

25065

WHO/GPA/SBR/89.2
Original: English
Distr.: General

GLOBAL
PROGRAMME
ON **AIDS**

REPORT FROM CONSULTATION
ON PSYCHOSOCIAL RESEARCH NEEDS
IN HIV INFECTION AND AIDS

GENEVA
25-28 MAY 1987



WORLD
HEALTH
ORGANIZATION



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I. INTRODUCTION

Of all communicable diseases, human immunodeficiency virus (HIV) infection and the acquired immunodeficiency syndrome (AIDS) present some of the most complex biological and social problems that modern society has confronted. The medical implications for the HIV-infected individual are broad-ranging, as indeed are the potential social impact on the individual, family and community.

Transmission of HIV is known to be related to specific behavioural practices and possibly to changes in patterns of social organization. The primary and secondary prevention of HIV/AIDS and the formulation and implementation of HIV prevention and control strategies will depend increasingly for their success on the type of data available to planners about the frequency and distribution of risk behaviours and the social factors contributing to them. Information on how people, groups, and institutions react to and cope with individual infection and the epidemic will similarly become of fundamental importance for the planning of health and social welfare programmes.

As with many communicable diseases and other public health problems, data concerning the behavioural aspects of HIV transmission, the social factors associated with it and the effectiveness of control measures, are so far limited. The nature of AIDS and its global magnitude, however, is such that information about its biosocial character must be urgently gathered and built on.

In order to review the current state of work in this area and identify priorities for social and behavioural research, a meeting was organized in Geneva by the World Health Organization's Special Programme on AIDS (WHO/SPA), on 25-28 May 1987. The meeting brought together 20 participants from 12 countries who represented a variety of disciplines including psychology, epidemiology, economics, medical sociology, anthropology and psychiatry. The meeting was chaired by Dr M. Carballo (SPA). Professor A. Coxon, Dr M. Micklin and Dr D. Pitt served as facilitators to the working groups. A list of participants is given in Annex 1.

The meeting was opened by Dr J. Cohen, Special Adviser on Health Policy to the Director-General of WHO. While rapid progress is being made, he said, in the virology and immunology of AIDS, the development of an effective vaccine must be recognized as a long-term goal. In the short term much more work will be required on the behavioural aspects of HIV transmission and on the impact of AIDS on individual and community life. Research in this area needs to be directed at the rapid provision of a basis for practical, scientifically sound, socially acceptable, and economically feasible intervention strategies.

Dr J. Mann, Director, WHO Special Programme on AIDS, then referred to the three parallel though consecutive epidemics, namely the silent epidemic of HIV infection, the more obvious epidemic of AIDS, and the epidemic of social, political and economic reactions to AIDS. This last epidemic, he said, has all the potential to exacerbate an already difficult medical and social problem.

In defining the scope of the meeting Dr M. Carballo reviewed the background and the objectives which were:

- to review existing knowledge and ongoing work on psychosocial factors in HIV transmission;
- to identify priorities to current and projected research needs in the development of intervention programmes for national AIDS prevention and control;
- to propose methodological approaches to the study of identified priority areas;
- to identify a network of researchers available for work in this area and to determine how biosocial scientists could best help strengthen national research activities.

II. NATURE OF THE PROBLEM

The first cases of AIDS were described in 1981 among male homosexuals in the USA. Since then what was originally thought to be a relatively small and demographically contained epidemic has fast assumed pandemic proportions. By May 1987 46 628 AIDS cases had been reported to WHO from over 100 countries, representing an increase of 14% over the previous two months. However, in many countries where diagnostic facilities and health care infrastructures are relatively underdeveloped, a large number of cases of AIDS are probably both undiagnosed and unreported to central authorities.

In North America, Western Europe, Australia and New Zealand, HIV has been transmitted predominantly through homosexual and drug-injecting behaviour although there are indications that the numbers of women infected with HIV through heterosexual contact are also increasing. In the African Region and parts of the Caribbean and South America, on the other hand, HIV transmission has been primarily heterosexual. In Asia, the prevalence of AIDS is still low, accounting for less than one per cent of the world's reported cases.

