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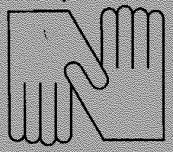

AIDS
NURSING GUIDELINES

Second report of the RCN AIDS Working Party

Nursing guidelines on the management of patients in hospital and the community suffering from AIDS

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Members of the Working Party

Ms M Barlow Senior Nurse (Occupational Health), Royal Marsden Hospital, London
Mr T Cotton Staff Adviser on AIDS, London Borough of Hammersmith and Fulham
Mr K Fortune Senior Nurse, St Mary's Hospital, London
Ms H Glenister District Infection Control Nurse, Waltham Forest Health Authority
Ms M Lee Adviser in Nursing Practice, Royal College of Nursing
Ms M Marks Senior Nurse, Continuing Care, Royal Marsden Hospital, London
Ms A McCreaner Health Adviser, STD, St Mary's Hospital, London
Ms S MacQueen Senior Nurse, Infection Control, Hospital for Sick Children, London
Mr R Pratt Head of Department (Continuing Education), Charing Cross Hospital, London
Ms V Todd District Adviser (Infection Control), Bloomsbury Health District
Mr R J Wells Adviser in Oncology Nursing, Royal College of Nursing (Chairman)
Ms J Woodward Senior Lecturer in District Nursing, Chatham, Kent

In Attendance

Ms B Weller Nursing Officer, DHSS, London

The Working Group wishes to thank all those who assisted in the compilation of this document. Special thanks to: Dr Paul Schober, Registrar in Genito-Urinary Medicine, University College Hospital, who contributed the section on the disease, Frances Pickersgill, Assistant Professional Officer, Association of Nursing Practice, Royal College of Nursing, who contributed to the section on intensive care units, the Royal College of Midwives, who kindly proof-read the section on maternity and neonatal care, the Terrence Higgins Trust, which provided the appendix on support groups, and the Standing Conference on Drug Abuse, which helped greatly on the sections dealing with drug addicts.

Throughout this text the use of the male gender equally implies the female.

Preface

The original guidelines produced by the RCN Working Group on Acquired Immune Deficiency Syndrome/HIV related diseases, and issued in February 1985 were generally well received by the profession. Since that time, much more detailed information has become available and, where this is relevant, it is incorporated into these revised guidelines.

The composition of the working group has expanded to include other spheres of practice, whose practitioners have been expressing concern at the lack of information available to them.

In the Preface to the original document the hope was expressed that the guidelines would assist nurses and other health care providers to give safe, effective and meaningful care to these patients. This remains the working party's paramount objective.

The action of nurses working in areas where patients with AIDS or AIDS related conditions are cared for, have either responded well to the demands that caring for this condition places upon them, or remain prejudiced against client populations, and/or phobic about contagion.

The working party re-iterates the responsibility of all nurses to offer appropriate and meaningful care to the sick. There is no 'opt-out' clause for caring for patients with AIDS/HIV related diseases, and refusal to care may well result in disciplinary procedures being taken against the nurse for unprofessional conduct.

It is essential that the information contained in this document is disseminated to all health care providers, and especially those with direct involvement in the care of persons with AIDS. The working party believes most strongly that education is the most effective tool available to diminish prejudices against minority groups, reduce fear of contagion, and portray an accurate and differential picture of AIDS and human immunodeficiency virus.

New literature and information on this condition appears almost daily, and nurses are reminded of their responsibilities under the United Kingdom Central Council rules for keeping their own professional knowledge updated.

Schools of nursing have a tremendous role to play in educating nurses on this subject. The working party believes it should be incorporated into the curriculum to prepare students of nursing to face some of the issues raised in the management of this condition.

Since the original document, there has been no increase in the number of reported cases of transmission of the virus from patient to health care personnel (two confirmed transmissions only), but this should not allow for any degree of complacency, and should serve to remind health care providers of the necessity to exercise extreme care when handling the blood or secretions of any patient, without compromising the high standards of care that all patients have a right to expect.

If Acquired Immune Deficiency Syndrome continues the exponential growth which has already been observed in most countries where the disease now exists, then the patient population of this disease will most likely continue to increase inexorably until effective measures to combat it have been discovered by scientists.

The alarmist and uninformed stance taken by some sections of the media is worrying. This is bound to have an impact on care providers and lead them into believing that they may be at greater risk than is the case.

The aim of this report is to ensure that all health care providers will be protected, and patients cared for using all available knowledge and nursing skills.

The report again consists of three main sections, each of which has been expanded:

1) Staff protection
2) Guidelines for care
3) Psychosocial support for nurses, patients and significant others.

In the time which has passed since the introduction of the original document, a wealth of new literature has become available, and where this is relevant, it has been included in appendix 1 and 2.

The working party would again wish to thank all those who helped in its deliberations, and to those who submitted so much useful information which was of great value.

Introduction

In the original guidelines, reference was made to the Human T Cell Lymphotrophic Virus 3, (HTLV3), and the Lymphadenopathy Associated Virus (LAV). At a meeting of the International Committee on the taxonomy of viruses, held in May 1986, it was decided that in future, Human Immuno-Deficiency Viruses (HIV) would be the accepted nomenclature for this group of retroviruses, and this guidance has been followed throughout this document.

Acquired Immune Deficiency Syndrome (AIDS) was first highlighted in late 1979 and early 1980 in male homosexuals in New York, Los Angeles and San Francisco. The disease first appeared in the United Kingdom in 1981 when four cases were reported with one death.

Originally thought to be exclusive to homosexual men, eventually other members of the public began to manifest the disease: these included bi-sexuals, heterosexuals, intravenous drug abusers and their partners and haemophiliacs. At present almost 30 per cent of sufferers in the United States of America do not fit into the homosexual/ bi-sexual category and therefore a health problem exists which affects all sexually active people outside of monogamous relationships.

The disease

Acquired Immune Deficiency Syndrome is part of the spectrum of disease caused by human immunodeficiency virus (HIV) infection. This virus, previously known as Human T Cell Lymphotrophic Virus III (HTLVIII) and Lymphadenopathy Associated Virus (LAV), causes an impairment of the body's cellular immune system which may result in infection by organisms of normally no or low pathogenicity (opportunistic infections) principally Pneumocystic Carinii Pneumonia (PCP), or the development of unusual tumours, principally Kaposi's sarcoma (KS).

Infection occurs after virus in the blood, semen, vaginal secretions or breast milk of a carrier gains entry to a particular form of lymphocyte — the helper T-lymphocyte — of the host. After a variable period, antibodies to the virus appear in the blood. This seroconversion may coincide with a transient glandular fever-like illness. These antibodies do not seem to be protective as the virus continues to be found in the helper T-lymphocytes where its continued replication destroys these cells and hence causes disordered immune function. The current experience of HIV infected individuals is that many remain as asymptomatic infectious carriers. Some of the remainder may be asymptomatic but develop a persistent generalised lymphadenopathy (PGL), others, in addition to the enlarged lymph nodes, develop symptoms such as night sweats, diarrhoea, weight loss and malaise, this latter condition is called

AIDS related complex (ARC). Examination of the blood may show abnormally low platelet and neutrophil counts as well as low lymphocyte counts.

Only individuals with an opportunistic infection or unusual tumour can be diagnosed as having AIDS. This has occurred in approximately 2.5% of infected British haemophiliacs and in about 30% of infected Manhattan homosexuals. This shows the error in calling the HIV antibody test the 'AIDS test'. Of the first 168 British AIDS cases, 41% had Pneumocystis Carinii Pneumonia (PCP) (mean survival time 12.5 months), 26% Kaposi's Sarcoma (mean survival 21.2 months), 26% opportunistic infections other than PCP (mean survival 13.3 months) and 7% PCP and KS (mean survival 6.6 months).

A recently recognised development is the recognition of HIV nervous system involvement with late manifestations such as fits, pre-senile dementia and painful peripheral neuropathy. Early manifestations include personality changes and memory disturbance. As control measures depend on altering infected individual's behaviour the dementia may carry serious implications.

Screening tests for HIV infection

In 1985, a blood test able to detect antibodies to the retrovirus which causes AIDS (known as HIV — Human Immuno-Deficiency Viruses) was introduced in the United Kingdom. Antibodies produced by the body as a result of HIV infection are non-neutralising and are not effective in combating the infection. However, they are markers of exposure to this virus and consequently, are the basis of the present screening tests. These antibodies are known as 'anti-HIV' and three main types of blood tests are available to test for their presence: (1) enzyme-linked immunosorbent assays (ELISA), (2) radio-immunoassays (RIA) and (3) Western blotting.

If an individual is found to be positive for anti-HIV using the above tests, this indicates:

1. that they have been previously infected with the virus and
2. in the present state of knowledge, they are presumed to be currently infected and capable of transmitting this infection.

