

# **CARING FOR PATIENTS WITH AIDS**

**A nursing and other  
support service perspective**

**Compiled by the  
Department of Nursing Science  
Unisa**

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## FOREWORD

Aids is one of the most devastating health problems that has ever faced the world. All members of the health and social services professions as well as all citizens have a duty to help contain its spread.

The Rectorate of this University assisted the Department of Nursing Science to initiate its ongoing contribution to combating Aids, by sponsoring a Symposium on Aids, and by financing the visit of an internationally known keynote speaker from overseas. The Symposium is but the beginning of the work of nurses in the campaign against Aids. It was designed to alert nurses to their responsibilities. I believe it has done so in great measure.

Our role as nurses is a three fold one :

- \* education of the public about Aids and its health and social related problems;
- \* education of nurses and midwives on how to fulfil their educational and caring roles;
- \* providing safe and humane nursing care.

Our request is that each one who receives this publication will involve him or herself in the work that needs to be done. Stopping Aids is up to each one of us, our families, our loved ones, our friends and acquaintances.

**If every health professional practices and teaches responsible behaviour based on understanding of this vicious condition and on strong personal values, AIDS can be stopped.**

**Charlotte Searle. D Phil, RN., RM.**

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1.

## **AIDS AS A NATIONAL HEALTH PROBLEM**

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The first reports of the acquired immune deficiency syndrome (AIDS) came from the United States in 1981 and since then 72 004 cases from 128 countries have been recorded by the World Health Organization. It is believed that between 5-10 million people worldwide have been infected with the causative virus. In South Africa 98 cases have been reported since 1982, 76 of them being South African citizens. Three black South Africans have recently been diagnosed as having AIDS and a small number of blacks have been shown to be infected with the virus. It is thus obvious that AIDS is spreading in South Africa and every medical practitioner should be aware of the facts of the disease so that he is capable of diagnosing the disease, taking care of the patients and educating the lay public in AIDS prevention. The essential facts of this disease are presented here.

### **DEFINITION**

AIDS is a syndrome of opportunistic diseases, infections and certain cancers, occurring in people with acquired immunodeficiency following an infection with the human immunodeficiency virus (HIV).

### **AETIOLOGY**

AIDS is caused by a retrovirus currently known as the human immunodeficiency virus. It is a RNA virus which has to revert to its DNA form to replicate. This it does through the presence of an enzyme called reverse transcriptase. The HIV is a slow

growing virus giving lifelong infection and it has an affinity for lymphoid cells, that have the CD4 receptor on their plasma membrane. The main cell of this lineage is the helper T cell or T4 cell.

### **EPIDEMIOLOGY**

In Western countries, AIDS affects mainly homosexual and bisexual men (71% in USA), intravenous drug users (17% in USA), recipients of blood or blood products (4%), heterosexual contacts of people with AIDS, children born of infected mothers and people with unknown risk factors.

In Africa the disease is essentially heterosexual with a prevalence ratio, male to female, of approximately 1:1. Although the main mode of transmission is through the use of contaminated blood, unsterile needles, syringes and infusion sets may be significant. There is no medical evidence of vector borne or casual transmission.

### **IMMUNOLOGY**

The disease is characterised by cell mediated immune deficiency. This results from infection by the HIV of helper T cells (T4 cells), followed later by a cytotoxic effect of unknown mechanism. The loss of these T4 cells results in severe immune deficiency as the helper T cells are central to the immune response. Although antibody response to new antigenic challenge is impaired, hypergammaglobulinaemia is often seen in AIDS cases. Elevated levels of serum B2-microglobulin are also found in severely affected individuals and are a bad prognostic finding. Infection with HIV leads to the development of both core protein and envelope glycoprotein antibodies. The presence of such antibodies can be detected by several tests and indicates exposure to the virus. Currently a viral antigen capture test is also available to detect viral antigens in body fluids such as serum and cerebrospinal fluid. Antigen can usually be detected in the early stages of infection before the appearance of antibodies, and terminally in some patients when the core antibodies tend to disappear. Antibody production takes 6 - 12 weeks in most people but longer in some.

## **DIAGNOSIS**

The following criteria should be satisfied before a diagnosis of AIDS can be made :

1. There should be laboratory evidence of infection with the HIV. This is usually achieved by demonstrating the presence of antibodies to the virus. In the absence of antibodies a diagnosis may be made by viral isolation or viral antigen detection by means of serological tests.
2. If possible, laboratory evidence of deficient cell mediated immunity should be demonstrated. The following tests should be done : 1) total lymphocyte count, 2) T cell subsets, 3) delayed hypersensitivity skin testing using a number of antigens and 4) lymphocyte proliferative studies using various mitogens.
3. There should be clinical evidence, either definitive or presumptive, of opportunistic infections, certain cancers and/or direct central nervous system involvement due to virus infection of the brain. Some 60% of cases of AIDS develop pneumocystis carinii pneumonia. A patient with HIV infection who presents with a chronic dry cough of 4 weeks or longer with increasing dyspnoea has pneumocystis carinii pneumonia until proved otherwise. X-ray chest or gallium scan will show bilateral diffuse pneumonitis. Deranged blood gases and elevated serum lactic dehydrogenase levels are commonly seen in pneumocystis carinii. Transbronchial biopsy or broncho alveolar washings should be carried out to demonstrate the protozoan which causes pneumocystis. Counselling before and after antibody testing is a sine qua non. The most common opportunistic diseases are shown in Table 1.

## **CLINICAL SPECTRUM OF DISEASE**

The clinical presentation of HIV infection is shown in Fig. I. Following on infection, a viral illness may be seen in some people. It is similar to glandular fever with signs and symptoms such as fever, sore throat, headaches, myalgia, rash and enlarged glands. After the initial viral infection a period of several years may elapse before further clinical manifestations appear. During this latent period the patient is referred to as an asymptomatic carrier. Between 20-40% of asymptomatic carriers will eventually develop full blown AIDS. Before the onset of AIDS some will develop persistently enlarged glands in the next



and axilla, which may be followed by prolonged fever, weight loss, chronic diarrhoea, malaise and oral thrush. The presence of these symptoms often herald the onset of AIDS.

The clinical picture of AIDS will vary with the complicating opportunistic infection or cancer. Infection of the brain by the HIV may be the first and only manifestation of AIDS or it may complicate other opportunistic diseases. Some patients may present with multiple opportunistic diseases. The prognosis of patients with AIDS is extremely grave.

## **PREVENTION AND TREATMENT**

### **Prevention**

Perhaps the most important fact about AIDS is that it is a preventable disease. Ideally this could be achieved by the development of a vaccine. Although much effort and money have been directed towards the production of a vaccine, it is unlikely that a vaccine will be available within the next 4-10 years. In the absence of a vaccine, health education and counselling to create a sense of awareness and reduce the risk of transmission by employing safe sex practices is imperative. Other factors that may prevent the spread of AIDS are 1) ensuring a supply of safe blood and blood products, 2) no sharing of needles and syringes, and 3) deferment of pregnancy among high risk subjects. Surveillance to monitor the size of the problem and how it is changing is an important component of prevention.

### **Treatment**

The treatment of AIDS consists of the treatment of the HIV infection and the complications resulting from the immune deficiency.

A number of chemotherapeutic agents, such as Zidovudine or AZT, Ribavirin, Suramin, Foscarnet and HPA-23 have been used as anti viral-agents, with limited success. So far only zidovudine has been approved for use in several countries. It is administered orally in a dose of 250 mg four hourly and has been shown to cross the blood-brain barrier. However, it is very expensive and toxic to the bone marrow, necessitating blood transfusion in many people.

Details of specific treatment of opportunistic infections and certain cancers, such as Kaposi's sarcoma, is beyond the scope of this article.

## **CONCLUSION**

Medical practitioners have a central role to play in the prevention and treatment of all people afflicted with this disease. Future generations will judge how civilised we were by the way we handled the AIDS problem.

Table 1

OPPORTUNISTIC INFECTIONS ASSOCIATED WITH AIDS

Parasitic

- \* *Pneumocystis carinii*
- \* *Toxoplasma gondii*
- \* *Cryptosporidium*
- \* *Isospora bielli*
- \* *Giardia lamblia*
- \* *Strongyloides stercoralis*

Fungal

- \* *Cryptococcal neoformans*
- \* *Candida Albicans* (Disseminated)
- \* *Histoplasma capsulatum*

Bacterial

- \* Atypical mycobacteria
- \* *Mycobacterium tuberculosis* (Disseminated)
- \* *Nocardia asteroides*
- \* Other bacteria
  - *Legionella pneumophila*
  - *Strep pneumonia*
  - *Salmonella*

Viral

- \* Cytomegalovirus (Disseminated)
- \* Herpes simplex
- \* Progressive multifocal leucoencephalopathy
- \* E.B. Virus

NEOPLASIAS FOUND IN AIDS

- \* Kaposi's sarcoma
- \* Non-Hodgkins lymphoma including extra nodal lymphomas such as primary lymphoma of the brain
- \* Hodgkins lymphoma - still controversial

2.

**NURSING IMPERATIVES AND ETHICAL ISSUES**  
**IN PROVIDING NURSING CARE TO PATIENTS WITH AIDS**

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Ladies and gentlemen I am grateful for the honour of being invited to speak at this symposium on AIDS organised by Unisa.

**INTRODUCTION**

Acquired Immune Deficiency Syndrome presents us with many questions, for which, at present, there are few answers. No one truly knows where the virus appeared from, or how it spread so rapidly throughout the world. It would sometimes seem as though there are as many theories about this as there are people researching the condition. Groups in society or whole countries or continents have been identified as the source, but as yet there is still little real evidence to support such theories.

The answer to such questions may be valuable in scientific terms, but from a nursing perspective they are less important. The apportioning of "responsibility" is not a feature in the realms of care, it is sufficient that we be aware that a very real health problem exists which requires the mobilisation of nursing's unique skills in order to meet the demands which the onslaughts of this condition present us with. Are these demands so unique that they merit high lighting from amongst all the other nursing challenges we face and indeed meet every day of our professional lives? I have divided the nursing imperatives as I see them, into four groups

Knowledge  
Care  
Advocacy  
Education

## KNOWLEDGE

If we look historically at the reactions of society to the emergence of new and seemingly dangerous illnesses they are characterised initially by alarm and panic, followed quite rapidly by feverish attempts to discover curative agents. Indeed, McNeil in his book 'Plagues and People' wrote "the first efforts at ritualizing responses to a plague take extreme and ugly forms".