AIDS cuts across all socioeconomic and ethnic lines, primarily affecting the young adult population, who are sexually active.

The implications for family life and economic productivity are significant. The age groups most at risk are those entering or already at the peak of their reproductive period and at the same time central to a variety of activities which are of fundamental importance to the maintenance of society. Any epidemic threatening this age group necessarily immediately has the potential to undermine the social, economic, demographic, and political structure of society.

AIDS, however, is only the final manifestation of infection with the human immunodeficiency virus (HIV). It has been estimated that for every case of AIDS there may be between 50 and 100 HIV-infected persons. Because epidemiological data on HIV infection are still emerging and incomplete, it is not clear what proportion of these infected individuals will go on to develop AIDS. It can at present be anticipated that between 40% and 60% of them will develop AIDS during the five to seven years following initial infection.

Although the long-term social, economic, and political implications of AIDS cannot yet be fully appreciated, there have been instances of negative reactions against HIV-infected people. Individuals known or suspected of being infected with HIV have at times been discriminated against in relation to employment, housing, education and insurance. Calls for mandatory screening have become more common despite the questionable effectiveness of such a measure. Travel across borders by individuals suspected of HIV infection, and certainly by those with AIDS, have similarly been affected.

Where such responses occur, persons engaging in high-risk behaviour may be reluctant to come forward and voluntarily participate in HIV risk reduction programmes. Many forms of behaviour implicated in HIV transmission (such as drug injecting, prostitution, and homosexuality), are socially proscribed which has traditionally contributed to difficulty in sustaining participation in treatment programmes or other risk reduction initiatives.

III. SOCIAL AND BEHAVIOURAL ASPECTS OF HIV TRANSMISSION

Epidemiological studies in Europe, the Americas, Africa and Australia have documented only three modes of HIV transmission:

1. Sexual intercourse (heterosexual or homosexual);
2. Exposure to blood, blood products or donated organs and semen. Exposure to blood principally involves transfusion of untested blood or the use of unsterilized syringes and needles by IV drug users;
3. From infected mother to child - before, during or shortly after birth (perinatal transmission).

3.1 Sexual behaviour

A number of attributes of sexual behaviour are known to be associated with transmission of HIV: multiple partners and frequent unprotected sexual exposure (anal or vaginal). Individuals and groups typically involved in such behaviour have demonstrated higher than average rates of HIV infection, although to different degrees in different countries and social settings; the distribution and frequency of the risk behaviours involved, however, is unknown for most populations.

To what extent in any given society it is common for people to have multiple partners remains unanswered. In parts of urban Africa and to a lesser degree in parts of urban Latin America the practice has been reported to be a response to the rapid social changes that have taken place from well established social structures to newer more flexible and less well defined situations in which traditional patterns of marriage and/or union do not carry with them the same sanctions and support typical of rural society. Migration from rural to urban areas has been significant in recent years; it has been age and sex selective and for the most part has been a migration of young males. Moving to cities alone, without their families of origin, and in the absence of traditional support and control mechanisms, they have sometimes adopted new social customs and practices, mixing selected aspects of traditional and "modern" cultures to create new ones that are perceived to be appropriate to, and satisfying in their immediate situation.

In North America and Western Europe urbanization took place earlier and the problems typically associated with massive migration are now fewer. There has nevertheless been evidence of recent changes in sexual behaviour patterns there too.

During the 1960s and 1970s there were "liberalizing" movements that, among other things, emphasized sexual freedom in the choice and number of partners inside and outside marriage. Sexual behaviour patterns among young people are thought to have been significantly influenced by those changes.

The real scope and magnitude of the changes that have taken place, however, are currently difficult to assess. There have been few studies of sexual behaviour in recent years; not since the one undertaken by Kinsey and his associates in the United States in the 1940s and 1950s has there been any large-scale survey of sexual life-styles. Although the Kinsey survey was flawed by imperfect methodological procedures and a focused selection of sample populations, it remains the only major reference point for North American and, by extrapolation, Western European society.