Most patients with AIDS/ARC are positive for anti-HIV and it is currently estimated that there are in excess of 30,000 individuals in the United Kingdom who are anti-HIV positive but asymptomatic. This number is expected to increase significantly in the coming years. A negative blood test for anti-HIV does not necessarily indicate that an individual is not infected with this virus. Some individuals may take up to three months from date of exposure to seroconvert to anti-HIV positive, and during this time they are infected and infectious. It is also known that a few individuals infected with HIV do not produce

anti-HIV detectable by current screening tests. However, these individuals are also infected and infectious.

Indications for anti-HIV Testing

Most authorities agree that screening for the presence of anti-HIV is indicated in the following situations:

1. Blood transfusions (all donor blood in the United Kingdom is now screened).
2. Organ transplant donors and donors of semen.
3. Patients in renal haemodialysis units.
4. Women in high risk groups who are considering pregnancy.
5. On request, from individuals who are concerned that they may have been exposed to this virus.
6. In some diagnostic situations.

A positive blood test for anti-HIV does not indicate that a person either has AIDS, nor can it predict if AIDS will develop. Currently, approximately 30-50 per cent of individuals who are positive for anti-HIV will progress to either fully expressed AIDS or to other forms of AIDS-related ill-health. It is presently not known if the remaining anti-HIV positive, asymptomatic individuals will develop any ill- effects as a consequence of their exposure to this virus, although it is possible that some will.

Counselling, confidentiality and informed consent

Individuals must give informed consent before being tested for anti-HIV. Informed consent implies that the reasons why the test is advised are carefully explained to the individual and equally, that the results will be carefully discussed. In individuals who have positive tests, counselling will be necessary. If counselling is not available, testing should not be done. The results of anti-HIV tests must be strictly confidential. A positive result may have enormous psychological implications and may adversely affect the individuals employment, marriage and other relationships. It may also preclude an application for life insurance (for example, a mortgage application would be unsuccessful). Under no circumstances must the results of anti-HIV testing be casually communicated to other health care workers, unless they are providing direct patient care. To do so would not only be illegal, but also a grave breach of professional ethics and a violation of the Code of Professional Conduct of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting.

Screening of health care workers

There are no indications for, or benefits of, routine screening of health care workers. Following inoculation injuries, rather than screening for anti-HIV, it may be preferable to have a specimen of blood taken and stored (under strict security) and tested later if ill-health develops.

The diagnosis of AIDS and AIDS-related complex (ARC) is made by clinical information, not by serological testing of blood for the presence of anti-HIV. **With the increasingly high numbers of asymptomatic individuals who are positive for anti-HIV, nurses must now assume that all blood and body fluids from all patients are potentially hazardous. Sensible nursing care strategies must be adopted to minimise the possible risks associated with them.**

Health care workers who may be HIV antibody positive

'Routine screening for HIV antibodies of health care providers, especially those involved in invasive procedures, is not recommended . . . since the risk of transmission in this setting is low.' MMWR (1986) 35 14 11 April CDC Atlanta.

Had the condition of AIDS/HIV infection received a more balanced reporting in some sections of the media, many of the problems now being witnessed with this condition would have been greatly lessened, not least of which is the employment of health care workers who are HIV antibody positive.

The working party wishes to express its desire that this situation should not get out of hand, and that the problems of health care workers who are HIV antibody positive should be handled with tact, sensitivity and complete confidentiality by the occupational health services. Failure in this area may well encourage health care workers not to declare their health status to present or prospective employers.

Where health care providers have been screened and have declared their positive status, occupational health nurses are reminded of their responsibility to maintain strict confidentiality about this information as with other health status information of workers within their purview. Knowledge that such confidentiality exists will encourage health care providers to discuss their health problems with, and seek solutions from, the occupational health services.

At the present time, guidance from the Department of Health and Social Security on employment of HIV antibody positive health care providers is not available and, therefore, the working party has looked to available guidance published by the Centres for Disease Control, Atlanta, Georgia, and has adapted this for use in the United Kingdom.

There is no evidence available to suggest that transmission of the virus from health care provider to patient has ever taken place. The possibility of this happening is probably even less likely than transmission from patient to health care provider.

The working party recommends that health care providers who are HIV antibody positive should not be barred from employment in the health service, nor does it recommend any areas where HIV antibody positive personnel should not be employed. The working party stresses the need for such persons to follow good practice guidelines in the performance of their duties, as laid down elsewhere in this document.

All occupational health staff must ensure that they have adequate knowledge of this condition so that they are able to offer the correct help and advice to their clients. In addition, they need to be aware of outside agencies able to offer advice and support for persons who are HIV antibody positive.

The working party recommends that occupational health staff make every effort to attend a counselling course on the support of persons who are HIV antibody positive.

Confidentiality

In October 1985, the Department of Health issued a series of booklets on Acquired Immune Deficiency Syndrome (AIDS) to all doctors in England and Wales. Booklet number two contained the following section on confidentiality.

'The strictest confidentiality must be maintained when an HIV antibody positive individual is identified. Where a person is tested for HIV infection or for its complications and it is thought to have been sexually transmitted, Health Authorities have an obligation to maintain confidentiality of information under the terms of the National Health Services (Venereal Diseases) Regulation 1974 (S11974.9). Unless the patient has given his/her consent, personal health data relating to him/her must not be disclosed to anyone for any purpose other than the health care of that patient except where the disclosure is necessary to prevent the spread of infection. Disclosure of this information for purposes other than medical or public health reasons could lead to serious consequences for the informant. Adequate safeguards to protect individuals against unauthorised disclosure must be adopted.

'For nurses the main objective must be to protect the patient's identity from inappropriate disclosure both inside and outside the hospital.

'Access to medical records in the clinical setting should be restricted to relevant personnel, the medical records should be kept in a safe location where access can be monitored.

'Before discussing the patients condition with lovers, family and friends, it is essential that staff ascertain exactly what the patient has told this important group about his/her illness and lifestyle, to ensure that enquiries are answered accordingly and consistently.'

Currently HIV infection and AIDS remain very emotive topics. However, the social implications for the patients are immense. It is, therefore, essential that all staff regardless of status familiarise themselves with the Venereal Disease Regulation, 1974.

Nurse to nurse communication must be confidential.

Health education

In addition to delivering the highest level of care possible to those suffering from this illness, the nurse has responsibility to educate those likely to transmit the disease, and those at risk of becoming infected. It is essential to remember that not all those people who carry the virus will manifest or suffer the disease. They may, however, transmit the disease to vulnerable subjects. Therefore, those whose lifestyle or behaviour puts them at risk of infection should be advised to observe certain precautions within their particular life-style; and should not at the present time donate blood (unless for research purposes), blood

products, semen, breast milk, body tissues or organs. Such education and advice must make the subjects aware that they have an important role to play in preventing further the spread of this condition.

Sexually active individuals outside a monogamous relationship

People within this group should attempt to develop monogamous relationships, thus reducing the risk of contracting or transmitting the disease. For those who may be carrying the virus there must necessarily be a curtailment of some of their sexual activity; anal contact of any kind should be avoided, evidence shows that the retrovirus cannot pass through an intact effective condom. Therefore, their use will greatly reduce the risk of transmission. There should be no contact with body fluids, that is, excessive saliva, or semen, faeces, blood and urine. These restrictions apply equally to heterosexuals and homosexuals.

Health education is much more effective when the adviser stresses the things which can be done to maintain or promote a meaningful relationship and at the same time encouraging safe sexual practice. Mutual masturbation, dry kissing, frottage (body rubbing), hugging, massaging, gentle touching, all of these are safe and are worthwhile substitute displays of affection and intimacy.

AIDS/HIV related diseases in Africa

There is an increasing incidence of AIDS/HIV related illnesses in some parts of Africa. This incidence is equally distributed between males and females. People intending to visit Africa should be made aware of the risks inherent in casual sexual encounters, and of being a recipient of blood which may not have been tested for antibodies to HIV. Those potential travellers who are unaware of which countries present the greatest risk are advised to contact their travel agent or the DHSS for relevant guidance for travellers.

Injecting drug users

Obviously, the best advice that the health care provider can proffer is for subjects to seek help with their problem and to give information on drug abuse centres. Where such advice is not welcome, they should be counselled to stop injecting drugs if at all possible. If they are unable to comply with this advice, then they should be advised to use only sterile

equipment, including needles and syringes, when preparing drugs. They should not share their equipment, or use the equipment of other injecting drug abusers. Injecting drug abusers who are HIV positive should be advised to follow 'safe sex' guidelines to prevent transmission of the virus.

Non-injecting drug users

Again the advice must be to cease using non-injectable drugs of any description. Alternatively, those who intend to continue this practice should be advised to do so in the privacy of their own home and not in public places where the use of such drugs is not only illegal but also exposes the subject to risk of infection by the virus due to the reduction of inhibition brought about by these drugs.

