant neoliberal ideology of individual responsibility for health, differing scientific vocabularies and ways of conceiving paradigms, as well as the tendency to focus on human rights solely in the civil and political arenas has created barriers to conceiving human rights frameworks oriented towards health (Mann et al. 1999, 8).

The empirical evidence on which the human rights framework in health is constructed consist of global, national and community policies and practices that have an impact on individual and collective health. Issues of concern include the consequences of war, conflict, and environmental degradation, poor living and working conditions, as well as the availability and access to care and treatment which form the prerequisites for a healthy and sustainable life

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in society (Mann et al. 1999, 7-21; Feitsma 2001, 9).

Underlying this conception of the intrinsic link between health and human rights is the notion that social justice is inextricably connected to health. As medical psychologist Nancy Adler (Adler et al. 1999, 181) has pointed out, public health issues throughout history have been linked to socio-economic status. Sanitation, hygiene and immunization campaigns, as well as national health care systems, are some practical examples of how nations are able to act to mitigate the strongest impact of income disparities on collective and individual health by developing more comprehensive approaches that promote the public good.

Though health and social policies are generally formulated on a national level, the logic of globalization increasingly affects state governance. Neoliberal ideologies that promote the market and privatization at all costs, as well as individual responsibility for what are often collective problems, militates against the further development of comprehensive and inclusive health and welfare policies. Moreover, the demands that many poorer nations face to restructure their economies in order to pay off exorbitant debts to wealthy countries represent an enormous barrier to efforts to cope with public health problems such as HIV/AIDS, malaria and tuberculosis. When financial resources are utilized to pay off foreign debt rather than invest in disease prevention and health promotion activities, inevitably the health of the population declines, which makes development even harder to achieve. Emigration thus often becomes the only possibility for individuals and families to survive.

The pressure of globalization creates growing socio-economic inequalities not only between nations but within nations. These disparities have a negative impact on human rights by limiting the opportunities for individuals and social groups to achieve the basic preconditions of health as outlined by the WHO. People affected by HIV/AIDS in particular tend to represent the most vulnerable groups in global society and thus face the greatest challenges to gaining access to care and treatment. A human rights framework must therefore address the factors that constitute the continuation of the AIDS pandemic, specifically poverty and unequal access to global health resources, from a standpoint that promotes international solidarity.

Migration and health

The migration experience itself can present many risks to health. Migrants fleeing from war, environmental degradation or poverty may face all of the deleterious effects of poor infrastructure, the lack of health care provision, violence, exposure to infectious disease and poor nutrition. Migrants may also face significant personal risks during the journey with regard to safety. Women, in particular, often face gender-specific risks, such as rape and reproductive health problems, as well as frequently bear the responsibility for caring for children and elders.

The rights of migrants in host societies have a great impact on determining the preconditions of health. State health and welfare policies determine the eligibility criteria of inclusion and exclusion, which then establishes the possibilities for individuals to obtain access to care and treatment. Contextual conceptions of the nation, state and citizenship strongly influence how newcomers or strangers are viewed and treated in each society, which can have an impact on outreach and information efforts. Moreover, notions of transnational identity affect how people construct their sense of home, community and belongingness. As migration health expert Manuel Carballo has pointed out: Despite its positive features migration has nevertheless always presented complex health and social questions. Even when migration is planned and structured around well calculated national labor needs, the entry of new human resources into a society often prompts unforeseeable health and social problems that are difficult and costly to manage. Health and social services, together with housing and employment, for example, are sectors that are immediately challenged by the process of mass in-migration (Carballo 2001, 270).

National responses to the impact of migration on health and well-being, in all of its manifold expressions, should therefore be seen as an important human rights issue. In recent years, there has been growing discussion of the position of denizens or long-term residents who live much of their lives in countries where they may have few democratic or social rights. Many national social and health care services exclude those who do not have the requisite permits and papers accepted by authorities. The lack of culturally and linguistically appropriate social and health promotion policies and practices, as well as interventions planned in cooperation with diverse communities, can result in significant health disparities among migrants living on the margins of society. Poor living conditions and poverty also have a negative impact on social and health well-being. In short, health and human rights challenges for migrants do not necessarily end when they arrive in their new host countries. The diverse legal and social positions of migrants in host societies reflect the complexity of global society.

The epidemiology of HIV/AIDS in the European Union

Epidemiology is a cluster of scientific methods that are used in cooperation with national public health systems to assess the distribution of health-related conditions in various populations as well as to control the outbreak of health problems in the population. Through complex surveillance, notification and sentinel systems, epidemiologists seek to achieve the early detection and control of disease in society. Epidemiology, however, always functions in an imperfect world where comprehensive information may be ambiguous or unavailable. Social science research methods are therefore important adjuncts to epidemiological investigations, and can provide significant information that contextualizes and deepens understanding of infection rates and their impact on individuals and communities.