3.2 Homosexual behaviour

In Western Europe and North America, the majority of AIDS cases have occurred in homosexual men. In these regions homosexuality has become more openly recognized in recent years and "Gay" movements have emerged in a number of major cities. Although they may by no means reflect the true distribution of male homosexuality, they are an indirect indicator of the geographic distribution of homosexual practices.

Covert male homosexual behaviour no doubt exists over and beyond what is suggested by these gay movements and/or communities. The openness with which some men identify themselves as homosexuals is a relatively recent trend and may apply to only a small proportion of those with this sexual preference.

Case histories of HIV-infected homosexual men indicate a high frequency of exchange and number of sexual partners together with sexual practices such as anal intercourse. The relatively high incidence and prevalence of sexually transmitted diseases among many homosexual men has also been implicated as a possible co-factor for HIV transmission.

Few surveys on homosexual behaviour have documented the distribution of high risk practices. The response by homosexual men to the HIV/AIDS epidemic has not been described and it is unknown how risk reduction initiatives are being taken up or whether appropriate information, education and counselling is reaching them in ways that are acceptable. Nor is much known about the extent to which self-help groups are proving effective in providing support to individuals prior to and following infection.

3.3 Prostitution

Because of their exposure to multiple and frequently changing sexual partners, men and women who provide sex for money are also at high risk of HIV infection. In some cities of Central Africa and North America, seroprevalence surveys among female prostitutes have indicated rates of HIV infection that are considerably higher than for other groups. Because their clients are often new and anonymous, however, it is often difficult for prostitutes to insist on the use of condoms. This is particularly so when prostitution is the main or only source of income and clients insist on high risk sex.

The definition of prostitution is difficult. Unemployment and poverty lead both men and women to provide sexual favours for money, shelter, gifts, and food. Sex for reward is often irregular and dependent on financial needs at the time. Cultural attitudes that condone multiple partners for men or sexual favours by women may also blur the demarcation line between what is and is not prostitution and may make the structure of intervention complex.

A systematic study of male and female prostitute behaviour is called for, especially with a view to determining how their work is organized, the specific behaviour they engage in, what knowledge they have of the risks they are exposed to, their attitude to risk reduction, their ability to reduce risks, the range and selectivity of their clients.

3.4 Substance abuse

In North America, Western Europe, parts of Australia and New Zealand, drug-taking by injection has become one of the most apparent and significant forms of risk behaviour associated with HIV infection and AIDS because of needle and syringe sharing practices.

Drug use, whether narcotic or alcohol, diminishes the capacity to take and to implement decisions. In the case of sexual behaviour, there are indications that the skills required for the effective use of condoms and the selection of sexual partners are influenced by the use of narcotic drugs or alcohol.

For a variety of reasons including social marginalization, legal prosecution and previous failures to mount effective and acceptable interventions, drug injecting has continued to be a highly covert activity. Information on drug injecting practices, the profiles of people involved, and the types of ancillary behaviour associated with injecting is, as a result, sparse. Although the sharing of needles and syringes (and possibly other equipment) has been implicated as the mode of transmission among drug injectors, there are few data available that could be used effectively by health and social planners in formulating risk reduction interventions. Patterns of drug injecting, including the rate of and reasons for sharing equipment, the ways in which equipment is cleaned, and the effectiveness and acceptability of different cleaning methods remain relatively unknown.

Although it is thought that some people move in and out of drug injecting and are a potential source of sexual transmission of HIV to the larger community that does not use drugs, there are few data either to substantiate or to disprove this. Little is known about the mobility of people who inject drugs, whether they move in order to facilitate drug use, or whether drug use is simply an occasional corollary of travel. Information on these areas is essential for the understanding of HIV transmission and its spread by and among drug injectors.

Because drug users of all types need to finance drug purchases, both women and men are known to sometimes use prostitution as a means of financial support. They may also be more inclined than others to accede to the demands of clients demanding unprotected sexual intercourse and high-risk practices.

