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HIV/AIDS

Minorities, immigrants and HIV/AIDS epidemiology

Concerns about the use and quality of data

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A European Community concerted action charged with assessing AIDS prevention for migrants and/or ethnic minorities raised the problem of the quality and possibility for misuse of existing HIV and AIDS data. Basing statistics on the number of foreigners in a country is problematical as numbers are affected by variations in definitions and policies concerning immigration. Categorizing by ethnic origin raises serious definitional problems. For the numerator, epidemiology must be based on AIDS case data since systematic HIV testing of migrants is excluded on both practical and human rights grounds, but there are reasons for both over- and under-reporting of AIDS in migrant groups. Underlying issues of stigmatization and of racism are discussed. While there is need for improvement in the epidemiological data collected, both planning and evaluation of HIV/AIDS prevention programmes should more reasonably be based on proxy indicators, essentially those of knowledge, attitudes and behaviours, as well as on good ethnographies.

Key words: AIDS, ethnic origin, HIV, migrants

A recent European Community concerted action of research charged with assessing HIV/AIDS prevention for migrants and ethnic minorities (Haour-Knipe 1991) described the situation in 12 European countries (Belgium, France, Germany, Greece, Italy, The Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and United Kingdom). Two major inter-related themes were identified: the problem of targeting HIV/AIDS prevention activities without simultaneously stigmatizing an already marginal group and the (mis)use of epidemiological data concerning HIV and AIDS. The problems around the quality and use of existing epidemiological data concerning migrants are discussed here.

WHY MIGRANTS?

'Migrants' were loosely defined to include asylum seekers and sojourners as well as more permanent immigrants. All European countries have foreign or migrant populations (*figure*).

Official figures show that in 1990, Germany had the largest foreign population among European countries, with over 5 million foreign residents, followed by France with over 3.5 million and the UK with just under 2 million. In percentages, Switzerland had the highest proportion of foreign residents (16.3%), followed by Belgium (9.1%) and Germany (8.2%).

Particularly at their inception, some AIDS prevention programmes for migrants or ethnic minorities were more or less explicitly based on the idea that they may be disproportionately affected or are at particular risk, as seems to be the case in the USA (Hopkins 1987, Gayle et al. 1990, Brundage 1991, Thomas & Quinn 1991). While this may not necessarily be the case in Europe, there are several reasons why migrants should be of concern. First, by moving from one country to another, migrants are particularly affected by world-wide differences in both HIV patterns and prevention efforts: being in a high incidence country with a low level of prevention knowledge can be dangerous. Second, as the

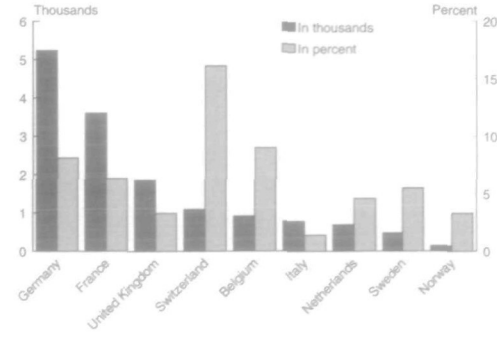

Figure Foreign population in selected European countries, 1990
Source: OECD, Trends in International Migration

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target year 2000 for 'health for all' approaches, it is increasingly evident both that social inequalities in health persist and that on the world level HIV and AIDS are distinctly related to them (Ramalinguaswami 1992). Some migrants or ethnic minority peoples may be among the least privileged members of the societies in which they are living and migrant health often falls between gaps of countries programmes, particularly where prevention is concerned. Third, the situation (Zwi & Cabral 1991) of some migrants or members of ethnic minorities may lead to potential exposure to risk due to

- lack of access to information and to health care;
- difficulties in comprehending prevention messages, because of language difficulties, but more importantly because of profoundly different understandings and approaches to sexuality or to relationships between the sexes;
- particularities in living situations, for example, because of legal restrictions on family reunification, which may favour transitory sexual relationships;
- social and economic difficulties which could lead to such risk behaviours as clandestine prostitution or injecting drug use.

