AIDS prevention through health promotion

Facing sensitive issues

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Preface

This book is intended primarily for health promotion planners and educators dealing with the spread of acquired immunodeficiency syndrome (AIDS) in their countries. It examines one particular aspect of the AIDS pandemic: the reaction of individuals and groups to AIDS, and how health promotion programmes can take these reactions—which are often irrational from a public health point of view—into account.

The idea for this publication came from discussions with colleagues working in AIDS control, who pointed to major problems in their efforts to design information and education programmes about AIDS. They perceived a need for more insight into some of the sensitive issues surrounding AIDS, such as the denial by certain groups of the extent of the problem, the reluctance of decision-makers to admit that "unacceptable" sexual behaviour exists, the difficulties encountered in designing effective messages without offending religious beliefs and moral convictions, the social taboos that discourage open discussion about sexual behaviour, and the extreme fear experienced by some at low risk of AIDS who over-react and call for isolation of infected people.

Following these discussions, it seemed useful to search for examples of how others have faced the problems caused by reactions to the AIDS pandemic: reactions of denial, fear and blame, often retreating behind social mores and taboos. This publication presents case studies of this nature. It is divided into four sections. Part 1 focuses on the health promoters themselves: how they can deal with their own emotions and reactions to AIDS and AIDS education. Part 2 focuses on target audiences: how their emotional responses to AIDS can be used to increase the effectiveness of educational messages. Part 3 illustrates how patients and peer groups can motivate others to change risk behaviour, while Part 4 focuses on decision-makers and "gatekeepers", who can help or hinder health promotion, and examines how their support can be enlisted.

Although many of the case studies are based on experience in industrialized countries, where the epidemic first came to public attention, they are not without relevance to developing countries. The growing body of experience in developing countries now being recorded should, as it is

published, provide a most useful complementary source of information and lessons learnt.

This collection of case studies is the product of collaboration between WHO and the Royal Tropical Institute in Amsterdam, Netherlands. The contributions of Riet Berkvens and Maeve Moynihan of the Royal Tropical Institute are gratefully acknowledged.

Contents

PART 1

Starting with ourselves

This section looks at the strong emotional influences experienced by health promoters in dealing with HIV and AIDS. Maeve Moynihan poses a number of questions that could be asked to illustrate how emotions can influence the professional judgement of health workers. Hilary Dixon and Jane Springham take the exercise further. From their experience of training professionals to respond more effectively to AIDS, they are aware of the strong emotional reactions that may emerge in response to the concepts of death, promiscuity, anger, sexuality and pain. They provide examples of how confused or unrecognized values and feelings can impede education, and they offer practical suggestions for overcoming those barriers.

Emotional responses to the AIDS pandemic

Maeve Moynihan[a]

The current situation

As the problem of acquired immunodeficiency syndrome (AIDS) affects more and more countries and greater numbers of people, provision of information and education has become a major weapon against the disease, and a way of encouraging appropriate reactions to it.

One of the lessons to emerge from the health promotion programmes that have been functioning for some years is that, at each stage of planning and implementation, decision-making tends to be affected by the emotions that AIDS arouses. Each programme has its own reactions to contend with as well as those generated by the press, by government announcements, and by the many interest groups within the community. Examples of decision-making that seems to be governed more by feeling than by thinking can be found at almost every level of society.

At the government level, examples can be found in decisions concerning the testing of visitors for the human immunodeficiency virus (HIV). Several national authorities require visiting students from some countries to be tested for HIV antibodies, but not students from others. Elsewhere, HIV antibody tests are required for new immigrants, but tourists, businessmen and diplomats are usually granted exemption. Elsewhere, decision-makers may attempt to minimize the extent of the domestic AIDS problem for fear of reducing the inflow of tourists. It is difficult, from a public health perspective, to see how these different measures can lead to reduction in the spread of HIV. The decisions seem rooted in an assessment of the political impact of interest-group reactions and popular sentiment rather than in considerations of public welfare.

There are also numerous examples of over-reaction among health professionals. In one country a group of senior nurses have refused to do thick blood smear tests for malaria. Elsewhere, nurses have refused to care for

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dying AIDS patients. Both groups know that their duties do not put them at risk if they observe simple precautions, but knowledge is not enough; their fear is so great that it prevents them from acting rationally.

Similar examples can be found at the community level. People who are at little risk may have an exaggerated fear of acquiring HIV infection, insisting on the imposition of rules tantamount to punishment for infected people. In one country, a schoolgirl who contracted HIV through a blood transfusion was enclosed in a glass box while she was at school. In another, a man dying of AIDS could not sell his car, because potential buyers were afraid of infection; the man was also asked to stay at home and not mix with his neighbours.