The emergence of AIDS into society and indeed our awareness initially had very little effect. Many people viewed it with a complacency which now seems alarming, and peoples of the world following the example of their government leaders believed that the impending disaster would not be a problem for them. Tragically, what society seemed to be saying, and said it for a long time, was it does not matter that we have not the drugs and skills to dealt with this new condition, for those who suffer from it (in the Western World)(homosexuals and drug users) are on the fringes of society and thus expendable. This is a very extreme thing to say, however if we look back over our shoulders to that very recent history we clearly see that lack of governmental concern in many countries was still apparent in 1983 and only changed when the virus began to infect people in the mainstream of society.

As the incidence of AIDS began to increase and the interface between societal groups was breached so the attention of the world media intensified. It was quickly recognised by the more mediocre sections of the media as having an ongoing scare value. It was at this point that any real hope of sound knowledge for the majority of citizens and health care providers, went out of the window. Causation was a moveable feast varying between Gays, God, the Americans, the Africans, mosquitoes and germ warfare, similarly we were informed of how infectious this virus was, and the protection we would need to prevent transmission to ourselves. There was even a check list in order to self diagnose! There were also some very contradictory messages.

We are perhaps reluctant to admit the influence of the media on our own activities of daily living and our opinions. We do not find it acceptable that they are in no small way influential on the way we dress, the cars we buy, the way we vote and all too sadly, what we think. Whilst this may not be true of this audience today the same cannot be said with any degree of certainty of society in general.

Health care providers are as much consumers of the media as the rest of society. We are part of that society and many of us are influenced in the same way. Therefore there was not a sudden rush to seek out the reporting of this condition in the better newspapers, or to examine the wealth of literature which was beginning to appear in medical and nursing journals, and there is still a marked tendency to accept the more vivid interpretations of AIDS.

How much easier it would be to face the challenges of caring for people with AIDS if we could erase much of what has happened over the past six years, leaving behind only the truth.

The time is 1983, the place, Paris, the people, Professor Luc Montangier and Professor Barré Senoussie, the place, the Institut Pasteur. Montangier's team have discovered the causative organism of AIDS, the retrovirus they called lymphadenopathy associated virus (now called HIV). Hot on the heels of this discovery came knowledge of how the virus could be transmitted, and more importantly, how it could not. The modes of transmission were much more limited than we had been led to believe, being confined to the various sexual routes parenteral and peri-natal routes. Now we could safely dispense with the theories of airborne, social and lavatory seat contamination.

Acquired Immune Deficiency Syndrome is the sum total of the spectrum of diseases caused by HIV. Infection causes an impairment of the body's cellular immune system which may result in infection by organisms of normally no or low pathogenicity - the so called opportunistic infections. Principally, Pneumocystis Carinii Pneumonia (PCP), or the development of unusual tumours such as non-hodgkins lymphomas and Kaposi's sarcomas. There are more than a hundred conditions, or if you like a hundred sorrows, to which these unfortunate people may be prone, amongst them, blindness caused by cytomegalovirus, herpes lesions almost anywhere on the body, oral infections such as hairy leukoplakia, and tragically cerebral damage.

It is reasonable to say that you do not die of a syndrome but of the sum of its parts, therefore people with AIDS die of conditions very similar to those affecting other people in society : cancer, respiratory problems, generalised infections and metabolic disorders.

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 seconversion 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 carriers with a potential to infect others by the previously described routes. 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, a state known as AIDS Related Complex or ARC. Only individuals who are HIV antibody positive and who have an opportunistic infection or unusual tumours can be diagnosed as having AIDS.

The World Health Organisation believe that between five and ten million people in the world today are infected with HIV, and that the majority of these individuals are heterosexuals. WHO also admit that these numbers may be an under estimation.

Prophitt says, "Our ability to care is in direct proportion to our vulnerability" to which Wells adds "Our vulnerability is in direct proportion to our lack of knowledge".

## CARE

One of the real tragedies of the past few years has been our tendency to concentrate on where to care, rather than how to care. This has resulted in many people with AIDS viewing care as punitive rather than supportive and restorative.

I am as concerned as any other nurse that my colleagues should practice their profession in a safe environment - and we have a duty to provide that environment. We seem to ignore however that there are many dangers, other than HIV, to which nurses are exposed every day, and which have caused us relatively little concern up until now.

I do not intend to relate the number of studies showing that the risk of health care workers being infected with HIV are very remote - these are freely available for you all to read, suffice it to say that a nurse suffering a needlestick injury from an HIV antibody positive individual has less than a 1% chance to sero-converting to HIV. Should the individual be Hepatitis B antibody positive she has more than a 20% chance of sero-converting to Hepatitis B.

I cannot stress strongly enough the need for all health care providers to adopt Universal Blood and Body Fluid precautions with all patients - that way we need fear no one.

The challenge of excellent care for people with AIDS is not only limited to those working in clinical areas; nurse managers and nurse educationalists must also face up to their responsibilities to provide resources, leadership and education - they must shoulder some of the blame for the tragedies which have occurred in the past, due to their failure to respond to this condition.

The ideal of care in the clinical setting is to leave control with the patient. To participate in those regimens, which it is hoped will make him well again, and give him knowledge so that he can care for himself and protect from future illnesses. This can be interpreted as knowing when to lead, when to follow, and when to be at the side.

I have said many times that people do not die of a syndrome - which is what AIDS is, but of the multiplicity of illnesses which comprise a syndrome.

Pneumocystis pneumonia is a grossly debilitating and life threatening condition which requires urgent nursing management with drugs such as pentamidine, these can now be administered through a nebuliser as well as intra-venously - for many people with AIDS this means they can be cared for at home.

The variety of cancers which beset people with AIDS, including Kaposi's and Lymphomas are often very difficult to treat by conventional methods due to the persons immune compromised condition, with the result that they frequently fungate with resultant physical and psychological pain.

In addition ,diarrhoeal disorders, cachexia and malabsorption which drain the patient of energy, sap their resolve and can make life unbearable due to gross weight loss.

There is also of course the challenge of dealing with shame. So many of those who seek or need our help, have, in addition to their physical problems, to bear a burden of shame, which society has decided to impose on them.

Acute care of someone with AIDS is extremely expensive and may soon be beyond the resources of the health care system. Therefore it seems logical that whenever possible these people should be cared for within the community setting, as happens in other countries.



A community setting is the most appropriate one in which to meet the needs of this client population. It is wrong to incarcerate people with reduced life expectancies when there are alternatives. People with AIDS offer community nurses the opportunity to prove that care at home is best - but in order to do that they must look to the additional skills they will need, and demand that these are made available to them. An inability to care in the community is much more marked than a reluctance to care.

In many areas, and for many illnesses, great strides have been made. In our area of specialist interest, cancer, we have new and more effective chemo-therapeutic agents, refinements in surgical and radio-therapeutic techniques. In short we have had the satisfaction of seeing many cancers put in their place. We are able to talk with many of our patients about their future, almost sure in the knowledge that they have one. We now have the challenge of patients who in addition to having untreatable cancers may become blind, deaf, paralysed and suffer dementia before they finally succumb. Not for these patients the medical pronouncement of a cure.

We should heed in the care of people with AIDS the words of Alison Kitson, who exhorts us to set aside the medical protocol and getting better is all important. By following this model we presume that our patients cannot feel better unless they get better. For many the road to getting better may involve painful treatments, nauseating drug regimes, exhaustion, discomfort and sometimes despair. We, their nurses, help them along this rugged road to attain their goal - to get better. Implicit in this recovery is that by getting better they will feel better. This concept is one which most nurses in an acute setting can relate to. For people with AIDS getting better is a far-away goal, not yet within our gift, or within their reach - to follow the medical model is to deny them everything.

If feeling better were dependent on getting better then the future for all those people with incurable conditions would be untenable. We have to highlight the differences between the notions of getting better and feeling better. When our patients are racked with pain, cachexic, dyspnoeic, disfigured and suffering the unbelievable assaults that this condition inflicts upon the, there will be a loss of resolve and determination, they will become bruised and forlorn, they may even believe what the media says about them; that they are designers of their own sorrows and not worthy of care. We can still help. We can make pain more tolerable, and somehow those experiences and future plans of our patients, which in the past evoked a sense of well-being, wholeness and hope for the future can be reharnessed into life

priorities and hope for the immediate tomorrow, to make the individual feel better. One of my patients said to me "when you are dying tomorrow assumes a much greater significance".

Helping someone who believes there is no hope feel better without offering false hope is a wonderful challenge for us all. It is separate and yet should be complimentary to the medical goal, but it can never be achieved in the absence of closeness, tenderness, dialogue and contact.

Care also encompasses the needs of those close to our patient, whoever that might be. AIDS has exposed many nurses to ways of living and loving that they may not have appreciated before, and of which they may not approve. Approval has nothing to do with care. It has nothing to do with supporting the bereaved. In health care disapproval is something we express at home. We have to learn to broaden our perspectives in order to meet needs, and we must realise that we can empathise without approving.

For many years nursing has been talking about what it is worth. Well, now it has the opportunity to prove its statements. It can of course only do this if 'nursing' has a research basis to the care we give. You don't need me to tell you that the nurse researchers have hardly been flocking to see what difference their work will make in caring for these patients - I have difficulty in recalling anyone who is undertaking long term research into people with AIDS.

People with AIDS present nurse researchers with unique opportunities to research into the effects of nursing care on a patient population who, at this moment in time, are not going to recover. They have the challenge of proving that although nursing cannot affect the outcome - it can greatly alter the path to the outcome, and by improving the care of people with AIDS they will ultimately improve the care of all patients.

### ADVOCACY

When I see headlines like this I think the world, and particularly health care has gone mad. What fiendishness possesses man to make him heap indignity upon undignity, and why do we - nurses, not prevent it?

Patient advocacy is often one of those trite phases which trip glibly from our tongues, when we know it will cost us nothing in terms of battling colleagues for what we believe to be right. I wonder if you share my sense of shame at what appears to be a

declaration of open season on the rights of people with AIDS. Health care providers frequently cry, "I must have information that my patients have AIDS so that I can care properly", and I would agree with them. Somehow it doesn't always stop there - that information is dropped in conversation with other colleagues not directly involved in care, who pass it on to someone else, and suddenly the media has it.