Part 1
Staff protection

The aim of these guidelines is to minimise the risk of infection to health care staff and other patients, while giving effective care to the client. It is essential that all staff involved in the clinical management of a patient with known or suspected HIV infection should be informed of the precautions to be taken. The clinician in charge must inform the infection control officer when such patients are admitted to hospital.

If patients require the services of the community health care staff, the referring hospital/general practitioner should inform them of the patient's condition and the infection control measures this may warrant.

Members of staff who are immuno-deficient/compromised either through illness or therapy, or suffering from exfoliative skin conditions, should be advised not to nurse these patients, before discussion with the occupational health adviser.

Procedure guidelines

The nursing care required by patients with HIV infection will vary considerably. Many sero-positive patients may be self caring, while those with clinical symptoms of AIDS will need intensive nursing support and care. Transmission of HIV virus may occur sexually, perinatally and by inoculation. No other routes of spread are known. Therefore, the most important infection control measures are based on the prevention of inoculation accidents with used 'sharps', and the avoidance of frank contamination of skin and mucous membranes with blood and other body fluids. Therefore, it is strongly recommended that health care workers take measures to avoid contaminating themselves with blood/body fluids from all patients in their care, thus reducing the risk of infection from HIV and other infectious agents. Any cuts or abrasions on hands should be covered with waterproof dressings and gloves worn if contamination is likely.

Hospital care

There should be no distinction in the precautions taken between patients in the high risk categories, asymptomatic HIV infected patients, and those with clinical AIDS. It must be remembered that some patients with HIV infection may not have antibodies to the virus at the time of initial testing and, therefore, these precautions represent good clinical practice and should be followed in the care of all patients.

1. Single room isolation

Many patients with known or suspected HIV infection may be nursed safely in the open ward. However, it is considered prudent to nurse the following in a single room. Those patients who are:

a. Bleeding or likely to bleed.
b. Incontinent.
c. Post-operative — with wounds.
d. Unconscious.
e. Suffering from open skin lesions.
f. Mentally disturbed or confused.
g. Have added infection risks, ie pulmonary infection.

2. Protective clothing

It has now been established that for normal social contact between patient and carer it is not necessary to wear protective clothing.

Disposable plastic aprons and gloves are worn when exposure to blood or body fluids is anticipated such as:

a. Collection of specimens for ward or laboratory analysis.
b. Venepuncture and the administration of injectable drugs.
c. Invasive nursing procedures, for example, intravenous infusion care, catheterisation, wound dressings.
d. Attending to patients' sanitary needs and for the disposal of excreta.
e. Handling used instruments, and linen or dressings soiled by body fluids.
f. Dealing with spillages of body fluids.

Masks are not necessary as a routine. However, it should be borne in mind that the patient may have an added infection which may require the use of masks. When indicated, pleated high filtration rate masks should be used.

A face visor or goggles should be available for use if splashing of body fluids is likely. Normal spectacles may be used for eye protection, if worn.

3. Use of ward equipment/facilities

Ordinary crockery and cutlery may be used by the HIV infected patient provided there is no bleeding from the mouth. If bleeding of the mouth is present, exclusive or disposable utensils may be required. Although the virus has been isolated from saliva there is no evidence of cross infection by this route.

Patients nursed in a general ward may use the ward bath and toilets unless open bleeding perineal lesions are present. In this instance they should be given their own washing equipment and use a commode. All sanitary articles should be cleaned after use with an appropriate chemical disinfectant (see point 6). Bedpans and urinals can be

processed normally in a correctly functioning washer that achieves adequate cleaning and raises the temperature of the article to 80°C for one minute.

4. Disposal procedures

a. All used disposable articles should be sealed in the appropriate plastic bags, labelled with a hazard warning and sent for incineration (see 'The Safe Disposal of Clinical Waste' HSAC 1982 ISBN 0.11 8836412).

b. Linen soiled with blood/body fluids must be placed in a water soluble plastic bag (alginate stitched or polyvinyl alcohol), labelled with a hazard warning and double bagged in accordance with local practice for the processing of infected linen (see HM(71)49 Hospital Laundry Arrangements).

c. Autoclavable instruments and equipment should be returned to the CSSD for sterilisation. Items should be correctly bagged and labelled according to local policy. Any prior decontamination of equipment should be carried out as recommended by the infection control officer. Any agreed procedure should be written into the local policies of the ward/department involved. For the decontamination of non-autoclavable equipment seek the advice of the infection control officer or nurse.

d. All specimens and request cards must be labelled with a hazard warning to indicate danger of infection. Lids on containers must be securely fastened and the specimens sealed in individual plastic bags, without the use of staples, pins or paper clips. The request form must be kept separate from the specimen container to avoid contamination. Laboratories should have prior notice of the arrival of all specimens from patients with suspected or known HIV infection.

All specimens for analysis should be collected by trained staff who are aware of the infection risks and the precautions to be taken. This will include finger prick tests on diabetics and venepuncture.

Specimens should be transported in an autoclavable container with a sealable lid. The carrying handle of this container should be fixed to the base, not to the lid.

e. Devices for cardiopulmonary resuscitation should be readily available to enable this procedure to be carried out without direct mouth-to-mouth contact.

f. Spillages of blood or body fluids should be dealt with promptly, using an appropriate chemical disinfectant, for example, sodium hypochlorite solution (10,000 ppm available chlorine) and disposable paper towels.

g. Decontamination of a vacated patient's room should be carried out after use, in accordance with local policy, for the cleaning of rooms used by infected patients. Any spillage must be dealt with before the cleaning procedure is started.

h. In the event of death, last offices should be performed observing the same precautions which were in operation when the patient was alive. The body should be laid out in a shroud and family/friends given the opportunity to view the deceased and pay their last respects. After this the body should be identified with danger of infection labels and placed in a plastic cadaver bag before removal to the mortuary for collection by undertakers, who should be informed of the risks of infection and any precautions to be taken. It is not a requirement in law for the body to be cremated.

5. Accidents

Meticulous care in the use and disposal of 'sharps' is essential. They must be placed in the correct sharps disposal box immediately after use, by the person using them (see 'Specifications for Containers for Disposal of Used Needles and Sharp Instruments' DHSS TSS/S/330.015 Dec 1982). Used needles should not be resheathed, as this increases the risk of inoculation accidents. At present, there is no active treatment for staff who have had an inoculation accident with a 'sharp' used on a patient with HIV infection. Therefore, such accidents must be avoided at all costs.

In the event of such an incident, the puncture wound or cut should be thoroughly washed with soap and water, and bleeding encouraged. An accident form should be completed. Staff should report to the occupational health department for further advice as soon as possible. Health authority guidelines for the reporting of accidents should be followed.

Staff appointed to designated units where AIDS patients are cared for should be afforded the opportunity to discuss 'serum storage'.

6. Chemical disinfectants

In vitro tests have shown that a number of chemicals and detergents are capable of inactivating HIV. These include alcohols, phenols, hypochlorite and glutaraldehyde.

Spillages of blood or body fluids should be dealt with using either sodium hypochlorite (10,000 ppm available chlorine) or freshly activated 2% glutaraldehyde. For surface cleaning of areas where contamination may have occurred, but is not visible, a lower concentration of hypochlorite (1,000 ppm available chlorine) will suffice. Freshly activated 2% glutaraldehyde can also be used to decontaminate non-autoclavable equipment such as endoscopes, prior to routine cleaning and disinfection. In such cases the articles should be immersed in the solution for a minimum of one hour, then cleaned before being subjected to its normal disinfection programme.

Specific guidelines on the disinfection of articles and equipment used by patients with HIV infection is being prepared by the DHSS.

Further information on disinfection and sterilisation is available in the Revised guidelines — LAV/HTLVIII, the causative organisms of AIDS and related conditions' produced by the Advisory Committee on Dangerous Pathogens.

Guidelines for operating departments

The consultant in charge of the patient should be responsible for seeing that all members of the surgical team are aware of the infection hazards and the infection control measures to be taken.

a. General principles

1. The operation should be scheduled to allow time for adequate cleaning of the theatre and decontamination of equipment.
2. If hair removal is essential, the use of depilatory creams is recommended.
3. The operating team should be limited to essential staff only.
4. Avoid the use of equipment which cannot be easily decontaminated.
5. Disposable theatre gowns and patient drapes are recommended. All theatre personnel should wear a disposable plastic apron under their surgical gown.
6. For wounds which require post-operative drainage, a closed drainage system should be used.
7. At the end of the operation, blood should be removed from the patient's skin and the wound covered with an impervious dressing that will contain exudate.

