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Migrant populations: The development of something to evaluate

Summary

The setting up of the "migrants" of the European Community "Assessing AIDS Prevention" Concerted Action in 1989 practically coincided with the start of HIV/AIDS prevention activities for migrants in European countries. This article discusses the migration situation in Europe, why migrants may, or may not, be important for HIV/AIDS prevention, and the particular difficulties inherent in such prevention. Government-sponsored and NGO programmes for foreigners in 12 European countries are described. Conclusions: programmes need to be based on the right to know rather than on notions of risk group. The category "migrants" includes people with vastly different backgrounds and needs. Migrants or ethnic minority populations cannot be assumed to be reached by HIV/AIDS education messages directed towards the general population of that country, but specific programmes for them should follow the model developed for other general populations, with culturally adapted messages aimed at the entire population, followed by specific targeted interventions for particular sub-groups. For both aspects it is essential to work with the target community, in synergy between "top down" and "bottom up" programmes. The main needs in the field of HIV/AIDS prevention among migrants are for:

- adequately funded programmes,*
- serious evaluation, both of baseline information and programme evaluation,*
- international networking and cooperation concerning programmes, materials and methods, and research.*

The problem

Unlike for the three other population-oriented work groups in the European Community "Assessing AIDS Prevention" Concerted Action (men with homosexual be-

haviour, injecting drug users, general populations) the setting up of the "migrants and travellers" group during the summer of 1989 practically coincided with the start of HIV/AIDS prevention activities in the field. The situation changed

radically over the succeeding two years:

- from the point of view of migration, profound modifications have been occurring, reflecting dramatic socio-political shifts both within Europe and without, and
- the issue of HIV/AIDS prevention among migrant, or foreign, populations is coming out into the open: programmes have been established, international links forged, and some basic principles formulated.

The article summarizes the work of the migrants group, briefly discussing the migration situation in Europe, why migrants may, or may not, be important for HIV/AIDS prevention and why such prevention is particularly difficult when such groups are concerned. We then discuss the development of programmes over their first two years, the bases and problems common to them, and such evaluation as was done. The final chapter will deal with the lacunae and needs that have been revealed by this survey of HIV/AIDS prevention activities directed towards migrants in European countries. This article is intended as a summary: the complete "migrants" report, which includes twelve detailed country reports, is avail-

detailed country reports, is available from the project coordinators at the University Institute of Social and Preventive Medicine in Lausanne¹.

Who are the migrants?

Migration patterns reflect both world economic development and world political events. Thus European migration patterns over the past couple of generations have reflected the sequels of wars and colonialism (bringing, for example, people from the Indian subcontinent to the United Kingdom, Algerians to France, people from Suriname to The Netherlands, Brazilians to Portugal). It is interesting to note, for example, that at about the same time within the same Caribbean region, people from Trinidad and Jamaica left for London, Puerto Ricans for New York, Surinamers for Amsterdam, and people from Martinique and Guadeloupe for Paris². A period of economic expansion in Europe in the 1970s, in addition, brought vast waves of labour migration.

A simple, straightforward way to compare the numbers of migrants to various countries has yet to be contrived: the Organization for Economic Co-operation and Development (OECD) "continuous reporting system on migration" (SOPEMI) annual analyses depend on the calculations of the individual reporting countries, numbers which may be subject to variation due to policy differences and to different ways of counting between countries¹). Thus, with all due reserve, OECD reports would seem to indicate that in absolute numbers among the countries covered in this survey, Germany (West at the time) has the largest foreign population (4.530 200 in 1987), followed by France (3.752 200 in 1985) and the United Kingdom (1.736 000 average in 1984-1986). In percent, Switzerland has the highest proportion of

foreigners (15.3% in 1988), followed by Belgium (8.6% in 1987), and Germany (7.6% in 1987)³.

A goodly proportion of this migration takes place within the continent. The foreign population of the European Community countries alone is some 12.800 000 individuals, or about 4%, but subtracting the citizens of one EC country living in another EC country (shortly to become nationals as common borders go into effect) reduces these numbers to 7.800 000 or 2.4%. If citizens of other industrialized countries (the non-EC European countries such as the Norway and Sweden, or Austria and Switzerland; North America; Japan and so forth) are also subtracted, this percentage falls to 1.9%⁴.

Within Europe, labour migration movements had generally been from south to north, in a pattern that started changing a few years ago⁵. Gross emigration from Italy and Spain has declined and reversed, while it has remained steady from Portugal, Yugoslavia, and Turkey. At the same time, flows of skilled workers between the highly industrialized countries seem to be increasing: the OECD estimates that 1½ million French live abroad, there is movement from other Nordic countries to Sweden, and from Austria to Germany, Switzerland and Italy³.

Since labour migration all but ceased in the mid-1970s in the northern half of Europe, family reunification is becoming a principal source of foreign residents, along with people seeking asylum, as we shall see below. As for immigrants *settled* within European countries, the average length of stay is increasing. In their work, immigrants are moving into the tertiary or services sector. More are self-employed, and there are relatively more women and fewer men employed (in part, the increased labor force participation of European women has led to increased need for services and domestic

help, which in turn has led to increased employment of foreign women, both legal and illegal).

To the totals must be added a massive influx of asylum seekers (more than doubling from 75 thousand in 1983 to 182 thousand in 1987 in 14 European OECD countries), particularly to the Nordic countries in relative terms, and to Germany and France in numeric terms. People seek asylum for reasons of persecution, obviously, but part of the recent increase is also due to the fact that, as labour migration restrictions have tightened, people who otherwise may have arrived in search of work now do so, administratively, as asylum seekers. Many hope to work the two or three years it will take as their cases are being reviewed. Thus it is becoming increasingly difficult to differentiate between "economic migrants" and political refugees. It is also very difficult to know what becomes of those refused refugee status. It is reasonable to think many may enter clandestine status, or seek asylum in another country. Illegal immigration persists, despite efforts at control. European countries are attempting to put in parallel their immigration policies, particularly as concerns people from non-EC European countries, but policies to contain migratory flows are proving difficult to implement. Constraints from bilateral relations between different sending and receiving countries (for example with former colonies) make it difficult to harmonize

¹) Countries vary as to who is or is not considered a foreign national (for example people from former colonies in France, Portugal, or the United Kingdom), differences which may themselves change over time (as in the UK where inhabitants of former colonies were no longer automatically considered to be British citizens as of the 1970s). Differences in policy concerning naturalization, between Sweden and Switzerland, for example, where the acquisition of citizenship is encouraged in the former but not in the latter, also obviously affect statistics.

migration policies between European countries. Regional factors, such as propinquity with countries having high population densities or high unemployment, also play a role in migration patterns.