Tschudin wrote "out of the ethic of caring comes advocacy". Advocacy is not, as some people suspect, making decisions for patients, or acting "in loco parentis", it is ensuring that no one usurps the needs, rights and humanity of patients.

Nurses need to be sure, however, about those things they are advocating for. Are they merely interceding for adequate treatment, patient information, better standards of care. These are certainly advocacy issues, but it is much more than that. Consider the patient who has come to hospital for some routine surgical procedure, he is thirty five years old, single and gives another man as his next of kin. The surgeon decides that he wants the man tested for antibodies to HIV before surgery but will not tell the patient in case the result is negative. This is not a new situation, it probably happens regularly in many hospitals throughout the land. A denial of somebody's human rights and flagrant breach of medical and nursing ethics. What to do? There is a true advocacy role here - not initially to worry the patient with this information - but to discuss with the doctor the reasons why - how will the result modify the way he operates, how will it effect the care that he gives? Advocacy in this situation would ultimately be making it clear to the doctor that the nurse will not participate in this assault, and will, if necessary, inform the patient of the denial of his rights.

In situations such as this the nurse has a duty to take the matter to a higher medical authority, and has the right to expect the support of her nursing superiors when issues of non-maleficence and beneficence are at stake.

The ethic of patient advocacy - especially for those with AIDS, is more difficult to fulfil than to talk about. To espouse this role may be fraught with danger for the nurse, and may seriously hamper aspirations to popularity, clinical development and career advancement. It is never easy to be unpopular and those nurses who act as advocates for those with AIDS are frequently so. Is it right to expect a nurse to jeopardise her career prospects in the course of ensuring the rights of her patients, especially these patients? Perhaps the challenge here is for advocates for the advocates - what an awful condemnation that we should even

need to consider it! Advocacy demands the knowledge which allows assertiveness, and the belief that nursing is a profession accountable only to peers and consumers in the practice of that profession and the enhancing of the knowledge which is the basis of the profession.

Not to recognise that people with AIDS have a right to confidentiality, respect, advocacy and the other inalienable rights of the sick, is ultimately to deny those rights to ourselves.

## **EDUCATION**

Since the emergence of AIDS some seven years ago, many millions of words have been written on the subject, and amongst all the rubbish and half-truths is the information we need to go forward.

Nursing forms the basis of health care and as such must not only have a significant impact on the quality of care received by people with AIDS, it must impact on the extent of HIV epidemic itself through preventative education. Just as there is confusion on how to care for people with AIDS, so it is with educating nurses' about the condition.

Knowledge of the size of the problem as we know it to be, and the likely exponential growth of the numbers of those affected requires that nursing education respond effectively to meet the demands of new knowledge needed by nurses and indeed to re-emphasise the basic tenets of care.

Knowledge of HIV infection and AIDS must be incorporated into the basic nursing curriculum, at whatever level that is offered. You will notice I said incorporated - it would be wrong to insert a module on AIDS into the educational curriculum, this would be to signify that AIDS related illnesses are different and alarming, they are not - merely unusual in such a young and previously health group. The emergence of this problem has highlighted gross deficiencies in the educational curriculum, especially in the areas of human interaction and sexuality. How soon I wonder will educationalist respond to this challenge.

Nurses are in a unique position to prevent transmission of HIV through education. We have seen in some areas of the world a dramatic response to the health education message. In San Francisco in 1982 22% of the unexposed Gay population developed anti-bodies to HIV. The department of health in that city launched a campaign called 'Safe Sex Works'. In 1983 the figure

campaign and others like it have brought about the fastest and most effective changes in behaviour seen in any population at risk from disease. If other parts of the world do not have access to this information or fail to respond then the picture will be very bleak.

In order for us to perform, as health educators to prevent illness - we must first understand the illness, and then understand ourselves and be happy with what we know. Too often we believe that because we do not approve of certain lifestyles or condone habits and behaviours which are foreign to us, we have no part in health education. The question is not and never has been do you approve or disapprove, rather do you want to prevent the spread of HIV - which, if unchecked, may very likely impinge on your family one day.

Much changes daily about this condition and as the disease comes into focus we modify our interventions to reflect these changes. It is now clear that AIDS is not just a problem for small groups in society, but has the potential to threaten society as a whole, and it is this belief which should make us target our educational strategies as widely as possible. These strategies must also be understood by those whose behaviour we seek to modify - sadly this has not always happened.

What are we talking about then is educating the public about a largely sexually transmitted disease with the potential to kill. We will need to develop the trust of those we seek to influence and this may require spending long periods of time in close proximity with our clients, and we will need the unique attributes of empathy and sensitivity. The reward will hopefully be that we will cease to witness young men and women suffering the degradation and insults of this condition, and that candle-lit vigils in the memory of the ever increasing number of casualties of AIDS will diminish.

We must target out preventative education carefully. Who do we wish to influence and how! We need to reach every sexually active individual not in a monogamous relationship, every injection drug abuser, and every young person on the threshold of sexual awareness.

Influencing the behaviour of young people is a high priority. Coming to sexual awareness is often a very difficult time for young people. Contradictory messages cause confusion and can be dangerous. Our messages to the young must be unequivocal - before we address the issues of safe and safer sex we must talk of the value of trust, respect, love and concern for others. I

am sure that some of our present educational strategies give the impression that sexual intercourse is compulsory. We have to address the value of human relationships, and of course not use ourselves or our generation as examples. Advice on safe and safer sexual practices should be offered when it is most appropriate.

The manifold problems which beset our society are often reflected in the number of people who revert to the use of drugs for a solution, conversely, we see an increase in the use of so called 'designer' drugs amongst the young upwardly mobile. To many people injecting drug abuse is abhorrent, and immediate reactions are that people should 'kick the habit' but often it is not that simple. For those who use on a regular basis, drugs are a part of every day existence, and for social users they are fun. No one ever believes they will become an addict, ask any smoker!

Obviously our educational interventions should be geared to helping people curtail the habit, but when that is not possible we have to face the challenge of helping them to do it safely. This may mean entering them into needle and syringe exchange schemes, or teaching them how to clean needles and syringes properly.

The greatest health education challenge is that of safer sex for those not in one to one relationships. One laconic observer once remarked "No sex - is safe sex" and whilst I would not wish to undermine the validity of that statement it is not a realistic message for us to convey.

Due to developments in the area of family planning, one of the methods of preventing the spread of HIV and other sexually transmitted diseases, the condom, has fallen into disrepute. We have whole generations of people who do not know how to use them or indeed what they look like. Condoms are not generally a part of love making and therefore people may be embarrassed at the suggestion of using them. Indeed we may be embarrassed to suggest it. However, if we are to come to terms with the AIDS problem, health education must be effectively taught for all.

## **CONCLUSION**

Those are just some of the imperatives which face us today - another speaker would have probably presented you with different ones.

We, nurses, must lay the foundations on which nursing can go forward to care for people with AIDS and control the spread of

HIV. There is no model at present, in many countries for nursing involvement at national level, and the challenge to us in this country is to help your world-wide colleagues to overcome that.

Nurses are accompanying persons with AIDS through an extremely difficult process, and we have a head start over many other professional groups in addressing these challenges. Nursing has stayed close to the root of health practice offering support and sustenance whether cure was available or not. There is a uniqueness in accompanying patients "through something" whether that leads to cure, continuing illness or death.

There are those who believe that the resolution of AIDS will have a bio-medical genesis - but who will administer the drug, and who will manage the side-effects? Bio-medical solutions may be many years away - and when they arrive will they only be available to the rich countries of the world?

We do not have all the answers to this condition, but if we are to meet the needs adequately then nurses must function as catalysts to change the way we think of and behave toward the sick and we have to ensure that what nursing exemplifies is better understood by the bio-medical community.

Who will speak up on behalf of people? There is a desperate need all over the world for humanism and realism about AIDS. To realise what it means to take care of someone who is young and wasting away.

The incidence of HIV infection and AIDS will undoubtedly increase in the years ahead, and will sadly touch many health care providers. I believe these experiences will make us more resourceful, improve our education and ultimately make us better carers. Don't please, any of you, hide in the fools paradise of believing this is not a problem for you. It will be! Let us remember that with knowledge, understanding is gained, ignorance dispelled, prejudice confounded and power unleashed. Let us take that power and use it for our patients and never loose sight of the fact that ultimately it will be nursing humanism and realism which will make the difference.

3.

### **AIDS - A SOCIAL WORK PERSPECTIVE**

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#### **INTRODUCTION**

AIDS - the acquired immunodeficiency syndrome - is an unprecedented public health problem facing the entire world. No cure is in sight and no vaccine is likely to be forthcoming for several years. People who have AIDS are severely stigmatised and HIV infected people and AIDS sufferers are usually treated with fear and are avoided. We in Southern Africa have three years, at best, in which to overcome prejudices and to implement facilities for the care of HIV infected people and their families on a large scale. All professional people involved with the HIV infection, whether from a medical sociological psychological or social work perspective have the responsibility to equip themselves with the facts about AIDS, and to establish realistic resources for the care and understanding of the increasing number of people who will suffer from this sad and lonely disease.

#### **THE ROLE OF THE SOCIAL WORKER**

Broadly speaking the role of the social worker evolves around the three main social work methods, namely casework, groupwork and community organization.

##### **(a) Casework or individual counselling**

The main aim of the individual counselling of AIDS patients and their families is to help them to come to terms with the social psychological impact of AIDS on their lives. This task does not differ in essence from counselling any other terminally ill patients. The aims are similar - namely to



help the patient to retain his quality of life for as long as possible and to die with dignity. However, due to the fact that AIDS is confused with moral issues and because an AIDS scare is propagated by the media the recognised stages of a terminal illness syndrome namely denial, anger, hope, bargaining, and acceptance are intensified and complicated by physical and social isolation, stigmatisation and loneliness. Both patients and their families develop a great need for secrecy about the patient's condition in order to protect themselves against discrimination and rejection.

Homosexual patients have to cope with a double stigma namely that of AIDS as well as the fact that they are gay. On top of this homosexuals often have to break the news to family and friends that they are both gay and dying of AIDS. In order to meet the psycho-social needs of homosexual patients it is essential that the social worker should understand the process of homosexual and bisexual development patterns. It is necessary that social workers acknowledge and work through their own anxieties and prejudices concerning AIDS in order to accept the patient with compassion and acceptance.