Have available for use:

1. Disposable gowns, drapes and plastic aprons.
2. Face visors or goggles.
3. Adequate supplies of an appropriate chemical disinfectant.
4. 'Sharps' disposal container.
5. Plastic bags for disposable items and linen.

b. Preparation of theatre and equipment

1. Clear rooms of all non-essential equipment.
2. The anaesthetic machine should be stripped of non-essential items. Autoclavable or disposable breathing circuits should be used.
3. A measured quantity of sodium hypochlorite solution should be put into suction bottles.
4. The theatre table and patient trolley should be protected by a water repellent laminate or equivalent.

c. Procedures during and after the operation

1. A runner should be available outside the theatre to avoid the necessity of a member of the operating team having to leave the theatre.
2. In keeping with good practice, all bloodsoaked swabs should be handled with forceps. After counting, they must be put into bags for incineration.
3. At the end of the operation, all staff should remove their disposable protective clothing before leaving the theatre. Used instruments should be handled as little as possible, before being sent for sterilisation.
4. The contents of suction jars, urine and other body fluids must be carefully emptied down the sluice hopper, taking care to avoid personal and environmental contamination.
5. All disposable suction and anaesthetic tubing should be sent for incineration.
6. Non-autoclavable equipment should be dealt with in accordance with agreed local practices.
7. Spillages of blood or any other body fluids should be dealt with using the recommended chemical disinfectant before routine theatre cleaning is started.

After surgery the patient should be allowed to recover in the operating room.

Community care

Staff caring for HIV infected patients at home should follow the principles of infection control previously outlined.

To date there is no evidence that social contact with others presents a risk of transmission of infection. Normal domestic methods of hygiene and waste disposal will suffice with those patients who are asymptomatic. Crockery and cutlery may be handwashed in hot soapy water or processed in a dishwasher. Personal linen and clothing may be washed in a domestic washing machine in the normal manner. Soiled articles should be processed separately in a hot wash (93°C minimum for ten minutes). Patients should be advised not to share items such as razors and toothbrushes. Females should dispose of used sanitary towels/tampons either by flushing down the toilet or by burning.

For those patients who have AIDS or HIV related illnesses and require nursing care at home, it may be necessary for arrangements to be made with the local authority, for the collection of waste for incineration and for the laundering of infected linen. Staff should ensure that they have supplies of any necessary protective clothing, disinfectants (household bleach, diluted 1:10 with water will suffice) and appropriate disposal bins for 'sharps'. It will be necessary to arrange for incineration of the used 'sharps' at the nearest health clinic or hospital.

Any non-disposable/non-autoclavable nursing equipment used to care for these patients must be decontaminated before re-use, in accordance with advice from the health authority's infection control officer/nurse.

Maternal and neonatal care and AIDS

All women and neonates who are sero-positive or have AIDS will require all the general aspects of care and infection control measures outlined in the guidelines for other such patients.

The following recommendations are for specific aspects of care required by the mother and baby in the antenatal, intra-natal, post-natal and neonatal periods.

A. Antenatal care

1. A policy for testing pregnant women at particular risk may be considered. A counselling service will be required both when discussing the test and if a positive result is received.

2. Unnecessary blood tests should be avoided. Gloves should be worn for venepuncture and giving injections.

3. If admission is necessary, special precautions (see B7 and C4) are only required if there is potential or actual bleeding or rupture of the membranes.

B. Intrapartum care

1. Staff in attendance should wear disposable plastic aprons and gloves during the woman's labour, adding a disposable barrier gown, mask and eye protection, boots and surgical gloves for vaginal examinations, the delivery and perineal suturing.

2. Intrauterine catheters, fetal scalp electrodes and fetal blood sampling are to be avoided, as far as possible, because of a risk of transmission of infection to the fetus.

3. The placenta should be examined in the delivery room. No part of the placenta, cord or membranes should be retained unless on specific medical instructions. The placenta is disposed of as infected material by incineration.

4. If a cord blood specimen is required, full precautions must be taken.

5. Guidelines on spillage of body fluids, operative procedures disposal of soiled linen and sterilisation and disposal of used equipment are as for other sero-positive or affected patients.

C. Postnatal care

1. The woman should have a single room with adjoining toilet facilities.
2. The midwife should wear a disposable plastic apron and gloves when examining the perineal or surgical wounds and when handling bedpans, sanitary towels, breast pads and blood stained bed linen.
3. Breast feeding is contra-indicated and expressed milk cannot be donated to a milk bank, as breast milk may contain HIV.
4. The toilet, bidet and bath should be cleaned after use with one per cent sodium hypochlorite solution.

D. Care of the baby (who has a high risk of maternally transmitted infection)

1. Mucus extractors must not be used. Mechanical suction apparatus must be available for use if suction is required.
2. The baby should be washed in the delivery room, the midwife wearing a barrier gown, gloves and mask and eye protection until all blood has been removed.
3. Disposable napkins should be used, at least for the period that meconium is being passed.
4. Gloves must be worn when providing cord care until the umbilicus has healed.
5. Gloves must be worn when taking any blood specimens from the baby. Specimens must be labelled with a hazard warning to indicate danger of infection.
6. In the event of a stillbirth the baby should be washed (as in D2), hazard labels applied to the wrist and ankle and the shrouded body sealed in a plastic cadaver bag with a hazard tape.

E. The mother and baby at home

1. The community midwife and health visitor who will be visiting the mother and baby at home, should be informed during the pregnancy and again before the mother and baby leave hospital, so that they understand the needs and have any necessary equipment. Guidelines for care in the community are as for other affected or sero-positive patients.
2. Contraceptive advice and counselling must be given, and the woman advised to ensure that her partner wears a condom during sexual intercourse.

Children and AIDS

As yet, most cases of AIDS, AIDS related complex and HIV infection in the UK have occurred in adults, however, increasingly there is awareness of the disease in children.

'At risk' children

Children in the following categories must be considered 'at risk' of acquiring the infection.

1. Children who are nationals of or who have lived in:
Africa; Middle East; USA; Caribbean.
2. Children from the above areas who have received blood transfusions, especially in the neonatal period.
3. Children born to intravenous drug abusers or who are drug abusers themselves.
4. Haemophiliacs and children born to haemophiliacs.
5. Children born to HIV antibody positive mothers.

Clinical aspects

Transmission of infection to children may occur in the following way:
a. Transplacental, or during the post natal period.
b. Transfusion of infected blood or blood products.

Infection resulting from sexual child abuse has not yet been reported.

Evidence from the USA indicates that two thirds of children born to asymptomatic antibody positive mothers will develop clinical symptoms of AIDS by two years of age. Furthermore, pregnancy may activate the virus in the mother and produce clinical symptoms. Pregnancy is, therefore, probably contra-indicated for women who are HIV antibody positive.

Children who have received an infected blood transfusion, especially in the neonatal period, have an increased risk of acquiring AIDS.

AIDS produces a widespread clinical picture in children and neurological rather than immune deficiency symptoms may be the presenting feature. The clinical presentation of AIDS may include one or more of the following:

1. Repeated episodes of infection, especially diarrhoea or candidiasis in association with repeated upper respiratory tract or ear infections.
2. Generalised lymphadenopathy.
3. Protracted diarrhoea and failure to thrive.
4. Children who are neurologically normal for the first year to 18 months of life, then show evidence of regression of milestones or demyelination or spastic paresis.

Breast milk

Breast milk from an infected mother may contain the virus and, therefore, no such milk should be used to breast feed or donated to milk banks. Mothers who fall into an 'at risk' group should not be encouraged to donate breast milk to human milk banks.

Immunisations

Children who are HIV antibody positive or who have AIDS should not be given live viral vaccines. BCG should also not be given.

Schooling

About 30-40% of haemophiliac children in the UK have been found to be HIV antibody positive, though wide variations exist. Since current evidence shows there to be no risk of transmitting HIV infection in the school setting, the child should be allowed to attend school freely and be treated in the same way as other pupils. Alteration in intellectual or physical performance should alert school staff to the possibility of psychological or neurological problems.

Counselling and confidentiality

Parents of HIV antibody positive children need to be aware of the potential for social isolation if the child's condition becomes known to others in the school. Those involved in educating and caring for these children should be sensitive to their need for confidentiality and their right to privacy.

It must also be emphasised that both parents and the child will need support and counselling and this is also likely to be needed by teachers and others involved in the direct care of the child at school. The number of people aware that a child is infected should be restricted to those who need to know, to ensure the proper care of the child when conditions, such as bleeding, arise.

Young and handicapped children

Young children who are HIV antibody positive but are not handicapped, can be placed in nursery schools or nursery classes or in whatever other provision would be appropriate. Where a child is antibody positive and developmentally delayed or handicapped, these facts will be taken into account along with medical and nursing advice to the local education authority. This complies with the educational needs of each individual child under the requirements of the Education Act 1981.

Incontinence

Good hand hygiene, along with disposable plastic aprons and gloves should be worn as protective clothing. Urine and faeces should be discarded into the toilet in the normal manner. In the community, potties should be washed and dried with a paper towel after use. Soiled waste, ie nappies and pads, should be incinerated. If this cannot be done, the rubbish, including protective clothings, should be placed in yellow plastic bags and effectively secured. Arrangements should be made with the appropriate local health authority for collection of waste for incineration.