The members of the European Community Concerted Action Work Group attempted to determine whether the epidemiological data existed to assess HIV/AIDS prevalence and exposure to risk, to judge the quality of existing data and whether and how it might be used to evaluate both needs and the programmes designed to meet defined needs. HIV and/or AIDS data concerning foreigners or ethnic minorities was available for nine countries for 1989, but was too fragmentary and biased to be of use, for the reasons discussed in the following sections.

WHO IS A FOREIGNER?

The closer one looks the harder it is to define who is a foreigner. Both the United Nations (1991), and the Organization for Economic Co-operation and Development (1992) now publish migration statistics, but with provisos as to both their quality and comparability among countries. The OECD statistics given in the *figure* concern *nationality*, while the UN database concerns *place of birth*. The former is usually based on population registers monitoring people going into and out of the country and the data is thus entirely dependent on the quality of recording. The OECD notes, for example, that departures are generally less well recorded than arrivals. Data concerning place of birth comes from census information and quality is inversely related to the marginality of the populations being counted. Although attempts are being made to standardize data collection procedures, it is not presently possible to cross-relate between foreign born and foreign. An example of the magnitude of the difference comes from two of the countries presented in the *figure*. In 1990, Sweden had 480,000 residents of foreign nationality, but 790,000 foreign born residents. The different ways of counting almost double the numbers for France, too. In 1982 France had 3,680,000 residents of foreign nationality, but 6,001,000 foreign born.

Both ways of counting are subject to bias. By definition, established figures concern only registered foreigners and an increasingly large, but unknown, number of clandestine residents must be added to the totals. Neither way of counting takes into account asylum seekers or such factors as having more than one place of residence.

As for nationality, country policies in granting of citizenship skew the data considerably. While most northern European countries recruited labour in the 1960s and the mean overall length of stay of foreign workers in EC countries is now more than 13 years (Callovi 1990), subsequent policies may be quite different. Germany, for example, still refers to the people recruited from Turkey 20 years ago not as immigrants, but as 'guest workers' (Marie 1990) and many of Switzerland's foreign residents have been living in the country for two generations without requesting citizenship. In contrast, France and Belgium accord citizenship relatively more easily (OECD 1992). Thus, the Turkish migrant worker in Switzerland may be foreign while his twin brother in Belgium may be Belgian.

Colonial heritage affects immigration statistics in several European countries, as in the UK, where workers were recruited mainly from former colonies whose inhabitants were British citizens until the matter came up for vivid debate in the 1970s (Marie 1990). In several European countries people born in former colonies, who may come from very different cultural backgrounds, are nationals by both ways of counting.

In contrast, culturally similar people born in neighbouring countries are at the moment of different nationality, although approximately five million of Europe's current 'foreigners' are soon to become demographic artefacts when citizens of one EC country living in another are no longer considered foreign (Callovi 1990).

In sum, a global category 'foreign' tells nothing about linguistic, cultural and social differences that may cause problems in HIV/AIDS prevention.

WHAT ABOUT ETHNIC ORIGIN?

Since it is pertinent to know about health problems in various subgroups, health statistics in some countries, for example the UK, avoid the notion 'foreign' or 'resident' and instead list 'ethnic origin' (the three UK categories are black, Asian/Oriental and other/mixed). American sources also categorize ethnic minorities (the categories usually being black or African–American and Hispanic). Categorizing by race or by ethnic origin, although more appropriate for capturing cultural differences, poses other problems, most notably in definition. There is the problem, for example, of what should be done in cases of various degrees of mixing. What race, for example, should be assigned somebody with one black grandparent — or with two black grandparents (Wyatt 1991)? Replacing race with ethnic origin does not seem to help much. Hispanics in the USA may come from Mexico or from Spain or perhaps from both if one takes several generations into account. Along the same lines, the issue has not been addressed of how many generations in a country

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it might take before one might change ethnic origin or whether or not this might change again if the individual were to move on to a third country.

WHAT TO MEASURE?

