



When family participation in HIV care becomes crucial

By Richard C, Brown, MD

A person who is infected with HIV is faced with a lifetime of anxieties, needs, obligations and fears. It is impossible for such a person to manage this situation alone. Yet few people have resources and friends outside the family who are willing to care for a sick person even for a few months. Fewer still can count on sustained assistance for years.

The family must become involved if the patient is not to be banished from familiar society to an existence of destitution and abandonment.

Unfortunately the extended rural African family, long recognised for its obligations to its own members, is changing to an urban nuclear family



Nazareth Hospital photo

Health workers talk to family members at Nazareth Hospital

model. This smaller household unit cannot respond to needs of its members as easily as in the olden days.

Such an evolution makes it especially difficult for the ailing sick to get help.

Nevertheless, help from the family must be forthcoming because there are essential needs that the HIV patient has, and which nobody else can meet.

Here are the basic needs to

be met:

- Lodging and bedding
- Nourishment and hydration
- Body cleanliness, laundry
- Shopping for small items
- Medication and reminders
- Keeping appointments
- Transport assistance
- Conversation and human contact
- Constancy and acceptance.

Yet serious barriers impede the family's acceptance to meet these basic needs. The messages of hopelessness, imminent death and the belief by a many patients and families that there is nothing to be done, continue to overshadow the good news of anti-retroviral therapy (ART).

The main barriers to family acceptance are ignorance of the miracle of HAART, denial

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Bristol-Myers, Roche announce new information on efavirenz, rifampin

Bristol-Myers Squibb Company has released a new and important change in the efavirenz (Sustiva) package insert.

The pregnancy category for efavirenz has been changed from category C (risk of foetal harm cannot be ruled out) to Category D (positive evidence of foetal risk).

This information is contained in a 'Dear Healthcare Professional Letter' from the company dated March 2005. This change is a result of four

retrospective reports of neural tube defects in infants born to women with first trimester exposure to efavirenz including three cases of meningomyelocele and one Dandy Walker Syndrome. As efavirenz may cause foetal harm when administered during the first trimester to a pregnant woman, efavirenz should be avoided in women



of child-bearing age if at all possible. If it is necessary to use efavirenz, women of childbearing potential should undergo pregnancy testing before initiation of the medication and barrier contraception should always be used in combination with other contraceptive methods.

Meanwhile, Roche Pharmaceuticals has also issued a drug-interaction warning regarding the

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From The Editor

P. O. Box 22418, Kampala, Uganda. Tel (queries): 256-31-307245/ 307228. Tel (admin.): 256-41-542352/ 542283; website:www.atlc-africa.org

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Kindred can contribute to HIV care

In 1988, as a young reporter with *The New Vision* newspaper in Uganda, I specialised in covering the advent of AIDS, which was known in Rakai District, where it first emerged, as "slim". The name originated from the appearance of patients who were quickly losing weight and dying from an unknown disease. Over the next ten years, I was to see family roles changing with children becoming parents as the number of child-headed households grew. It was the neighbours who took charge when tragedy struck a home. Death was sweeping through homes at such a pace that many families thought they were not safe. This scenario of communities working together highlighted an essential point — the significance of families

in Africa in the face of an enemy, in this case, AIDS. Attending the World AIDS Day in Rakai in 1992, I realised that nearly every family in that district had been affected by the scourge. Statistics for Uganda show that not any one single family has been spared the burden of AIDS. For many communities, the family remained the only refuge for "AIDS victims", at a time when stigma both in the communities and hospitals abounded. Hospice-Africa has a story to tell about the unity, dedication and resilience that so many African families showed at a time when death from a little known disease was claiming their own. The worth of family-centred care as highlighted by this edition of the newsletter therefore, cannot be over-

emphasised. After all, many patients will return to their families after being hospitalised. The Hospice programme (page 8) and Nazareth Hospital (page 1) to mention but a few, are examples of caregivers that have worked out modalities of re-introducing patients into their families after hospitalisation. The Infectious Diseases Institute is also encouraging family members to seek care on a single day. If replicated, projects dealing with HIV care will be able to provide complete patient-care as well as maximise financial and human resources. The changing structure of modern day families should however be considered. Projects in Africa need to explore different mechanisms of coordinating family involvement.

The family is central

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that there can be improvement, shame for having brought AIDS into the family, anger at the infected one and rejection from the family.

The task of getting the family involved in AIDS care means lowering these barriers to family acceptance. At Nazareth Hospital, we have found that the following measures help:

- Early HIV testing and early disclosure of the patient's HIV status to the patient and to at least one family member. This disclosure is best done by the highest ranking healthcare provider who cares for the patient. When HIV testing and disclosure is done early, there is easier acquiescence to testing and the results are readily accepted.

- Target a key family member to coordinate the care of the patient. All family members need not become involved in the early stages of these

discussions. An experienced counsellor is essential at this point. At Nazareth Hospital, we have counsellors during visiting hours and during weekends, which is more convenient for family members.

