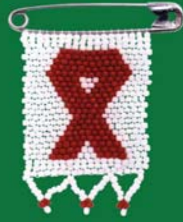
The MRC KwaZulu-Natal AIDS Forum

KZNe News



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Ed's say:

Dear Forum members, *change,* sometimes as good as a holiday, is also thought to be the spice of life… On that note, I am happy to announce that the AIDS FORUM will soon be entering a new phase of life, after the expected collaboration with the Centre for HIV/AIDS Networking (HIVAN) in Durban.

The idea behind this collaboration is based on the need to develop the Forum at local and provincial levels. Being informed is being armed and this requires improved communication and networking with partner organizations who hold a similar vision. (see page 7).

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Living with HIV by David Patient

David Patient has been positive for almost 20 years and is one of the longest-surviving (and healthy) people with HIV in the world today. When he was diagnosed, his doctor told him that he had six months to live and that he should not come back to the doctor's office, as the other patients would object. This is his story on how to promote a healthy and rewarding lifestyle.

If you have HIV in your body, what do you expect to happen? Is it really possible to stay healthy, even if you have HIV? Yes, indeed. However, to do this, you would need to first decide whether you want to live longer. This may sound strange – "Of course everyone wants to live a long time!" you say. Unfortunately, this is not always true. Therefore, the first thing to do when you find out that you, or a friend, has been told that they have HIV, is to speak to them about their future. It is important that they do not give up their education or future goals. They need to know that there are ways to stay healthy for many years, but this requires them to remain motivated and focused on living, not dying.

There are specific activities that a person living with HIV can start to help their body stay strong. Exercise every day – even 20 minutes of walking – will help their body stay strong. They must also ensure that their body temperature does not get cold for too long,

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A Personal and scientifically based perspective on indigenous herbal medicines in the treatment of HIV/AIDS - a clinical perspective

Glenmore Pastoral Centre

Living with HIV continued

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as this will weaken their body's ability to fight HIV. This means eating a good breakfast every day, with energy foods such as maize meal, mandioca, sweet potato, and other starches. It is also a good idea to eat a little chili or curry each day – about one-quarter teaspoon three times a day - to help the body stay warm.

Wherever possible, the person living with HIV needs to eat nuts and seeds, as these contain a substance called selenium. Brazil nuts – one a day – has enough selenium, but it can also be obtained from peanuts, sunflower seeds, and cashews. Selenium has the ability to slow down HIV's activity, and is therefore very important. Another substance that is important if you are living with HIV, is zinc. Zinc helps your body to fight infections. It is found in pumpkin and squash seeds. These can be dried or roasted, and eaten as a snack.

Most people get sick with stomach problems at some time in their life. However, if you are living with HIV, this can be more serious, as this can lead to losing a lot of muscle, called Wasting Syndrome. If this happens, you need to eat more protein (beans, peas, meat, fish) to replace the muscle. It also helps your stomach to eat Papaya at the same time, as this helps to digest the protein.

Eating garlic is a very simple way of preventing many illnesses that can weaken the body. Make it a habit to include garlic in your food every day. Prevention is easier than curing!

It can be lonely when you are living with HIV, as people may treat you differently. This is called stigma. A person living with HIV needs to have good friends to talk to. If they do not have such friends, they can ask for support from an HIV/AIDS organization. Find a real friend. Do not allow people to treat you as if you are dangerous! It is perfectly safe for you to hug, kiss, hold someone's hand, sleep in the same bed, share the same cups, knives and plates. HIV is only transmitted through sex, blood, and mother's milk. You deserve respect like everyone else, so demand it.

If you are living with HIV, wear a condom every time you have sex. This will protect your partner from becoming infected. If your partner is also living with HIV, then you still need to wear a condom, as the HIV in each person's body is slightly different. Therefore, without the condom, it is possible to become infected with a different type of HIV, which makes it more difficult for your body to stay strong.

Do not hesitate to consult a doctor or health professional if you are ill. Sometimes, these illnesses are not serious. However, there are some illnesses that people living with HIV get, that are quite serious, and they need to be treated quickly.