Drug injecting for non-medical or recreational purposes is now relatively widespread in most major cities of North America and Western Europe. There is increasing evidence that it is a major public health problem in certain cities of Asia, the Pacific, and Central and South America.

3.5 Injecting and other skin-piercing practices

In resource poor countries injecting for medical reasons can also pose problems. Where coverage by formal health care services is limited or its acceptability is low, injections are often provided by lay persons. In some areas the number of injections given outside the health care system is estimated to exceed or equal the number given by trained health care staff. This occurs all the more in communities where people prefer injection to oral medication and where they believe it to be easier and more effective. Failure to follow sterilization procedures and excessive re-use of injection material may

be practised widely in these areas. To date, however, little is known about the characteristics of people who give injections; who their clients are; the extent to which the injector or client understands the danger of using contaminated needles and the need for sterilization of the injecting equipment; or whether there is a predisposition to reduce the risk of HIV infection either by reducing dependence on injections or ensuring that needles and syringes are sterilized.

Other skin-piercing practices require consideration for the potential transmission of HIV. These include group circumcision practices; ritual scarification rites and scarification for medical purposes. Although some information from anthropological sources is available on some of these practices, much more needs to be known about the exact circumstances in which they take place, the social background of the practitioners concerned, the manner in which skin-piercing instruments are managed, and whether changes in these practices are feasible.

IV. SOCIAL PERCEPTIONS AND EXPLANATORY SYSTEMS

To develop effective strategies for informational and educational activities information is required on: data on local attitudes to AIDS; the knowledge of different groups about AIDS; the way in which HIV is transmitted; willingness to change or modify behaviour where necessary; and the priority that is given to AIDS within their perceived hierarchy of diseases. Information is also needed on how health care workers respond to AIDS and cope with the range of demands made of them.

4.1 Knowledge, attitudes, beliefs and practices

The dictum of W.I. Thomas that "if a situation is defined as real, it is real in its consequences" is of particular relevance in designing AIDS prevention and control strategies. AIDS intervention strategies need to be specifically targeted to the requirements and potentialities of different groups all of whom may have different definitions of reality. They need therefore to be based on, and respond to, what different people know and believe about HIV infection and its implications for health and welfare, as well as the extent to which they believe it to be preventable and within their control.

Data on knowledge, attitudes, beliefs, and practices about AIDS are fundamental to the monitoring and evaluation of intervention strategies. Time trends in what people know and believe about, and how they act in response to, AIDS is an important indicator of the impact of information and education strategies. They may, however, reflect other factors such as the growing exposure of individuals to AIDS among friends and acquaintances or to newspaper reports. As such, surveys should not, unless they include specific questions on that subject, be used to infer the progress of information and education strategies per se.

Enquiring into belief systems and perceptions of health and disease, is not easy. For example, the individual's background - cultural, socioeconomic, sex preference - may all interact to influence knowledge, attitudes and beliefs as may ethnic and educational profiles. Concepts of health care, the utilization of health care services, the use of medication and responses to pain have also been shown to vary between groups. Research into the influence of socio-cultural and other factors on perceptions and response to HIV infection and AIDS is needed.

4.2 Risk perception and risk-taking

Perceptions of, and responses to, risk and risk-taking need to be studied. In other health-related areas such as smoking, driving and alcohol consumption it is apparent that there are individuals who either have misperceptions of what constitute risk behaviours or, when informed, nevertheless deny this information and continue to practice them. In many circumstances there is also a tendency to deny the relevance of current behaviour to health and disease. Especially with regard to practices and behaviours that are gratifying or that enhance social status, the tendency to deny risk is common. Thus, for example, adolescents may reject information on smoking and disease, arguing that it applies to older people who are visibly more affected by respiratory diseases. Underlying this response may be the fact that smoking is seen as prestigious or as a sign of maturity among peers.