Nazareth Hospital has set aside a "Family Room" where patients who are nearing discharge are cared for by family members in preparation for home care. In the Family Room, visiting hours are extended so family members can spend longer hours with the patient. Social workers also make follow-up home visits to the patient and give the family encouragement.

Involving the family in the care of AIDS patients is never easy, yet it is always essential. The simple measures we use at Nazareth Hospital seem to help.

The writer is a doctor at Nazareth Hospital, Kiambu District in Kenya

Bristol-Myers, Roche

From page 1

prescribing of ritonavir-boosted saquinavir with rifampin (rifampicin). Drug-induced hepatitis with marked transaminase elevations has been observed in healthy volunteers receiving ritonavir 100mg/saquinavir 1000mg twice daily. In a Phase I, randomized, open-label, multiple-dose clinical pharmacology study in healthy volunteers, 11/28 (39.3%) subjects exposed to rifampin 600 mg once daily taken together with ritonavir 100 mg / saquinavir 1000 mg given twice daily (ritonavir boosted saquinavir) developed significant hepatocellular toxicity during the 28 day study period. Among these subjects, transaminase elevations of up to > 20 times the upper limit of normal values were noted and one subject was admitted to the hospital with marked transaminase elevations. As a result Roche have issued a warning that Rifampin SHOULD NOT be administered to patients also receiving saquinavir/ritonavir (ritonavir boosted saquinavir) as part of combination antiretroviral therapy (ART) for HIV infection.

How Zidovudine works

Kristin Hurt, PharmD, profiles the drug zidovudine also known as Retrovir®, AZT or ZDV.

Zidovudine belongs to the anti-retroviral (ARV) class of nucleoside reverse transcriptase inhibitors (NRTI).

Indications and Use^{2,3}

AZT is indicated for treatment of HIV infection in adult and paediatric patients when used in conjunction with other anti-retroviral agents. It is used for prevention of mother-to-child transmission and post-exposure prophylaxis (PEP).

Dosage and Administration^{2,3,4}

Adults - AZT 600 mg daily, generally given as 300 mg every 12 hours, taken with or without food. When using AZT either in Combivir® or Trizivir®, the dose is one tablet twice daily.

The usual IV dose is 1 mg/kg given as a 1-hour infusion every 5 to 6 hours. IV therapy should only be administered when the patient is unable to take oral therapy.

Pregnant Women⁵

A dose of 300 mg twice daily may be initiated after 14 weeks gestation until the start of labour. During intrapartum/postpartum an oral regimen of AZT 600 mg and lamivudine 150 mg at the onset of labour, followed by AZT 300 mg every three hours and lamivudine 150 mg every 12 hours until delivery.

Paediatrics⁶

In paediatric patients less than 4 weeks of age, 4mg/kg/dose twice daily, and patients 4 weeks to 12 years of age at a dose of 180 mg/m²/dose twice daily to a maximum of 300 mg twice daily.

Renal and Hepatic Impairment^{2,4}

AZT clearance significantly decreases with severe renal dysfunction. Thus, in patients

with severe renal impairment, including hemodialysis or peritoneal dialysis, AZT should be given as 100 mg orally every 6 to 8 hours. No dosage adjustments need to be made in patients with mild to moderate hepatic impairment. A lower daily dose may be needed in patients with severe hepatic dysfunction; however, specific recommendations have not yet been made. These patients should be more closely monitored for AZT-associated hematologic toxicities.

Precautions and Contraindications^{2,4}

AZT should not be used in any patients who have experienced prior hypersensitivity to the drug in any of its dosage forms. Discontinue treatment in patients with symptomatic lactic acidosis, which may present as persistent fatigue, abdominal pain and distention, nausea and vomiting, difficulty breathing or shortness of breath, or enlarged fatty liver.

Patients should also be made aware of other possible complications associated with AZT use, including bone marrow suppression, primarily anaemia and neutropenia, as well as myopathy or myositis and fat redistribution.

Side Effects^{2,3,4}

A significant number of patients treated with AZT experience various gastrointestinal and non-specific side effects, which may include headache, malaise, nausea, vomiting, and loss of appetite. The drug may be taken with food in order to help alleviate some of the gastrointestinal symptoms. Fortunately, these symptoms generally resolve within the first few weeks of starting therapy.

AZT is associated with bone marrow suppression, which most commonly presents as anaemia or leukopenia. Close monitoring for signs and symptoms of bone marrow suppression, including haemoglobin

count is essential. Persistent anemia may require blood transfusion and/or dosage adjustment of AZT if discontinuation of the drug is not an option. The thymidine analog-NRTIs, including AZT and stavudine, are associated with fat redistribution. One phenomenon is lipodystrophy, including central obesity or fat accumulation or dorsocervical fat enlargement, also known as a "buffalo hump." A varied presentation is lipoatrophy, which often includes facial and extremity wasting. These manifestations do not necessarily improve upon therapy discontinuation.

Drug Interactions^{2,4}

In vitro data suggests antagonism between stavudine and zidovudine and therefore should not be used together.