In the hospital situation the social worker can act as a liaison between the patient and the professional team, consisting of doctors, nurses and the family or lover of the patient, who provide medical or socio-psychological care to the patient. It is the task of the social worker to initiate new resources for the care of AIDS patients and their families and to help members of the professional team to utilize existing services. Due to the fact that more terminal patients prefer to die at home (Smith 1984 : 14) as well as the sheer number of the people involved, care of AIDS patients should be community based in order to be cost effective.

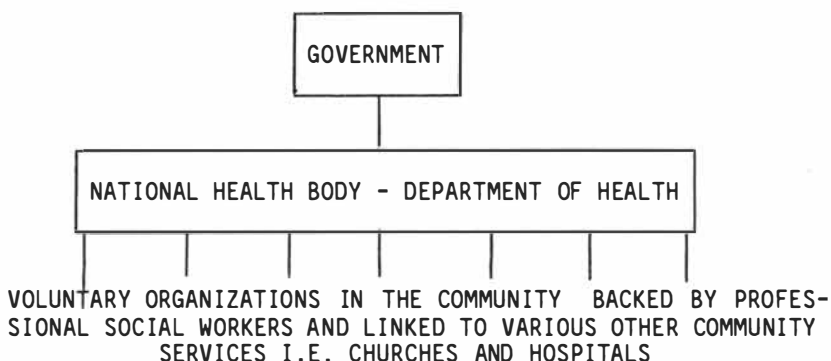
(b) **Groupwork and community organization**

Research done by the Institute for Sociological and Demographical Research of the Human Sciences Research Council have thus far indicated that the most cost-effective strategy against AIDS would be to follow the lead set by voluntary organizations such as the Gay Men's Health Crisis in New York, Shanti in San Francisco and GASA 6010 in Cape Town. It is the social worker's task to develop these types of voluntary organizations and to establish links between them

and the professional services that would enable continuation and co-ordination of services to AIDS patients and their families. Such a community based organization must provide the following services :

- (i) A 24-hour telephone counselling service consisting of lay counsellors trained and supervised by professional counsellors (social workers) to deal with all AIDS-related matters and refer AIDS sufferers and HIV infected people for professional help.
- (ii) A professional counselling clinic run on a weekly or daily basis.
- (iii) A self-help group for HIV infected people supervised by a social worker. These types of groups are based on the value of shared experience and mutual support of people with the same problem.
- (iv) A service group whose task it is to befriend and assist persons with AIDS or AIDS-related illness and to provide them with services such as transport, shopping, household chores, etc. and to take them on regular outings.
- (v) A day care centre for AIDS patients where they can receive all the necessary professional services of doctors, nurses and social workers etc. and be occupied in a meaningful and financially worthwhile manner in order to be as self-sufficient as possible.
- (vi) An AIDS action group that will have the following tasks : To educate the general public on AIDS related matters and undertake a safer sex campaign amongst people who participate in high risk behaviour such as promiscuity and drug abuse. Education of those persons whose sexual pattern has not yet been formed; Co-ordination of services for AIDS sufferers and their families; Monitoring of the effectiveness of services provided by the organization in question; Stimulating research on the social and psychological impact of AIDS on various groups; Providing a source of knowledge and information about AIDS and to monitor local changes and responses to Government measures and report these and special needs directly to a

National health body whose main task it will be to co-ordinate services and research efforts on a National scale and to subsidise voluntary organizations that adhere to specific standards of service laid down by the Department of Health and Population Development. Overseas experiences have shown that without Government subsidisation no more than "Wendy House" services can be provided. Schematically the community based network of services that should be developed by social workers to combat the AIDS problem on a large scale can be presented as follows :



## CONCLUSION

AIDS has posed a dramatic challenge to all who care for terminally ill patients and their families. It has forced us to reconsider death, dying, bereavement, sexuality, racism, homophobia and above all the quality of care that terminally ill patients receive. Apart from the fact that pioneering work like that of Küber-Ross (1970) brought increasing interest to the dying patient and his family - since 197- more than 4 000 publications have been written - research (Van Niekerk 1984 : 71) has shown that dying patients are increasingly isolated and de-personalised. This isolation and de-personalisation of the dying patient is enhanced when the patient does not conform to the standards set by care-givers. The following excerpt from a book by Glaser and Strauss (1970) appropriately entitled *Anguish* : a case history of a dying trajectory, serves as an example of what is today still taking place in many hospitals in the country and abroad : "Mrs. Abel's last days began with the ward's sentimental order in desperate state, verging on complete breakdown because

of the growing intolerance with her. This intolerance was not coupled with the staff's awareness of impending death; meaning, of course, that they have to manage it. The supervisor went into immediate action to shove up the sentimental order and solve the problem of Mrs. Abel. She applied various tactics to spread the burden of care, which we find in many dying situations when they have become an ordeal to the staff. ... The staff thought up ways of putting Mrs. Abel in a location so all could watch her without coming near - such as by the window readily seen from the nursing station. The supervisor, as well as staff, jumped at the chance to turn some of Mrs. Abel's care over to the student nurse. They said, 'We should give her a medal for putting up with and taking care of Mrs. Abel'. However, in the end they rejected the student because of her concern, care and communication with Mrs. Abel, which was in contrast to their unabiding intolerance and inadequacy in dealing with Mrs. Abel's talk on dying ... In the staff's mind, a discharge, whether out of hospital or transfer to another ward was the only solution to the crushed sentimental order to their ward."

Taking care of the dying is an emotionally draining task but I do believe that we as professional care-givers can, together with the help of volunteers organised in community based settings, meet the challenge and provide an acceptable and caring environment for people with AIDS, their families and loved ones.

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4. CARING FOR PATIENTS WITH AIDS - AS A PASTOR

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PRETORIA

The pastoral caring for patients with Aids does not differ substantially from the pastoral caring for patients with any other illness.

My definition of pastoral caring is as follows :

"I as an individual is a pastor with a divine calling, specific knowledge guided by a sensitive conscience, who meets another individual in his specific need, with the intention to guide him to ultimate spiritual health. This guidance moves along the lines of what God wills for him in his situation. Pastor and patient together seek to understand what this means to the patient in his need and to answer by making free and responsible choices in the realm of what Viktor Frankl calls the Tragic Triad of Life, i.e.

1. Guilt
2. Suffering
3. Death.

Because Frankl's teaching is so relevant to the point in question, I explain what he means :

1. Guilt : It is mans prerogative to become and feel guilty. One has to take responsibility for one's actions. To try to explain away one's guilt is to see him as a mere victim of circumstances and that is to take away his human dignity.
2. Unavoidable suffering : Means that one is faced with a situation that one cannot alter or avoid.

3. Death : Is a reality before which one cannot close his eyes. And seeking death prematurely by euthanasia or suicide robs one of one's dignity and basic sense of meaning.

I explain a few more of V. Frankl's basic terms :

1. The will to meaning

One is called to answer life's questions put to you - to answer is what Frankl calls the will to meaning.

Man is always reaching out for meaning ... always setting out on his search for meaning ... this is man's will to meaning.

2. Medical ministry

This aims at changing a patient's attitude towards unavoidable suffering e.g. an incurable disease, the loss of a loved one, etc.

3. Self-transcendence

This is the human potential to rise above one's self and one's circumstances, e.g.

- \* illness
- \* to help someone else
- \* to love someone else
- \* to fulfil a task

4. Self detachment

By this is meant man's potential to distance himself from his situation e.g. to look at his symptoms (illness) like an onlooker. By doing this man can assume a new and different view and more wholesome attitude towards his situation.

N.B. This is the corner stone of paradoxical intention.

5. Meaning

One can find meaning in all these predicaments by changing one's attitude.

Frankl explains

- \* Creative values
- \* Experiential values and
- \* Attitudinal values

He specifically stresses attitudinal values. This means that a person suffering from aids can either hopelessly succumb to this unavoidable suffering, or find meaning there in by discerning what God wants to teach him in his suffering.

Frankl's logotherapy offers a philosophy of life and a method of counselling which is more consistent with a basically Christian view of life than any other existing system in the current therapeutic world.

My personal pastoral caring for patients with aids incorporates biblical teaching as well as logotherapy, and the ultimate spiritual health I set as goal for these patients, is the ultimate meaning that is to be found in a personal relationship with Jesus Christ, our Lord.

Aids has opened an exiting and inviting missionary field for us and I am personally eager to enter it and invite you to do likewise.

### Pastor's own experience

The pastor should take note of his own experience in encountering an aids patient, and handle this experience wisely and professionally.

He experiences on approach - avoidance conflict - because on the one hand he is called to minister to the patient's spiritual need - but on the other hand he experiences a feeling of aversion and even fear - ungrounded fear - of contagion.

He must climb over this barrier to be close and near this member of his flock.

### One has to remember that :

- \* The aids patient is a terminally ill patient
- \* He is also a very lonely person - people avoid him
- \* If he is a homosexual one has also to remember that he is a marginal person living in two worlds - the homosexual and the hetero-sexual world.

These peculiar features call for appropriate and efficacious ministering and counselling on the part of the pastor.

### **Appropriate ministering and aid to the Aids :**

1. Jesus did not avoid the lepers when he encountered them. In fact, it is cited that on one occasion he even touched a leper - contrary to the strict health and religious laws of that time.

Like Jesus, we must, figuratively speaking, come very near these patients to care for them.

2. We must not condemn them.
3. We must not react with horror toward the aids patient.
4. Above all, we must care for the aids patient with loving and tender care - motivated by a disposition of grace and mercy.

### **Specific needs of the aids patient :**

1. The aids patient is a revealed, a disclosed person, especially if he is an homosexual. He could have concealed the fact that he was gay - but now it is public knowledge. Figuratively speaking, the blanket is jerked off and the patient lies naked and feels ashamed, guilty and harassed.
2. The aids patient is a terminally ill patient and the essence of caring must be to guide him in the dying process - helping him to live a high quality life up to the dying moment.
3. Despair, feelings of rejection, loneliness, guilt and aggression can all be handled by Christian love on the part of the pastor and grace coming from God.
4. The specific need of the so-called innocent victim of aids, must also be met : They are the minority cases who contracted the disease via other ways than the homosexual way - e.g. babies born of parents with aids and others. They usually ask the "why"-question and feels angry and rebellious and aggressive.