The dominance of sex in the lives of most people, especially the young, may influence acknowledgment of risk. Research on risk perception and risk-taking in sexual behaviour and drug injecting is fundamental to the planning and targeting of intervention strategies.

V. COPING STRATEGIES

One of the crucial concerns of health planners is the support needed by the HIV-infected persons with AIDS, and their families. Reports indicate that the type and degree of both physical and psychosocial stress associated with HIV and AIDS may be higher than with other diseases for which there is no cure. This stress may be expressed in terms of aggressive behaviour, withdrawal or denial or, at the family level, in conflict and disorganization. Not all individuals and families are able to deal with HIV/AIDS in constructive ways and cope in ways that minimize psychological morbidity. In all cases there may be difficulties with regard to promoting and supporting behaviour change and the positive adaptation to HIV infection and disease.

5.1 Family

The family has been the traditional source of support to individuals in times of illness; and will be the source of care for many people with AIDS. For gay men the family of choice may be men with similar sexual preferences; sharing of a similar risk perception and cohesiveness may be a positive force in generating a willingness to care for sick friends and an understanding of the range of needs being experienced. The fact that many gay men are already affected by AIDS may, however, lead to fewer individuals becoming willing and able to care for others. Because many gay men have often left their families of origin, or of marriage, they may be reluctant or unable to return to them for care and support.

Among HIV-infected heterosexual individuals, the notion of turning to family for support is sometimes constrained by fears about how they are going to be received, and by feelings of guilt. Acknowledging HIV infection involves recognition of behaviours that may have been hidden from families and which cause conflict and rejection. Families may be constrained in their capacity to respond to the needs of an HIV-infected member by lack of medical knowledge, doubts about transmission, lack of physical facilities to deal with the chronically ill person who needs constant care and, in the case of the small family, simple lack of people who can share the load of caring.

While there are reports of families coping well and providing the type of physical and psychosocial care that helps reduce psychological problems and ensures quality of life, there are also reports of families that are not able to cope constructively.

Self-help groups and other community-based groups have often been able both to provide shelter, psychosocial support and medical care. In the USA and in Western Europe, the response of community-based groups evolved because hospital-based programmes were not always able to give the type of care required, or the psychosocial support needed by people with AIDS. It may also reflect the fact that many people with AIDS come from marginalized groups whose behaviour is sometimes viewed unfavourably by health care staff. Health care workers themselves also often harbour feelings of fear or doubt; they may be reluctant to expose themselves to repeated contact with people with AIDS, again potentially contributing to the communication difficulty between patients and staff.

Whether or not alternative care programmes have enhanced the quality of life among people with AIDS and their families has not been systematically assessed. The fact that such programmes have emerged and continue to grow in number, however, suggests that reported maintenance of quality of life and satisfaction with services may be attracting other clients.

Since the number of people with AIDS is likely to increase over a five to ten year period and impose new demands on health care systems, it is important that more attention be given to how and why alternative health care programmes are evolving and, being managed, and to their impact on the health and well-being of the patients.

In many developing countries the potential role of traditional health-care practices also merits greater consideration. A body of knowledge, experience and expertise may exist and be relevant to the broader needs of AIDS care; however the contribution that such practices could make to health maintenance and reduction of patient load on formal health care systems remains to be assessed.

5.2 Children

Transmission from infected mother to child - before, during or shortly after birth - is occurring in communities where HIV infection is being transmitted heterosexually. Stress is experienced by families in caring for infants who may have HIV antibodies but whose infection status may not be known for long periods of time. At times it impairs the ability of parents to respond and provide the care and stimulation infants require. Where children are old enough to understand the meaning of illness and of death, this stress is shared by them too.

An equal but less well recognized stress is experienced by children living in families where one or both parents or another sibling is infected and where the fear, if not the reality, of seeing them become ill and die is constant. These children in turn may go on to be orphaned and be exposed to the risk of inadequate care, psychosocial stimulation, and nutrition. Opportunities for fostering children from families known to have been affected by HIV and AIDS have sometimes been constrained. The alternative has been to hospitalise children, where they have again experienced a degree of neglect albeit at high cost to the health care system.