Above all else, get educated about HIV and AIDS. The more you know, the more control you have over your life. You have a future that you need to create, and knowledge is power.

Sim, eu posso! Tu também!

Until there is a cure …

Neil Orr (Research Psychologist

David Patient (living with HIV for 20 years)

Vida Positiva, CNCS Mozambique.

Neil Orr is the author of the booklet 'Positive Health' - which is a guide to dealing effectively with HIV/AIDS. Says Neil: " This is not 'positive thinking' - it is a realistic hope, based upon solid scientific research."

For those of you interested in obtaining this booklet (available in English and Zulu) you can contact::

Empowerment Concepts, tel: 083 226 9466 or Fax: 083 8 226 9466 or via E-mail: neil_orr@yebo.co.za / drp@mweb.co.za

Ethembeni Care Center - at the heart of community life

Tucked away among tranquil surroundings, some twelve kilometers north of Richards Bay on the N2, is Ethembeni Care Center - originally, a joint venture by local industries to care for employees and their families in times of illness. Opened on World AIDS Day in December 1997 but dogged by extreme stigma, the centre remained empty until 1999.

Today, the center caters for patients who require recuperation, rehabilitation, convalescence and palliative care. It has also broadened its care base, to include patients with all types of secondary medical ailments, pre as well as post operative care, rehabilitation and rehydration therapy.

Ethembeni is registered by The Board of Health Funders and the Department of Health as a sub-acute, non-profit care facility. Encompassing a seventeen-bed medical center, Ethembeni serves as a bridge between hospital and home and relieves the financial burden from AIDS patients and their families.

Ethembeni Care Center has four service areas. The most dramatic is the above-mentioned bed care 'in-patient' facility, which offers a short stay in the center. Another focus area is the home-based care unit run by community health educators. The health educators are chosen by the Amakhosi, who identify key leaders within their communities to come to the center for a 10-week training course that equips them with the knowledge needed to return to their individual communities and assist with training and community services. The educators are involved with patient visitation, education, food security training, school presentations and the formation of support groups. Below is an outline of the services available:

- Educator training
- Family Education & training
- Primary school aids awareness and prevention presentations
- High school support groups
- Community support

Outpatient Services

- Counseling including pre and post HIV testing, coping skills and resource materials
- HIV/Aids Management and treatment workshops
- TB management and treatment

Community Services

- Community Health support groups
- Condom distribution
- Food Garden workshops
- Voluntary Counseling and testing
- Mother to child transmission clinics

Training Services

- Home based care-giver training
- Patient-appointed carer training
- Management and treatment of HIV/Aids
- Peer Leadership course for corporations and small business
- Healing of Opportunistic infections utilizing indigenous plants and herbs
- Training for school teachers
- "AIDS in the Workplace" training

In-Patient Services

- Counseling
- Rehydration
- Rehabilitation
- Palliative care

Please note that your physician must take care of the admission arrangements. A pre-authorization number is required if the patient has a medical aid. Otherwise, admission is as a private patient. Within the past four years Ethembeni has exceeded all expectations. Its 17-bed occupancy rate each month is approximately 97%, drawing patients from local industry and surrounding communities.

The Woza Moya Project – Hillcrest AIDS Centre

The Hillcrest AIDS Centre runs a variety of community-based projects. Among them, the Woza Moya project, that focuses on finding ways to reward/motivate caregivers.

The Woza Moya Project is an innovative HIV/AIDS support and care programme initiated by the Hillcrest AIDS Centre. The project incorporates both home-based care and income generation activities for the Embo, Kwa Nyuswa and Molweni communities in KwaZulu-Natal's Valley of a Thousand Hills. The purpose of the project is twofold. Firstly, patients and families in the Hillcrest and Valley of a Thousand Hills area receive unconditional, high quality and compassionate home-based care and support for HIV/AIDS related conditions. Secondly, volunteer caregivers from the Woza Moya project earn a regular and sustainable income from the sale of their products and/or the production of foods for their own consumption.