Fear gives rise to a need to apportion blame. In some countries blame has often been attached to homosexuals. Indeed, AIDS has sometimes been portrayed as happening only to white homosexual males. The people who insist on viewing AIDS in this way often claim to be at no personal risk at all.

People who engage in high-risk behaviour often use the same defence mechanisms. In some countries, men do not consider themselves to be homosexual if they have sex with women as well as with men. By identifying the same group—white, male, and homosexual—as the people to blame, others can deny that the disease has anything to do with them. They may even avoid seeking information about AIDS for fear that their self-image will be threatened.

This combination of denial and blame has been found to operate among decision-makers also. Certain community leaders have claimed that their communities are completely risk-free (and by implication, blame-free) and have stopped all discussion of sexual behaviour in general and AIDS in particular. Similar patterns of denial and avoidance have been found among some communities of prostitutes (Schoepf, 1988).

These brief examples of the way people have reacted in different cultures cannot indicate the great complexity and variation of the reactions. Each country, and each group and person in the country, develops an individual approach to the disease, depending not only on the numbers of patients and spread of the disease, but also on reactions and adaptations to it. In addition, the situation in any given country is continually changing.

However unique it may seem, AIDS is not completely different from other public health problems. Brandt (1988), writing on the history of sexually transmitted diseases (STDs) and the lessons they might have for those working with AIDS, made four important points:

- The emotion that the disease arouses has influenced and will continue to influence medical approaches and public health policy.
- Promotional activities that attempt to stop undesirable sexual behaviour on the basis of fear alone do not work. However, those that combine a judicious amount of fear with a practical way of modifying high-risk sexual behaviour (which in STD control usually means promoting the use of condoms) can have some success.
- Compulsory testing, *cordons sanitaires,* and other similar measures are not effective.
- Even when treatments and vaccines become available, they will not easily modify or end the pandemic.

These points have a direct bearing upon the subject of this publication, and indicate the path that health policy-makers must take. Health promotion activities are of central importance to efforts to prevent and control AIDS. If the right approaches and policies are to be adopted, professionals must somehow learn how to handle strong emotions that may be only half-consciously recognized.

Reactions of health professionals

It may be thought that the professional judgement of health workers is never clouded by emotion. One way to gauge this is to ask the questions listed below—recognizing that the area is one where there are few right answers—and monitor the person's emotional reactions.

The health workers should be asked to imagine that they are visiting a hospital outpatient clinic and see two mothers with babies; one baby has measles, the other has AIDS, acquired from the mother, who is HIV-infected.

- What is their first response to the two mothers? Is it the same for both?
- What if the mother was infected with HIV by a blood transfusion rather than by sexual contact? Does their attitude to her change?
- Will they put more effort into treating the baby with measles because