Biting

Habitual biters of any age will pose a problem. Some will be in community care and most may be severely mentally handicapped. These children should be individually assessed.

Toys

The sucking of thumbs or mouthing of toys or chewing of pens or pencils is not considered a risk.

Children's games and social practices

Sometimes children wish to confirm friendship with one another by cutting or pricking the skin and mingling their blood (blood brothers/sisters). Games such as these should be strongly discouraged.

Education

Schools can contribute to the general level of knowledge and awareness of AIDS through health education.

Hospital admission

Children must not be put into isolation just because they are antibody positive. Children may be classified in the following way:
1. Those who are antibody positive and who have persistent generalised

lymphadenopathy without immune suppression. This group of children need only be nursed in isolation in the following circumstances:

a. If external bleeding occurs or is likely to occur.
b. If diarrhoea is present.
c. Following surgery.

The child should be allowed out of isolation as soon as they have recovered from the above.

2. Those who present with the clinical syndrome suggestive of AIDS or AIDS related complex. This group of children should be nursed in single room isolation. Parent accommodation should be made available.

Part 2
Guidelines for Care

Introduction

Patients with AIDS present nursing with innumerable challenges. They are suffering from a rare and highly publicised disease which will be of great interest to everyone. Patient advocacy is essential if they are to be protected from unwarranted intrusion into their privacy and personal space.

Developing a terminal illness early in life and for which medical science can offer little hope at the moment has a devastating impact upon the patient, his family and significant other. This loss of hope puts enormous responsibilities on the deliverers of nursing care to ensure that the care and support they give is of such a high standard that it ameliorates this sense of hopelessness and offers the best possible quality of life.

Much of the fear experienced by patients is due to their not knowing what is being done to them. Simple explanations of procedures and nursing care will alleviate this and help involve them in their own care and gain their co-operation.

The disease

When patients with AIDS become immune-deficient/compromised and thus prone to infection, they usually develop what are known as opportunistic infections caused by organisms which live within all of us but cause no problems while the cellular immune ratio remains intact. The list of infections to which AIDS patients are prone may usefully be grouped into four categories:

1. Protozoan agents — including Pneumocystis, Toxoplasmosis, Giardia, Entamoeba and Cryptosporidium.

2. Viruses — including Herpes simplex, Cytomegalovirus, Epstein-Barr virus and Hepatitis 'B' virus.

3. Bacterial agents — including Salmonella, Shigella, Myco-bacterium avium intracellularae, Pulmonary nocardiosis and Legionella pneumophilia.

4. Fungal agents — including Cryptococcus neoformans, Aspergillus, Histoplasma capsulatum and Candida albicans.

In addition patients may succumb to tumours which are viral in origin, such as Kaposi's sarcoma and non-Hodgkin's lymphoma.

Nursing interventions

In order that nurses can plan their nursing interventions effectively to minimise the effects of any of the previously mentioned infections, these are listed below showing the sites of infection and the symptoms that these may produce:

Protozoan agents

Agent	Sites of Infection	Symptoms
Pneumocystis carinii	Lungs	Pyrexia, dry cough and dyspnoea
Toxoplasma	Brain, lymph nodes, blood	Severe headache, cerebral changes with epileptiform attacks, confusion, pyrexia, lymphadenopathy
Giardia lamblia	Intestine	Anorexia with concomitant loss of weight, nausea, vomiting and diarrhoea
Entamoeba histolytica	Intestines, liver	Anorexia with concomitant loss of weight, diarrhoea, nausea, frank blood in stools, jaundice
Cryptosporidium enteritis	Intestine	Severe diarrhoea

Viruses

Agent	Sites of infection	Symptoms
Herpes simplex	Mouth, genitalia, buttocks, hands, brain	Cerebral changes, with confusion, epileptiform attacks, coma, fever, skin lesions, lymphadenopathy, perianal lesions, mouth clusters

Cytomegalovirus	Lungs, liver blood, lymph nodes, eyes, gut, urine	Pyrexia, cough, dyspnoea, severe stomach pains, lymphadenopathy, blindness
Epstein-Barr	Blood, brain, lymph nodes, liver	Pyrexia, lymphadenopathy liver malfunctions, tumour formation
Hepatitis 'B'	Blood, liver, joints	Jaundice, swollen joints with severe pain, pyrexia, anorexia, intolerance of alcohol. Many patients will be asymptomatic

Bacterial agents

Agent	Sites of Infection	Symptoms
Salmonellae	Blood, intestine	Fever, rigor, diarrhoea, skin rashes
Shigella species	Intestine	Diarrhoea, frank blood in stools, pyrexia
Mycobacterium avium intracellularae	Liver, lymph nodes, spleen, bone marrow, lungs	Excessive perspiration, pyrexia, liver malfunctions, lymphadenopathy, cough with copious sputum
Nocardia sp	Lungs	Dyspnoea with severe pain, pyrexia, cough, haemoptysis
Legionella pneumophila	Lungs	Pyrexia, cough, dyspnoea

Fungal agents

Agent	Sites of infection	Symptoms
Cryptococcus neoformans	Skin, lungs, brain	Headache, general rigidity, dyspnoea, cough, pyrexia, cerebral changes leading to mental confusion
Aspergillus species	Lung, brain, blood	Cerebral changes, epileptiform attacks, confusion, cough, haemoptysis, headache, pyrexia
Histoplasma capsulatum	Skin, lungs, lymph nodes	Marked weight loss, pyrexia, excessive perspiration, cough, lymphadenopathy, skin rashes
Candida albicans	Mouth, throat, eyes, genito-urinary tract, oesophagus, gut	Typical white rash in mouth, tenderness and painful swelling of the gums, dysphagia, chronic eye infections, blindness

The nursing care plan for a patient with AIDS must be as complete and personalised as possible to meet the total individual needs of that patient and to prevent, whenever possible, the sequelae of his disease. Early nursing interventions will help minimise some of the side effects of the opportunistic infections that can be seen. The problems encountered by patients with AIDS will be many and varied and listed here are just some of them with suggested interventions.

1. Respiratory infections

Note the patient's ability to clear his airway in the normal way, if unable, intervene using sterile suction catheter as described in Part 1. Observe patient's repiratory ability: is he short of breath, or distressed on exertion? Observe and note skin colour and nail beds. Introduce physiotherapy, coughing and deep breathing exercises as early as possible. Carry out postural drainage when necessary.

2. Nutrition

Many patients with AIDS suffer severe weight loss, and often anorexia. Allow, whenever possible, the patient to eat what he likes, when he likes, while trying to introduce good nutritional routines. Small, frequent feeds which are low in residue and high in calorific and protein value are often well tolerated, especially if they are well presented and in small amounts. In extreme cases give total parenteral nutrition or naso/gastric tube feeding. Liaise closely with dietician/nurse nutritionalist.

3. Diarrhoea

This can be an extremely distressing feature of this illness. Good nutrition (as above) should be encouraged and, where appropriate, anti-diarrhoeal agents administered. Meticulous care of the anal region should be carried out following voiding and a light coating of petroleum jelly applied to prevent soreness.

Patients with stomas

Where the patient has had a stoma for some time, he will be accustomed to changing the appliance and caring for his own stoma, and should be encouraged to continue. The stoma care nurse should be advised of his admission to hospital, or to community care, so that should there be any change in body shape following weight loss, the stoma care nurse will advise the patient on a more appropriate appliance.

At such times when the patient, because of his illness, can no longer care for his own stoma, disposable plastic aprons and gloves should be worn. Bags, wipes and so on, should be incinerated and any contaminated linen or clothing coped with as described in the text.

4. Mouth infections

The buccal mucosa is easily damaged providing an ideal focus for infection. Appropriate and regular mouth care should be instituted as early as possible and, where possible, carried out by the patient who should be made aware of the principles of mouth care. Encourage the use of soft children's toothbrushes, dental floss and mild mouthwashes.

5. Skin care

Good skin hygiene will prevent the build-up of surface bacteria which could present a threat to the immune-deficient/compromised patient. Encourage the patient to bathe or shower daily using a pure soap and soft flannel or sponge. The moisture of the skin should be maintained by the appropriate use of baby lotion or similar substance.

6. Generalised infections

These may be minimised by meticulous care of those areas where invasive procedures have been carried out. These include intravenous and central venous sites, wound sites, following exploratory investigations, injection sites, in-dwelling catheters and naso-gastric tubes. Any pyrexia of unknown origin should be stringently investigated so that early interventions can be instituted to prevent the rapid onset of septicaemia.

Patients who are immune-deficient/compromised should be advised to stay away from crowded and smokey places. Nurses who have infections must not be allowed to nurse immune-deficient/compromised patients.

