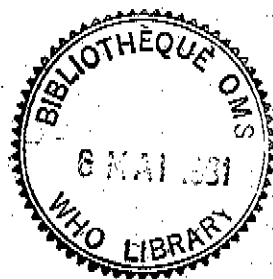


# SUICIDAL BEHAVIOUR AMONG PEOPLE WITH HIV AND AIDS



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:

SUICIDE - psychology

SUICIDE - prevent/control

HIV INFECTIONS

ACQUIRED IMMUNODEFICIENCY SYNDROME

EPIDEMIOLOGY

RESEARCH

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# SUICIDAL BEHAVIOUR AMONG PEOPLE WITH HIV AND AIDS

## Report on a WHO Consultation

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Note

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## Introduction

The psychological implications of having AIDS or AIDS-related complex (ARC), or knowing that one is HIV-seropositive, may be so threatening that patients develop self-destructive and suicidal behaviour either upon hearing the diagnosis or at later stages in the disease. There are indications that HIV-infected people and ARC/AIDS patients constitute a high-risk group for suicide, although in medical reports opinions diverge as to the frequency and characteristics of suicidal behaviour in this group. Scientific knowledge is restricted to a few reports estimating the relative risk of suicide and describing suicidal feelings among people with HIV. The European contribution to these research efforts has been very small.

To meet the psychosocial needs of these people, including suicide prevention, reliable information is needed. Evaluation of the occurrence and characteristics of suicidal behaviour will not only contribute to our understanding of coping processes and suicidal mechanisms in the HIV/AIDS group, but also serve to improve understanding of suicidal behaviour in general.

Suicidal behaviour in people with HIV/AIDS may be characterized as an important but neglected research area. The WHO Regional Office for Europe therefore invited a small group of researchers to review research in this field and find ways of promoting it.

The Consultation was attended by 12 participants from 8 countries (10 temporary advisers and 2 representatives of WHO).

The main purposes were:

- to obtain an overall view of completed and planned research on suicidal behaviour in people with HIV/AIDS;

- to analyse the research strategies possible in the present situation, and to describe and give priority to important research topics;
- to discuss means of collaboration with a view to making recommendations to international and national organizations.

## Background

Reports from the United States suggest that the relative risk of suicide in adult men with a diagnosis of AIDS is up to 36 times that of men without the diagnosis.

HIV-related suicides are likely to be attributed to the psychosocial turmoil attendant upon learning that one has a highly lethal disease. However, there is reason to believe that HIV may affect central nervous system functioning early in the course of the illness, predisposing seropositive individuals to catastrophic reactions. Some authors report that suicidal behaviour occurs comparatively soon after seroconversion, while others report it at advanced stages of the disease.

The etiology of both early and late-stage suicidal behaviour requires thorough investigation of depression, addiction to alcohol or drugs, personality disorders, neuropsychiatric disorders, (lack of) social support, and ways of coping with both the disease and substandard living conditions. The important risk factors include problems in interpersonal relationships (with parents, relatives, partners), which may be aggravated during the course of the illness.

There are reports of HIV-related suicides in people who showed a history of suicidal behaviour and psychiatric treatment long before they had seroconverted. Some childhood traumatic experiences and/or personality developments may predispose to self-destructive lifestyles that increase the risk of

AIDS. Suicidal behaviour might reflect a lifelong, characteristic way of coping. Contracting HIV might even be seen in rare cases as a deliberate means of self-destruction. This might also be involved in non-compliance with or maladaptive behaviour towards medical treatment.

As seropositive individuals develop AIDS, the stigmatizing attitudes of others may add to their psychosocial distress. Cognitive deficits, memory loss, personality changes and psychoses may contribute to a cumulative risk of suicide.

From a mental health care perspective, psychological counselling should be available for those who consider testing and for those who have been given a positive test result. Also, in later stages, psychological counselling, psychotherapy and psychiatric treatment should be available when needed. From this point of view the psychosocial care available to HIV patients in some countries must be considered insufficient to meet all demands. It is possible that in some cases impulsive suicidal behaviour reflects shortcomings in crisis-intervention facilities.

Suicidal behaviour in HIV-infected people may be to some extent similar to suicidal behaviour in other patients with life-threatening and debilitating diseases such as Huntington's disease, multiple sclerosis and forms of cancer. Among drug- or alcohol-addicted infected people, suicidal behaviour may not be different from that of addicts without the diagnosis. This holds true also for people with (neuro-) psychiatric disorders, with or without a diagnosis of HIV. But the accumulation of several risk factors in one person who is already vulnerable to emotional distress, and has to deal with steadily decreasing vitality, stamina and resilience because of the disease, makes the need for professional guidance and surveillance all the more necessary.

Another related phenomenon reported at the Consultation was an unwarranted but excessive fear of having contracted AIDS, which leads some people to consider or perform suicidal acts. Although it is rare, this particular excessive fear should not be overlooked by mental health care providers.