The pastor, inspired by the love of God and faith, ministers to the aids patient to help him find meaning in his suffering, and



to take a positive stand in the face of his condition and help him rise above all confining restraints. Frankl calls this the "defiant power of the human spirit", and I quote :

"The spiritual core of a person can take a stand, whether positive or negative, affirming or denying in the face of his own psychological character structure, as when attempting to overcome a habit or resist an urge. This potentiality essentially inherent in human existence is called in logotherapy the psychopoetic antagonism or the defiant power of the human spirit. What is meant thereby is man's capacity as a spiritual being to resist and brave whatsoever kind of conditioning, whether biological, psychological, or sociological in nature."

This potentiality is embedded in a living faith and a deep sense of meaning that transcends all illness and suffering. But the pastor also have an educational and kerygmatic task and that is to call all people back to responsible living, loving and responsible sex. Churches, homes and families should work together.

5. **VOLUNTARY SUPPORT SERVICE FOR PEOPLE WITH AIDS**

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Clinical Psychologist

1. **INTRODUCTION**

My title was "Voluntary support services for patients with AIDS. I have changed "patients with AIDS" to "people with AIDS" for a number of reasons. Voluntary services deal with people who have been affected by AIDS long before they become patients. When they attain "patient" status they are generally taken care of by hospitals or hospice organisations and the need for voluntary services is then not as great.

Voluntary organisations need to provide services for anyone who has been touched by the AIDS crisis. This includes :

- The "worried well"
- Pre and Post Test (HIV AB) Counselling
- Ongoing counselling for persons who are HIV AB+
- Counselling at the stage of diagnosis of HIV related illness
- Counselling at AIDS diagnosis stage
- Counselling fullblown AIDS patients
- Counselling partners, family and friends of the above-mentioned
- Counselling health-care workers.

## 2. SERVICES AVAILABLE

In an attempt to cater for the abovementioned needs, the following voluntary organisations have developed :

### a) GAB Counselling Service

GAB Counselling is a private and autonomous telephone crisis line and AIDS counselling service. It has been in operation for 5 years and functions from an office in Hillbrow.

The telephone crisis line operates from 7 pm to 10 pm every evening. Tel. 643-2311. This service deals with all gay related difficulties and those which cannot or should not be dealt with telephonically are referred elsewhere.

The telephone crisis line and AIDS counselling service is run by a team of voluntary lay counsellors who have undergone a 14 week training course and who have been carefully selected before training. The lay counsellors work under the supervision of our professional counsellors.

The GAB counsellors attempt to deal with the full range of AIDS related difficulties (see 1b above).

Cases are referred from a number of sources such as the hospitals and private practitioners. They are referred to me (726 1457) and I obtain basic information telephonically. A counsellor is then selected to work with the person and when the person is someone with full-blown AIDS, counsellors are encouraged to work in pairs. AIDS related calls also come in on the telephone crisis line and are dealt with by the counsellor on duty.

### b) HIV Counselling Clinic

This is a new service which has been started by a group of concerned professionals. The service presently operates each Tuesday evening from 7 pm to 10 pm. It is located at the AIDS Training and Information Centre at SAIMR. This service is merely accommodated here and is not linked in any way to SAIMR.

The services offers counselling mainly to HIV infected people. Counselling is however available for anyone affected by the AIDS crisis.

c) **Informal Support Groups**

Various independent groups have formed such as social groups for persons who are HIV AB+. Other groups may exist of which I am not aware.

In working with people who are affected by AIDS, it becomes evident that resources are sadly lacking. One of the most urgent needs is for a home to accommodate persons who have HIV related illnesses or who have fullblown AIDS but are not ill enough to be hospitalised. There is generally an urgent need for more people to become involved in providing the necessary support.

6. ORGANISATION OF HEALTH CARE FACILITIES  
FOR AIDS PATIENTS IN THE U.K.

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Professor Dryer, colleagues. The reactions of doctors and nurses to the onset of AIDS in the United Kingdom followed very similar patterns to that seen in other parts of the world. Due to the disinformation disseminated by the media about how infectious HIV was believed to be, and the fact that Armageddon was approaching us all, our immediate response was not how to care but where to care. A response I believe which cost us dear in our future interactions with people with AIDS.

There was a tremendous clamour in seeking to manage HIV as an infectious disease rather than a transmissible condition, following which, patients were unnecessarily isolated and felt rejected and unwanted. Concomitant to this reaction was the emergence of a much more dangerous condition amongst health care providers, that of AIDS Psychosis, and the foolish belief of some governments that they could legislate against a virus.

Along with new information, this degree of panic has lessened, though I am convinced that in some areas of the United Kingdom where they have not yet cared for persons with AIDS we will witness similar reactions when the first patients present for care.

Initially, due probably to Society's reaction to AIDS, and more pertinently the reaction of health care providers, people with AIDS gravitated towards the Capital for care and support. There, they rightly thought, they would be cared for without judgements being made upon them or their lifestyles; and that within the metropolis they would achieve a degree of anonymity escaping from the media hounding which has been such a distasteful feature of this condition.

None of us, I think, suspected the eventual drain on health care resources which would result from AIDS. Nor, do I think, were we ready to have our professional competencies challenged by a new and alarming virus. These two issues have shown us how to go forward in our organisation of health care facilities in delivering care. These illnesses and the people who present with them have, I believe, given us the opportunity to review our delivery of health care to all ill people, and perhaps get it right. Allow me please to go to the beginning and show you how we have developed, through change, our health care facilities for people with AIDS.

In 1981 we had obviously heard of AIDS, we had followed the news from America, and like them we believed that this condition was highly infectious and highly exclusive. The first patient in the UK had a terrible time. He was cared for in strict isolation, with very little human contact. His care providers dressed like spacemen, and his visitors were likewise attired. He wrote "I am living in a dream where I have been transported to another planet, inhabited by people but without humanity". Following his death, his friends and health care providers who were concerned about what had happened to him formed a trust to help those who were to follow. This was the first significant development in addressing the problem, and came from the voluntary sector.

Those who subsequently developed AIDS in the early days had similar experiences, however, they were not the usual, quiet, compliant, grateful patient population. Rather, they were young, articulate and demanding of their rights; they along with some of their health care providers exposed this unacceptable face of health care. One of the greatest plusses in those days was the emergence of doctors and nurses who realised the challenges that AIDS presented us with and wished to address them. They gained themselves a great deal of scorn and disapprobation by being critical of their peers, and of the conditions in which people with AIDS were cared for.

With the inexorable growth of the number of people with AIDS in the capital so specialist facilities were developed within which research and treatment could be carried out, and nursing care of the highest standards could be delivered. These places are not mini prisons, no one is incarcerated or unnecessarily isolated - they are places of hope and optimism.

We had realised several things. No one dies of AIDS but of the sum of its parts, and those parts we knew well - we had been caring for people with illnesses similar to the manifestations of AIDS for many years, there was nothing new about them, only about

the people who suffered from them. We also very quickly learned that these people who were immune compromised were much more at risk from us, than we were from them. Therefore isolation procedures when they were necessary became protective rather than punitive.

I have to blow the trumpet here for my own organisation for I believe that the swift response to this health care problem by the Royal College of Nursing was eventually responsible for nurses viewing this condition and these patients in a very different light, in helping them come to realise that we should isolate the disease not the patient. We offered guidelines for safe and meaningful delivery of health care.

We have three specialist units in London all struggling to keep their heads above water, due to health service cut-backs and increasing patient populations. They can no longer cope with the influx of people with AIDS from other parts of the country and will soon have to refuse these people and refer them back to their own local hospitals. When this happens, we expect some problems, which hopefully, will be transient - they will be similar to those seen whenever a person with AIDS presents for care for the first time.

You see, in trying to come to terms with the problems initially, we have I think, created a belief that one has to care for people with AIDS in specialist units. This is not so, and it is a false belief which should not be encouraged. It may be possible to care and treat in such units now whilst numbers are small, but what about ten years hence when the client population will have reached tremendous proportions? What will we do then? Build an AIDS town? Just as we build centres of excellence in other areas of care, such as cancer, this does not mean that these are the only places where people with cancer can receive excellent treatment and support, so it is with AIDS; and what are we attempting to achieve in the United Kingdom is an integration of these patients into the health care system. Every health district in the United Kingdom is required by the DHSS to have developed a strategy for dealing with AIDS, and many of them have done so. Some are better than others, and those who have developed punitive rather than restorative guidelines are quickly shown the errors of their ways. So, hopefully, over the coming months when the number of people developing AIDS related illnesses reaches 250 per month and then probably by 1991/2 2 500 a month - we will be ready to meet the challenge.

In organising health care facilities, one must be ever mindful of the phenomenal expense of caring for someone with AIDS in hospi-

tal. At present it is estimated to cost #20, 000 (80 000 rand approx) per patient. Obviously this is a huge drain on resources, and ways have to be found to keep costs as low as possible without affecting the quality of care.

One way which can be beneficial in reducing costs is to look at where patients are cared for. Hospitals are not necessarily the best places, in fact, they can, on occasions, be positively hazardous to some of these people. In San Francisco people with AIDS spend on average ten days in hospital from diagnosis to death. In the United Kingdom this varies between ten and sixteen weeks.

In my paper this morning I said that the community had a great deal to offer in the care of people with AIDS. I am utterly convinced of this, and as I said before, we have to prepare our community colleagues to help us meet the challenges.

In the United Kingdom, as in all other countries of the world, great demands are placed on the services of community nurses. After all, most people, if offered a choice, would want to be cared for at home. Frequently people with AIDS make demands on community nurses, for which we have not prepared them; giving intra/venous medications, nutritional advice and the management of a wide variety of distressing symptoms such as pain, diarrhoea and of course social rejection. We are beginning to offer education and training on extended role skills for community nurses to allow them to meet these very special patient needs, we do so knowing that these skills will benefit many people, such as those with cancer, who may in the future be able to be cared for at home.

As an interim measure until such courses are established and enough nurses properly educated, we have developed hospital based out-reach nursing teams in the major London centres caring for people with AIDS. These teams headed by a specialist nurse, visit patients in their own homes, site intra-venous lines, administer treatments and give advice on symptom management.

The teams do not work in isolation, they frequently collaborate with the plethora of voluntary support groups which have been established in the United Kingdom since the onset of AIDS. These groups offer a variety of services, counselling on all aspects of HIV infection from how to prevent it to how to live with it, mutual support groups for those who are HIV antibody positive, buddy groups who provide companionship and help for those who are alone and have AIDS, bereavement support groups and many other forms of help.



