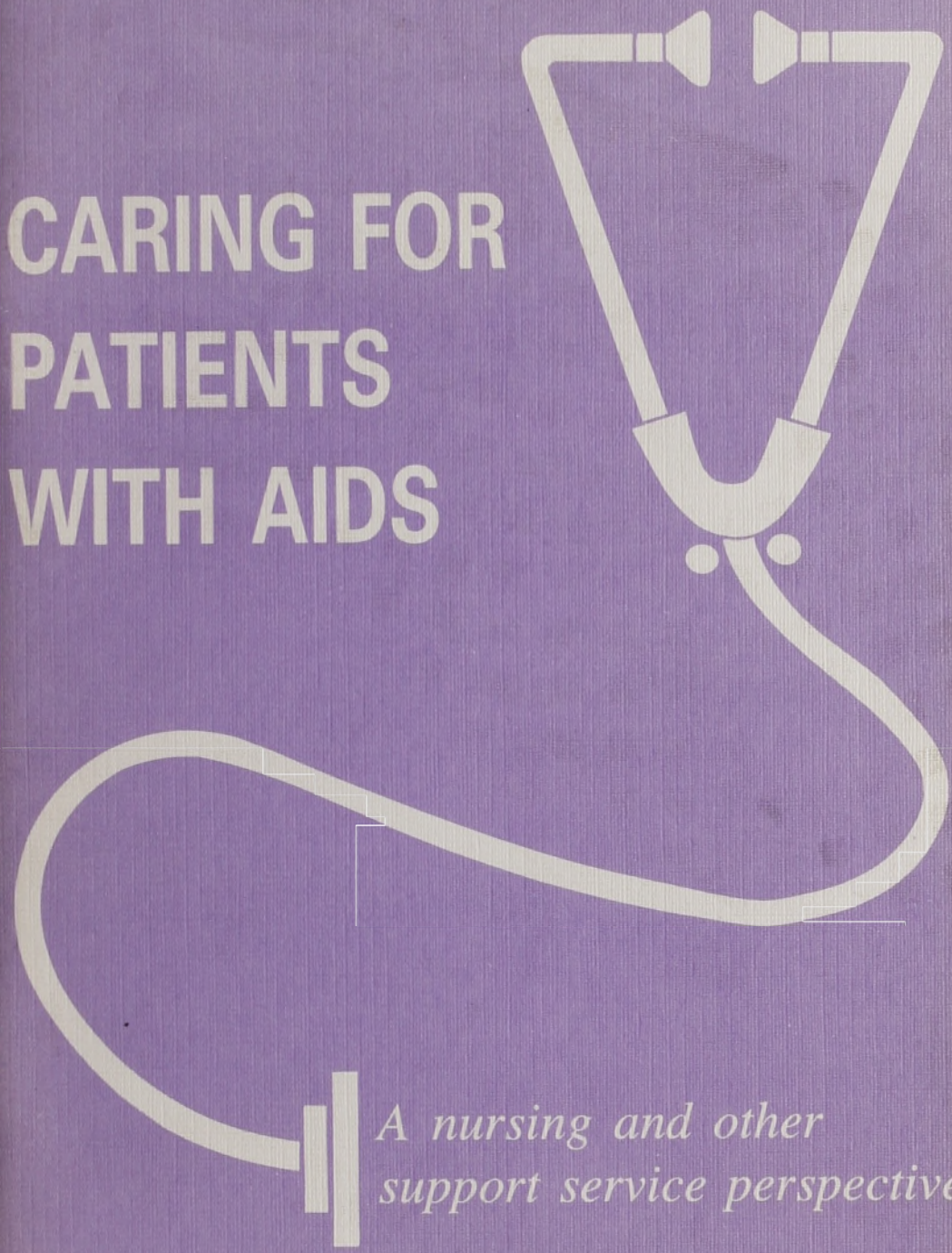
CARING FOR PATIENTS WITH AIDS



A nursing and other support service perspective

CARING FOR PATIENTS WITH AIDS

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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.

PROFESSOR AND HEAD : DEPARTMENT OF NURSING SCIENCE

UNIVERSITY OF SOUTH AFRICA

20 April 1988

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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 ration, 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 cehydrogenase levels are commonly seen in pneunocystis 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 glandlar 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 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)
* Nocordia 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 riualizing 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 cytomegalvimus, 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 pentamadine, 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 ,diarrhoearal 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 i,proving 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 needs 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-malficience 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 inpinge 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 thresh-hold 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.

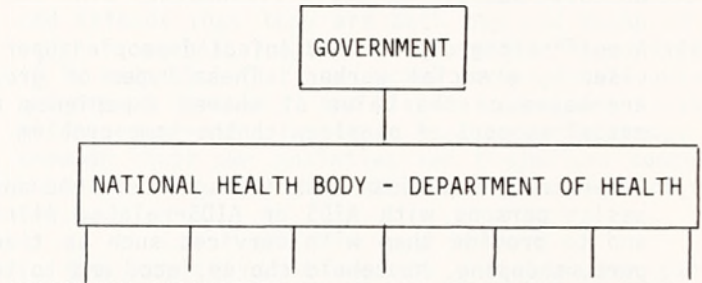
(iii) A self-help group for HIV infected people supervised by a social worker. These types of groups are based on the value of shared experience and mutual support of people with the same problem.

(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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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.

Mans 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 distantiate 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.