According to data collected by the European Center for the Epidemiological Monitoring of AIDS, despite reductions in HIV-related morbidity and mortality, HIV remains a major public health problem in Europe. General trends in Western European HIV epidemiology indicate that youth, women, migrants from endemic areas and, to a lesser degree, gay and bisexual men account for an increasing amount of new infections. Currently, approximately 720,000 people are living with HIV in Western and Central Europe, with 22,000 people newly infected in 2005 (UNAIDS 2005).

Eastern European nations exhibit different epidemiological patterns. The largest epidemic in all of Europe is in the Russian Federation, though it is centered in a certain areas (UNAIDS 2004). According to UNAIDS, the epidemic in the Eastern European region can be characterized as diverse, reflecting an earlier stage of the pandemic than Western Europe, and increasing rapidly among young people in particular. Injecting drug users and prisoners are particularly vulnerable to infection and sexual contact is becoming an increasingly common means of the transmission of HIV. Prevention efforts as well as access to care and treatment remain inadequate. Regional prices for anti-retroviral drugs are among the highest in the world. In Russia, for example, fewer than 10% of people requiring these treatments were receiving them (UNAIDS 2005, 49).

Due to the broad availability of anti-retroviral treatment in Western Europe, rates of AIDS remain very low. Although anti-retroviral treatments have proved to be highly effective in managing the progression of HIV disease, a small but significant proportion of people remain unaware of their infection. For example, according to recent epidemiological estimates, though HIV incidence in the United Kingdom has risen by 20% each year between 1999 and 2002 (Power 2004, 108), up to 31% of people living with HIV do not know that they are infected (Hamers and Downs 2004, 91). For a variety of reasons, many of these people have impaired access to counseling, prevention and health promotion services. It is an epidemiological and social science challenge to identify which groups of European residents tend to be excluded or marginalized in national outreach efforts and explore the reasons for this.

At the same time, it is important to remember that 95% of people living with HIV/AIDS reside in the developing world. UNAIDS statistics also show that under 1% of adults aged 15-49 years have access to voluntary counseling and testing services in the 73 low and middle income countries most affected by the pandemic (UNAIDS 2004). A high prevalence of HIV infection has a negative impact on social cohesion, family and community stability, as well as national and regional socio-economic development. The multi-dimensional consequences of HIV/AIDS create an irresistible force that can push people to migrate to other countries in search of the preconditions for economic survival. Global trends can thus drive local epidemics in places far from pandemic centers.

Western European epidemiological data suggests that migrants and ethnic minorities are becoming an increasingly significant group in HIV/AIDS figures. Some studies indicate that migrants tend to present to medical practitioners later than nationals, making them disproportionately represented in AIDS statistics because they are unable to take advantage of early treatment options (e.g. del Amo et al. 1996). This information implies that HIV prevention efforts to reach migrant and ethnic minority groups that live on the margins of European society should be prioritized.

There are, however, many challenges to documenting epidemiological trends among migrants in the European Union due to the tremendous variety of ways that national public health services categorize ethnic, national and racial groups. As AIDS experts Julia del Amo et al. have noted that unlike the United States, many European countries find it socially unacceptable to categorize people by race or ethnic origin. They argue: Racial classifications have no scientific grounds and their significance has been undermined in the context of current genetic knowledge. What race *does* measure is the level of exposure to racism since race is, indeed a social construct (del Amo et al. 2004, 1870) [authors' emphasis].

Race and ethnic origin statistics, in collaboration with social research, can document which factors enhance or discourage access to prevention, care and treatment for HIV/AIDS. An epidemiological and social science focus on legal status and the entitlements (or lack of them) that migrants have in European care systems is a vital area of research that needs to be developed, though it faces many institutional challenges in the way that information is collected. By analyzing all of these factors, it can be possible to devise more appropriate services that reach out to all communities resident in the European Union.

The climate of HIV care in the European Union: important issues for migrants

The issue of migrants and HIV crystallizes many sensitive and politically charged topics in contemporary Europe, including migration, multiculturalism, infectious disease, the shifting borders of social inclusion and exclusion in a globalizing labor market, as well as the transforming role of the national welfare state. At the crossroads of HIV and migrants, much of the discrimination and exclusion that exists in European society at large is reflected in the gaps in national social and health care practices and policies.

The current political climate of strengthening and harmonizing restrictive immigration policies has the aim of preventing ”unwanted” or ”non-productive” migrants from entering the E.U. legally. Many national discussions have focused on the development of a transnational ”creative class,” which is seen as enhancing prospects to stimulate economic growth (e.g. Florida 2002). At the same time, governments often turn a blind eye to the growing number of asylum-seekers as well as undocumented migrant care workers, manual and casual laborers entering their countries to take poorly paid jobs that nationals often do not want, jobs which frequently lack adequate occupational, social and health protection. An important aspect of current European welfare state retrenchment is tightening eligibility for social and health care services, which often results in obstacles to access for migrants.