As the HIV/AIDS epidemic worsens, there is an increasing need for care for people with AIDS-related illnesses. While there are clinics in Molweni and Kwa Nyuswa, they are not easily accessible. High fares and travelling great distances, especially when people are very ill, is proving an obstacle to care. People often have to return to clinics several times to receive adequate treatment - particularly for tuberculosis – and receive little more than basic medication (rehydration is not offered at these clinics). Patient numbers at clinics and hospitals are overwhelmingly HIV/AIDS related and the quality of care is compromised because medical staff simply cannot cope, practically or emotionally.

To reach those people who can't get to medical facilities but can be cared for comfortably in their own homes, the Hillcrest AIDS Centre has employed three part-time nurses to provide palliative nursing care. Unfortunately even they are unable to meet the demand for care.

It is our belief that community members are in a unique position to provide ongoing care and support to the sick. Indeed, many are willing to give of their time on a voluntary basis. However, they require training, support, supplies and coordination as well as the means to sustain themselves, as most are unemployed.

In 1998, as part of the HIV/AIDS education programme, an income generation project was started in Molweni. The rationale for this was that it is difficult to impress on those living "hand-to-mouth," the importance of protecting themselves from a sickness that would only affect them in several years to come. Their most urgent need was to survive that day and the next. Initially, forty women joined the group and were trained in a range of skills, including beadwork, fabric painting, sewing, gardening and baking. The group called itself *"Woza Moya,"* which is a Zulu phrase meaning "Come, Holy Spirit" or "Come Change."

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When it became clear that we needed to train community people to provide palliative care, Woza Moya project members were approached. 16 women from Molweni were trained in home-based care through Sinosizo Home Based Care. A further 44 volunteers (including a few men) have since been trained in Embo and Kwa Nyuswa, totalling a 60-strong team.

Each caregiver is allocated, on average, 10 clients. They keep records of their visits and call upon the nurses when they need assistance or supplies. They work well together because they have developed a mutual bond through Woza Moya. In addition to receiving an income from their craftwork, caregivers earn incentive food parcels when they maintain their schedule of home visits and records accurately.

Woza Moya members are paid for their craftwork by the Hillcrest AIDS Centre, which then undertakes to sell the items. In October Woza Moya will be employing a part-time coordinator for the income generation project. This individual will market Woza Moya products and develop new items according to market needs as well as ensure a basic income for project members.

If anyone wishes to find out more about the items for sale, please contact Paula Thompson on (031) 765 5866 or hillaids@iafrica.com

"Preventing mother to child transmission of HIV – the infant feeding dilemma"

MRC KZN AIDS Forum – 27 & 28 August 2002 (Durban & Mtunzini)

A summary by:

Dr Nigel Rollins, Africa Centre for Health and Population Studies & the Department of Paediatrics and Child Health, UND

The Lancet recently published an article on the effect of HIV on infant mortality, suggesting that 20% of infant mortalities in sub-Saharan Africa are due to HIV.

Dr Rollins went on to say that 97-98% of those infants infected were infected through *vertical transmission* (MTCT: mother to child), not *horizontal transmission* e.g. adult to adult.

MTCT – when does it happen? MTCT occurs in three distinct phases: *Intra uterine*: pre delivery, *Intra partum*: during delivery and *Post partum*: after delivery (infection through breast feeding)

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The largest bulk of infection occurs during delivery or intra partum. Opting for an elective Caesarian section will however, almost totally eliminate the risk of transmission said Dr Rollins.

Timing of transmission: The highest reported rate of transmission from mother to child, given that no drugs (ARVs) were taken and the women continued to breastfeed, is about 40%. Other studies have reported figures in the region of 20%. What one could say according to Dr Rollins, is that if no ARVs are taken and women breastfeed for up to 2 years, the transmission rate is approximately between 30-40%. On the other hand, one could avoid breast milk altogether and that would stop that form of transmission.

It is however important to remember that ARVs do have a very positive effect on transmission during intra-uterine delivery phases.

Transmission incidence: The risk of transmission through breast milk is not constant during the first 2 years of life – the risk is greatest in the first 6 months of life.