During the early days when nurses and doctors were refusing or reluctant to care, it was these people who responded and supported people with AIDS. They gave care, they fed, they shopped, they counselled and were often caring companions on the journey towards death; very often it was they, and not us, who were there at the end, holding people so that they need not cross the void alone. I sometimes think that these superb people have a part of what should be our history and I am bereaved because of it.

They have shown and will continue to demonstrate, that, unique and vital working relationships can be established between the statutory and voluntary services. I cannot begin to imagine what we would have done without them, nor can I ever see a time when we will not need their help.

Nor has dying of HIV related illnesses been without trauma. I am sure you are aware that for the past twenty five years in the United Kingdom the development of the hospice movement has changed the face of dying - they have, and are doing a superb job. Therefore, we naturally turned to them when we needed help with those dying of HIV related conditions. Sadly most of them rejected people with AIDS, often with the excuse that they did not have the necessary skills to meet their needs, it was an awful and untruthful admission.

Our hospice movement, for the most part, is dependent upon voluntary contributions from local sources to remain viable and solvent, and due to media coverage they were rightly very afraid that money would cease to come in if they cared for someone with AIDS.

That is gradually changing but too slowly, and as always happens when we compartmentalise care, another hospice movement is emerging - the AIDS hospice. As existing health care fails to meet peoples needs so we create another tier to place on the already crumbling foundations of the health care system. You will have gathered by now that I am totally opposed to specialist facilities for people with AIDS, but in favour of special facilities for all sick people!

The first AIDS hospice in the United Kingdom will be opened by HRH Princess Alexandra on the 19th May. The Mildmay Mission Hospice is a Christian foundation for the care of the chronically ill. It will initially have nine beds for the care of people with AIDS, which will be increased to 17 by the end of the year. The hospice will support people with AIDS and their partners and families within the hospice or at home. Every room has facili-

ties for the partner to sleep with or close by a loved one, and the ethos is to help people live until they die. Later in the year the second hospice facility, the London Lighthouse, will open. This will offer twenty four beds, plus community care services.

Both of these developments are vital in order to meet present desperate needs, but as the problem increases we cannot go on opening such facilities randomly. There must come a time when the needs of people with AIDS will be incorporated naturally into our health care system.

Apart from the United States and some countries on the African continent, the rest of us still have time to assess what will be the demands on health care made by this virus in the future, and to plan accordingly. We must not attempt to do this in isolation. AIDS is a global problem, therefore we must look around us at countries with more experience than ours, and learn from their mistakes so that we might develop good systems of care, so that one day we might look back on these times and be proud that nursing made a difference.

7. THE NURSE EDUCATORS ROLE IN  
COMBATING AIDS

Mrs. J.E. Tjallinks  
University of South Africa

Madam Chair, Guests of Honour and Delegates.

For the AIDS patient at this stage, as pointed out by Orr "It is only nursing skills we have to offer in the ends" - knowledgeable, understanding and compassionate nursing care.

However, when four nursing colleges in the Republic were contacted recently they all indicated that they had not yet included AIDS in the curriculum. Apparently there were teaching programmes in the services.

The role of the nurse educator is spelt out clearly in the S.A. Nursing Association's Position Paper on AIDS. She is to ensure that -

- \* The epidemiology, nursing management and preventive aspects of the disease are definitely included in nursing curricula
- \* the student is able to relate ethical aspects of nursing to the care of a patient with AIDS
- \* the student is able to differentiate between nursing care skills that will and will not prevent self-contamination and cross-infection of the disease
- \* the student is able to adapt her internalised nursing skills to suit those required for the particular nursing needs of the AIDS patient.

At this point I should make it clear that I see the nurse educator in many spheres - not only in the nursing college, but also

in the inservice education department of a health care facility. I even see her in the community, because community involvement is an integral part of professional practice. Recent research however showed that 49% of tutors had no community involvement.

There are various strategies which can be used in teaching AIDS to students, professionals and the community. The information giving model is the method most commonly used. It uses teaching styles such as lectures, talks, films, videos and slide shows as ways of helping people learn about health and well-being.

Evidence suggests that facts about a particular health issue can bring about changes in behaviour, especially when the information is presented in a relevant way, when it is passed on through word of mouth, and when it is linked to discrete and identifiable behavioural changes.

However, the belief that people will act rationally and sensibly solely on the basis of the information they receive has long been questioned. People work on the information they receive, re-interpreting it to suit their own needs and values.

Crisis breed ethical dilemmas, and in situations such as the AIDS epidemic, in which health care providers must face the crisis squarely, we must also face the dilemmas. For this reason I would like to introduce values clarification as a teaching strategy for AIDS.

Values underlie all ethical decision making. In confronting the AIDS issue is thus not possible to divorce ourselves from looking at our value orientations of those with whom we work, of our families, and of society.

Values are standards that influence our behaviour. So understanding what values make us tick - and what values make those around us tick - should help us to predict behaviour.

Some of us, some of our students, and some of the individuals we supervise have value systems which are incongruent with caring for clients with AIDS. Because our profession must make care available, it is important to look at how we can clarify our own values - and help others to clarify theirs - so that we can make the needed changes.

Steele refers to Kirschbaum's definition of values clarification as

**"the process by which we increase the likelihood that our living in general, and a decision in particular, will, first, have a positive value for us and, second, for the society we serve."**

So each time we examine our values, we ask if we can live with a change - if a change is necessary - and we ask if that change is in the best interest of our clients. The model generally used for values clarification, as suggested by Steele, involves choosing, prizing, and acting.

The first step - choosing among alternatives - entails listing the available options. The next step is deciding which alternative is best for you, and the last step is making your decisions based on the fact that, that is the value to which you ascribe.

For example, the Roman Catholic Church in considering the abortion issue, looked at the alternatives, decided that they were opposed to abortion, and we know precisely where they stand.

Likewise, those people who understand the facts about AIDS should be able to say to those around them "This is how I look at the problem, I have the information, and I feel clear that this is the way we should deal with it".

So, values clarification gives the person more alternatives to choose from. Even more important, by getting acquainted with the views and values of others, one realises either that one is unique in one's perception of a situation, or that one is not all that individualistic at all. This might lead to the decision that you do not have to act according to what you think is collectively considered as right, but what you are convinced of.

According to Steele, values clarification should be a rational process. Very often, ethical problems are wrapped in emotion. We are asked to resolve ethical dilemmas on the spur of the moment, and that is when we are least able to do so. We need a rational process so that we can take all of the information we have, integrate it with our experiences, and use it knowledgeably.

Steele refers to Brummer's rational process of inquiring as to seek

**"to bring about the most comprehensively coherent system of ideas and experiences that is possible at any state in one's intellectual development".**

This process involves two steps. The first is initially treating all of the information that will have a bearing on a decision as having equal worth.

So, for example, even if a person's value system says, "I ascribe to heterosexual sexual activity" that person would still assign the same worth to the information that there are many homosexual individuals with AIDS, that he or she would assign to any other piece of information. He would not say, "I do not like those people. I do not ascribe to their sexual practices and I believe that they have brought this disease upon themselves".

The rational process requires a person to give each piece of information equal worth, then begin to sort out how he or she values each one.

During the second step of the process, he begins reflective thinking and critical evaluation - which helps differentiate between ideas that are more justified and those that are less justified.

For example, individuals who have lobbied to deny a child with AIDS admission to school have responded emotionally, saying, "we do not want this child in school with **our children**". That response was **not** the product of a rational process of inquiry. To be rational, before they'd make any decision, they would have had to analyse the facts. Clearly, they had not.

In addition to basing decision on the evidence at hand, we also have to be willing to change our value orientation based on new evidence as it comes in.

Brummer said that "to prize the value of **rationality** is to engage in an ongoing search for new evidence and in testing it against previously accepted ideas."

For example, when the media first reported that HTLV-III might be transmissible via an infected person's saliva, most of us were immediately convinced that we had to watch out for saliva. We've since seen, through more recent - and more scientific - reporting, that we do not have to be very concerned about saliva. As new evidence comes in, we have to correct our thinking.

We have to be very aware of that when we are dealing with people who have perceptions that are different from our own, because **they** may have value systems that **we** know nothing about.

As we continue to clarify and consider changing our values, we have to think about whether we consider ourselves at risk if we change them.

Do we think we'll be at risk not only for contracting AIDS, but for losing face with our families if we take on values different to theirs?

We have to consider **how** much risk we are willing to take on, in order to be an advocate for a cause that may be against the value systems of people we interact with often.

Engaging in a rational process of inquiry does not mean we should factor out all of the antagonism. In fact, it means we should factor out all of the antagonism. In fact, it means we should take into consideration that there **will** be some antagonism between and among the ideas that we are trying to sort out. Clear thinking alone will not change our values, but, according to Brummer it keeps antagonism to a minimum

**"because the process of rational inquiry seeks to give due respect to the widest possible pattern of consistent ideas and experiences."**

Another consideration we should take into account when we talk about values are perceptions, which are key elements in our ability to solve problems. Perceptions are built on our value systems - we all have some things firmly planted in our minds that make us choose one perception over another.

Nurses have to be responsive to the needs of society, and I think there is no greater need than to pay attention to a condition that is emerging as such a catastrophic health problem. Paying attention to the issues and data on AIDS will help us to resolve the ethical dilemmas it raises - and they are many.

For example, who has the right to know that a person has AIDS? How do we help make a life of quality for someone who is likely to die within two years of his or her diagnosis? How should we decide between individual versus social good - are we going to consider only the dignity of the client, or will we decide that society has a right to know a person has AIDS because, in essence, the health and welfare of members of society are threatened by the spread of this disease.

If we want to become clearer on any of these questions, and if we want to ensure that the AIDS sufferer is provided with humane and

compassionate nursing care - which may also contribute towards combating the spread of the disease - we have to begin by getting our own values straight.

Then we will be able to approach the very difficult issues which surround AIDS with the required rationality and assist others to do so as well.

I therefore propose that the essence of the role of the nurse educator in AIDS is **not** only to provide **knowledge**. Through **specialised teaching methods** she should assist students, professional colleagues and community members to clarify their own values about AIDS and its victims.

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8.

