

EUR/ICP/GPA 015

COUNSELLING AND CARE SERVICES FOR HIV-POSITIVE
INDIVIDUALS, AIDS PATIENTS AND THEIR CONTACTS



WORLD HEALTH ORGANIZATION
Regional Office for Europe
COPENHAGEN

TARGET 4

Reducing disease and disability

By the year 2000, the average number of years that people live free from major disease and disability should be increased by at least 10%.

Index

ACQUIRED IMMUNODEFICIENCY SYNDROME
HIV
COUNSELING
SOCIAL SUPPORT
DELIVERY OF HEALTH CARE

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COUNSELLING AND CARE SERVICES FOR HIV-POSITIVE
INDIVIDUALS, AIDS PATIENTS AND THEIR CONTACTS

Report on a WHO Working Group

Copenhagen

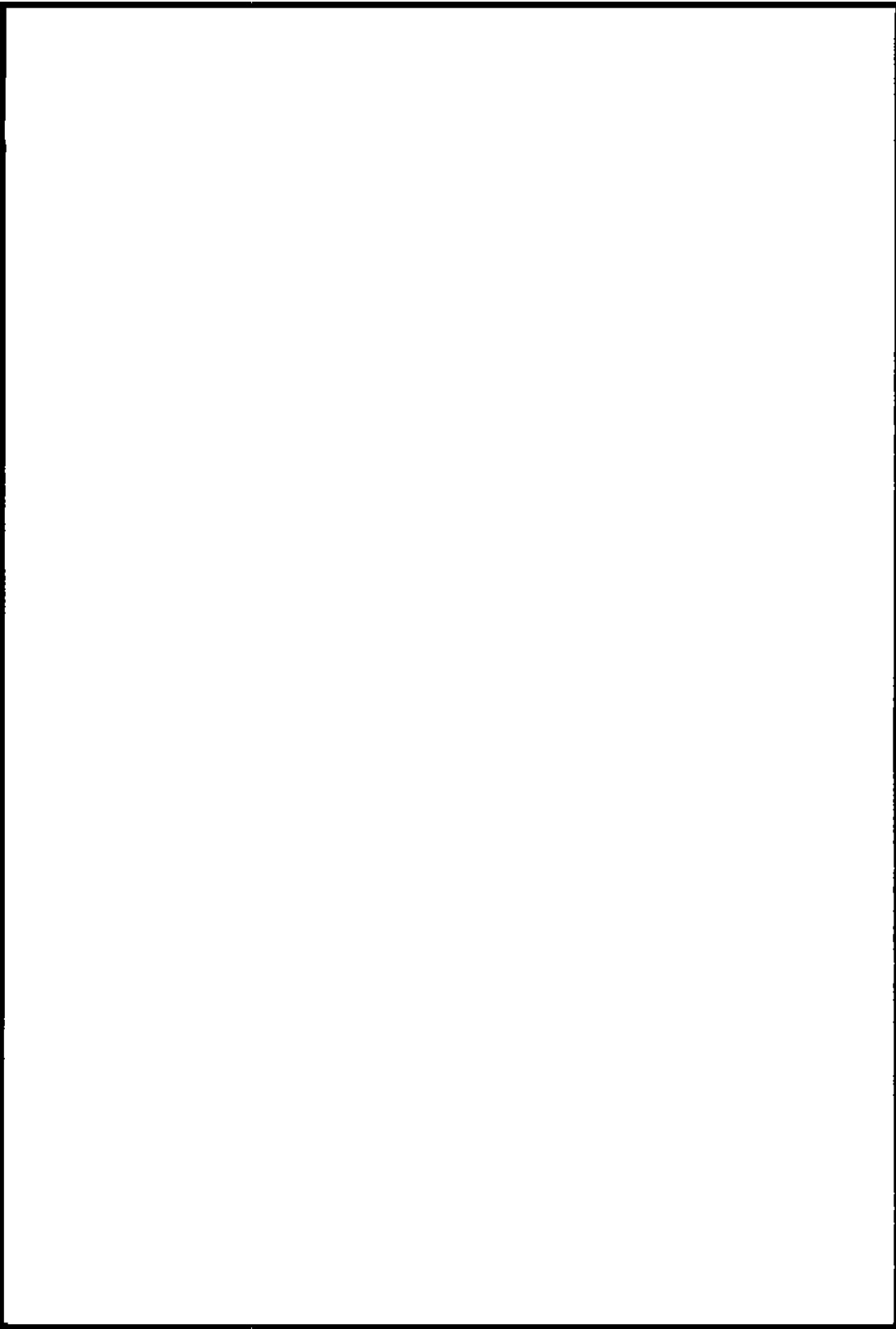
29 November - 1 December 1988

Note

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Introduction

The world is facing an epidemic of a disease for which at present there is neither a cure nor an early prospect of a vaccine. This epidemic thrives on human ignorance, fear and resistance to change. WHO estimates that 5-10 million people are infected with the human immunodeficiency virus, (HIV); 0.5-3 million of them are expected to develop the acquired immunodeficiency syndrome (AIDS) in the early 1990s.