To develop plans and programmes to meet the needs of children in such circumstances, more needs to be known about the psychodynamics of the process of coping, about how these can be enhanced, and about the type of support that can be provided through the community and surrogate families.

5.3 Psychosocial expression of HIV infection

Psychological and behavioural consequences of HIV infection and AIDS such as aggressive behaviour, withdrawal, passivity, shame, guilt, anxiety, and inability to deal with HIV-related illness or the prospect of it, have been amply reported. It is not known whether and to what extent these responses are influenced by socioeconomic background, culture, family situation, the social support available, or the clinical stage of the infection and illness.

If planning for care is to be targeted effectively and responsive to the special needs of individuals and groups, more needs to be known in this area. Case management and public health initiatives need to consider information about how different people respond to HIV and AIDS, how these responses can be predicted and how their impact can be managed. This need is particularly acute where there is indication of neurological damage and where consequent behavioural changes could affect ability to function within family and community.

5.4 Counselling

The psychosocial problems and needs associated with AIDS compound the medical problems. In many instances they adversely affect the ability of infected individuals to cope with their condition and can impair the likelihood of their assuming responsibility for prevention of secondary transmission.

To prevent HIV from being acquired or transmitted is a priority in all counselling programmes. To improve the chances of success in preventive counselling, emphasis needs to be given to working with families, friends, and lovers, as well as with the HIV-infected person. A core of counselling is helping the patient to achieve decisions on risk reduction and mobilizing the type and quality of social support needed to implement them. Major goals of counselling include the reduction of psychological morbidity, prevention of HIV transmission, improvement or maintenance of quality of life, and minimization of the need for hospitalization and other institutionalized care.

The demand for counselling will increase as more people are diagnosed with HIV infection and AIDS. Few countries, whether developed or developing, are likely to have the trained personnel or resources required to easily meet this demand. It may be necessary to explore different ways of providing counselling, including voluntary workers, self-help groups, and nongovernmental organizations. Community-based counselling in particular will need to be considered. Research is needed to assess the effectiveness of different training programmes and the level of supervision required for different staff.

Although counselling has been made available in a variety of health care situations, there is little information on its impact, either in terms of physical or psychosocial response. More research is needed if counselling is to be promoted as a means to behaviour modification and is to take up the challenge of reducing psychosocial morbidity and the patient load on hospitals. In the absence of systematically derived data it may be difficult to justify the financial and other resources required.

5.5 Family, marriage and reproduction

The ability of the family as a social institution to cope with social upheavals and maintain its structure has been affected by a number of social trends. Migration, urbanization, and industrialization have contributed to fundamental changes in the organization and function of the family. Since AIDS involves a complex combination of

medical, social, psychological, and economic pressures, it too, can be expected to bring about changes in the life-style and structure of families. It may also influence patterns of migration and residential mobility.

In certain parts of Central Africa, anecdotal evidence suggests that patterns of marriage are already being disturbed, and that larger numbers of women are separated or divorced as a result of suspected HIV infection. Subsequent sexual behaviour may lead to a heightened risk of HIV infection among them. In areas where the prevalence of HIV and AIDS is high, fear and suspicion of HIV infection in a partner may increase the likelihood of separation and divorce, with consequent implications for the well-being of divorced women in societies where there are few opportunities for economic independence.

Fear of HIV could equally promote early marriage, for example at menarche or an age generally associated with it. Were this to happen, patterns of fertility could be altered; young girls beginning their reproductive careers earlier will have more years of potential childbearing before them.

Changes in patterns of reproductive behaviour would focus attention on family planning and family planning methods. Method acceptability and service delivery issues will need to be reviewed. Attention will need to be given to the possible confusion about the contraceptive role of condoms as opposed to their prophylactic role in preventing HIV transmission. Within family planning circles concern has also been expressed about the possible confusion people might have between the promotion of condoms, which recently have been associated with contraception, and the overall field of family planning.