Finally, the radical changes in Central and Eastern European countries shifted the European migration situation on the east-west axis as well. Among the most dramatic current examples are people from the USSR moving to Israel, and people from the former Yugoslavia fleeing civil war. The opening up of frontiers and the liberalisation of the economies in the former eastern bloc countries is predicted to result, initially, in an increase in the number of unemployed and a consequent surplus of labour which could become a major source of would-be emigrants. There is reason for great concern about what will happen to the foreign labourers, especially from Vietnam, North Korea, Cuba, and a number of African states, now working in these countries.

Definitions and limitations

In this section we lay out some basic definitions and variables in some detail since the definition problem permeates most of what is said or written about HIV/AIDS education among migrants.

The original focus of the European Community concerted action group concerned "migrants and travellers" a category found to be too vast in practice. Migrants and travellers can be seen as mirror images of each other, since migrants can be defined as coming TO a specific country, and travellers as LEAVING it for more or less brief periods²⁾. The specific subject of travel is quite different from that of migrants, and is more logically situated as a specific target group for general population campaigns. The necessary specialized work has begun with the

setting up of the Netherlands AIDS Committee/WHO European Office "AIDS and Mobility" project³⁾: the literature on HIV risk and travel has been competently reviewed, and a theoretical framework set, in the background paper for this project⁶.

This article focuses uniquely on migrants.

Migrant groups should first be defined by how long they have been in the host country: respectively as asylum seekers, accepted refugees, clandestines, short term migrants, long term migrants, second third and subsequent generations, and minority ethnic groups.

The difference between asylum seekers and refugees is a critical one. People arrive by many different means seeking asylum, some because of political persecution, others more for economic reasons, and but with little realistic hope of being accorded refugee status. Refugees, on the other hand, have been accorded the status either by the United Nations, often after screening in a camp, or by the host country. While asylum seekers often live in precarious social and economic situations, accepted refugees are usually given government help until they are able to function on their own.

The other theoretically distinct groups often overlap and/or change. Those refused asylum may go clandestine, individuals having originally arrived for a short term stay as workers may now be families into their third generation in the country, and so on.

The term "migrants" covers quite diverse situations in addition to the amount of time spent in the host country. Some of the chief variables that characterize different migration situations are:

- the reason for the migration, or "push/pull" factors (what was being left behind, and towards what was the migrant coming)
- sex, age, family status, or place in the life cycle
- socioeconomic status and education
- culture: particularly important for our purposes is the amount of cultural difference existing between guest and host populations. The larger the cultural difference between the two, the greater the possibilities for misunderstandings.
- contextual factors in the host country, such as the number of other migrants already in the country or seeking entry, the ratio of people from outside European countries compared to those from within Europe, and the country's economic situation. The growth of foreign populations can pose problem of social and economic integration, varying from country to country but mentioned in practically all of the national reports done for the present survey.

We will be dealing in different countries with quite diverse categories of "migrants": for example travellers in Greece, asylum seekers and clandestines in Spain and Italy, all of the above in the Netherlands, and long-installed minority ethnic groups in the United Kingdom. In the interest of simplicity, and because of all of the factors discussed, we argue for a certain amount of "fuzziness" in definitions. Throughout this article, the term "migrant" is used loose-

²⁾ The United Nations, the World Health Organization, and the International Organization for Migration define travellers as people entering a country for three months or less.

³⁾ Contact: European Project "AIDS and Mobility", Polderweg 92, 1093 KP Amsterdam, Netherlands (tel: +31 206 939 444).

ly, and should be interpreted to variously mean asylum seeker, seasonal laborer, sojourner, member of an ethnic minority group, and so on.

Why are migrants important for AIDS prevention, and why is this difficult?

In this section we discuss the reasoning upon which the concerted action work group “assessing AIDS prevention among migrants and travellers” was originally based. Three troublesome subjects are discussed: the question of whether or not migrants may be at particular risk of HIV infection, the role of travellers in the spread of HIV, and the risk of stigma.

a) Are migrants particularly at risk?

The focus of each of the concerted action population-oriented work groups (men with homosexual behaviour, injecting drug users, general populations, and migrants and travellers) was on information and behaviour change, but among groups differently affected by AIDS: two were fairly urgently involved in HIV/AIDS prevention, both epidemiologically and in the public mind, whereas one was less directly so. In the terms of a few years ago, two were “risk groups” and one was not.

There was some question as to just where to situate migrants.

At one extreme, the occasional project describes “migrants” (or a given ethnic group), globally, to be at particularly elevated risk of transmission of HIV. The parallel is sometimes made to sexually transmitted diseases, where it is sometimes argued that STD rates may be higher for foreign than for host populations⁷. This line of argument was rejected from the outset by the present EC concerted action work group.

The reasoning upon which our mandate was based was more that of risk situation. It was pointed out that migrants often tend to live in economic, sanitary, and housing situations less adequate than that of the host population. They may be more subject to unemployment, to poverty, to poor housing conditions. Some may live separated from partners and families because of legal restrictions, many more may be lonely. Social support may be lacking because of geographical distance, and social constraints may not operate when people are far away from those who know them. Migrant’s social and legal situation in the host country may be precarious, flagrantly so when the migration is clandestine or when there is a context of racism, or more insidiously by the simple fact of being foreigners. It was hypothesized that such conditions may perhaps lead to poorer health in general, less access to health services, and to a higher incidence of HIV-related risk behaviours in specific⁸.