## COMBATING AIDS - THE ROLE OF

### THE COMMUNITY NURSE

Mrs. L. Langley  
Baragwanath Hospital

### INTRODUCTION

The role of the Community Health Nurse can be likened to that of the front line soldier. She is one of a team who needs to try and combat something unknown and presumably of such vast proportions that it seems incomprehensible.

### AIM

The aim of the Community Health nurse is primarily to educate the public in an attempt to try and persuade people to change their lifestyles, their sexual habits and their prejudices, so as to work towards the combating of the spread of AIDS; and secondly, it is to teach them how to cope with living with AIDS in the community.

### EDUCATION

The primary task of the health worker of today is education. Much is being said about AIDS in all the media, but very little is really known about it. That which is known generally has caused a wave of emotional shock in both nurses and the public. The community nurse now has to equip herself with sufficient knowledge to awaken the public out of this petrification, and to accept the spreading of facts and not fear. One is not born with this deficiency - it is acquired and therefore preventable, and it is for the community health nurse to join hands with her colleagues in showing the community the true facts and what hope there is.

1

She needs to teach awareness, the facts of the disease and then how to prevent it. As there are already many, many cases (Dr. Sher speaks of 10 000 known cases in South Africa in Jan. 88), she needs to establish an information centre where people can receive information on the prevention of the disease, as well as on how to live with AIDS in the community. Counselling of groups, such as pre-marital couples can be done there, as groups, or individuals can be addressed on this subject.

The education must be aimed at bring about change in the behavioural pattern of the public.

### **TESTING**

As yet no large scale testing is being done, and the use of this is debatable, as having the knowledge of being infected is not the prime issue, as it is then too late to do anything about it. The necessity at hand is to look at one's lifestyle and change or adapt it so as to prevent one from acquiring or spreading AIDS.

Some places do a fair amount of screening in the Sexually Transmitted Diseases Clinic, whereas others do routine testing on the mother presenting at ante natal clinic because of the possibility of spread to her unborn infant. Large scale testing of mine workers is done. People at risk, e.g. the chronically ill, adolescents, school groups and those attending family planning clinics as they are the most sexually active group, should also be done. This is only done on an individual basis at the moment. It is the responsibility of the community health nurse to inform the person that they are being tested for HIV and if necessary to do pre-testing counselling on the person to prepare them for what they may learn when the result of the test is known. If the knowledge of the existence of the disease can send you into a state of petrification, imagine what it will do to one when a positive result is imparted to you. The person must be prepared for the possibility of such news. It must also be stressed that two positive results need to be obtained before the diagnosis can be confirmed, as false positive results have been known in the past. If patients know they are to be tested for HIV they may refuse to be tested.

### **COUNSELLING**

After diagnosis, follow up and monitoring must be commenced. Counselling makes out a very large portion of the management of AIDS. The patient has to be counselled into accepting the fact

that they are infected, close friends or/and relatives have to be included. To many of them it may come as a tremendous shock, not only to realise that their loved one is infected, but for many it is the first indication that this person has led either a homosexual existence or one of promiscuity. This counselling will be a team effort, but as it is the community nurse who will be nursing the patient for varying periods, it will also be she who lives through this devastating experience with the patient.

### **CONFIDENTIALITY**

Patients confidentiality in this case will have to be viewed slightly differently than in most other cases, as it can directly affect the lives of many other people including health team workers. This will have to be discussed with the patient as the fact that she is an affected person will have to be divulged to e.g. her dentist/doctor/midwife and her spouse. This confidentiality must obviously be limited to those who are directly concerned with the patient. The patient must give permission that his condition may be divulged, or do the informing himself.

### **NURSING**

Lastly she now has to nurse this patient in the community. In the beginning her nursing care will be limited to education and counselling of the positive HIV patient, following him up and monitoring his condition, as well as tracing, testing, educating, counselling and the monitoring of his contacts.

Presently monthly monitoring of HIV positive patients is done, but one wonders if this will have to be three monthly monitoring if the numbers escalate beyond expectation.

This follow up for antigens and antibodies must be at clinic level and be continued for 5 years after detection. The WHO recently stated that more close follow up and monitoring of babies born with HIV should be done by the community nurse.

If and when the condition of ARC or AIDS develops and the patient deteriorates, she will have to liaise with her hospital colleagues on the treatment he gets in hospital, plan his discharge and continue home nursing till his next period of hospitalization.

The nurse, as a team worker, will keep her health team colleagues posted as to the home circumstances and social support needed.

In her caring for the patient at home she will involve the entire family. To start off she will encourage the patient to do as much for himself as possible in the line of washing his clothes and bedding. When it is the mother she must be taught that her baby's excreta and blood may be as infected as her own and that even soiled nappies are to be treated with care. Contraception is a very important aspect of preventing the spread from mother to child and the mother must be discouraged from having any more pregnancies. Even after for e.g. a sterilization, the patient must be encouraged to use a condom.

Relatives and friends must be taught that normal social interaction, sharing furniture, food utensils, bathrooms and toilets is not infectious, but also inform them how to live together with this infected person so as to protect themselves from him and him from them due to his immuno deficiency. She will have to identify immediate friends and family who are themselves at risk and handle the situation. With this she can prevent the people from ostracising the AIDS patient and how they can help him with living that part of life still left for him, meaningfully.

Another role which the community nurse will have to learn to develop will be that of coping with death. Up to now it has been limited mainly to the aged dying of cancer. Counselling the young, virile person could be a very different experience. But death is at this point very much part of the living AIDS patient and one must afford them the opportunity of discussing it, preparing spiritually, emotionally and economically for when they will no longer be with us. As the sexually active are also the economically active.

## **CONCLUSION**

The community nurse is the person who will act as the axle round which the health team is co-ordinated in treatment and assistance of an AIDS patient and his family. She must also be a source of information for the community and a never ending pit of emotional support for the AIDS patient. So if ever she had a comprehensive role to fulfil, this is it.

9. THE ROLE OF THE OCCUPATIONAL HEALTH NURSE  
IN COMBATING AIDS

Mrs Acutt  
Occupational Health Nurse

It is Professor R.S.F. Schilling who said : "Occupational health is no longer a narrow field of public health that merely concerns itself with the identification and control of specific occupational diseases. It aims at the health protection and promotion of health of workers, and the identification and control of health hazards in workplaces, including those not only of a physical, chemical and biological nature, but also psychosocial factors that have harmful effects on the health and productivity of workers" (Schilling, 1981 : 1).

Thus the occupational health nurse provides a professional health service to maintain and promote the physical, mental and social well-being of the worker at the place of work.

In order to make a contribution in combating AIDS the occupational health nurse has to play several different roles :

1. PERSONAL ROLE

In her personal role she must be responsible and mature, friendly though not familiar in order to instill confidence in her and to encourage the worker to discuss problems of an intimate nature. She will deal with the problem with tact and discretion and yet be firm when referring the worker or recommending a line of action.

In her dealings with management too, she must be recognised as a responsible and reliable person whose advice must be acted upon in the interests of the company and all its employees.

## 2. PROFESSIONAL ROLE

Being registered with the South African Nursing Council as a general nurse and preferably as an occupational health nurse or a community health nurse, the occupational health nurse will recognize her professional limitations whilst maintaining a high standard of nursing care and professional conduct.

She will keep up to date with new developments in the medical and technical fields, including new legislation. In this way she will realise the role that she can play in combating AIDS by educating the employees.

Whether it is on a one to one basis when a worker comes to the medical centre for treatment of a day-to-day illness or for a supply of condoms, or in a more formal talk to a group of employees, perhaps in showing a film during the lunch break, or a lecture to the FIRST aid teams. It could be while in consultation with the managing director or in a meeting of safety representatives that the opportunity presents itself.

The occupational health nurse does not let a chance to educate people about AIDS go by. She puts up posters, hands out pamphlets and writes articles for the company newsletter, reaching many who would otherwise make no effort to find out the truth about AIDS for themselves.

The professional occupational health nurse will keep herself informed of the latest developments by attending monthly meetings of her local South African Nursing Association and her Professional Society of Occupational Health Nurses as well as seminars and the like. She will read scientific nursing and medical journals and communicate with local experts on AIDS such as the wonderful staff of the Rheumatology Department at the Johannesburg General Hospital or Dr. Reuben Sher and his team at the South African Institute of Medical Research.

## 3. ADMINISTRATIVE ROLE

The administrative role of the occupational health nurse conjures up thoughts of efficient management with good recordkeeping and control of medicines in the medical centre.

However communication with management through regular reports as well as with employees and liaison with outside agencies, such as local health authorities, the employees' general practitioners and also their families forms part of administration.

An important aspect of administration is the company health and safety policy.

### 3.1 The Company Health and Safety Policy

We do not as yet have a law in this country that enforces a company to have a written statement of their general policy towards health and safety at work such as the Health and Safety at Work Act of 1974 in Great Britain.

However it is the occupational health nurse's duty to initiate the formulation of such a policy, should her company be without one. The policy should be revised regularly and should include a statement to the effect that the employer undertakes to provide safe working conditions without risks to health and maintains the right to subject employees to health screening on a regular basis and on return to work after sickness absence of a certain number of working days.

The policy should include a statement to the effect that an employee shall take reasonable care to protect his or her own health and safety at work and to also a statement that the employee shall take reasonable care to avoid adversely affecting the health or safety of any other person through any act or omission at work.

This last statement would make an employee liable to disciplinary action against him should he report for work suffering from a contagious disease without the permission of his doctor and the medical personnel at work.

## 4. ETHICAL ROLE

As important as the aforesaid roles, if not more so, is the ethical role of the occupational health nurse. She is never influenced by political, religious, racial or social considerations and maintains strict neutrality in any controversy between management and an employee.

The occupational health nurse takes note of all matters concerning the health and welfare of employees, but such knowledge remains confidential as are the medical records. Should management require clinical details of any employee it may only be given with the employee's written permission. It is important that employees know that the information they may give the medical personnel is confidential.

## **5. WELFARE ROLE**

It is sad to say that the welfare role of the occupational health nurse is frequently neglected for she is often the only person to whom a employee can talk concerning work and home problems.

Young adults see her as the "mother" of the company and confide in her and she can create much goodwill by showing interest and concern. She makes time for counselling and has a good working knowledge of the company pension and medical schemes as well as sick leave and other benefits in order that she may give the best advice, always referring the case appropriately where necessary.

