

## EDITORIAL

# AIDS and mental health

Adapted from the opening address for the AIDS Conference, Amsterdam

When the first cases of AIDS appeared and the news about the nature of the new disease spread the developed world was stunned. This could not have been the consequence of the fact that the new disease caused people to be sick and die: people have been sick and were dying from many other causes ranging from war to traffic accidents and from pollution to influenza. Nor could it have been because the victims were so numerous – there were many other causes of death and disease affecting many times the numbers of people affected by AIDS. Malaria alone counted its victims in hundreds of millions and suicide would kill at least a 100,000 people in Europe each year. Nor could it have been because of the bad way in which people were ailing and losing hope – there were so many other manners in which people or nature have been making humans suffer and lose dignity or die. Numerous other reasons for the world's reaction were clearly at play ranging from the ethical issues arising in dealing with AIDS to the forbidden ways in which the illness was contracted. Among these reasons there was one which was particularly important: AIDS was a disease which has shattered our confidence and interrupted the series of our victories over nature, over insects, over disease and even over death.

In the seventh decade of this century everything seemed within reach given a little more good will, a little more time, a little more money. Traffic accidents were cruel life-takers but we had found methods to prevent their occurrence by building better roads, driving better cars and drinking a little less while doing so. New surgery dealt painlessly with a variety of previously lethal afflictions. Pollution was clearly controllable by legislation whenever governments and individuals became serious about it. Even neuropsychiatric disorders proved to be amenable to primary prevention and effective treatment in a large proportion of cases.<sup>1</sup>

AIDS came as a blow to this confident and optimistic, technologically perfect, almost brave new world: a communicable disease was at large, impervious to all known treatment, spreading inexorably and killing in ugly and undignified ways. The behavioural changes which seemed to be necessary to prevent its spread were different from those involved in reducing skiing accidents. Nothing seemed to work as it should and a series of predictable reactions followed. New treatments were promoted without credible evidence about their effectiveness. Individuals, nations and certain professions were declared culprits and found themselves scapegoated in a violent way. Lies and alarming news emerged with ease and could not be fought effectively. Soon after the world admitted that the disease exists it became unusually easy to find

resources for research clearly expressing a hope that the magic of science will wipe out the disease which may be a harbinger of many other threats to society's progress.

The developing countries reacted differently. The third world suffers from innumerable ills and diseases: one more, no matter how lethal or invasive, can be more easily overlooked in the host of those sapping the strength of the nation and making the life of individuals and communities a high risk proposition throughout its duration. Gradually however the attitude changed: HIV infections became recognized as a new problem, governments reacted, money and other resources from inside and outside found their users.

Thus, by the mid-1980s the world was mobilized. While myths still abounded, ignorance blocked progress and many obstacles of a moral, traditional and economic nature barred the way, nevertheless attitudes and responses were beginning to change. Figures coming in from all corners of the world were frightening. Problems accompanying the disease were clearly serious, numerous and growing. Initial concerns were focussed on physical aspects of the ailment and on research needs. Gradually the focus shifted towards societal and economic aspects of the infection. The psychosocial and neuropsychiatric problems and the necessity to do something about them were recognised much more slowly and resources to deal with them were much more difficult to find. This is still so in many countries and even internationally: but there seem to be signs that priorities might shift to include these conditions as well.

Psychosocial and behavioural problems related to the HIV infection can contribute to its spread and complicate its course and management. Abuse of drugs and high risk behaviours are among the most important reasons for the spread of the illness. Dementia and other grave syndromes related to brain damage and to diseases complicating AIDS are a public health problem of vast proportions. Reactive depression and other mental disorders complicate management. Burn-out in staff and relatives renders health service tasks more and more difficult.

There are various ways in which these problems can be grouped: perhaps the simplest is to think about them as those being experienced by the infected individuals, those experienced by others who look after them and those which society as a whole has to face. The distinction however is not easy to maintain and the three groups of problems intertwine and affect each other's magnitude and nature. Depression in a relative affects the course of disease in the infected person and a change of societies' – or communities' – attitudes to the disease affects the quality of life and medical outcomes

of diseases. Nevertheless, the division into these three groups is possible and sometimes useful when intervention strategies are examined.

(1) *The problems for affected individuals*

Neuropsychiatric and psychosocial problems in infected individuals are numerous, often grave and difficult to handle. In part this is because they emerge burdened with stigmas of mental illness, sin and fatality; in part because they are not well understood. It is as yet unclear which of the neuropsychiatric and psychosocial disorders occurring in the infected individuals can be directly and causally linked to the presence of the virus in the brain and to the neuropathological changes which can be found on post mortem examinations, and which are psychological reactions to the illness or to the inevitability of imminent death. The certainty of the causal connection diminishes with the diminishing severity of disorders: mild cognitive disorders for example described with considerable frequency in HIV infected individuals could be due to organic causes, to psychosocial reactions to the multiple stresses to which HIV positive individuals are exposed, to the complex relationships between exhaustion and cognitive function or to a combination of all those. Suicide and some of the affective disorders are more frequent in HIV positive individuals but it is also quite frequent – and more frequent than in the rest of the population – in the groups which are at high risk for AIDS. Research and service interventions are also blocked by the curse of Babel: clinical descriptions and neuropsychiatric and psychosocial problems occurring in HIV infection are imprecise, and instruments still used for their assessment are of doubtful validity and reliability.