There is a need for basic research on attitudes to contraception, pregnancy postponement, method acceptability and, in particular, condom use patterns.

VI. RECOMMENDATIONS FOR RESEARCH

The need for multidisciplinary research in all the above areas is evident. For the planning of prevention and control activities, the development of educational initiatives, and the ongoing monitoring of trends over time, data need to be gathered on the social determinants of risk-taking behaviour, perceptions of HIV and AIDS, the expression of illness, and coping.

Each of these areas represents a relatively discrete entity that calls for special research approaches, methods and timing. For conceptual and operational purposes it is useful to divide the areas into the following three main categories:

- high risk behaviour;
- explanatory models/systems;
- coping responses.

6.1 High-risk behaviour

In this area it is recommended that research be undertaken on:

- (a) patterns of sexual behaviour and factors underlying their prevalence, distribution, maintenance, and change;
- (b) male homosexual and bisexual behaviour response to the AIDS epidemic and factors contributing to risk reduction or to the perpetuation of risk behaviour;

- (c) drug-injecting behaviour (for non-medical purposes), including factors contributing to the presence or absence of risk reduction in relation to, for example, sexuality, childbearing, and contraceptive practices;
- (d) monitoring of risk reduction interventions such as needle exchange, needle cleaning, and educational outreach projects, with special attention to factors that enhance or impede the efficacy of the interventions;
- (e) injecting practices (for medical purposes), especially outside the formal health care system, with special emphasis on the contexts in which injections are given, for what purposes, to whom, by whom, and with what risk of HIV transmission;
- (f) male and female prostitution and the ways in which risk reduction strategies can best be facilitated and strengthened in relation thereto.

6.2 Explanatory models/systems

Three priority areas are proposed:

- (1) knowledge, attitudes, beliefs and practices within given population groups and over time;
- (2) risk perception, assumption of responsibility for one's own behaviour, and confidence in one's ability to bring about the necessary changes in the personal and environmental/social factors involved in risk-taking;
- (3) development of analytical frameworks of motivating factors associated with risk behaviour.

6.3 Coping responses

Within this area seven priorities can be identified:

- (1) development and assessment of alternative approaches to counselling and their impact on behaviour change and psychosocial morbidity; assessment of how different human and institutional resources can be mobilized for counselling; implications for service performance; and the impact on clients and patients;
- (2) ways in which individuals and families cope with HIV and AIDS, their sources of support and needs in different social and cultural contexts, including those children living in AIDS-related situations;
- (3) the role of alternative and traditional health care systems in enhancing quality of life and psychosocial morbidity of the HIV-infected; and the ways in which such systems can be strengthened and coordinated;
- (4) ways in which HIV/AIDS affects perceptions of reproductive health and family planning methods and services; ways in which these services can help in AIDS prevention and control;
- (5) behavioural expressions of HIV infection in different health, social and cultural contexts, and ways in which they can be measured and predicted and their impact minimized;

- (6) the impact of HIV infection and AIDS on health worker-patient relationships and the work performance and needs of health care staff;
- (7) the impact of HIV infection and AIDS on such demographic factors as infant morbidity and mortality, migration, and marriage patterns.

VII. RESEARCH APPROACHES

The proposed areas of research call for a variety of methodological approaches. In some, descriptive data can be generated through population-based surveys using relatively standardized methods. The additional use of more qualitative approaches would enhance the understanding of these issues and should be considered in conjunction with survey methods.

The use of psychometric, ethnographic and other psychosocial research approaches would be particularly appropriate in explanatory models/systems research especially for in-depth information on the psychological and social factors that underlie particular behaviours. Additional methods such as focus group techniques which are useful in generating information quickly on relatively homogeneous groups and can be employed together with other more systematic methods should also be used.

7.1 Research networking

The research strategies being proposed share a number of underlying objectives and characteristics. They all seek to increase knowledge and understanding of the causes and consequences of HIV infection and AIDS; at the same time, they are designed to strengthen the capacity of national institutions and committees to undertake research and convert the findings into policy alternatives. Much of the work to be done can, in one way or another, be advanced by collaborative research efforts that bring together national scientific research groups and institutions for comparative surveys and studies.