Current data on *HIV seroprevalence* is highly unlikely to reliably reflect the situation in the migrant population of a given nationality or ethnic origin in the host country. Systematic obligatory HIV testing is to be ruled out, both for human rights and practical reasons (Haut Comité de la santé publique 1992). Specific to migrant populations where HIV testing is concerned may be the situation of 'captive audiences', such as that of asylum seekers. Although no European country currently has a policy of compulsory testing of new immigrants, in some countries newly arriving asylum seekers may be 'offered' the possibility of HIV testing without knowing that they have the right to refuse. Difficult questions are raised in such a situation, for instance, how to do adequate follow-up counselling in the recipient's language, how the result might affect the individual's chances of being granted asylum status or whether or not to treat when chances are high that the person will be returned to a country where such treatment is not available. In sum, HIV seroprevalence is of dubious value either as a measure of needs among ethnic minority groups or as an outcome measure for evaluating programmes for minorities (Colebunders & Heyward 1990).

Difficulties arise even when data is limited to *AIDS cases* (Blaxter 1991). In some countries, for example, data on foreign AIDS cases includes both residents and tourists. Ethnic minorities may be over-represented on public records, since in many countries a range of services are both officially and unofficially available to members of the local population who know how to use them. Migrants may thus appear on public records simply because they are easily identifiable and have neither the economic nor knowledge resources to go to caregivers who can assure complete confidentiality. On the other hand, there are valid reasons to think just the opposite: they may be under-represented among officially listed AIDS cases since they have less systematic access to testing and/or treatment.

At the end of the line, *mortality data* concerning migrants and stigmatized diseases may not be accurate. It has been noted, for example, that syphilis is likely to be under-reported (Alderson 1981) and death certificate data concerning AIDS has been called into question, as doctors may be reluctant to list AIDS as cause of death (King 1989). Reporting of AIDS-related deaths may be higher if officials worry less about stigmatizing where foreign or minority patients are concerned. On the other hand, under-reporting among minorities due to ethnic misclassification has been found in the USA (Lindan et al. 1990). Higher incidences of drug use among minorities, also in the USA, confound the issue since deaths due to infections among injecting drug users with AIDS may not be counted as AIDS deaths (Des Jarlais & Friedman 1988).

If such data as cause of death gives trouble, the reliability of data concerning such 'soft' issues as transmission route and when and where infection was acquired is even more difficult to evaluate. It is easy to imagine, for example, how the more subtle and intimate details concerning ethnic origin and mode of transmission could get lost when patient and information-taker do not share a common culture and language. When announcing a positive test result it may be tempting, for example, to take at least one easy route by classifying ethnic origin on the basis of skin colour and transmission mode on the basis of presumed continent of origin.

DISCUSSION

The problems discussed above raise doubts about the validity of cross-country comparisons related to AIDS and migrants. Is it then possible to use existing data to assess the situation within a given country to determine:

- are migrants, or some sub-groups among them particularly affected by HIV and by AIDS? and
- can data be used for programme planning and evaluation?

Before comparing migrants to the 'general population', the data available within a country should be carefully examined to identify and take into account measurement biases. In addition, the issues underlying these comparisons ought to be considered. Stigmatization and racism often underlie. Migrants or foreigners are particularly ready objects for stigmatization: epidemic disease has always been seen as coming from 'elsewhere' and so, of course, do migrants or foreigners. Stigmatization, in general, has been especially acute in the cases of HIV and AIDS. The problem at hand, HIV among minorities, puts all of the above concepts together in a particularly volatile mixture (Haour-Knipe 1993). Stated as such, the question 'Are migrants particularly affected by HIV or AIDS?', for whatever reason it is asked, arouses fears of 'disease-bringing foreigners' and of drain on health care resources.

Two recent examples come from the UK and from Switzerland. In the former, in a letter in the Lancet (Chrystie et al. 1992), a team of virologists report a 9–fold increase in HIV prevalence among women attending antenatal clinics at one hospital in London. A high proportion of these women were classified in their notes as being from ethnic minority groups, largely of African origin. In the latter, the Swiss Federal Office of Public Health (1992) points out that more than 17% of the population living in Switzerland who are of foreign nationality are proportionately just as affected by AIDS as the Swiss population thereby calling for culture-specific prevention efforts.