## **CONCLUSION**

In conclusion I would like to point out that a person suffering from AIDS is employable but that the decision to appoint him rests with management. However once a person is employed he may not be dismissed solely because he suffers from AIDS and employers will need to take a reasoned view based on all the circumstances weighing up factors such as the individual's ability to continue working satisfactorily, the possibility of a move to different duties (perhaps shorter hours), any medical advice received, and whether continued employment is against the employee's, the employers or the public interest.

The occupational health nurse will continue to educate the working population and give unending support to the employee who may be infected with the AIDS virus.



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10.

**THE CARING FOR THE AIDS PATIENTS**

**THE ROLE OF THE MIDWIFE**

Mrs Mohlamme  
Midwife

**INTRODUCTION**

Madam Chair, I must thank the organisers of this symposium who have invited me to speak on the role of the Midwife in the caring and prevention of AIDS. Once more thank you.

Madam Chair, as previous speakers have defined AIDS, it is perhaps also important to mention what other names it has - "Gogo" or "passengers without passports".

- \* The word AIDS has come to the ears of many people - the literate and the illiterate people. But now the problem facing us is that how many people know about AIDS?
- \* And those who know or can explain what it is, have a responsibility of making the masses understand. The fact is that the "Gogo" or "passengers without passports" is in the country now. So the aim and objectives of this symposium I presume, is for the people to share ideas to help in preventing spread of this "Gogo".
- \* Once people hear about AIDS, they are overcome by fear, stress and uncertainty.

**MODE OF SPREAD**

\* **Transmission by parental inoculation**

A large inoculum of HIV containing blood given by the intravenous route, carries an extremely high risk of infec-

tion. This information is derived from studies of accidental needle-strick inoculations among health care workers.

\* **Sexual transmission**

HIV is fundamentally a sexually transmitted virus which is transmitted by both homosexual and heterosexual activities.

\* **Intravenous drug use**

Has an important role in the transmission of HIV infection.

It is also stated that the ninety percent of intravenous drug users are heterosexuals and 30% are women, of whom ninety percent are in their childbearing years, which really causes concern.

\* **Migrant labour**

The massive shifts of people to urban areas have also facilitated the rapid spread of the infection.

\* **Perinatal transmission**

HIV infection in infants and small children have occurred as a result of maternal-to-offspring transmission of infection during pregnancy or perinatal period. HIV may be transmitted from infected women to their offspring by three possible routes :

- to the fetus in utero through the maternal circulation
- to the infant during labour and delivery by inoculation or ingestion of blood and other infected fluids
- to the infant shortly after birth through infected breast milk.

**GENERAL ASPECTS OF CARE** (at Baragwanath Hospital)

Staff are reminded to minimize at all time risk of exposure to blood and patients' secretions.

Careful resheathing of injection needles and the disposal thereof.

Any form of physical examination, wearing of gloves is important.

Care must be taken in taking bloods.

N.B. No patient with HIV positive must be discriminated against. These patients are admitted in the isolation wards like all other patients.

Any form of discrimination will mean losing them and not being able to make a good follow up which means losing these patients forever. This is self-defeating to the entire strategy of the care of HIV positive patients.

### ANTENATAL CARE

1. Pre-counselling is required both when discussing the test and if a positive result is received.
2. Wearing of gloves when taking bloods and giving injections.
3. If patient is identified as being HIV positive, the bio-hazard warning sticker on all blood samples are placed in a separate bag. Laboratory staff be notified.
4. Patient bedlitter, marked also with bio-stickers.
5. If admission is necessary, special precautions are required.

### LABOUR AND DELIVERY (could also be in Isolation Delivery Area)

1. Staff in attendance should wear disposable plastic aprons, gloves during labour.
2. Procedures such as vaginal examinations, delivery as well as perineal suturing, gloves should be used.
3. Intra-uterine catheters should be avoided as far as possible because of the risk of transmission of infection to the fetus.
4. Examination of the placenta must be done in the delivery room, while still gloved and gowned.
5. The placenta is disposed of as infected material and incinerated.

5. Body fluids, soiled linen and equipment used, must also be treated as infected and either disposed of or sterilized after thorough cleaning with Biocide D.

### POST NATAL CARE

1. Post delivery patients are transferred to isolation units.
2. There, she will have a single room, with adjoining toilet facilities.
3. Those in attendance should be well acquainted with Barrier Nursing.
4. Breast feeding is contra-indicated at this moment in time.
5. The cleaning of the bidet, bath, etc. are done with "Biocide D Extra".

### CARE OF THE BABY

N.B. Babies are at high risk for maternally transmitted infections.

- \* Only mechanical suction are to be used.
- \* Baby washed in delivery room, midwives are to wear protective clothes and gloves as for delivery until blood is cleared off.
- \* Disposable nappies while meconium passed.
- \* Gloves to be worn for the following procedures :
  - Cord care until healed.
  - Blood specimens and bags containing these specimen be marked correctly.
  - Stillbirth - Bio-hazard labels to the body and double plastic body bag as well as bio-hazard labels.

### ON DISCHARGE

- \* Referral to the HIV counselling clinic which has been set up at Baragwanath Maternity Ante Natal Clinic. This counselling clinic for the HIV positive patients is conducted by a

Midwife, an Obstetrician, Paediatrician, Psychiatrist and Social Worker.

- \* The main aim of this clinic is to follow up all the post delivery patients for counselling, support and education.
- \* The community health nurse/or clinic must also be notified.

### **COUNSELLING OF HIV POSITIVE PATIENTS**

It is important for midwives and all in attendance to treat these patients with strictest of confidentiality, lest they are lost in the community because of being dehumanised and exposed.

It is important if patients are going to be able to cope, that their doctors talk openly and honestly to them about their condition. Patients want to know so much about what they can do to help themselves, and how they can prevent transmitting the disease to others and what treatments are available to them.

A detailed handout is a useful adjunct because it enables the patient to review the facts outside the doctors office where stress means that much of what is said is forgotten.

It is vital that if the test is to be performed on relatively well patients, that they understand that it is a test which indicates the likely presence of the AIDS virus, and that a positive result does not in itself mean AIDS.

For better co-operation of the patients the result should be treated in the strictest of confidence.

In conclusion, although we are confronted by a public health problem of potentially catastrophic dimensions, it is essential to appreciate that unwarranted fears of HIV transmission have compounded the suffering of young men, women and children infected with HIV and blunted an appropriate societal response aimed at reduction of transmission.

### **SOURCES**

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Department of Obstetrics & Gynae, Baragwanath Hospital Protocol.

**COMBATING AIDS -**

**THE ROLE OF THE TRADITIONAL HEALER**

Patience P. Koloko  
Traditional Healer

Madam Chairman, I am greeting all the professors, doctors, traditional healers, doctors, nurses and all. On behalf of the traditional healers I am just going to cut matters short about the today's topic.

First of all you have heard all the people who were talking here about this dangerous disease. I am not going to start from what they have already discussed like these :

1. What is aids
2. What are the signs and symptoms of it
3. Where it comes from
4. How can it be prevented.

My main point of being here is this : I would like to inform you that we traditional healers can cure any one with this disease if you can please give us some of the patients suffering with aids. Be sure that you make the final diagnosis before administers the treatment. By taking the wrong medicine you allow the germs to build up resistance and they become more difficult to treat.

The earlier you consult the healers or doctors the sooner the better. If you discover that you have an aids, ask all your sexual partners to go for treatment. By doing this you can put a stop to the spread of the disease.

The only thing which I suggest if the patient came to you in hospital or you come across with any one suffering with aids, please contact myself or any South African Traditional healer doctor who is registered by the Council and let us treat him.

I am telling you the truth that people will come back and tell others that herbs and mutis have worked wonders for himself. We are now eager to work hand in hand with you medical doctors to show people that our ancestors (Amadlozi), really help us in fighting with all types of disease, so even aids can be cured by mutis and herbs. Our problem is this : we haven't come across with a patient with aids but as far as we have learned the signs and symptoms of it we are sure that we can treat it.

People are worried about this disease some thinks that they can get it by sitting next to another. No. It is a condition when the body's immune system, the part that fight infection, becomes damaged and it is a sexually transmitted.

I am warning people who are not believers for I was one of them thinking that traditional herbs are dangerous and it is only medical doctors with their medicines who helps.

Really, the medical doctors and traditional healers doctors if they can unite they can play a big role in the health of a patient. By working together.

To tell you the honest truth I have been sick for years attending the medical doctors only but they got fed up that I don't get better and I don't die changing all arthritis treatment but I was always complaining of pain in my joints and swelling. I did not know why I was so sick. Until I was taken by my cousin who is a principal at Matialapye school in Botswana to some of the traditional healer doctors they were saying the same thing and in South West Africa Namibia and Oshakati they told me the same thing.

So I have then used some herbs and mutis from then I have picked up back to a normal person there was no swelling of the limbs or difficult in walking and holding the things with my hands.

To cover and conclude my talk - aids which is our topic today can be cured and can be prevented only if we work together.

I warn those people who run after girls and we all them (Amasoka) to use condoms if they are not satisfied with one lover.

Please, when you find that you have got aids signs and symptoms do not hesitate. Consult your nearest healer or doctor before you spread it.

I am sure that this disease is to the Indians and other nations where they make sex men from men not the African people for they



do sex from men to women. And we have no African patients with aids like to other nations and countries.

The only thing which I promise you is this : we are educating our people to be careful about the disease and how to protect themselves for we can not stop them in doing sex to their wives for it is nature.

I conclude with my oath to assure you of my talk to you.

### THE HEALER'S OATH

I, a healer, invoking all my ancestral shades to be my witnesses, that I will fulfil this oath and this written covenant to the best of my ability and judgement.

I will look upon him who shall have taught me this art even as one of my own parents. I will share my substance with him, and I will supply his necessities if he be in need. I will regard his offspring even as my own bretheren, and I will teach them his art, if they would learn it, without fee or covenant. I will impart this art by precept, by lecture and by every mode of teaching, not only to my own sons but to the sons of him who has taught me and to disciples bound by covenant and oath, according to the law of medicine.

The regimen I adopt shall be for the benefit of the patients according to my ability and judgement, and not for their hurt or for any wrong. I will give no deadly drug to any, though it be asked of me, nor will I counsel such.

Whatsoever house I enter, there will I go for the benefit of the sick, refraining from all wrongdoing or corruption. Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not to be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets. Pure will I keep my life and my healing art.

Amen