Collaboration in this research area should involve, and systematically attempt to develop and strengthen, networks of social and behavioural AIDS research centres linked with WHO through formal and informal communication channels. Newsletters, research exchange reports, and international research workshops and symposia should all be considered for this purpose.

In order to promote and support cross-national comparative research, generic or core research designs and data collection instruments should be developed. International technical working groups should be convened to develop the instruments and help in their application. They should also be involved in the translation of findings into policy options so as to improve operational programmes and the formulation of health care policies.

Coordination of research by WHO would both help ensure intercountry comparability and consistency with WHO/SPA global objectives and strategies. The needs, interests, and concerns of individual countries must, however, always be given priority.

VII. TRANSLATING RESEARCH INTO ACTION

The ultimate goal of basic and applied research is to provide guidance for programmes and policies. Social science research findings in the development of health and social welfare policies and programmes have so far been employed to a limited extent. One of the reasons has been poor communication between researchers and policy-makers.

A central feature of the WHO Special Programme on AIDS work in social and behavioural research should be the explicit recognition of the need for research to be problem-oriented and for its results to be directly translatable into policy alternatives. Research projects supported under the Programme should be designed with policy-makers and policy needs in mind.

Findings from research should be presented in ways that are meaningful to policy-makers (e.g., written policy briefs, national workshops and, where possible, clearly stated alternatives and the rationales for them). National and intercountry seminars should be organized to bring together researchers and policy-makers to discuss research findings and their significance for national and international planning.

IX. TECHNICAL WORKING GROUPS

International technical working groups should be set up to prepare study designs, protocols, and research instruments in close working relationship with primary Collaborating Centres. They should also be in a position to provide Collaborating Centres with technical advice and support wherever appropriate. Technical support may need to include assistance with data handling, analysis, and reporting. In setting up technical working groups care should be taken to draw upon resources that ensure both geographical and technical discipline representation.

X. COLLABORATING AND PARTICIPATING CENTRES

In each of the research areas described above it may be necessary to establish Collaborating Centres; these should be centres of excellence capable of providing guidance on regional and interregional research projects. Collaborating Centres should be selected with regard to the local epidemiology of AIDS and recognition of the differences within and between countries. It may be appropriate to have more than one centre in each region or country. Wherever possible and appropriate, Collaborating Centres should also be encouraged to participate in the implementation of research projects and not only provide support and advice.

Participating centres, that is, centres primarily involved in undertaking the research should be identified as soon as possible and in as broad a range of countries as possible. They should be selected on the basis of their experience and capacity for research, as well as of their interest in participating in the project. They should always be encouraged to work closely with national AIDS committees so as to be able to better respond to local needs and concerns, and should work within the overall guidelines set by national AIDS prevention and control plans. In any networking of centres and in developing collaborative projects, potential participating centres should be visited by individuals or teams representing the technical working groups responsible for the research areas outlined above and WHO in order to assess their capacity for the research and involvement in the project.

XI. RESEARCH STEERING COMMITTEE

A research steering committee should be established to advise periodically on social and behavioural research needs, directions and methods and the application of findings to international and national policies and programmes. The steering committee should assist WHO in identifying potential participating and collaborating centres and those centres which require research capacity strengthening.

The composition of the committee should reflect the different relevant technical disciplines and include, for example, medical sociology, anthropology, social and clinical psychology, and social work.

XII. COMMUNICATION/INFORMATION

An information service should be established to provide researchers, research institutions, and the wider public with the most up-to-date research findings. The regular dissemination of information through position papers, technical papers, working papers, guidelines, manuals, and bibliographies will enhance networking and updating of researchers with findings and experiences elsewhere.

An information service should seek ways of maintaining regular and frequent contact with all collaborating and participating centres and encourage frequent contact between researchers through meetings specifically designed to increase the exchange of information.

ANNEX 1

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