AIDS : PSYCHOLOGICAL AND SOCIAL PERSPECTIVES

This article addresses the importance of counselling people with AIDS or HIV infection and the need for developing support groups. The AIDS pandemic has given rise to many responses ranging from fear, panic, irrational judgements, stigmatisation and condemnation to concern, organisation and social and political motivation. Reactions of fear and stigmatisation have tended to manifest themselves in the individual suffering from AIDS as severe psychological trauma. As both a mental health and social welfare issue, AIDS presents a special problem to progressive health care practitioners. Against this scenario, the adequacy of official reactions to AIDS, and hence of the existing social welfare structures, are once again brought sharply into relief.

Crisis for society

AIDS-related deaths, suicides and the practice of "gay-bashing" by self-appointed AIDS vigilantes represent the extremes of the social dimension of this crisis. The public's reaction reflects large-scale ignorance which needs to be countered by an extensive educational programme aimed at preventing further spread of the disease and undoing the prejudiced ideas held about AIDS. In South Africa, where prejudice constitutes a psychological "pillar" of apartheid, the inappropriate management of AIDS could easily lead to AIDS becoming divisive, with further justification for unfair practices and policies.

Crisis for the individual

"I don't know how to live my life anymore ... if I am going to die then I'd want to use the time differently. I don't know if it's right to kiss my lover anymore. Maybe the worst part is not knowing ... waiting for the other shoe to drop is just hell."

(Conversation between a psychologist and a patient diagnosed as HIV positive.)

For some people, being diagnosed as seropositive (HIV positive) leads to serious practical and emotional consequences. On a practical level it may mean loss of employment, rejection by a partner, family and friends; exclusion from established social networks and even total ostracisation. It may also mean exclusion from life insurance policies or medical aid schemes and difficulties in obtaining adequate medical care, presuming such care is available and affordable. On an emotional level a person's reaction immediately after diagnosis is often one of initial denial, extreme shock, severe anxiety and despair. Chronic depression and feelings of guilt may develop rapidly. The trauma of a breakdown in relationships and wider social ostracisation - together with the miseries of impaired daily and social functioning as the person's condition worsens all contribute to the person's emotional reactions.

Counselling and issues in counselling

From the above brief introduction it is clear that what might broadly be described as "AIDS counselling" will follow two paths ... education, on both a social and individual level, and individual, supportive counselling.

Education

Education is vital for two reasons - the first is to prevent further spread of the HIV (Human Immunodeficiency Virus). A recent article in the Morbidity and Mortality Weekly Report (vol 17 no 5-2) points out that the virus is transmitted almost exclusively by behaviour which can be modified by people, for example ways of relating sexually with others. It follows that an educational programme aimed at influencing relevant behaviour will help prevent further infection. This is not to suggest that a person who is infected is responsible for that, rather it acknowledges that people have it in their power, within limits, to protect themselves. The second reason is that there is no cure at present and so spread of the disease can only be controlled by educating people on preventative measures.

Thus any educational programme will need to aim at:

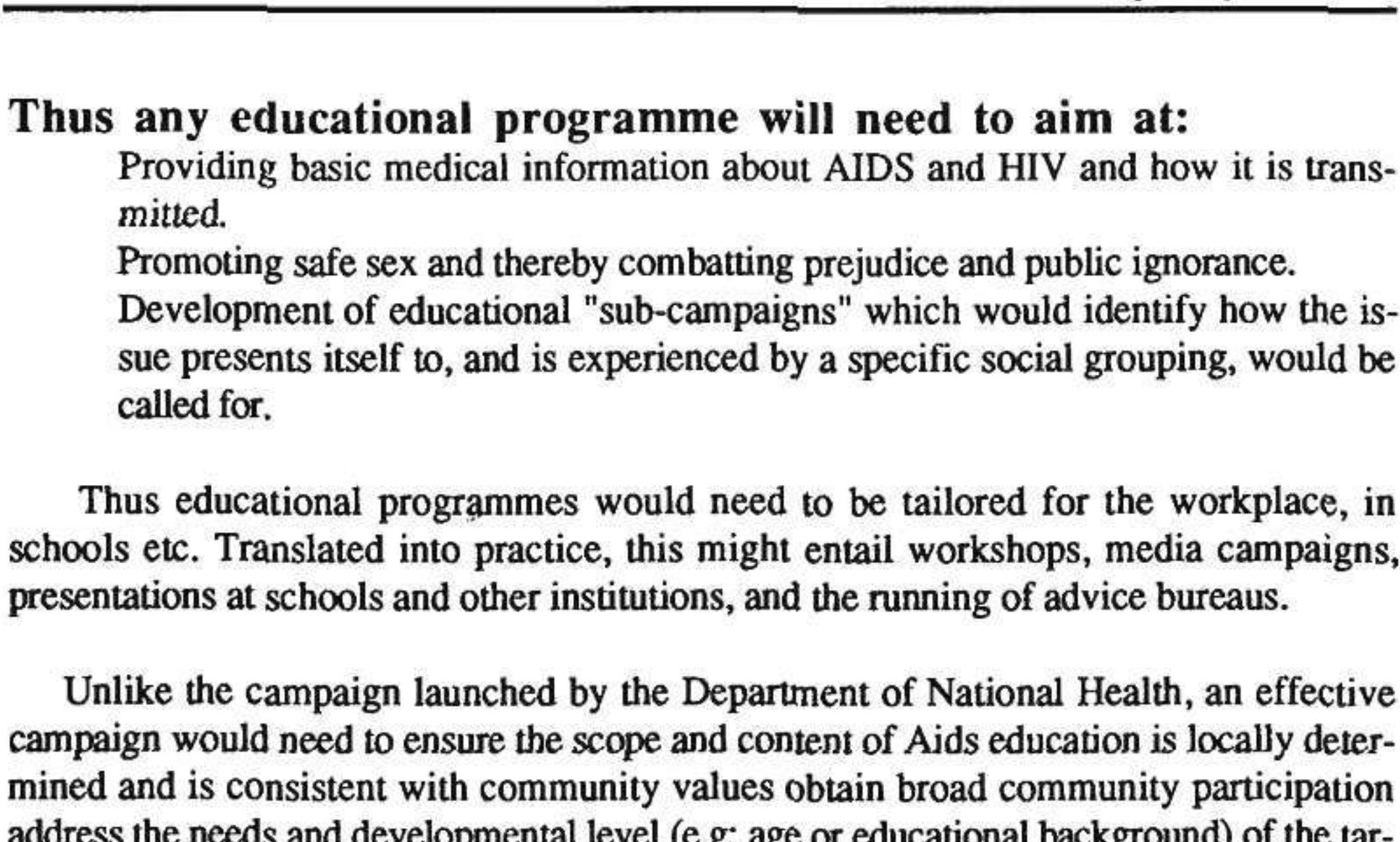
Providing basic medical information about AIDS and HIV and how it is transmitted.

