

5. VOLUNTARY SUPPORT SERVICE FOR PEOPLE WITH AIDS

Erica Eckstein
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.

Richard J. Wells, FRCN
Adviser in Oncology Nursing
Royal College of Nursing
London

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 till 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 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.

BIBLIOGRAPHY

1. Aggleton, P. and Homans, H. 1987. Training the AIDS Educator. Nursing Times. October 7, Vol. 83, No. 40 p. 40-44.
2. Faugier, J. 1987. Aids awareness. Nursing Times. September 30. Vol 83, No. 39 p. 20.
3. Howie, C. 1986. Teaching aids. Nursing Mirror. Dec. p. 3-9.
4. Obe, T.S.W. 1987. Aids, ethics and medicine. Nursing RSA. Vol. 2, No. 6, June p. 36-37.

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.

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.

BIBLIOGRAPHY

Baker, M., Coetzee, A.C. (ed.) 1983 An introduction to occupational health nursing in South Africa. Johannesburg : Witwatersrand University Press.

Schilling. R.S.F. (ed.) 1981 Occupational health practice. 2nd edition. London : Butterworths.

Sher, R. 1988 Aids Overview. Nursing RSA Vol. 3 No. 3. Cape Town : Juta.

Slaney, B. (ed.) 1980 Occupational health nursing. London : Croom Helm.

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

The New England Journal of Medicine.

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 todays 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