## Epidemiology

From an epidemiological point of view HIV-related suicides are thought to form only a small percentage of all suicides in the European countries. Estimates are hampered, however, by a lack of adequate registration of causes of death in mortality statistics. There is no doubt that many HIV-related suicides are missed by coroners and those who certify deaths. Drug-overdose deaths are difficult to ascribe unequivocally to suicide or to accident. Some suicides will be concealed under natural causes, others are reported as due to abstention from treatment, or are ascribed to complications of the disease when in reality they are cases of euthanasia or physician-assisted suicide.

There is agreement that HIV-related suicides are underreported, but the magnitude of the problem is unknown. Given the size of the HIV pandemic, the percentages of HIV-related suicides in the total number of suicides must be considered relatively small in most European countries. The figure may be less than 5% now, but it could increase as the epidemic spreads in the near future.

The percentages of HIV-infected people showing self-destructive tendencies, suicidal ideation or suicidal behaviour are unknown. Most patients are supposed to have some suicidal ideation at or around the time of testing/diagnosis or during the course of the illness. It is possibly rare to find a patient without suicidal fantasies or more serious suicidal ideation.

However, the actual proportion of patients attempting or eventually committing suicide may also be quite considerable.

In cohort studies of people with HIV followed prospectively, small samples and short follow-up periods make it difficult to establish results conclusively. Methodological difficulties, e.g. in recruiting representative cohorts, and ethical principles of confidentiality make it very hard to design sound empirical research. The American literature includes four independent studies which document an increased risk of completed suicide among persons with clinical, symptomatic AIDS. These studies suggest that people with AIDS are approximately 16-36 times as likely to die by suicide as the general population.

In Marzuk's research in New York in 1985, it turned out that 12 out of 361 suicides in males aged 20-59 were connected with AIDS (= 3.3%). Of the total number of suicides (male and female, all ages), AIDS-related suicides accounted for 1.8% (12 out of 668). In a city with approximately 3475 AIDS patients among 7.2 million inhabitants, the absolute frequency of AIDS-related suicides is still rather small, although the relative risk is clearly elevated.

Retrospective studies of percentages of suicides among all deaths of people with HIV are rare. In a Swedish study by the Institute for Forensic Medicine, based on autopsies on all those who had died suddenly of external violence or poisoning or otherwise under unclear or suspect circumstances, a total of 16 948 bodies were examined during a five-year period, of which 85 were HIV-positive. Out of these 85 HIV-positive, unnaturally deceased persons, more than half died of a heroin overdose not judged to be intentional. The next cause of death was suicide - 21 persons, or 25%. The suicide risk in these people seemed to correlate with to the duration of the HIV infection and to become manifest with the onset of AIDS symptoms.

Regarding attempted suicide, there are indications that people with HIV have a rather high risk, particularly in the early stages. Suicide attempts tend to cluster in the first six months after diagnosis, showing the importance of pre- and post-test counselling.

There are anecdotal reports of patients at the end stage of the disease being helped to die by the withholding of treatment, by increased levels of medication, by passive or active forms of euthanasia, or by (physician-) assisted suicide. As legislation in nearly all countries forbids both passive and active ways of helping someone die, there is absolutely no systematic information about these cases.

Only in the Netherlands are cases of euthanasia and assisted suicide, including HIV-related cases, reported to the Attorney-General's office. Provided certain standards of careful handling have been fulfilled there will be no prosecution. In principle euthanasia and assisted suicide are illegal, but for these cases the principle of "force majeure" applies. The majority of cases, however, are not reported to the Attorney-General, because of the many possible complications, such as life insurance reimbursement difficulties. Of all registered cases of euthanasia and assisted suicide in the Netherlands (in 1988 there were 181 cases, in 1989, 336), the Attorney-General's office states that less than 5% concerned end-stage AIDS-related cases.

Owing to restrictive legislation in European countries, physician-assisted suicides and euthanasia remain hidden and criminal. As a consequence there continues to be a danger of unprofessional handling of requests for help. Perhaps here, too, opportunities for suicide prevention are being missed.

The devastating effects of end-stage AIDS confront care-givers with ethical, philosophical and religious problems. Care-givers may be vulnerable to emotional

distress as a consequence of their intense personal involvement. It is not certain whether their particular needs are met through counselling. They as well as partners, friends and relatives may also be considered a target population for suicide prevention.

## Conclusions

Having considered the sources and quality of information, including the available empirical knowledge about HIV-related suicidal behaviour, the participants concluded that there is a strong need for better information. The size and characteristics of the problem cause enough concern to warrant further study, especially with the number of people with HIV increasing. What is needed first is a general fact-finding stage during which the size and characteristics of the problems are investigated from different angles. Then there should follow a stage of methodology development and collection of detailed information to test the hypotheses suggested. Until now the information from different sources has been so uneven, and there is so much uncertainty, that it would be premature to develop cross-centre comprehensive research programmes at the moment.