At the same time it was thought that migrants may have less access to HIV education and/or information. They may come from countries in which AIDS is relatively unknown to the general public. They may be less education (in some countries a good many migrants are unable to read) and/or they may be unable to understand the local language. Living in marginal situations they may simply have been untouched by information campaigns directed towards the general populations of a culture whose attitudes concerning sexuality in its various permutations (and/or concerning drugs) may be far different from their own.

b) Epidemiology and travel

The importance of people who travel for the spread of HIV from one population to another is undeniable⁹. Present in the minds of

many is the image of “Patient Zero”, implanting HIV in one country after another in Europe and north America¹⁰. It is reported that the first AIDS cases in Yugoslavia and in Turkey were among people who had been migrant workers in western European countries^{11,12}. In Jamaica, too, the first cases were brought home by people who had been migrant farm workers¹³. The probable role of tourists in introducing HIV in Third World countries has been amply demonstrated^{14,15}.

Relatively early, European travellers and expatriates were reported to have brought AIDS back with them when they returned^{16,17}, and a respectable number of letters to medical journals, particularly in the early years of the epidemic, drew attention to possible spread of the disease through travel (see 6 for a thorough review of the literature on HIV and travel).

c) The risk of stigma

AIDS has profoundly shaken the way we see disease, relationships, our societies. HIV has made us alter definitions of what is inside the cell and what is outside, and its transmission from one person to another has caused us to question what we know, and especially what we do not know, about sexuality and about intimacy¹⁸. Migrants slip right into the center of these themes: they usually come from outside, and (to take a comparison perilously close to images and phantasms about the dangers of foreignness) if they integrate into the host society, they may eventually graft onto the social body. Stigmatization is linked to public misconceptions, in general and specifically when it concerns AIDS^{19,20,21}. By being foreign, other, migrants then represent a risk group for stigmatization. It is always the “other” who brings disease, and minority groups may be “those who are merely thought

to be at risk because of their otherness"²². Taking an example from next door can be useful, recalling the global image of syphilis, called the French disease by the English and the Turks, while the French attributed it to the Italians, and the Italians to the Spanish. The Spanish, in turn, blamed those returning from Hispaniola when Christopher Columbus returned.

We know that in Africa, AIDS is sometimes, called the "European" or "the American" disease, and only very recently European and American scientific debate seriously postulated that the disease must have originated in Africa...

If today at least 50 countries have tried to tackle the problem of the spread of HIV by trying to block it at the border²³, the blaming of migrants for diseases has a long history, and throughout history various attempts have been made to control disease by controlling the people who may have it. As least as far back as biblical times, when leper colonies were mentioned, individuals with certain threatening diseases were often segregated to the outskirts of towns, away from the "non-infected" community. Aliens within a community, who may be of another nationality, or who may simple belong to an ethnic or indigenous population group or have social or physical traits distinguishing them from the "general population", may be particularly suspected of harboring a contagious disease. Since principles of solidarity and mutual aid usually only applied to members of one's own community, aliens associated with serious diseases could be denied entrance or expelled. During medieval epidemics, for example that of bubonic plague which struck Europe in the 14th and 15th century, deaths were in many instances attributed to the sole physical presence of aliens, setting off waves of persecution of communities of those thought to have introduced and spread the disease.

The European historical and legal foundations of border controls surrounding HIV/AIDS have been discussed in a paper prepared for the migrants and travellers group²⁴. The issues as they affect migrants to European countries are discussed at some length elsewhere¹, and can be summarized in the expert conclusion that compulsory testing and restrictive policies are to be considered impractical, ineffective, wasteful, and discriminatory (see²⁵ for a detailed discussion of the numerous, potential harmful consequences,²⁶ for a thorough discussion of human rights issues, and^{27,28,29} for UNHCR and WHO positions).

The point is one that has direct relevance of programmes, as will be discussed below. Specifically, when emphasis shifts from control to information, basic assumptions are transformed in a critical epistemological shift: fruitless and potentially harmful calculation of risks are sidestepped, and all segments of the population are put on an equal level. The assumption that underlies obligatory measures such as testing, that people will necessarily behave irresponsibly, is replaced by the assumption underlying education, that, enabled, people will behave responsibly.

The development or programmes over two years

At the beginning

Unlike for the other concerted action work groups, there was no existing network of individuals working in the field of migration and HIV/AIDS prevention with which to begin. Indeed, the work of the group itself has been a spiral form of process evaluation. In this section the steps followed in beginning to create a network are described, and the development of activities is sketched from the first

programmes through to some preliminary evaluations.

When a computer search of the literature and combining of AIDS conference abstracts during the summer of 1989 reflected the newness of the field by producing a disappointingly thin file of relevant literature, it was necessary to turn to the field, asking AIDS officials in European countries, international organization professionals, congress participants, and anyone else reported to possibly know, for names of people working in the field of HIV/AIDS prevention among "migrants"⁴).

It became apparent through such networking, and later on in site visits, that, although not much had been published, the "migrants and travellers" area was developing extremely rapidly. Many of the activities were very new, however, with little, if any, coordination between countries. Two or three countries already had established "top down", government sponsored programmes, whereas in many more "bottom up" activities were taking place, ranging from large voluntary or non-government organizations (NGOs) of vastly different sizes, from, for example, The Red Cross, Caritas, and The International Planned Parenthood Federation, to organizations consisting of two or three people, or isolated individuals.

The first "top-down" programme discovered in this survey was established in a context in which the issue of foreigners, or migrants, as they relate to AIDS was highly pertinent, in the French speaking part of Belgium, in 1986. At that time there was a good deal of concern being expressed about AIDS-affected people from former colonies coming to the country for care. This programme managed to

⁴) Including migrants, travellers, ethnic minorities, foreigners, and so on within broadest possible definitions. "What do you mean, migrants?" was a question often asked at this point.

remain discreet in the face of rather frantic media debates in several countries about the drain on health care resources that just such a phenomenon could present, and about “windows” by which HIV might escape “risk groups” and infect the indigenous heterosexual population.

The next government-sponsored activities to be established were in 1988, in both the Netherlands and the United Kingdom, where long-established ethnic minority groups already had many other programmes established, and where pressure came either from the groups themselves or from health professionals who worked with them. These programmes sprang from an expressed concern that minorities were not being reached by campaigns addressed to general populations or to more specific target groups.