UNAIDS statement on Exclusive Breast Feeding (EBF) and HIV: When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-positive women is recommended.

HIV-positive mothers who chose to breastfeed: Exclusive breastfeeding is recommended during the first months of life: To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks of replacement feeding (including infections other than HIV and malnutrition).

Breastfeeding transmission:

Dr Rollins: when talking about breastfeeding one generally talks about 'mixed' breastfeeding (mixed breastfeeding is opposed to exclusive breastfeeding, the former refers to breastfeeding which is sometimes switched with other feeds that are not breast milk.)

A Durban study group who were exclusively breastfeeding (EBF), showed a lower transmission rate than women who were mixed breastfeeding. The reason for this was that some of the mothers were not exclusively breastfeeding; therefore they were not always emptying their breasts that resulted in stimulating breast inflammation or *Mastitis*. *Inflammation of the breasts increases the viral load in breast milk.*

Formula Feeding (FF): It has also been shown that after 1 week, FF will do some damage to the lining of the gut. *Mixed Feeding (MF):* Was shown to damage the gut.

Benefits of EBF – by the WHO (World Health Organisation):

Optimum nutrition until 6 months, micronutrients, protection from infectious diseases, cognitive development, decreased allergy, delays maternal fertility, decreased maternal ovarian and breast cancer.

The big dilemma says Dr Rollins, is the dilemma of preventing MTCT vs improving overall child survival. We need to consider the following: we need to balance the risks for each individual woman, Should health workers decide for the woman as with other health policy?, do mothers really have choice? what is the role of the community in supporting mothers in their choice? And what about the government's role? Policy to date has not been evidence-based and some of the studies, such as the Durban study group mentioned above, although very suggestive, need to be repeated and do not have all the information at hand to actually create policy.

Can we achieve EBF?

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Although an EBF pilot study at Hlabisa in 2000 indicated some 66% exclusivity success rate at 3 months, Dr Rollins believes that EBF would still need much more commitment and support from the community as well as the health services.

What happens at 6 months of age?

After 6 months of age and after weaning, malnutrition is a problem. UNICEF indicated that of all infant mortality world wide, 50% has been attributed to malnutrition.

So what do we recommend?:

Tell mothers the facts, place greater emphasis on quality of counseling, training of both primary HIV counsellors and supporting health staff, emphasize exclusivity of either EBF or Exclusive Replacement Feeds (ERF), support either choice

And what about the introducing the provision of free Forumula?:

It is unknown what effect exactly the provision of free Forumula would have in the community at large, said Dr Rollins. The cost and sustainability he felt, would probably take up some 52% of the budget and it would severely reduce the incentive to breastfeed. This route also unduly influences choice in counseling.

So how does one make infant feeding safer in areas of HIV prevalence?

One can improve BF and FF practices, provide effective counseling, limiting practices to plus/minus 6 months before embarking upon a positive safe transition, ARVs to mother and BF infant and possibly exploring the use of breast milk banks.

Questions and Answers:

Q: What is the impact of BF on the mothers, long term?

A: A study conducted in Kenya, showed that it increased the mortality of BF mothers – however there were very major problems around that Kenyan study regarding evaluation protocols.

Q: What about sterilized milk packs?

A: The intention behind the idea is commendable, but this will not be available here within the next 2 years. I also don't think it is a very realistic option.

PLEASE NOTE: The above report is a 'report back' on a talk given by Dr Nigel Rollins and statements and references in this report are based on her personal expertise and research. For further information and questions please contact: rollinsn@mrc.ac.za

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The joint venture between the MRC KZN AIDS FORUM and HIVAN will involve collaboration on three aspects of the Forum: Forum members will be given the option of joining the HIVAN data base and HIVAN will host E-NEWS and the electronic discussion forum on an AIDS FORUM mini site within the HIVAN website.

The discussion forum which is still under development, will aim to pre-empt online discussion about upcoming Forum topics.

With an eye to the future, the Forum is also holding talks with the AfroAids portal, which will launch the forum onto an HIV/AIDS information portal for southern Africa from December.