Promoting safe sex and thereby combatting prejudice and public ignorance.

Development of educational "sub-campaigns" which would identify how the issue presents itself to, and is experienced by a specific social grouping, would be called for.

Thus educational programmes would need to be tailored for the workplace, in schools etc. Translated into practice, this might entail workshops, media campaigns, presentations at schools and other institutions, and the running of advice bureaus.

Unlike the campaign launched by the Department of National Health, an effective campaign would need to ensure the scope and content of Aids education is locally determined and is consistent with community values obtain broad community participation address the needs and developmental level (e.g: age or educational background) of the target audience In order for people to understand AIDS education, they must have basic education about sex, medical terminology and drug abuse.



Media should aim at education rather than creating panic

Counselling

Counselling would be offered to a person infected with the HIV virus or who has what is called "full blown AIDS". Counselling would also be offered to the person's partner and/or family where needed or requested. The aim would be to manage the psychological problems arising from knowledge and fear of HIV infection and to provide support together with an educational programme which would take into account the infected person's life history and lifestyle.

Points of intervention

There are various points at which the counselling could take place: before an HIV test; after the test where the person continues with high risk activities although the diagnosis remains negative; where the diagnosis is seropositive. Pre-test counselling includes taking a sexual history, assessing likely risk, and providing information and advice about AIDS and the test itself. Of crucial importance is preparing the person for the possibility of a positive result.

In the case of a negative result further advice will be necessary in terms of protection from infection, along with advice for regular testing. Counselling to help the person cope with being in a group involved in high risk activities with the resultant uncertainty and anxiety will also be necessary; consent and confidentiality must be met at all times.

A person with the symptoms of AIDS, or who is diagnosed as HIV positive and begins to develop symptoms of AIDS, presents special counselling problems requiring a specific programme of crisis intervention. The life threat, miseries of sickness, physical and mental degeneration, isolation from society and emotional and mental anguish, material support, and self- help support groups require immediate attention. Linking with other services becomes very important. These may be located in the hospital or community, for example gay support groups, drug dependency agencies, social services, church support groups. Effective management immediately after a positive test result begins with the establishment of a life line. The counsellor will have to respond to the questions and practical problems which tend to be raised almost immediately - "whom do I tell?", "what do I say?".

Access to medical treatment, future sexual options, financial and legal management are issues that have to be faced. The patient or counsellor should not try to guess how long it will take before the person dies as this will contribute to depression and undermine the motivation and compliance required in counselling and treatment respectively. Thereafter begins the often long, slow and painful counselling directed at helping the person cope with death and dying.

Towards a service approach

AIDS exposes a patient to an array of diseases of indeterminate duration which may be incapacitating or fatal. This, coupled with the nature of the AIDS patient's emotional reactions, renders a pure crisis intervention model inadequate. Unlike other crises, AIDS is not self-limiting. It is not a crisis that is limited by time with reduced coping and problem solving capacity. With the progressive physical deterioration the person's total defensive and coping strategies are tested. There is a dual uncertainty - what illness or specific health crisis is next; and when does death become a reality? Confusion and emotional shock may occur and this, together with the use of drug therapy for pain, may make counselling difficult. Problems in counselling also arise when attempting to balance support in overcoming the immediate crisis of an opportunistic disease and preparing the patient for death. The first requires hope, the second leads to hopelessness. This conflict will most likely remain an issue until both counsellor and patient acknowledge "cues of death recognition". At this point a clear and appropriate response which helps the patient plan for the adventof death, is required.

Another issue which may arise in counselling concerns gay AIDS patients. If the patient has maintained what is called an "in-closet" life style (not allowing people to know that they are gay), then being diagnosed as having AIDS will most likely force the patient into "coming out". Here ostracisation is often double-edged; the patient is ostracised for "being" gay, and for having AIDS. This can result in increased guilt and anxiety. In this situation additionai, supportive counselling is needed; especially since patients may have been denied support systems that they might have been able to utilise had they not been gay.

The above serves to outline issues in counselling AIDS patients. Not all issues have been identified or addressed, such as the case of women who have AIDS and are pregnant, or women who give birth to infected infants. Educating and counselling around AIDS in South Africa will have to recognise the economic and political structures which contribute to most social and personal problems; and of the endemic lack of resources in the hospital and community along with fragmented health care services.

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