The development phase

During the winter of 1990 the field of HIV/AIDS prevention among migrant populations developed rapidly. For the concerted action work group it quickly became apparent that simply listing the diverse government and non-government activities taking place, as well as the relationships between them, would require considerable knowledge of the terrain in two different areas of expertise: that of the migration situation in the various countries, and that of HIV/AIDS prevention. It was thus decided to find national reporters who could describe the situation in their particular country⁵⁾.

As the existence and intent of the work group became known, professionals from several countries wishing to establish HIV/AIDS education programmes for migrants expressed interest in participating. It became evident that an opportunity was developing to transform a first small technical work group into the more direct

intervention of a workshop which could be immediately useful to professionals charged with establishing programmes in their individual countries. The focus strictly on research shifted slightly, towards a more active stance of providing a first forum at which people working in the field of HIV/AIDS education for migrants and minorities could exchange experiences, and perhaps, though the demonstration of interest from such a body as the European Community, indirectly promote the establishment of new programmes.

Included in the survey are of course the countries in which activity was already established when the task began (Belgium, the Netherlands, and the United Kingdom). An additional goal was met, to include countries from both northern and southern Europe, to reflect the quite different migration conditions and problems in the two regions. Several “other” countries are those in which activities were being established, and some which had activities projected and expressed an interest in participating, in some cases at the expense of their own programmes. In sum, the work group and related survey grew to some extent serendipitously, and there are necessarily some omissions, particularly along the east-west axis. Since finances did not permit a complete survey of HIV/AIDS education programmes for migrants and travellers in all European countries, the present survey is indicative, not exhaustive.

The countries included in the survey are: Belgium, France, Germany, Greece, Italy, the Netherlands, Norway, Portugal, Spain, Sweden, and Switzerland, and the United Kingdom.

Programmes existing

What follows is a very brief summary of programmes existing as

they are described in national reports. The bases are sketched, as are some of the main problems.

First of all, concerning overall *migrant health*, data was disappointing. Several reports show that the “healthy migrant phenomenon” tends to operate (the people who self-select to migrate are generally in basically good health). Exceptions to good migrant health often seem to be primarily due to living conditions in the host country, and are distinctly poverty-related. Clandestine migrant populations are particularly at risk, and especially their children. How migrants use health care services clearly depends on the system: in one instance cited they seem to rely on family physicians, while in another the hospital is used. Preventive health measures such as nutritional, prenatal, and dental care tend to be neglected. Again, data remains inconclusive, revealing the need for a good general review of migrant health studies with proper control of variables (see³⁰ for France, and³¹ for Germany).

The extent to which *health services and specialized HIV/AIDS prevention programmes* are available to migrants varies to some degree with the length of time they have been in the country: “migrants” long enough established to become “minorities” in several northern European countries, for example, have access to a certain number of specialized health services (even if these services are merely the presence of translators). Where health structures for migrants did exist, it has been possible, although not

⁵⁾ This task required putting together information, usually for the first time, from the two different fields involved, migration and HIV/AIDS prevention. In countries in which no programmes had yet been established, finding the right person to do the job required considerable field work, done by asking in telephone conversations or on site visits until several people in a given country indicated that a given individual would be the most appropriate.

necessarily straightforward, to use existing organizations as a platform for organizing, stimulating, and coordinating HIV/AIDS education programmes. Thus (to cite only the countries covered in the present survey) we now have programmes more or less directly government-sponsored and relatively centralized in Belgium, France, the Netherlands, Norway, Sweden, Switzerland, and the UK. In Germany programmes are mixed, sponsored by regional governments and non-government organizations.

According to reports prepared from the countries concerned, the recent reversal in migration trends in the south of Europe has caught existing structures unawares, and services are lacking. The HIV/AIDS prevention programmes that exist for migrants in these countries are run either by non-government organizations or by local authorities, and are severely limited by lack of both financial support and institutional structure: programmes tend to be carried out on the simple basis of "somebody has to do something", which means that activities are often performed during the worker's "free time". Clandestine migration, by definition impossible to enumerate, receives particularly alarmed references and brings dramatic attention to the lack of official structures and programmes for entering migrants in general according to country report⁵.

The question as to the *bases* of programmes, or why there should be special HIV/AIDS education for migrants, has been at the very heart of the group's work. Some national programmes are, or were, based at least partly on the idea that migrants in general, or some subgroups thereof, may be at particular risk of HIV infection. In Norway and France, for example, high HIV prevalence in the country of origin was originally cited as one reason to target migrants, and Spa-

nish and Italian programmes justify intervention at least in part on the basis of a higher incidence of risk behaviours among some groups of migrants in the host country⁶).

Other programmes, particularly the pioneering United Kingdom and Netherlands programmes, relocated the question, shifting from calculation as to who might be more or less at risk, to assuming that everybody has the right to know the basics of protection. This position has the great advantage of neatly sidestepping potentially harmful calculations, putting all segments of the population on an equal level, and specifically assigning governments the responsibility for health education. The Norwegian example is particularly instructive in this regard. The conceptualization and actualization of HIV/AIDS prevention programmes for migrants in Norway changed considerably during the time this concerted action was in progress. A first model was top-down and highly medicalized, as exemplified by the targeting of people from high HIV prevalence areas as risk groups in need of special education efforts. While this model may have been epidemiologically correct, it was politically offensive and ultimately unsuccessful since it alienated those potentially most in need of prevention efforts. With the hiring of two cultural anthropologists the emphasis shifted to working with and through immigrant groups, in a model predicted to be much more successful. Evaluation was underway at the time the report was written.

By rejecting the notion that, as a group, migrants are especially at risk of HIV, programmes do not by any means intend to imply they are no risk, however. Within any group, and just as in the "general population", there may well be individuals with high risk behaviour who need the same sorts of specific education strategies as others to help them reduce their

risk³². The specifics where migrants are concerned include two basic, interconnected, and fundamental principles. One is that, although the HIV prevention message is the same as for the general population in the country, and specific segments thereof, it cannot be presumed to reach migrants unless it is culture-specific. The other is that prevention must be done in collaboration with the migrant population itself.

