ABC of AIDS

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COUNSELLING

AIDS counselling has two main aims.

Education
Safe sex
Public ignorance

Support
Individual counselling to prevent
psychological morbidity

The first is to educate sexually active people to avoid and stop the spread of the human immunodeficiency virus (HIV). Counselling and health education of individuals is the only demonstrably effective means of motivating reliable changes in sexual behaviour.

The second aim is to prevent and manage the psychological morbidity arising from fear of and knowledge of HIV infection. Again, an individual's fear of HIV infection is reliably managed only by individual counselling. When counselling is not provided or is insufficient severe, chronic psychological or psychiatric disturbance may result. Suicides have occurred, for example, where counselling services have been absent.

These two aims—education and support—are necessary because the acquired immune deficiency syndrome (AIDS) can so easily be prevented by changes in sexual behaviour and because the stigma associated with AIDS can lead to overwhelming fears of rejection and oppression. The public's ignorance of the true nature of HIV infection, routes of transmission, and consequences means also that the test for HIV antibodies is widely misunderstood. Counselling therefore has an important part to play well before knowledge of infection is reliably determined with the antibody test.

When is counselling necessary?

Before an HIV test
Sexual history and assessment of
likely risk
Information and advice

After the test and diagnosis
Counselling and support
Follow up of patient and partner
Referral to other agencies:
Terrence Higgins Trust
Body Positive
The Samaritans

There are two stages at which counselling is necessary: before blood is taken for antibody testing and when a patient is found to be seropositive.

Pretest counselling requires a discussion about the meaning and potential consequences of the test. Preparation for the possibility of a positive result (if the sexual, drug use, or other history indicates) is essential in helping to minimise adverse psychosocial consequences if the result is indeed positive.

A necessary component of precounselling is therefore a thorough sexual history, so that the counsellor can gain a clear understanding of the likelihood of infection. The specifics of the sexual history will obviously have a considerable bearing on the need for antibody testing.

When a patient is found to be seropositive or diagnosed as having symptoms of HIV disease the period immediately afterwards will usually be characterised by shock, acute anxiety, depression, often impulsive despair, and social trauma. The alert doctor will ensure that community support is on hand to cushion the patient at this highly vulnerable time. Patients invariably perceive a diagnosis of HIV infection or seropositivity as life threatening, and their normal psychosocial responses may, if unattended, lead to serious practical and emotional consequences, especially if the social confidentiality of the patient is not strictly preserved and continued access to counselling is denied.

Counselling before HIV testing

The test

Is not a test for AIDS

Necessitates sufficient time elapsed for seroconversion to have occurred

Indicates only previous exposure to HIV

Gives no indication of prognosis, severity of infection, or infectiousness

Practical consequences of being identified seropositive

Ineligible for future life insurance or some mortgages

Possible difficulties obtaining dental and medical treatment

Precluded from some types of employment and employers
Dismissal by some employers with resulting financial burdens

Potential psychological consequences of being seropositive

Unresolvable uncertainty

High level anxiety, depression, guilt, and obsessive disorders

Relationship implications

Other issues

All persons potentially at risk should adopt safer sex and risk reduction guidelines

Themes in counselling

Characteristics of the worried well

- Low risk sexual history
— including covert and guilt inducing sexual activity
- Poor postadolescent sexual adjustment
- Social isolation
- Dependence in close relationships (if any)
- Multiple misinterpreted somatic features
— usually associated with undiagnosed viral or postviral states (not HIV) or anxiety or depression
- Psychiatric history or a high level of consultation with general practitioners or physicians
- High levels of anxiety, depression, and obsessional disturbance
- Increased potential for suicidal activity
- Repeated negative HIV tests

AIDS anxiety

With the advent of government health education and media coverage many people present voicing fears about their possible exposure to infection. These fears often show a misunderstanding of the routes of HIV infection or of true seroprevalence at the time they feared they might have been exposed.

Anxieties within this group commonly relate to non-sexual modes of spread, such as shared toothbrushes, cooking and eating utensils, towels and linen, and bathrooms and non-sexual touching and kissing. People worried about such contact usually respond positively to clear, rational discussion of the known routes of infection and the absence of risk associated with such activities.

The worried well

The worried well are more difficult to manage. Patients in this group present with multiple physical complaints, which they interpret as sure evidence of their HIV infection. This occurs despite often repeated assurances that, on the basis of their sexual history, they could not (or would be extremely unlikely to) have come in contact with HIV. Typically, fears of infection reach obsessive proportions, and frank obsessive states are often seen. HIV seems to act as a vehicle for the expression of their psychological vulnerability and sexual guilt.

This group shows a variety of characteristic features (see box), including a low risk sexual history, social isolation, multiple misinterpreted somatic features, a high level of medical consultation, and high levels of anxiety. These patients are rarely reassured for more than a brief period after clinical or laboratory confirmation of the absence of HIV infection. They represent a major drain on counselling resources, and further referral for behavioural psychotherapy or psychiatric intervention is often indicated.

People positive for HIV

Themes that arise during counselling of people positive for HIV—whether they have symptoms or not—often mimic the crisis responses to life threatening news seen in patients with cancer but with the added pressures of social stigma and the threat of social oppression. Effective management requires allowing time for the shock of the news to sink in; there may be a period of emotional “ventilation,” including crying and hysterical speech. The counsellor should provide an absolute assurance of strict confidentiality and rehearse the solutions to practical problems such as who to tell, what needs to be said, the involvement of loved ones, access to medical and dental practitioners, future sexual options, and financial and legal management. When patients are diagnosed with HIV disease counselling will also include discussion of possible treatment regimens and usually the question of prognoses. It is important to avoid the trap of attempting definitive estimates of life expectancy, which may encourage chronic depression and undermine the patient's motivation and compliance.