Health care systems have had to deal with this new disease, often with insufficient knowledge and resources. Problems have had to be tackled, and patients' needs met. In particular, the growing numbers of people with HIV and AIDS, and their contacts, need counselling and psychosocial care. Many countries are trying to provide these services, which now require discussion and evaluation.

In the summer of 1988, the WHO Regional Office for Europe analysed the counselling and psychosocial care available in 12 countries. This analysis formed the basis for the meeting of the Working Group on Counselling and Care Services for HIV Positive Individuals, AIDS Patients and Their Contacts, in Copenhagen from 29 November to 1 December 1988. The Group was chaired by Dr Amelia Espariteiro Leitao, and Dr J. Gaub and Dr P. Groen were the Rapporteurs. The Group conducted its discussions in plenary session and in two subgroups. Annex 2 lists the participants, who comprised experts from 10 countries and staff of the Regional Office for Europe.

The Working Group met to discuss the results of the analysis of the services in 12 Member States of the Region, and to consider two issues in particular:

- counselling and psychosocial support of people with HIV, AIDS patients and their contacts; and

- the division of tasks between the primary and secondary health care sector.

For this reason health education and information on HIV for the general population were not considered. In addition, the Working Group did not discuss the problems of special groups, such as prisoners, children and pregnant women with HIV. The Group was asked, however, to identify issues needing clarification and follow-up, and recommend ways to facilitate the further development of counselling and psychosocial care for people with HIV and AIDS and their contacts.

Organization of counselling and psychosocial support

General aspects

Where in the health care system, primary as well as secondary, is counselling available? When is it delivered, and by which categories of personnel? How is this public-sector activity integrated with that of voluntary organizations?

The counselling needs considered here start with a positive result on a test for HIV. Some asymptomatic people take the test because they fear transmitting the disease or have general anxiety about HIV, while others take the test because symptoms have appeared. These different circumstances have implications for the organization of counselling and psychosocial support.

People with symptoms of HIV must be given access to counselling and psychosocial support in the setting in which their symptoms are investigated and treated. Although these services form part of the health care services for other diseases, they are particularly necessary in cases of HIV infection.

People with positive test results but no symptoms, on the other hand, need counselling and psychosocial support long before they require other kinds of services. They may prefer to receive counselling and support outside the health care system, or in outpatient departments, which must therefore have the necessary capacity and skilled personnel.

In either case, the confirmation of HIV infection has a serious, often devastating, influence on a person's life, and counselling and psychosocial support must be available with a minimum of delay. This consideration should determine its capacity. If it is a general policy to encourage people at risk of infection to be tested, the counselling they need should be available.

Counselling is important in preventing the further spread of HIV, and in helping people who are already infected. To be able to perform these functions, it must be organized on the basis of four main considerations. First, counselling should be given by existing structures in the health care system; special solutions for HIV and AIDS should be established only when absolutely necessary. It should be realized, however, that the AIDS issue may focus attention on inadequacies in these systems, and that AIDS can thus be seen as a stalking horse for changes in the system beneficial to other groups as well. Second, because the counselling of people with symptoms of HIV cannot be separated from their care, care providers should have the necessary skills. Third, counselling should be available at the places in the health care system where people with HIV present themselves. Presentation will vary according to local circumstances and the background of the person and his or her decision to be tested. The fourth consideration is the need to make counselling available with minimal delay.

As the number of symptomatic HIV cases rises, this situation must change. The prerequisites for meeting new needs include the education of primary health care

personnel, and the coordination of primary and secondary health care activities. Ultimately the patients' needs should determine the degree of involvement of the primary health care sector: structural barriers should not impede people's access to appropriate treatment, care and counselling.

Further, care and support must usually be given over several years and continuity of support is important for most people with HIV. The concept of a key person as a main contact is important. The key person should be readily accessible, and should have an up-to-date knowledge of the resources available to meet the various people with HIV.

Counselling skills should include a knowledge of the cultural and behavioural background of patients such as homosexual or bisexual men, haemophiliacs and intravenous drug users.

Counselling to some groups such as intravenous drug users, ethnic minorities and male prostitutes, may be complicated by problems of contact and compliance. Material incentives, including facilities for washing and cleaning and the provision of food and accommodation, will be important to maintain these groups in counselling and care.

Counselling should be not only available on demand from the patient, but actively offered in appropriate circumstances.

It should be realized that some people with HIV consciously decide not to seek counselling or other forms of contact with the health care system and they should be allowed to do so.

Counselling must also be available to the contacts of people with HIV and AIDS, which include sexual partners, family, close friends and others.

The role of voluntary organizations

Voluntary organizations have played a prominent role in work against HIV infection: they and individual volunteers provide valuable emotional and practical support through the buddy system. Voluntary organizations may represent or have access to groups with which the health care system cannot easily come into contact, in addition to meeting important needs that the health care system cannot handle. These organizations are thus an important resource to be considered in the planning of counselling and psychosocial support for people with HIV and AIDS, and their contacts.