One of the major *problems* involved in doing this is stigmatization, or implying by doing HIV/AIDS prevention that AIDS must be a problem specific to migrants (in other words blaming the target population). Other problems include gaining community trust, particularly in climates of racism, of rumours about deportations, and/or of local resentment of services for foreigners, and gaining the interest of particularly disadvantaged groups, who may be more concerned about malnutrition, high infantile mortality, or legal difficulties than about a less immediate threat such as HIV. Differences in culture, religion, and language, not to mention in world view, have to be overcome, quite often for people whose mode of communication is oral rather than written. Working with key informants, people who have the cultural knowledge from both sides adequate to be bridges, and in addition who have the respect of their community, is essential. Such people may be hard to find, however, and/or may be cultural deviants, or even become so in working with the government, or even with that is perceived as being

⁵) Discussion of epidemiological data concerning migrants, from whether or not it should be gathered to why it may or may not be reliable and/or useable, occupied a great deal of the group's attention. The arguments are outlined in the final report.

the government, on HIV/AIDS prevention.

Within the same ethnic community there may be substantial social and cultural differences, for example between first and later waves of refugees or other migrants. The intra-European migrant is quite likely to be a highly educated technician or a retired school teacher. A third of the Vietnamese, Pakistani, and Yugoslav migrants to Norway have passed university qualifying exams, although they are not likely to be working in the jobs for which they would be qualified. At the same time, within several migrant groups are sub-groups accumulating risk factors, such as poverty, marginalization within the host society and alienation therefrom. Some may be the stigmatized among the stigmatized, in contact neither with those of the same ethnic community, nor, for example, with local gay groups, drug outreach workers, sex worker groups, and so forth.

Finally, reaching clandestine migrants with prevention messages obviously poses severe additional problems, particularly if this is to be done by official health services. Getting even minimal help requires complicity between official and illegal bodies; the health worker is dealing with someone who officially does not exist, and, mismanaged, his or her intervention could lead to the client's being expelled from the country. Recommended strategies such as dealing with community leaders may be impossible since there may be no leaders among clandestine populations in European countries, and barely any community either.

Evaluation

The form of evaluation that by far has most been performed in the area of HIV/AIDS education for migrants, and a kind of evaluation that is essential, is formative

evaluation, in which the intended programme audience works closely with those who are planning the programme, on objectives, as well as on medium and on material development. Since HIV/AIDS prevention programmes for migrants and travellers are in their infancy, few, as yet, have been formally evaluated on other terms.

Baseline data

At the baseline level of analysis, we still have relatively little adequate data on which to evaluate need, and from which to evaluate eventual outcome. Many programmes were set up on the basis of a more or less urgently felt need in a rapidly shifting situation, and in most cases any evaluation that has been done has occurred simultaneously with interventions.

As pointed out in the introduction, there was hardly any published literature available concerning various European migrant or ethnic minority communities when the concerted action began. During the course of the survey a certain number of evaluation studies have been performed. Many are pilot studies, most have not been published: photocopies circulate internally, and some authors are reluctant, or sometimes refuse, to put them into the public domain. This section pulls out some common themes among the evaluation studies available in early 1991 and that could be reviewed, those from Belgium, France, Germany, Italy, Netherlands, Sweden, and Switzerland.

As for *populations studied*, two principal groups have been addressed in HIV/AIDS-related knowledge and attitudes studies among migrant communities in Europe; people from Turkey and people from African countries. People from Turkey are studied in Germany^{33,34}, the Netherlands³⁵, and Switzerland³⁶, reflecting the

size of the Turkish communities, especially in the two first countries, as well as the importance of cultural differences that make it difficult to assume that information campaigns addressed to general European populations have reached these particular guest communities.

For studies of people from Africa, the Belgian investigation³⁷ is prototypic, starting from the observation that press speculation about the African origin of AIDS, as well as a decision to require certificates of HIV negativity from third world students, had resulted in a climate of suspicion and hostility. This theme is followed up in the subtle French study³⁸, which manages to contact some of the most difficult-to-reach segments of the African population in Paris, such as the poorly educated of rural origin, women who normally remain at home, and traditional healers. The Italian study³⁹ addresses a somewhat different African population seeking asylum in Italy: two thirds of the Rome sample came from Eritrea, where AIDS incidence seemed to be relatively low at the time the study was done, as opposed to mainly people from sub-Saharan African countries as in the two other studies.

The other studies reviewed deal with Moroccans³⁵ and Surinamese⁴⁰ in the Netherlands, and with Spanish and Portuguese in Switzerland⁴¹.

The other approach is to study people who work with immigrants, especially with refugees. One of the German studies, as well as the Swedish, start with questionnaires distributed to personnel working with the target populations, in the case of the Swedish study assessing their HIV/AIDS-related knowledge, as well as needs and wishes for further training.

In *methodology*, the entire range of approaches is found: the Berlin study uses a telephone survey; the Belgian, Italian and Netherlands

studies use questionnaires, the Swiss studies use both questionnaires and ethnographic methods, and the French study uses focus group discussions (as well as additional interviews). A quantitative phase that had been foreseen for the French study did not prove feasible. The authors of the Italian study, on the other hand, note that their brief questionnaire in English was generally well accepted by respondents.

The *question asked* and subjects covered in the French study could be used as a model for the things one needs to know in order for messages to be adapted for a given culture: what is the meaning of being or of falling ill, about sexuality, marriage, family, having children, infidelity, homosexuality, prostitution, contraception, condoms – and what AIDS means in the home country and amongst that specific group in the host country.

Studies are too scattered over time and target group to permit any reasonable overall discussion of *results*, except for the very basic, but fairly striking, finding that even among the most marginal, least educated, and poorest fringes of the migrant populations in European countries, the vast majority of people are at least aware of the syndrome of AIDS (in most of the studies well over 90% of the respondents had heard of the disease – in only one study, among Turks and Moroccans in Amsterdam, this percentage was 80%). From there, of course, to knowing about the difference between HIV and AIDS, how HIV is and is not transmitted, and how to protect oneself is another matter, although most studies address the intricacies of false knowledge to some extent. Few have attempted to address protection-related issues such as IV drug and condom use among migrant populations (the exceptions are the Belgian and Swiss studies in which condoms are discussed).