The headline in a British newspaper concerning the former proclaimed 'Aids rise traced to migrants' (The Guardian, 7 February 1991), while about the latter a Swiss newspaper headed it's article 'Almost 20% of AIDS cases due to foreigners' (Journal de Genève et Gazette de Lausanne, 2 September 1992). It would be unfair in either case to hold research teams responsible for journalistic excesses and neither newspaper story was as bad as the

headlines would seem to indicate, but the damage is obvious and may hinder prevention efforts by raising adverse reactions in the concerned populations. More disclaimers and precautions in the original articles just might have helped anticipate misuse and head it off. Health officials need not only to work to improve the quality of the data being collected, but to carefully consider how it could be abused.

Another issue is that a global category of 'migrants' or 'foreigners' does not exist as an epidemiological entity any more than do 'general populations'. What do exist are subgroups, some with higher levels of risk, some without. Investigating the difference in the distribution of higher- and lower-risk within the two populations focuses the problem more appropriately. Furthermore, while HIV and AIDS may disproportionately affect some minorities in developed countries, prevention campaigns should be based on the principle of universal right to know, rather than on a notion of particular risk. Just as 'risk group' logic has been rejected in favour of 'risk behaviour', migrants or ethnic minorities should never be considered *a priori* 'at high risk' on the basis of presumed social origin. Even less should they be considered 'at risk' simply on the basis of geographical region of origin. Race should not be used as a proxy indicator for poverty, poor education or inadequate health care.

The quality of the available data concerning HIV and foreigners or ethnic minorities casts doubt on its usefulness. Several contradictory sources of bias in AIDS diagnoses among foreigners have been suggested. Existing epidemiological data is difficult if not impossible to use for international comparisons since category classifications are not necessarily equivalent. Case rates are variously calculated on the basis of current foreign nationality, of having been born abroad (in the two countries for which the data was available the second way of counting resulted in approximately twice as many foreigners) or on the basis of 'ethnic origin'. Those making the calculations on the national level may not be aware of the existence of the other ways of counting.

More importantly, AIDS case data comes too late — approximately 10 years after the risk behaviour the programme would have set out to prevent. HIV prevalence data presents similar quality problems, as well as ethical problems around the basis for testing.

At the same time, good epidemiological data can be vital as an alarm signal to highlight potential and existing problem areas. Health care workers concerned with minority populations have argued that until the extent of problems is known they are handicapped in doing their work, that not collecting data can be another form of racism and that keeping secrets is a good way to inflate problems bigger than they might otherwise be. If reasonably valid epidemiological data showing lower or equal incidences of HIV or of AIDS among minority groups should not be taken to mean that a particular segment of the population has no need for prevention programmes, higher rates can reveal particular areas of need for research and specific programmes.

One example, noticed by HIV/AIDS educators in both the UK and The Netherlands, concerns migrants from high prevalence countries, who need to know the risks of being infected on visits to their home countries (Dada 1991). Once foci of higher HIV infection within ethnic minority populations were identified and related to travel and unprotected sexual intercourse in given high prevalence countries, specifically targeted prevention efforts could be made. Similarly, migrants coming from or returning to low incidence countries should know about the problem and risks in higher incidence European countries. There is a significant risk that infected minority individuals from American and European countries introduce the syndrome when travelling to their home countries (Drucker 1990) as has already been demonstrated in Thailand (Apisuk 1990), Turkey (Wayling 1990), Jamaica (Figueroa 1990) and Romania (Hersh et al. 1991).

Thus, programme planning for HIV/AIDS prevention among migrants and ethnic minorities and the evaluation of such programmes, should more reasonably be based on proxy indicators, essentially those of knowledge, attitudes and behaviours, as well as on good ethnographies. Two examples can be drawn from Swiss studies of immigrant populations, in which it was found that programme planners definitions of concepts pertinent for AIDS prevention could be quite different from those found among minority groups (Fleury et al. 1991). Fidelity, for example, is not necessarily an adequate prevention measure among seasonal workers, for whom fidelity is based more on a common project of loyalty than on sexual exclusivity between spouses obliged by legal restrictions to live apart. In the second example, asylum seekers from some countries may incorrectly assume that commercial sex workers in the new country are state controlled, as they are in the home country and, thus, guaranteed to be free of disease. Knowledge and behavioural indicators are not only better adapted to understanding the nature of the problem, they are, after all, the factors on which prevention efforts are meant to intervene.

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