7. Cerebral symptoms

These may include personality changes, alteration of intelligence quotient, early dementia and fits. Such patients will require a great deal of sympathetic reassurance and support. Memory lapses and bizarre behaviour should be handled with kindness and tact. Where necessary, appropriate referrals to a psychiatric nurse, psychologist or psychiatrist should be made.

8. Depression

Depression is not an uncommon side-effect of this disease and may be helped if the nurse takes time to listen to the patient's fears. False reassurances should be avoided. His mental state may be improved if he is made a partner in his care. The patient should, whenever possible, be encouraged to mix with others to take exercise within the limits of his capabilities. This will help prevent debilitation, to improve his appetite and to give the patient an increased sense of well-being. Where necessary engage the assistance of nurses qualified in the care of the

mentally ill, who will be able to suggest appropriate strategies in combating depression.

9. Isolation

Isolation both at home and in hospital can be a predisposing factor to depression. Patients who are not at risk themselves or a risk to other patients need not necessarily be nursed separately. Where patients are nursed in isolation in hospital the nurse should spend as much time as possible with them with few physical barriers between them. Encourage the patient's visitors to evolve some kind of rota system for hospital visiting so that much of the patient's day will be occupied by people he wishes to see. This sense of isolation may be further exacerbated if rejection by family and other members of the gay community has occurred. This sense of aloneness will be perhaps more marked after the patient has left hospital. The Terrence Higgins Trust is operating a 'buddy volunteer' programme which may be useful in such circumstances. Requests for help can be addressed to the Trust (see appendix 3).

10. Kaposi's sarcoma lesions

Kaposi's sarcoma in AIDS resembles the African form of the disease. The lesions may be small, like petechiae, purplish in colour, or may initially be confused with unresolved bruising. Some lesions may be raised, nodular and heavily pigmented.

Kaposi's lesions can appear anywhere on the skin or mucous membranes, and as with any cancer, can spread to sites of visceral involvement, causing local and systemic complications. Common involvement is seen in the lymphatic system, gastro-intestinal tract, spleen, lung, liver, pleura and heart, which may lead to pain and obstruction or perforation in gastro-intestinal tract.

The skin lesions may be treated with radiotherapy. Usually this is a palliative treatment, comprising of a single shot (c.800 cGy) of radiation from a superficial X-ray machine to any skin lesions which are particularly distressing or disfiguring. Radiotherapy is also used to relieve pain from any tumour site. The recommended precautions for nursing care (Part 1) are applicable when radiotherapy is given.

In advanced disease, the lesions may spread to cover the patient's entire body and understanding the change in appearance he is experiencing will require great sensitivity from the nurse. Normally, the lesions will not require any dressing or specific care. If any exudate appears, the precautions in Part 1 should be followed.

Community care

There is a great need to ensure that the knowledge required to care for persons with AIDS in the community is made available to all care providers. Not unnaturally, most patients often prefer to be cared for at home. Dearth of information, irrational fears and lack of support for carers all too often mitigate against this, confining the patient unnecessarily to hospital. These problems are surmountable given good leadership and example.

Discharge

Liaison between hospital and community is paramount in achieving good community support/care. Early involvement of community staff to assess patient needs in the community will facilitate effective planned discharge. Patients with AIDS must be assessed with the same consideration offered to all other patients.

Support at home

If patients are made partners in their care while in hospital and taught how to care for themselves in order to remain well for as long as possible, then the role of the community nurse and other support services will be to ensure this self-care is continued and positive reinforcement is offered.

Community nurses must, during the well phase of the patient's time in the community, assume the role of 'permission giver'. The most important aspect of this will be permission to go on living as normal a life as possible. There is no reason why patients in the community should not lead as full a life as they are able, including a full range of social activities, such as visits to the pub, theatre, cinema. Obviously, they should be advised to attend these places when they are least crowded: early evening, or theatre matinees.

To remain well as long as possible patients should ensure that their self-care is effectively carried out, the most important aspects being: well balanced diet, good personal hygiene, gentle exercise within the limit of their capabilities and rest and sleep.

Teamwork

Care in the community setting requires total team involvement. Nurses, general practitioners, social workers, home helps and local government officers will need to participate as appropriate. Some patients will

require little or no assistance, others will require the full range of support services.

Problems may include housing, which is inadequate due to age, or in need of modification. Some patients may have been evicted.

There may be grave financial problems due to a multiplicity of reasons; for example, need for additional nutrition, loss of employment, or a partner losing time from work to help with caring.

Patients may be reluctant to raise such issues, and because they are not mentioned it should not be assumed that they do not exist. Entitlements should always be explained and offered.

Household contacts

It is perfectly safe for patients to return to home and family when well enough. Studies show that household contacts who are not sexual partners are at minimal or no risk of infection with HIV.

Confidentiality

The section in this document on confidentiality applies to both hospital and community.

11. Terminal care

The physical, emotional and spiritual needs of a dying patient are variable. He may need specialised clinical management, with palliative treatment offered, but also time and freedom for discussion with supporting staff, close friends and family.

Where possible, the decision of 'where to die' should be left to the patient, his friends or family. Home care is often preferable, allowing him much more control and freedom to relax among those close to him. Local authority and community services should be closely involved with any planning and contact maintained between hospital and community staff. When necessary, nurses specialising in terminal care should be consulted for advice in the management of difficult problems.

Ethical considerations — treatment in a critical care environment

Patients suffering from AIDS will have probably spent some, if not many, months in the full knowledge that their illness is fatal and that any treatments are only palliative. Generally, the condition which causes death in a critical care environment is Pneumocystic Carinii (PCP), this by respiratory failure. As with the onset of all terminal conditions,

clinical staff are prone to debate the best option available. The options under discussion may well include aggressive supportive therapy in an intensive care unit, as well as gentle, considerate help towards a peaceful death.

The first option is worthy of some study. Supportive treatment is generally an interim measure, while a curative therapy is used. However, if all available treatments have been exhausted, this must be discussed with the patient and anyone else he wishes to be involved. It would be unusual for a person, who has, hopefully, considered the implications of his disease, to wish to die in a place such as an intensive care unit. However, if all available treatments have not been exhausted, and a holding operation is desired, then the transfer of the patient to an intensive care unit should be avoided. To avoid distress to patient and family, which might be caused by such a move, it would be wise to ventilate, dialyse, feed parenterally and so on in the patient's existing unit. Careful thought must be given to considerations of this kind, always bearing in mind the best interests and wishes of the patient.

12. Symptom control

While it is unreasonable to suggest that all symptoms can be completely controlled, the patient with AIDS requires continuous effort to lessen the various problems which arise from advancing disease. There should be constant monitoring and modification on a daily basis. In areas where a Macmillan Nursing Service or hospice exists, their advice may be valuable.

The numerous books and articles written recently on pain control stress the importance of regular analgesia at a level which gives adequate pain relief. This may necessitate the use of strong narcotics on a regular basis, not 'as required'. The use of morphine or diamorphine is often indicated and is preferable to shorter acting drugs (for example, pethidine, dextromoramide). Other symptoms, for example, nausea and vomiting, constipation, shortness of breath, lethargy, thrush and so on, should each be reviewed regularly and prescriptions altered accordingly.

13. Chemotherapy/radiotherapy

When cancers of a viral origin arise there may be an attempt to control these using chemotherapy and/or radiotherapy. This is not without hazards in an already immune-deficient/compromised patient. The nursing implications of such treatments and the care these patients will require are dealt with in numerous specialist books which are listed in the appendix.

14. Drugs

There are numerous drugs used to treat the sequela of AIDS. Dosage and routes of administration may vary between centres, and the following notes constitute brief guidelines only. The data sheet for each product should be consulted for complete information.

Cotrimoxazole (Septrin)

Used in high dose to treat Pneumocystis carinii. Dose is usually given intravenously to begin with and oral therapy substituted later where appropriate. The usual duration of the course is two weeks.

Side effects: nausea and vomiting, diarrhoea, rash, blood dyscrasias (less common), glossitis.

Cautions: contra-indicated for patients hypersensitive to cotrimoxazole, trimethoprim or sulphonamides; patients with severe liver damage; patients with severe haematological disorders. Care with fluid overload and in renal failure. May need to give a folate supplement. NB: Septrin is also available as an intra-muscular preparation which should not be used intravenously.

Pentamidine

Used to treat PCP. Can cause serious side-effects which may lead to drug treatment being discontinued.

Side effects: pentamidine may also cause itching, hypoglycaemia, changes (minor and transient) in liver function.

Cautions: may cause marked hypotension, tachycardia and facial flushing. May have significant effects on clotting and fibrinolytic systems. Twenty-five per cent of patients have raised BUN occurring 5-14 days and returning to normal or pre-treatment levels 17-30 days after the start of treatment. Daily BUN and serum transaminase determinations have been recommended in the presence of impaired renal and/or hepatic function. The drug may have to be withheld if the measures rise without other likely explanation, therapy being resumed on return of these values to acceptable levels.