Process evaluation

Process evaluation, answering the question of what services are actually delivered, is usually present in some form from the very establishment of programmes: some programmes, such as that in the Netherlands, were precipitated, in fact, when people working in the field signaled that prevention messages were not getting through to minority populations.

The countries with the longer-standing programmes report ongoing process evaluations. The Dutch and the British, for example, monitor the numbers of course attenders, of telephone calls to hot lines (by independent market research in the UK), and so forth, and the Swiss have started to do so. Continuous evaluation is stressed in the Netherlands, along the entire range of activities. In fact evaluation is a precondition for funding of projects. Record is kept of the most frequently asked questions, most frequently occurring misunderstandings, and so forth. Certain of these projects have been described in detailed public reports^{42,43}, which, strikingly, present not only success stories, but also problems, bottlenecks and recommendations for a next time.

Programme evaluation

All of the national reports stress working with the community. This can be stated in the form of an hypothesis: that purely “top down” imposed programmes will be far less effective than collaboration with “bottom up” programmes emerging from the target group itself. The most successful combination undoubtedly lies in an effective synergy between the two. Evaluations of the Berlin project with Turks and the UK Bradford project with Asians should shed some light on this hypothesis.

Comments on evaluation

The question of HIV seroprevalence studies among migrants is occasionally raised, and HIV serological studies among some categories of migrants are reported from some countries (e.g. Norway, Italy, Sweden). Such practices are to be criticized on both scientific and human rights grounds, however. When all of a “captive audience” could be tested, for example of refugees or asylum seekers, major ethical and human rights problems are posed. On scientific grounds, the problems surrounding epidemiological studies of sexually transmitted diseases for any population are amply demonstrated in the same concerted action as this one (Renton). With migrant groups, additional technical difficulties, such as properly defining the denominator, make such studies risky science in most cases. It is dubious that HIV seroconversions, for example, as occasionally proposed, could be monitored to assess prevention efforts (see⁴⁴ for a review of evaluation studies worldwide).

Of more use is research as to how best to reach migrants with prevention efforts, and evaluations of whether or not information is getting through to minority populations. The difficulties inherent in doing such research should be apparent, however. Migrant populations may be more difficult to research than are autochthonous populations, due, once again, to the sensitivity of the subject matter to be discussed and, potentially, of the data obtained, particularly in view of the risk of stigmatization.

The studies reviewed above have demonstrated that such research is feasible, however, even among the most vulnerable populations. Detailed methodological discussions are to be found in the French and Swiss studies. One measure of the success of the French study, for example, is that at the end of the

meetings the exchanges generally ended with a request for further such meetings. A further measure of success is that at least parts of Belgian, French, Netherlands, and Swiss HIV/AIDS prevention strategies among their foreign populations are based on the findings of these studies.

It is too early at this point to make even tentative statements about methodology, although we have argued elsewhere that both qualitative and quantitative studies are necessary⁴⁵. Whatever the methodology, evaluation studies should be encouraged, done, and published so as to be accessible to people from other countries, especially those working with the same populations in various permutations. Ideally, researchers should also have the courage to write about, or at least to discuss, the unsuccessful attempts that have been made, since analysis of failures is far richer in lessons than are recitals about successes.

Generally speaking, assessment tools for migrants are the same as for any other target groups, with some specifics:

First of all, it bears reminding that migrant populations, almost by definition in most countries, have special language problems that make access, and also research, difficult. Questionnaires have to be translated, checked, back-translated, re-checked, and so on, and quantitative research is even more difficult when a proportion of the population studied does not know how to read. For qualitative research, translation of interview data is both expensive and a potential addition source of error.

Being extremely specific about anticipated outcomes is perhaps especially important where research and programmes concern migrants. This not only helps clarify thinking and goals, but also helps build the climate of trust so often problematical in dealing with those outside the mainstream of

the host society. Outcome measures of “did it work?” for migrants have to specifically include “was it acceptable?”

Similarly, as general guidelines for evaluation research among migrant populations, we propose that researchers should ask for the same elements of information as for the local populations. If one does not know the incidence of IV drug use, of casual sexual relationships, or of anal intercourse among the “host” population then asking this information of the “guest” population can too easily be perceived as stigmatizing.

A continuous process of monitoring and feedback is needed, as situations change rapidly. Not only do younger community members progressively enter the “market” of people needing HIV/AIDS education as in other groups, but communities may be in constant movement, or even entirely changed over a period of a few months, as when new waves of refugees or of people moving into the country arrive.

Sources of evaluation need special attention: “who does the evaluating?” In one disastrous example, which for obvious reasons never left the realm of hearsay (unfortunately, for the purposes of evaluation of evaluation...), assessment of need in a black community was made by a white team who produced a report filling with prejudices and racist stereotypes. Not only was the report unusable, it caused a good deal of ill-feeling and public relations damage. For migrants we can conclude that it is best that whenever possible the evaluators be people from the ethnic community concerned. In a point specifically discussed in the Swiss study, there is reason to believe that part of the reason for success of some studies among migrant populations was that the researchers were of the same nationality as the researched, or at least easily identifiable as fellow

foreigners in the host country. It would be worth while to systematize this observation if it holds true since the same point has been made about research with other potentially marginalized populations (cf. Pollak, this concerted action).

Feedback to the migrant community is essential. This is also an area in which international cooperation could be useful: it is at least possible, and certainly merits researching in the interest of efficiency and of international burden sharing, that an excellent evaluation done with one population in one context might be useful in another context. Similarly, one country’s foreigners can shed a unique light on the national programmes in the countries from which they come (see for example the Turkish report in Wayling’s survey of European countries,¹²).

The assessment itself

Finally, the performance of the European Community survey itself has been a form of evaluation. Lacunae have been revealed, and the demonstration of interest by such a body as the European Community has reflected valuable status on the field. In a spiral process, those beginning programmes were influenced in discussions with those whose programmes were longer established, and the exercise of commenting and updating successive drafts of the final report, performed by the national reporters, began to reveal that some things seemed to be working better than others. Some of the national reports, the Netherlands, for example, are being published apart, or circulated within and between programmes. The Belgian report was released on the occasion of press coverage of programme activities. The Italian report is being circulated in an attempt to prompt government action. Finally, the United Kingdom report has

served as basis for lively and essential discussions, an opportunity to forge a consensus among various divisions and authorities.