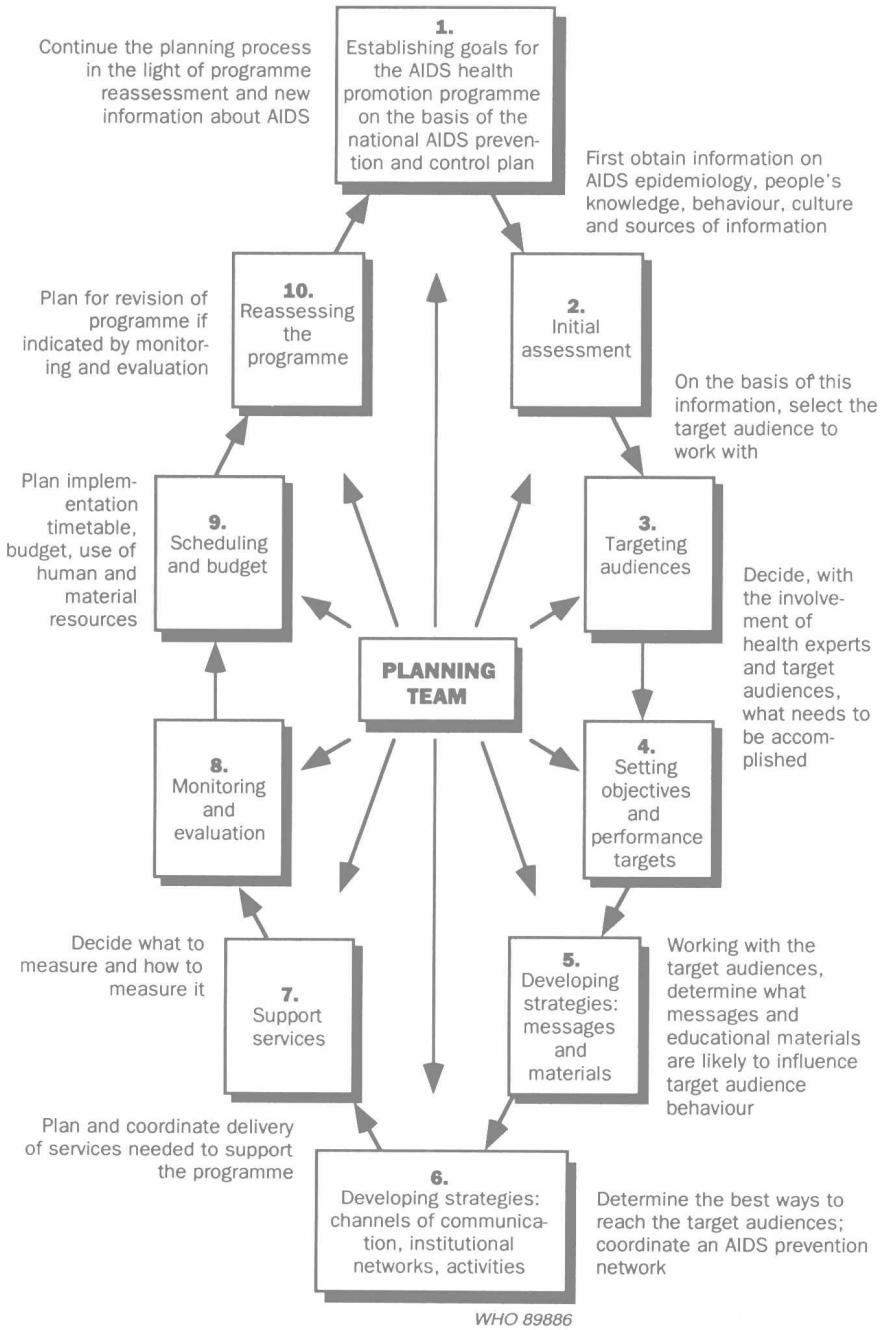

Fig. 1. Elements of planning for health promotion

he/she will live? Is there very little that can be done for the baby with AIDS? Will they become frustrated by spending time and effort on a child who will die?

- What about the mother who is HIV-infected? Would they have delivered her baby?
- Do they think that there is any possibility that they might be infected? How do they feel about their own death?

Next, the health workers should be asked to imagine that they have been asked by a voluntary organization to talk about AIDS to a group of teenagers who have dropped out of school.

- Do they know the common words used in the street for the male and female genitalia, for different sexual activities, and for condoms? Do they feel at ease using those words in situations where they are necessary for instruction? Can they discuss such things with their children or with their partners? Are they at ease demonstrating how to use condoms to a group of the opposite sex?

Finally, they should imagine that their AIDS programme has limited funds and they have to consider requests for support from three organizations—one working with people with haemophilia, one with homosexuals, and one with drug injectors.

- What are their criteria for setting priorities? Do they feel that one group has more moral worth?

The health workers should then consider whether answering these questions has provoked any feelings in them? Have they spotted issues that are sensitive for them? Most people would say yes; if health promoters admit to being influenced by their emotions, then it is worth while asking when and where this occurs. In the health promotion planning cycle (see Fig. 1), the health professionals' own objectivity and ability to learn might be most affected at step 2, the initial assessment, when information is obtained on AIDS epidemiology, people's knowledge, behaviour, culture, and environment, and at step 5, when strategies, messages and educational material are developed. As the cycle continues, the emotional reactions of the target audiences themselves come into play (WHO, 1989).

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Overcoming barriers in ourselves

Hilary Dixon[a] and Jane Springham[b]

What are the barriers?

Death	Sex	Isolation
Dying	Illness	Bereavement
Prejudice	Discrimination	Risk
Disfigurement	Dependence	Loss of employment
Sexism	Prostitution	Promiscuity
Anger	Pain	Conflict
Disability	Uncertainty	Racism
Drugs	Despair	Fear

In our experience of health promotion against AIDS, issues such as those listed above are likely to be raised in some form or another. For most people, merely reading the list probably conjures up emotive pictures or elicits an instinctive response.

Some of the subjects are taboo and rarely talked about even within an intimate relationship. Some elicit uncomfortable feelings we may prefer to avoid. Still others are associated with recollections from childhood, such as the way we were touched and spoken to, the atmosphere at home, the family, the physical environment, school, our peers, our religion. Our feelings about them have been shaped by the values and attitudes to which we were exposed when we were young, and gradually modified as we have gained experience ourselves. The values and attitudes of those around us were in their turn shaped by the whole range of religious, moral, legal, ethical, and social mores of the society in which we live. All of us bring these feelings, values, and attitudes into our relations with others, and what we say and do are greatly influenced by them.

In our professional lives, we cannot simply set aside this complex web of feelings, values, and attitudes for the duration of the working day, picking

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