Research is also needed to improve suicide prevention: although AIDS is terminal, efforts to prevent suicide at both the early and late stages are justified in order to allow patients to evaluate alternatives to treatment rationally, to put their lives in order financially and otherwise, and to sort out personal relationships with family and friends. Furthermore, suicide may be a consequence of bad terminal care. Suicide prevention also means improving that care.

Future research, involving prospective follow-up studies of large HIV cohorts, should examine the association between HIV-related neurological and psychiatric syndromes and suicide risk, the role of

concomitant psychosocial factors, the profile of those HIV victims who are at greatest risk, and suicide trends in this population over time. Although it will be impossible to obtain a total picture of the problem, an approximation is nonetheless feasible. The participants stressed that when future research is planned, the following should be borne in mind.

1. There may prove to be a conflict of interest between researchers, patients and care-givers. The desire to obtain information should never override principles of confidentiality or ethical standards. Approximate results estimated from different angles without violating ethical regulations will be enough. In studies of people with HIV infection, confidentiality is vital.

2. Research should be begun in close collaboration with national AIDS committees and national AIDS research programmes. National AIDS committees are advised to pay attention to suicidal behaviour among HIV patients and to collaborate with suicidology research centres.

3. A national and international standardization of definitions and terminology would be advantageous. It is important for international organizations such as WHO to take the lead and develop a standard set of definitions regarding various forms of self-destructive and suicidal behaviour.

4. An international standardization of measurements and methodology is also advisable. So far as possible, European research centres should use scales and questions that permit comparison between different studies. Research centres have been asked to exchange methodological expertise, plans and researchers in order to improve comparability.

## Recommendations

Having reviewed and discussed available knowledge on HIV-related suicidal behaviour, and emphasizing the need

for better information to understand and prevent suicidal behaviour, the participants recommended the following.

1. Each Member State is asked to give attention and support to research in the field of HIV-related suicidal behaviour and to devise means of strengthening the links between the suicidology research community and national AIDS committees or programmes.
2. The need for scientific development in this field requires more international collaboration and standardization. Research centres are asked to exchange methodological expertise.
3. Member States are asked to improve the possibilities for monitoring HIV-related suicides by means of mortality statistics and death certification procedures.
4. To generate better scientific data on the epidemiological picture of HIV-related suicides, in certain regions with high HIV rates it is urgent for forensic institutes and pathology departments in general hospitals to carry out research by doing postmortem tests for HIV-seropositivity on everyone dying suddenly from external violence or poisoning or otherwise under unclear or suspicious circumstances. Forensic institutes are asked to perform HIV tests at all autopsies, and certain general hospitals are asked to investigate all those who die on their premises for HIV-seropositivity.
5. While doing postmortem investigations, forensic institutes and pathology departments are asked to attend to the need for neuropathological investigations in HIV patients, to investigate possible relationships between neuropathology and suicide as a cause of death.
6. Centres which use the results of postmortem investigations are also asked to obtain background information on deceased HIV-infected persons such as

demographic variables, HIV-transmission group, drug abuse, alcohol abuse, and if possible information on suicide attempts, psychiatric treatment and medical treatment in the person's past.

7. Forensic institutes are also asked to provide postmortem results without delay. The publication of results on a regular basis (e.g. every three months) is important for the rapid recognition of changing trends.

8. Research centres which use psychological autopsies to reconstruct risk and precipitating factors in HIV-related suicides are asked to include lifetime suicidal behaviour, psychological/psychiatric impairment, and treatment before seroconversion. The need to study the social situation of HIV-related suicides as a possible precipitating factor is also stressed.

9. To improve the comparability of data on HIV-related suicidal behaviour, research centres are asked to use WHO/CDC\* criteria for delineating stages in the development of the disease and to use WHO definitions of suicidal behaviour.

10. WHO should also encourage international comparisons of prevalent attitudes towards euthanasia and physician-assisted suicides among HIV patients and the procedures used. An attempt should be made to improve knowledge of the frequency and characteristics of those HIV-related suicides which are not officially registered as such, or where the bodies are not subjected to postmortem investigation.

11. WHO should encourage certain research centres to investigate suicidal behaviour on the part of people who have not contracted HIV but who believe that they have or

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\* Centres of Disease Control, Atlanta, USA.

who have depression and delusions about it. Furthermore, treatment of AIDS-phobia syndrome should be evaluated at different centres.

12. WHO is advised to monitor developments in this field in the years to come. To throw light on both problems and advances, it should collect and disseminate information, including empirical knowledge, on a regular basis, for example by consulting temporary advisers once every year or two.

13. Research should be promoted to evaluate the effectiveness of pre- and post-test counselling procedures and crisis-intervention facilities. The management of patients and partners or family members at or around the time of testing in different settings, centres or countries should be compared in order to improve professional standards.

14. Different procedures in the psychological and psychiatric treatment of people with HIV at seroconversion and at later stages in the development of the disease should also be evaluated scientifically to improve mental health care delivery for these people.

15. Research should be undertaken to improve knowledge of HIV-related suicidal behaviour in specific settings where high-risk people are concentrated, for example in prisons and in treatment centres for drug addicts.

## Annex 1

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