Conclusions

Underlying the European Community concerted action mandate given the migrants and travellers group were two basic ideas: a question as to whether migrants and travellers may be at particular risk of HIV transmission due to specific factors, and the hypothesis that people of minority cultures and languages may have missed out on the general population HIV/AIDS prevention campaigns in the countries in which they are living. The group's activities have focused primarily on migrants, loosely defined as consisting of people who live in a country other than their "own" for periods of more than three months, as asylum seekers for example, all the way through to minority ethnic groups who may have been in the host country for several generations.

These activities took place within the context of a swiftly changing field. The European migration situation is shifting as South to north migration reverses and labour migration dwindles, all European countries attempt to deal with an influx of asylum seekers, and the political and economical picture of the continent is profoundly altering with changes in Central and Eastern Europe. At the same time, the situation concerning HIV/AIDS prevention programmes for migrants is also changing rapidly, with many new programmes being set up and modified.

The group's work was based on a national reporter strategy. Those responsible in some way for HIV/AIDS education activities for migrants provided descriptive accounts of programmes in Belgium, France, Germany, Greece, Italy,

Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, and the United Kingdom. The reports from the twelve countries show that, generally speaking, in northern European countries with relatively long-established ethnic minority populations, programmes exist. The main needs are for evaluation, both of baseline information concerning migrants HIV/AIDS-related knowledge and behaviours, and programme evaluation. In southern European countries migratory phenomena are relatively new, and have largely caught government authorities unprepared. The HIV/AIDS prevention programmes that exist for migrants are run either by non-government organizations or by local authorities, are severely under-funded, and unable to meet all the needs defined.

Several conclusions were drawn, for example that risk group logic is singularly unhelpful: targeting people from particular geographical regions for special intervention is liable to be as perceived as stigmatizing and to cause programmes to be rejected. The category "migrants" is a highly diverse one, including people with vastly different backgrounds and needs. Migrants or ethnic minority populations of whatever duration of stay in a country cannot be assumed to be reached by HIV/AIDS education messages directed towards the general population of that country, but specific programmes for them should follow the model developed for other general populations, with culturally adapted messages aimed at the entire population, and specific targeted interventions for particular sub-groups. For both aspects it was found to be essential to work with the target community, in synergy between "top down" and "bottom up" programmes.

Two major results to date of the EC concerted action concerning migrants and travellers are of note: First, the EC focus on migrants and

travellers has permitted exploration of the problem, and a preliminary inventory of the activities taking place in the field, helping bring HIV/AIDS prevention activities for this population into the public domain.

The second major accomplishment of the action was to permit networking to occur. This is especially important in the case of the migrants group: in many instances one country's migrants are another's autochthonous, and clearly all countries are dealing with similar themes and problems in different configurations. The importance of exchanges between those doing HIV prevention among Spanish workers in Switzerland and those doing similar work in Spain, or between those working with people from Africa in Belgium and in Portugal, for example, should be evident. The sharing of information and observations should help avoid the necessity for local programmes to repeatedly invent the wheel.

At the same time, as work progressed, the lacunae became increasingly apparent. A great deal of further work is necessary in two major areas: a) movement between Eastern and Western European countries and ethnic minority groups within the former, and b) asylum seekers.

a) Movement between Eastern and Western European countries: Massive efforts are being made to assure that HIV/AIDS prevention efforts are adequate in Central and Eastern Europe, an effort all the more urgent since movement of people between east and west has become possible. Public awareness, condom distribution, and so forth are rapidly improving⁴⁶.

There is reason for concern, however, that as long as socioeconomic imbalances persist between Eastern and Western countries, there will be a potential for exploitation in general, as well as,

specifically, for the HIV risk that concerns us here, in the sex industry. Evidence is a best anecdotal, partly since the phenomena are new, and partly since the issues raised are both delicate and potentially explosive. But there is at least a theoretical risk that the sex tourist “industry” turn towards this new field in which the public image is that HIV is relatively rare. From the other side, the history of the AIDS epidemic already contains cases in which economic desperation, and lack of awareness of HIV and of protective measures, has had tragic epidemiological consequences for regions of the world. Another issues with respect to changes in the former Eastern bloc concerns minority groups in these countries, people from developing countries who had been recruited as labourers. Within a climate of uncertainty and change, and of unemployment, there is reason for great concern regarding people who were already marginal in these countries. While what has been said about migrants in Western Europe could theoretically be applied to migrants in Central and Eastern Europe, this remains to be seen.

b) Asylum seekers: most of what has been said above, for example about working through the community, cannot be applied to asylum seekers. Asylum seekers seem to be nobody’s responsibility: they live on the margins of societies until, at present, more than nine tenths are refused refugee status. They may combine several risk factors besides marginal living conditions, such as severe economic precarity for some, destruction of social and family structures, lack of control over their future, and dependency on others.

HIV/AIDS prevention activities for asylum seekers, of no matter what nationality, are problematic in almost all of the countries surveyed. Several ethical dilemmas are posed, as exemplified in issues

surrounding testing. Human rights are threatened when asylum seekers are “offered” HIV testing without the recipient of the offer knowing that (s)he has the right to refuse. If testing is done, then can adequate counselling be provided, in the language of the affected individual? If the test is positive there is a very real dilemma concerning what to do about possible treatment. Should treatment clinically indicated by host country norms be started if there is high probability that the patient will be sent back to a country in which continuation is not available? To what extent can need for treatment serve as humanitarian grounds for granting of refugee status? So far only the questions are raised where asylum seekers are concerned: as yet there are no answers.

What remains to be done

On the level of programmes, in some countries immigration has preceded the setting up of structures to deal with it. There is urgent need for the setting up and proper funding of such structures, including HIV/AIDS prevention. There is an important role for government in this: although it has been pointed out that non-government organizations have an important role in HIV/AIDS prevention^{47,32} they should certainly not be relied upon to have the *only* role. Whether as immigrants or as travellers, as mentioned above, there is at the moment particularly urgent need for programmes to assure that people moving between east and west are sufficiently aware of how to protect against HIV transmission.