Among people with HIV, groups composed of gay men or haemophiliacs, for example, have traditions of voluntary involvement. To the extent that they supply essential services, such organizations should be encouraged and given financial support. Other kinds of infected people (such as heterosexual men and women, drug users, children and those infected through transfusion) lack these traditions. Voluntary organizations of such people should be encouraged or initiated, or the health care system must try to supply emotional and other kinds of support in other ways.

Evaluation

Since considerable resources are devoted to counselling and psychosocial support, studies to monitor their efficacy are needed. Very little is known about the evaluation of counselling, although studies have been made of the effects of counselling on halting the spread of HIV infection and changing high-risk behaviour in gay men, drug users and prostitutes. Apparently, there are few studies on the effects of counselling on an infected person's ability to cope with the infection and to remain independent of care systems for as long as possible.

Scientific evaluation of the outcome of counselling is important, but difficult to perform. Studies could perhaps focus on:

- effects on the spread of infection in sentinel surveillance groups; and
- effects on the quality of life of people with HIV and AIDS, satisfaction with counselling, degree of self-reliance, demands on the health care system, of HIV-positive individuals and AIDS patients in different counselling settings in different countries.

Division of tasks between health care sectors

HIV infection is still comparatively rare. In Denmark, for instance, the estimated number of people with HIV is three per general practitioner; the number of confirmed AIDS cases corresponds to one for every six general practitioners. HIV and AIDS, like other rare and severe health problems, have largely been handled by secondary health care. With few exceptions, infected people with symptoms have not been able to meet their health care needs through contact with general practitioners or other primary health care personnel.

The tasks in the treatment of people with HIV and AIDS should be divided between primary and secondary care in the same way as those of general health care, taking into account the special provisions that have traditionally been made for sexually transmitted diseases. Further, referral systems should allow patients easy access to relevant treatment and care. Access to specialist AIDS units for education and concrete advice (by telephone contact, for example) should be ensured for primary health care and drug treatment personnel. Finally, when a person with HIV becomes seriously ill, and unable to handle coordination and decision-making

alone, a key person becomes especially important to coordinate activities around the patient, in hospital and at home.

HIV and AIDS make special challenges to existing health care systems, which must be met. HIV and AIDS threaten to overcrowd the existing secondary health care units with severely and chronically ill people. This calls for improved continuity in the management of outpatients and inpatients, by the use of key people, for example. It may be necessary to improve community-based and hospital-based home nursing and to establish alternative accommodation for patients, such as communal residences, convalescence facilities for recovery after hospital admission, and chronic care facilities (hospices). In addition, certain groups need alternative sites for counselling, outside the health care system and should be approached via voluntary organizations.

As a complex new illness, AIDS necessitates education and training for personnel in primary and secondary health care. The hospital departments involved in the care of people with AIDS and HIV should be encouraged to perform clinical and behavioural research to establish multidisciplinary care teams (composed of physicians, nurses, psychologists, social workers and others), and to cooperate with primary health care. Since the treatment of people with HIV and AIDS requires handling sensitive information on lifestyle, the preservation of confidentiality is even more important than when dealing with other diseases. A safe but unimpeded flow of information must be established between the health care workers involved in treating any given patient.

Recommendations

1. Since the counselling of symptomatic people with HIV is part of the obligation of the health care system the places in the health care system where such people present themselves should have the capacity and skilled personnel to fulfil this function.

2. To ensure the maximum continuity of counselling and psychosocial support for infected people, each person with HIV should be provided with one or two key people, who should be employees of the health care system and responsible for maintaining contact with the person for a prolonged period.

3. There is a need for an exchange of ideas, experiments and comparisons of existing policies on the counselling and treatment of:

- intravenous drug users and other difficult to reach marginal groups (such as ethnic minorities and male prostitutes) who have or are at risk of HIV infection; and
- families with children who have HIV.

4. There is an urgent need to develop approaches to evaluate the needs for and effects of counselling both quantitatively and qualitatively. This could be done by comparing different approaches to counselling and care in different Member States, for example, and by correlating counselling with epidemiological measures, such as rates of seroconversion and the use of health care system and social resources.

5. The different tasks for secondary health care in dealing with HIV should be defined. Decisions are required on research, the range of clinical and

paraclinical services to be offered, contact with other health care personnel, and a role in education.

6. HIV is spread by heterosexual contact in Belgium, Greece and Portugal in a pattern that apparently differs from those in other Member States. Studies are urgently required to clarify this pattern and the measures to be taken against it.

7. The requirements for training of different groups of health care personnel should be defined.

8. Studies should be made on the modes of HIV transmission in prisons, and how to prevent it.

9. Studies should also be made of the needs for counselling and psychological support for health care personnel involved in the treatment of people with HIV and AIDS.

10. Member States should review their current practices in view of conclusions and recommendations of the present Working Group.

Annex 1

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