NB: Two cases have been recorded from the USA where it was thought that death could have been due to pentamidine.

Nystatin

Used in oral suspension for prevention and treatment of candida infections of oral cavity, oesophagus and gastro-intestinal tract.

Side effects: nausea, vomiting and diarrhoea occasionally reported, with doses above 4-5 million units daily. Otherwise no toxicity.

Acyclovir IV

Used to treat Herpes simplex and varicella zoster in patients with impaired immune responses.

Cautions: contra-indications if patient known to be previously hypersensitive.

Extravasation causes severe local reaction. Probenecid increases the half life of the drug.

Acyclovir tablets: used to treat mild Herpes where suitable, or for prophylaxis. It is poorly absorbed from the gut (20 per cent of dose).

Interferons

Used to boost immune system.

Presentation: Human Interferon a (leucolyte) 5,000 units/amp; B (fibroblast) 10,000 units/amp; y (type II and II F trial form).

Administration: must be given intramuscular or intravenously.

Side effects: pyrexia, shivering, malaise, fatigue, anorexia, pain and erythema at injection site. Some mild hair loss. Myelosuppression.

Ketaconazole

Used as effective oral broad spectrum anti-fungal agent.

Administration: oral. Should always be taken with meals.

Side effects: gastric upset, rash, headache and pruritis, can induce liver damage.
Cautions: Absorption is dependant on stomach acidity, therefore concomitant treatment with agents that reduce gastric secretion (antacids, H2 blockers and anticholinergic drugs) should be avoided.

Amphotericin

Use intravenously to treat systemic fungal infection.

Side effects: may include anorexia, fever, thrombophlebitis, nausea, hypokalaemia, nephrotoxicity, tinnitus.

Cautions: total daily dose of 1.5mg/kg should not be exceeded.

Blood Urea and Nitrates — serum creatinine should be checked

regularly and therapy may have to be interrupted if raised.
Where prolonged therapy is taking place, liver and bone marrow function should be monitored.
Corticosteroids should not be administered concomitantly unless necessary to control drug reactions.

Nephrotoxic drugs should be avoided.

NB: Do not administer within at least 12 hours of white cell infusion, as this may lead to pulmonary complications.

Part 3
Support

More than any other condition in recent years, AIDS/HIV infection has highlighted serious deficiencies in the ability of some nurses to meet the psychological needs of their patients. It is believed that this is due to a failure in basic nurse education in covering the essential nursing skills of developing interpersonal relationships, counselling, and understanding the lifestyles of others. At post-basic level there is a dearth of courses dealing with counselling and communication skills. Therefore, all those involved, patients, families, partners and nurses will require help, encouragement and support to combat the many problems facing all concerned.

If nurses are to be used to maximum efficiency in caring for these patients and other patients with high psychological dependencies, then much more emphasis during nurse training must be placed on counselling skills.

In this section as many of these problems as possible are highlighted and ways of dealing with them are suggested.

Nurses

When caring for patients with AIDS/HIV infection nurses may be coming into contact for the first time with lifestyles with which they are not completely familiar or may have formed opinions vicariously. It is essential that staff should be aware of their own feelings with regard to homosexuality, bi-sexuality or drug addiction before entering a situation where a patient may feel the need to discuss his life. To show any embarrassment or disgust to these patients may prevent them from confiding in other staff members for fear of rejection. It is essential that all those involved in the care and support of these patients realise that their initial and on-going attitudes may greatly effect the psychological outcome for these patients.

Many of these potential problems can be helped by good senior nurse and ward sister management, by encouraging nurses to discuss problems with them and working together to find solutions. It is necessary, when AIDS/HIV patients are admitted to a ward, for those in positions of leadership to ascertain the level of knowledge possessed by staff about the patient's lifestyle and to give further knowledge to dispel any misconceptions they may possess. In-service study days should be organised for all nursing staff and these should include input on lifestyle as well as the more technical aspects of the disease.

Support groups for nurses working with AIDS patients are of great importance. If 'official' support groups are not practical due to poor

nurse staffing levels, or a lack of suitably qualified people to conduct them, then regular informal meetings with the staff can help to reduce stress and tension in these areas.

A tremendous burden is placed on nurses caring for these patients, not only in understanding lifestyles and in supporting a relatively young patient population through an illness which at present has an extremely gloomy prognosis, but also to support family, friends and significant others, all of whom need expert care during their bereavement.

Nurses cannot be expected to offer this support if they remain unsupported. This places an increased responsibility on senior nurses to ensure that adequate knowledge and support is available for staff and for them to act as a role model. Similarly, senior nurses who require help in meeting these responsibilities must be given help and support by their superiors.

Some further reading which may be helpful in understanding patients' lifestyles is suggested in the appendix.

Patients

Due to coverage in the media, there can be few patients who are unaware of the high mortality associated with this illness. Many patients diagnosed as suffering from AIDS/HIV infection feel that they have been given a potential 'death sentence' along with the diagnosis.

Many of these patients will have been under investigation for several months before confirmation of diagnosis and their immediate reactions may well be inappropriate ones of relief and acceptance. However, nursing staff must be fully aware that these feelings may quickly change to those of anger, denial and 'why me'? Some patients may withdraw completely from family and friends, either anticipating rejection or fearing they may transmit the disease. When this occurs they will require much counselling and psychological support from their care givers.

For all patients with a confirmed diagnosis of AIDS sexual activity will have to be restricted in the long term and may present them and their partners with considerable difficulties. It is essential that the nurse ensures that the patient fully understands that these restrictions are not only to protect contacts, but also himself from the risks of further infections and to do so in such a way that the patient's feelings of rejection are minimised.

There are an increasing number of people likely to be at risk in the United Kingdom at the present time, all of whom will need different kinds of support. For ease of reference an attempt to highlight their individual problems and needs has been made. Though it must

be borne in mind at all times that HIV is now spreading to all sections of society.

Haemophiliacs

It would be unnatural for this group of patients not to express great bitterness at acquiring this disease. As far as the working party is aware, all haemophiliacs suffering from AIDS/HIV infection have contracted the condition via blood products (mostly factor VIII) which are essential to their continued health and well-being. They will very likely feel that nature has been unfair to them and will need a great deal of support to enable them to abreact these feelings and come to terms with the myriad of additional health problems this disease places upon them.

Their wives, partners and families will also need astute counselling and support. Having supported the patient through one life threatening illness they are now faced with a new set of health problems from which their loved one may not recover.

Anger and bitterness at the unknown donor of contaminated blood products are not unnatural reactions and the role of the nurse must initially be to allow full expression of these feelings before attempting to direct the patient's aggression into more worthwhile channels.

The immense skills of the Haemophilia Society must be fully utilised in the care and support of these patients.

Injecting drug users

There are many physical and psychological problems associated with injecting drug users and the physical aspects will need to be stabilised first. If the patient is attending a general practitioner, hospital, or receiving drugs from unit source his intake of substances must be maintained if compliance in his care is to be achieved. It does not seem appropriate or timely to wean him from his addiction while he is having treatment for his disease. Such attempts at controlling these aspects of his health will have to be postponed to a later date, in order to ensure maximum care and treatment for his AIDS.

Once the patient is stabilised it will be necessary first of all to meet his psychological needs. He may be suffering feelings of remorse and guilt that his drug abuse has brought him to this and he may well be feeling twice an outcast: as a drug abuser and an AIDS sufferer. He may require psychiatric help and the support of social work agencies before discharge.

Female drug users, or the female partners of drug users who have become pregnant, and are HIV antibody positive, will have many

problems which the nurse/midwife must attempt to help resolve. They may well know that the possibility of their developing AIDS is greatly increased after pregnancy, and they will have the same fears as all other potential sufferers. In addition, they may have severe guilt feelings at the very real possibility of delivering an infected child which may fail to thrive. These patients will need a great deal of support, skilled help and counselling.

Expert advice and information can be obtained from the Standing Conference on Drug Abuse — see appendix 3.

Homosexuals/bisexuals

Until now the majority of AIDS sufferers (HIV infected persons) in the United Kingdom have been homosexual. Some of these patients will be well adjusted in their sexual orientation, while others will be more secretive, fearing the disapproval of society towards their lifestyle. Thus, confirmation of an AIDS diagnosis may reveal details of their private life which they would wish to remain secret, adding further psycho-logical suffering which could result in expressed anxieties.

1. Feelings of guilt about their homosexuality.
2. Guilt at the possibility of having passed on the infection.
3. Fear of family and employer discovering their homosexuality.
4. Fear of rejection by society — both homosexual and heterosexual.

In addition the patients will have to come to terms with the fact that they are in a potentially life-threatening situation and will require careful guidance and counselling to help negotiate the enormous number of problems they face. This can only be achieved if all those involved in their care understand their lifestyle and refrain from making judgements on it. There are books which will aid this understanding, and make the nurse's role easier.