Psychological issues in HIV/AIDS counselling**Shock:**

- of diagnosis and possible death
- over loss of hopes for good news

Fear and anxiety:

- uncertain prognosis and course of illness
- of disfigurement and disability
- effects of medication and treatment
- of isolation and abandonment and social/sexual rejection
- of infecting others and being infected by them
- of lover's ability to cope and their possible illness
- of loss of cognitive, physical, social, and work abilities

Depression:

- over "inevitability" of physical decline
- over absence of a cure
- over the virus controlling future life
- over limits imposed by ill health, and possible social, occupational, emotional, and sexual rejection
- from self blame and recrimination for being vulnerable to infection in the first place

Anger and frustration:

- over inability to overcome the virus
- over new and involuntary health/lifestyle restrictions
- at being "caught out" and the uncertainty of the future

Guilt:

- over past "misdemeanours" resulting in illness "punishment"
- over possibly having spread infection to others
- over being homosexual or a drug user

Obsessive disorders:

- relentless searching for new diagnostic evidence on body
- faddism over health and diets
- preoccupations with death and decline, and avoidance of new infections

With all seropositive patients it is crucial to provide a "lifeline" for the first few days (telephone numbers of the clinic, community agencies concerned with HIV, the Samaritans) and, if possible, to ensure that they will not be left alone during this time (when suicidal impulsiveness or a catastrophic reaction is most likely). Likewise, patients should be advised against telling at this stage their result or diagnosis to others who are unaware of their attendance at the clinic. The reactions of others (especially employers) are quite unpredictable and may lead to adverse consequences. Once the patient has calmed down an appointment should be made to see him or her again, perhaps in the company of a lover, spouse, relative, or parent, within five days.

At the follow up session issues relating to safer sex; domestic, occupational, and recreational infection control; "health boosting" (healthy eating, drinking, sleep regimens, etc); and who should be told and how to tell them can be repeated. A partner can be involved only with the consent of the patient, but it is important for the following reasons:

- (1) Adjustments in sexual behaviour can be discussed and explained clearly to both.
- (2) Standards of hygiene can be clearly explained—for example, what to do after spillages of body fluid in the home.
- (3) Misconceptions about HIV transmission or infectiousness can be removed.
- (4) The partner's and the patient's psychological responses to the diagnosis or results, such as anxiety, depression, obsessional states, can be explained and placed in a manageable perspective.
- (5) The partner can be enlisted to help with the effective monitoring and management of the patient's condition.

Partners (and family members) often have higher and more chronic levels of psychological morbidity arising from knowledge of HIV infection in the patient than the patients themselves. Continuing support is often required to manage this, particularly as difficulties in the relationship that are not attended to (including role changes and fears about both partners being infected) will lead in many cases to a breakdown of the partnership, leaving the patient more acutely vulnerable.

In many cases follow up counselling will need only two or three sessions. The number of sessions largely depends on the physical health of the patient and the nature of his or her psychological response to infection. At follow up meetings it is important gently to screen for any indications of psychological or psychiatric vulnerability. The presenting themes seen in the worried well are a good indication of vulnerability in all patient groups.

AIDS: Safer sex guidelines**No risk**

- Solo masturbation
- Massage away from the genital area

Medium risk

- Wet kissing
- Fellatio (sucking) may be safe if you stop before climax
- Urination (water sports) external only
- Anilingus (rimming)

Risk increases with multiple partners

Low risk

- Mutual masturbation
- Dry kissing
- Body rubbing

High risk

- Anal and vaginal sex may be safe if a condom is used
- Fisting (insertion of hand or fist into rectum)
- Sharing sex toys and needles
- Any sex act that draws blood

Linking with community and statutory agencies

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HIV and AIDS counselling could not succeed without active liaison with established community advice and support agencies such as the Terrence Higgins Trust or social services agencies responsible for home help and housing. Such services provide much required support and back up counselling for both inpatients and outpatients. Links with these services should be planned as an integral part of any HIV/AIDS counselling initiative from the outset. Such links must be kept open and flexible to ensure that medical information and advice are consistent across all levels of intervention and to enable new crises to be managed effectively as they arise.

Counselling qualifications

Effective counselling requires the following qualifications.

(1) A thorough working knowledge of HIV and its clinical manifestations and an ability to keep up with developments in treatment and diagnosis in this rapidly changing subject.

(2) A working knowledge of the lifestyles of patient groups and an ability to discuss tactfully issues of patient sexuality and lifestyle.

(3) A working knowledge of the range of "backup" services available for patients with HIV infection and AIDS together with an ability to communicate effectively, tactfully, and sympathetically with people from a wide variety of backgrounds and lifestyles (medical and non-medical).

(4) The ability to recognise common psychosocial and clinical complications arising from HIV infection, including anxiety, depression, obsessive disorders, neurological indications, and suicidal risk. If counsellors cannot manage such issues themselves they must be able to recognise when to refer patients elsewhere.

Possessing relevant information, skills, and interest is often a more useful prerequisite than possessing formal counselling qualifications or belonging to a particular profession. Because counselling opportunities and needs so frequently arise in the context of general practice, establishing the availability of counsellors or the learning of such skills is an important requirement for the foreseeable future.