As the discussion of epidemiological figures in the previous section shows, there are clear indications that migrants and ethnic minorities resident in the European Union are increasingly affected by the HIV/AIDS pandemic. Health services and medication alone are not sufficient to ensure that people cope with living with HIV/AIDS. Nutrition, living conditions, level of income, support networks and social equality are all important factors that enhance the quality of life with HIV/AIDS, in addition to augmenting prevention efforts. Many migrants, particularly those without documents, live in precarious circumstances that present significant barriers to gaining access to care services.

A recent article in the British medical journal The Lancet reported: ”...migrants are frequently affected by strong barriers to HIV prevention and care, including cultural, socio-economic, linguistic and administrative or legal barriers - and, more generally, they might have to face stigmatization and social hostility. HIV/AIDS prevention, treatment and care programs should be adapted to reach migrant populations." (Hamers and Downs 2004, 90).

Research indicates that it takes an enormous effort on the part of practitioners and policymakers before equal access to HIV care by migrants as well as the general population is achieved (Bröring and Clarke 2000, 174). Coordinated efforts must be made in both the health and social care fields. Therefore, to reduce HIV infection and encourage prevention as well as provide more appropriate care, it is imperative to empower and work with target communities. This means, in the case of migrants, that it is migrants themselves that must be equal partners and stakeholders in the policy and practice process. In order to expand the tools and frameworks used to address migrant communities, research by migrants themselves (and not just on migrants) must be developed and supported.

Exploring the local context: Finland

The rate of HIV/AIDS in Finland is very low and stable in comparison to most European counties. According to recent statistics, under 2000 people have been diagnosed with the virus, the majority of infections are among men (UNAIDS 2004b, 2). Nonetheless, approximately 27% of total reported cases of HIV since 1983 are among 'foreigners,'[1] with the rate rising dramatically in recent years (National Public Health Institute 2005). However, these percentages must be approached with caution as the numbers remain so small that a few cases can cause a steep proportional rise. The growing number of 'foreign' HIV cases may reflect a greater number of incoming migrants from countries of high incidence.

In my own research on migrants living with HIV/AIDS in Finland (Clarke 2004), I intended to explore how migrants living with HIV/AIDS experienced social care in Finland. I thought that I would place these migrants at the center of the work by interviewing them and representing their realities and perspectives on their situation in Finland through the lens of social care. However, there were many difficulties in approaching people via clinics and support centers due to the stigma surrounding AIDS. I therefore turned to explore how migrants were constructed (or rendered invisible) in Finnish social care for people living with HIV. I used the term 'constructing' migrants very deliberately because I sought to explore how the meaning and social reality of migrants in the Finnish welfare state has been shaped and understood by social and health policies and practices. In other words, how did the system produce the needs of the migrant?

The study first explored how the Finnish AIDS pandemic was storied through an examination of the public policy that emerged from the early days of the pandemic. Despite these efforts to construct HIV/AIDS as an exceptional disease requiring special care, it remains highly stigmatized in most societies, including, to some extent, Finland.

The research then sought to locate migrants in Finnish social and health law, arguing that migrants occupy an ambivalent location in constructions of equality in the Finnish social and health care system. Through a textual analysis of health information material produced by AIDS agencies, the work examined the invisibility of migrants in these agencies and suggested that despite the relatively high proportion of migrants living with HIV/AIDS in Finland, their access to care is actually limited by the lack of recognition of their needs. The fact that migrants have not been stakeholders in the development of HIV/AIDS care policy and national prevention strategy, along with the consensus-oriented culture of Finnish policy-making practices, has tended to hinder the development of active migrant community responses to AIDS. Moreover, stigmatizing attitudes within migrant communities have also often made it difficult for migrants to find support among compatriots due to fears of ostracism.

The findings of my study suggested that while social and health care for people living with HIV/AIDS in Finland is on a very high level, migrants do tend to remain on the margins of the care system. There are many reasons for this, including the low number of people living with HIV/AIDS in Finland in general. While the lack of cultural competence training amongst social and health care professionals seems to play a role in service delivery, broader policy development questions are also significant. There appears to be a clear lack of knowledge about the needs of migrants in the social and health care services on the whole as well as avenues for migrants to participate in developing services as both stakeholders and researchers.

What this information should tell us is that 20 years into the AIDS pandemic we cannot afford to remain complacent about the seriousness of HIV/AIDS in the European Union. There is a great need to prioritize HIV prevention and care efforts and to target such efforts at the most vulnerable groups in society. We must examine the gendered, cultural and socio-economic contexts in which risky behavior occurs. This means that we must develop culturally, linguistically and gender appropriate means to raise awareness about HIV and find effective ways to promote prevention. These efforts cannot be solely in the area of health care but must be fully integrated into the social field. Social science research has a very important role to play in the fight against AIDS.

Notes

[1] 'Foreigners' are identified by physicians or through social security numbers. Finland does not collect statistics on membership in ethnic or racial groups.

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