The interaction between nurse and the patient's lover/family/wife/friends will also affect how the patient views his care giver and may be beneficial or detrimental, depending on how well such relationships are handled.

Relationships

Partner

The patient may have a permanent partner — a lover, husband or wife, and it is important that the nature of this close relationship is appreciated by members of the staff. Excluding the partner can cause many problems and a great deal of distress to everyone concerned.

Therefore, the partner's address and telephone number for contact

in emergency should be obtained and displayed prominently on the patient's notes. It is important to establish good communications with the partner and to involve him at an early stage in the care of his loved one. A partner will have other grave concerns which nurses must be able to help him with — 'Have I got AIDS?', 'Will I die?', 'Who will look after me?', 'Can I ever have another relationship?'. There is a very real danger that the future for the partner will be lonely, unfulfilled and very threatening unless his fears are alleviated and he is well supported.

The family

In attempting to meet the needs of the partner, the care of other close members of the family must not be overlooked. They too may be faced with many problems and adjustments.

Some parents may know of their children's sexual orientation and have come to terms with it. They should be encouraged to express their feelings and be given all the help and support they need.

The onset of this illness may make parents aware for the first time of the sexual orientation of their child, and they will need help and support in coming to terms with this and would wish to have further information. Nurses should be able to put them in contact with those who can help them find an understanding.

The patient's chosen lifestyle may, at some point, have alienated family and close relatives. They may display varying emotions when confronted with their child's diagnosis and prognosis; this may range from anger and complete rejection of the patient to total acceptance with great guilt feelings at their previous rejection of their son. It is important that the reaction of parents and family towards the patient should be carefully monitored and support and explanations be available at all times.

Friends

The patient will very likely have a broad spectrum of friends. They should be encouraged to visit and help support the emotional needs of the patient. They are only likely to do this if they are made to feel welcome in the ward.

The nurse must ascertain exactly what the patient has told his friends about his illness and answer their enquiries accordingly.

Wives

Some AIDS sufferers are bi-sexual and may be married. If the patient also has a regular male lover this may place the nurse in a very difficult situation regarding the giving of information. Wherever possible the nurse should be guided by the patient as to who receives what information. It is, however, essential that the nurse records the

information given to prevent a breakdown in communication between colleagues.

The news of this illness will be a tremendous blow for the wife who will share many of the feelings of the patient's male partner. In addition, she may feel that she is being viewed as inadequate in the handling of her personal relationships. Nursing staff can do much to assuage such fears by sympathetic and tactful handling of the situation. Any children of the union may also be made aware of their father's sexuality, and this will require very sensitive help and support.

There is, of course, the additional problem that the wife may also be infected with HIV. If this is so, then she will require the full scope of help and counselling skills advocated for all infected persons.

Appendix 1
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Appendix 2
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Appendix 3

AIDS/HIV Support Groups

There follows a list of support groups dedicated to persons with AIDS or HIV infection. As new groups are frequently being formed, the list is by no means exhaustive, and if a group is not listed for your area or region, check with your local genito-urinary medicine clinic (STD), which may have knowledge of local groups.

East Anglia Region
Cambridge AIDS Help Group,
287 Newmarket Road,
Cambridge CB5 8JE.

Mersey Region
Merseyside AIDS Support Group,
63 Shamrock Road, Birkenhead,
Merseyside L41 0EG.
Telephone line: 051 7080234. Wed 7-10 pm.

Northern Region
AIDS North,
P O Box 1BD,
Newcastle Upon Tyne NE99 1BB.

Northern Ireland
Cara-friend,
P O Box 44,
Belfast BT1 1SH.
Telephone lines: Belfast 222023. Mon-Thurs 7.30 pm — 10.00 pm.
Londonderry 263120. Thurs 7.30 pm — 10.00 pm.

North Western Region
Manchester AIDS Line,
P O Box 201,
Manchester M60 1PU.
Telephone line: 061 2281617. Mon, Wed, Fri 7-10 pm.

Oxford Region
OXAIDS, c/o Harrison Department,
Radcliffe Infirmary,
Oxford.
Telephone line: 0865 246036. Wed 6-8 pm.

Oxford Body Positive,
Freepost, Nether Westcote,
Oxford OX7 6BR.
Telephone line: 0865 246036.

Reading Area AIDS Support Group,
P O Box 75, Reading,
Berkshire.
Telephone line: 0734 503377. Thurs 8-10 pm.

Milton Keynes AIDS Support Group,
P O Box 153, Wolverton,
Milton Keynes.
Telephone line: 0908 312196. Mon 7-9 pm.

Scotland
Scottish AIDS Monitor,
P O Box 169,
Edinburgh, Scotland.
Telephone line: 031 5581167. Tues 7-10 pm (ansaphone at other times).

AIDS Information and Counselling Service,
129 Kilmarnock Road,
Shawlands, Glasgow G41 3YT.

South Western Region
Aled Richards Trust,
2 Cliftonwood Crescent,
Cliftonwood, Bristol BS8 4TU.
Telephone line: 0272 276436. Thurs 7-10 pm.

Thames Regions
North East Thames
Camden AIDS,
Area Three Social Services,
West End Lane, London NW6

PASAC, P O Box 130,
Colchester, Essex.
Telephone line: 0206 560225. Mon, Wed 7-9 pm.

North West Thames
Bedford Gay Helpline,
38 Cherry Walk, Kempston,
Bedford.

South East Thames
Medway and Maidstone Gay Switchboard,
P O Box 10C,
Chatham, Kent ME4 6TX.
Telephone line: 0634 826925. Thurs/Fri 7.30-9 pm.

Sussex AIDS Helpline,
P O Box 17, Brighton BN2 5NQ.
Telephone line: 0273 734316. Mon-Fri 8-10 pm.

South West Thames
CALM, P O Box 11,
Bognor Regis, West Sussex PO21 1AH.
Telephone line: 0243 776998. Mon, Wed, Fri 7-9.30 pm

Trent Region
Nottingham AIDS Info Group,
Sharespace, 49 Stoney Street,
Nottingham.
Telephone line: 0602 585526. Mon, Tues 7-10 pm.

Wessex Region
Bournemouth AIDS Support Group,
P O Box 263,
Bournemouth BH8 8DY.
Telephone line: 0202 38850. Mon, Tues 8-10 pm.

Solent AIDS Line,
P O Box 139,
Southampton, Hants.
Telephone line: 0703 37363. Tues, Thurs, Sat 7.30-10 pm.

West Midlands
AIDS Concern Midlands,
79 Stanmore Road,
Edgbaston, Birmingham B16 9SU.
Telephone line: 021 6221511. Tues 7.30-9.30 pm.

Yorkshire Region
Bradford Gay Switchboard Collective,
643 Littlehalton Lane,
Bradford BD5 8BY.
Telephone line: 0274 42895. Sun, Tues, Thurs 7-9 pm.

Leeds AIDS Information and Counselling Service,
11 Plaintree View,
Shadwell, Leeds 17.

Leeds AIDS Line,
64-68 Call Lane,
Leeds LS2.
Telephone line: 0532 441661. Tues 7-9 pm.

West Yorkshire AIDS Support Group,
1 Cambridge Street,
Hebdon Bridge, West Yorkshire HX7 6LN.

Irish Republic
Gay Health Action,
10 Fownes Street,
Dublin 2, Eire.
Telephone line: Dublin 710939. Mon-Fri 11 am-4 pm.

National Groups
The Terrence Higgins Trust,
BM AIDS,
London WC1N 3XX.

The Terrence Higgins Trust is a registered charity which offers help and advice to AIDS sufferers and their significant others. In addition, they offer a 'buddy volunteer' scheme, for people living in London, aimed at befriending and helping those with AIDS. Telephone number: 01-278 8745.

Body Positive,
BM AIDS,
London WC1N 3XX.

Body Positive is a national support and advisory group for those infected with the HIV virus. It is entirely voluntary, and operates from a base in London.

The Haemophilia Society,
P O Box 9, 16 Trinity Street,
London SE1 1DE.
Telephone number: 01-407 1010.

The Haemophilia Society offers help, advice and support to those persons suffering from haemophilia, and their families.

Standing Conference on Drug Abuse (SCODA) Ltd,
1-4 Hatton Place, Hatton Garden,
London EC1N 8ND.
Telephone number: 01-430 2341.

SCODA co-ordinates activities of non-statutory agencies in the drug field. It also publishes detailed guides to specialist drug services throughout the country.

The Nurses Support Group,
53 Mirlees Court, Camberwell,
London SE5 9QW.
Telephone number: 01-274 5442.

The Nurses Support Group offers advice and help to health care providers with HIV problems.

London Lighthouse,
178 Lancaster Road,
London W11 1QU.

London Lighthouse is a charitable project to establish a hospice incorporating a small residential unit to act as a continuing care facility for those persons with AIDS. In time, it will provide a counselling, training and information service.