To break the vicious circle of misunderstanding and render research and service easier the World Health Organisation (WHO) has brought together groups of leading specialists and produced together with them definitions for all the neuropsychiatric and some of the psychosocial disorders occurring in HIV infection.<sup>2</sup> It has also undertaken a major international study in a variety of cultures aiming to produce instruments for the assessment of mental and neurological functioning in HIV infected individuals and to validate these instruments.<sup>3</sup>

In both of these efforts the results have until now been most encouraging: we were able to demonstrate that it is possible to create a system of assessment and diagnosis which is internally consistent, congruent with the International Classification of Diseases (WHO, 1992)<sup>4</sup> acceptable to scientists in the different disciplines concerned and applicable in different cultures. The instruments will be released soon and it is to be hoped that they will be used in research and in clinical practice the world over: a common language is undoubtedly a first prerequisite for communication, sharing of data and collaboration.<sup>5</sup>

Such collaboration will not only help in developing the knowledge necessary for the conduct

of effective programmes concerned with the benefit of patients suffering from AIDS: it is highly likely that the assessment tools – for example the neurocognitive tests – and the insights gained in studies of the relationship between demonstrable brain damage and psychological functioning in HIV infection will help the development of behavioural science and of psychiatry in general.

The WHO multicentric study<sup>3</sup> also aims to obtain data about the frequency and form which neuropsychiatric and psychosocial problems related to HIV infections in different cultures can have. The detailed assessment of some 1200 individuals – including carefully matched groups of HIV negative, seropositive but clinically asymptomatic, and seropositive individuals with symptoms – should provide firm evidence about the nature of these disorders in different cultures: a follow-up study over three years will produce data about the longitudinal development of the condition and create a network of centres in different parts of the world, all using the same methods and sharing experience and resources.

Dependence on the abuse of alcohol and other drugs are among the main risk factors for the infection and complicate its course. Here the Organization took a slightly different tack: it concentrated on the exploration of evidence about the frequency of different types of drug abuse and on the assessment of treatment or prevention strategies which could diminish the danger of HIV infection even if the drug abuse problem proves to be resistant to interventions. The definition of methods for changing drug abuse related behaviour is just as much a problem here as it is in relation to other high risk ways of living.

(2) *The problems facing carers*

The second group of problems arise in those who are close to people with AIDS or look after them professionally. The burn out syndrome occurring with an increasing frequency in various occupations in the field of health has already been called a major epidemic in its own right. Its causes are many, ranging from low salary and repetitive work to the frequent failure to see recovery in a patient, the constant need to deal with stigma and the feeling of danger to oneself. Many of these features are present in the instance of AIDS and a number of reports speak of the refusal to continue working with AIDS patients, of excessive fatigue, minor psychiatric problems and the appearance of burn-out syndrome in many services. Epidemiological assessments of these problems are still lacking and numerous methodological difficulties are likely to make the interpretation of data of future studies difficult: nevertheless it is high time to carry them out, linking them wherever possible with intervention programmes.

Members of families of those affected suffer from a multitude of problems and need help. Much of this is material support: the role of moral and psychological support however is crucial and unfortunately widely neglected. The World Health



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Organization has so far concentrated on the production of guidelines about counselling, the organization of relevant services and ways to diminish stigma and prejudice – at community and at individual level – directed against HIV infected individuals and those who surround them.<sup>6</sup> While the technology has thus become available its application – with the exception of a few settings – is lagging behind and needs a major organizational and motivational push if progress is to be achieved.

### (3) *The problems for society*

The third group of problems is at the doorstep of society: there is at present still much to do to create appropriate legal bases enabling health services to perform their duty well. There is also the urgent need to produce realistic options for the care for the large numbers of individuals who will be affected by neuropsychiatric problems related to the HIV infections – from the most severe such as dementia to the more insidious ones such as the various mood disorders. WHO has recently produced its first estimates of the numbers of individuals likely to be affected by these problems and it is clear that the current already insufficient health care provisions for the mentally ill will become so overtaxed that they will fail in their mandate. WHO has developed strategies of mental health care which could be used to help countries in this respect: but the determination to start programmes must come from the countries themselves. Care for people affected by a neuropsychiatric problem related to HIV will have to face the unprecedented triple challenge of stigma attached to mental illness, of stigma and fear attached to AIDS and of the lack of effective treatment methods: a triple challenge which must be faced now.

Also at the door of society lies the need to deal with numerous ethical issues and solve problems related to massive behaviour change. These challenges relate to changing sexual behaviour, to reducing drug abuse, to educational efforts which could increase tolerance to disease and disability, to appropriate information spread and to numerous other issues affecting the spread of AIDS and living in a community of people or nations in general. So far WHO has concentrated on the provision of sound information about techniques available for work in this field and has collaborated with countries in the framework of national AIDS programmes.<sup>7</sup> Much more however will have to be done both by the Organization and by its member states if progress which seems to have been occurring is to be maintained.

Cutting across these three groups of problems are research needs. WHO, having consulted leading experts and institutions, produced a series of recommendations about future investigations. These are many: the most pertinent however relate to the need to establish – in

as many countries as possible – the research infrastructure which will allow a concerted and lasting programme of collaborative studies involving scientists from different disciplines and working in different settings, worldwide. Specific recommendations deal with research on the effectiveness of treatment, with the evaluation of policy alternatives, with further basic neuroscience studies and with crosscultural differences in the expression of symptoms and in their assessment.

Until now WHO has served as the public health platform on which researchers, clinicians and health decision makers could meet to exchange experience and agree on action. A public health platform however is never neutral: it is biasing debates towards action which will benefit the largest possible number of people in the shortest possible time and at the lowest price. There may be no other instance in which such a platform can be as useful as in the instance of dealing with neuropsychiatric and psychosocial problems related to HIV infection and AIDS.

A platform however can not be useful if it has not attracted outstanding people of good will armed with knowledge and willing to work together. This editorial is written in the hope that this will happen and that such people will take an active part in the global fight against misery caused by neuropsychiatric problems related to HIV infection. WHO's programmes provide one opportunity to do so: there are however numerous other occasions in research, training, teaching or health education.

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