In countries in which programmes already exist, there is great need for evaluation. The number of studies that could be reviewed for the present concerted action amounted to under a dozen, most of them unpublished, and many pilot studies. Evaluation needs to

be built into programmes from the beginning, and field workers should be encouraged make their studies public. The overt reason for this is of course to share experiences, but another reason underlies: field workers need to be given the opportunity to sit back and reflect on their experiences by discussing and writing about them. It is probably safe to assert that AIDS-related work is rarely comfortable or easy, but HIV/AIDS prevention among migrants contains some specific stresses. It means shifting between worlds, dealing with a certain number of people whose problems are severe and whose needs are great, sometimes working clandestinely in order to protect the recipient. It means going out in the evenings to festivals, but also to talk about difficult things in foreign languages. Programmes run on the basis of the urgency of the need tend to wear out their personnel, and one way to prevent this is to build in time to sit back and reflect.

Similar reasoning underpins the need for a *forum for exchanges* and for *international cooperation*. One of the greatest needs expressed throughout the work group’s activities has been that for opportunities to meet and exchange experiences across European countries; the need for international and inter-institutional cooperation has also been repeatedly stressed and should be obvious.

Finally, the necessity for more *research* has also been mentioned in several areas. The survey has demonstrated the need for a properly controlled and international study of overall migrant health. The lack of evaluation research was mentioned above. Process research is also needed concerning sharing materials. Cultures of origin differ, but there are equally pertinent cultural differences among European host countries, differences which require country-specific processes of adaptation

from immigrants. It is possible but not yet demonstrated, that materials and methods developed in one country can be used with the same ethnic population in another country. There may be a single common European solution to preparing HIV/AIDS information materials for a given guest population, or there may be a common process by which each country develops its own specific materials, but this needs to be researched.

HIV/AIDS prevention activities for migrants, and this survey itself, have remained fairly close to the field. Enough elements are now present, and there is a need to raise the level of theorization, to put campaigns in the socio-cultural context of countries, for example by studying links between economic factors (unemployment, especially), numbers and types of foreigners, racism, and policies concerning migrants. Another fruitful area would be to speculate on the role, positive and negative, of minority group conflict and criticism in the development of programmes, perhaps by comparing countries in which such conflict has been blatant with others in which it does not seem to have occurred. Still another would be to pursue the themes raised in the stigmatization chapter, in which foreignness and outsidersness are somehow linked with disease.

Much remains to be done. Migrants are people who cross boundaries. Diseases also cross boundaries. In an increasingly open context, it is up to us to see to it that knowledge and experience will also cross boundaries.

Zusammenfassung

„Migranten“: Die Entwicklung eines Evaluationsobjekts

Die Gründung der Gruppe „Migranten“ der konzertierten europäischen Aktion „Evaluation der AIDSprävention“ fiel mit dem Beginn der Präventionsbemühungen für Migranten zusammen. Dieser Artikel stellt die Situation der Fremdarbeiter und Asylanten in Europa dar und diskutiert die Gründe, weshalb die Migranten wichtig oder nicht wichtig für die AIDSprävention sind, und die spezifischen Schwierigkeiten, die mit einer solchen Prävention verbunden sind. **Schlußfolgerungen:** Die Programme müssen eher im Recht zu Wissen als im Begriff Risikogruppe verankert sein. Die Kategorie Migrant umfaßt Personen, mit weit verschiedenem kulturellen Hintergrund und Bedürfnissen. HIV/AIDSerziehungsbotschaften für die Gesamtbevölkerung erreichen nicht mit Sicherheit Gastarbeiter oder ethnische Minderheiten, aber Programme mit gleichem Inhalt wie die für die Gesamtbevölkerung, die aber spezifisch auf die Minderheiten zugeschnitten sind und ihren kulturellen Hintergrund berücksichtigen, müssen entwickelt werden. Deswegen ist es wichtig mit der betroffenen Gemeinschaft zusammenzuarbeiten, damit die Programme jeweils gleichzeitig „von oben nach unten und von unten nach oben“ inspiriert werden.

Wichtigste Notwendigkeiten im Bereich der Prävention bei Migranten sind:

- eine genügende Finanzierung;
- eine strikte Evaluation, bestehend aus einer Nullmessung und einer Programmevaluation;
- eine international vernetzte Zusammenarbeit was die Programme, das Material und die Interventionsmethoden sowie die Forschung anbetrifft.

Résumé**Les migrants: Le développement d'un objet d'évaluation**

La mise sur pied du groupe «migrants» de l'action concertée européenne «Evaluation de la prévention du SIDA» a pratiquement coïncidé avec le début des activités de prévention du VIH/SIDA destinées aux migrants dans les pays européens. Cet article présente la situation de la migration en Europe, discute des raisons pour lesquelles les migrants pourraient ou non avoir une importance dans la prévention du SIDA et les difficultés propres à une telle prévention. Les programmes pour les étrangers initiés par les gouvernements ou des organisations non gouvernementales de 12 pays européens sont décrits. **Conclusions:** les programmes doivent être basés sur le droit de savoir plutôt que sur la notion de groupe à risque. La catégorie «migrants» inclut des personnes dans des conditions et avec des besoins très différents. On ne peut tenir pour acquis que les migrants ou les minorités ethniques sont atteints par les messages de prévention adressés à la population générale des pays où ils résident. Des programmes suivant le modèle de ceux destinés à la population générale mais spécifiques et culturellement adaptés doivent être mis sur pieds. Ils devraient être suivis d'interventions ciblées destinés à des sous-groupes particuliers. Pour ces deux aspects de l'intervention, il est essentiel de travailler avec la communauté, de façon à ce que les programmes soient à la fois inspirés «d'en haut et d'en bas». Les besoins principaux dans le domaine de la prévention des migrants sont:

- des programmes dotés d'un financement adéquat;
- une évaluation rigoureuse, comprenant un bilan de base et une évaluation du programme;
- un travail de réseau et de coopération au niveau international qui concerne les programmes, le matériel et les méthodes d'intervention utilisées, ainsi que la recherche.

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