AZT has an antagonistic relationship with ribavirin, a nucleoside analog used in hepatitis C treatment, as well as the chemotherapeutic agent, doxorubicin. Avoid concomitant use of AZT.

Various other drug interactions have been reported; however, specific dosage adjustments to account for these interactions have not been made. AZT concentrations increased when given with valproic acid, probenecid, fluconazole, methadone, and atovaquone. Cautious monitoring of efficacy and toxicity should be employed when using AZT with any of these agents. Similarly, AZT should be used cautiously with other drugs that cause bone marrow suppression.

Pregnancy, Lactation, and Post-Exposure Prophylaxis^{2,3}

AZT is pregnancy category C. However, it has been studied in pregnant women to determine its efficacy for prevention of mother-to-child transmission, during which a similar frequency of congenital abnormalities was noted in

both the AZT and placebo groups.

AZT is excreted in breast milk. Due to the risk of adverse effects as well as HIV transmission, infected mothers should be instructed not to breastfeed their infants.

Use of AZT as part of a two or three-drug regimen is recommended for PEP in persons exposed to HIV.

Monitoring Parameters^{2,4}

Monitoring should be every three months for hematologic toxicities, including anaemia and leukopenia. For patients with severe anaemia or significant neutropenia may require more frequent monitoring and/or dosage adjustments.

Storage Requirements²

Oral presentations should be stored at 15° to 25° C (59° to 77° F).

Presentations^{2,3}

Retrovir® oral formulations are tablet (300 mg), capsule (100 mg), and strawberry-flavoured syrup (50 mg per 5 ml). Oral AZT is also marketed as a generic 250 mg tablet and in two combination tablets, including Combivir® (AZT 300mg/lamivudine 150mg) and Trizivir® (AZT 300mg/lamivudine 150mg/abacavir 300mg).

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The writer is an ID/HIV Speciality Resident Northwestern Memorial Hospital Chicago, Illinois



QUESTIONS

with

Francis Kalemeera

Which ARV drugs are used together in patients on TB therapy? — SM, Kampala

Dear SM,

The principles for treating TB in both HIV-seropositive and seronegative patients are the same except for the potential of drug-drug interactions and side-effects for the seropositive patients on antiretroviral therapy. The WHO guidelines recommend that people with TB/HIV complete their TB therapy prior to beginning ARV treatment. However for those that need ART together with TB therapy one of these regimens is used: ZDV/3TC/EFV, d4T/3TC/EFV, d4T/3TC/NVP and AZT/3TC/NVP. The dose of efavirenz is increased to 800mg daily from 600mg because of the liver enzyme induction by the rifampicin. Further considerations: for patients with a CD4 count <50 or with extra-pulmonary TB, start TB therapy and one of the above EFV containing ARV regimens as soon as TB therapy is tolerated. Patients with TB and CD4 count 50-200 should be started on TB therapy with antiretrovirals being introduced after the initial phase. For those with a CD4 count >200 treat TB and monitor CD4 counts if available: start ART according to the ART guidelines. But can triomune instead of the EFV-based regimen be used? Triomune can be used in such case as the continuation phase of TB therapy where Ethambutol, instead of Rifampicin, is used together with Isoniazid (EH).

When the whole family is given medication, there is no temptation to share medicine

Time to move away from individual to family care

By Keith McAdam

WHEREAS AIDS is largely a family disease, globally it has been treated in most cases, as an individual disease. For instance, the Infectious Diseases Institute (IDI) has the Adult Infectious Diseases Clinic (AIDC), which serves as the out-patient section of the national referral AIDS clinic of Mulago Hospital. The IDI also supports the Paediatric Infectious Diseases Clinic (PIDC) located in Upper Mulago, in conjunction with other partners such as the US Centers for Disease Control and Baylor University, Houston, Texas, USA. Members of one family individually walk to either of these clinics and receive care as individuals.

Such an approach might lead to several problems like lack of disclosure to partners, fear of stigma and rejection, and the sharing of medication. It also leads to wastage of time and resources. Some families currently have a member visiting AIDC or PIDC almost every day: One day for a parent or grandparent, another day for a child. This becomes a huge drain on family time and resources.

These challenges are likely to grow as the number of patients seeking HIV/AIDS care increases. Due to the availability of ARVs, the patient load has gone up rapidly over the past half year. The average daily visits at AIDC increased from about 140 patients in November 2004 to 203 in April 2005. An average of 30 new patients were seen at AIDC daily. The paediatric clinic is experiencing similar growth.

To address these challenges, discussions are going on at IDI and Mulago Hospital on the possibility of moving from individual to family-based care. There are three possible models:

- Giving basic training to family members and empowering them to supervise basic care
- Healthcare workers going to the homes of the clients to care for families
- People coming to the clinic as a family. Instead of making separate visits to the clinic, a family would be seen on the same day. Physicians, gynaecologists and paediatricians would be available at the family care centre to take care of the different needs of each age category.



Father and son wait for care at the IDI, at Mulago Hospital

Whatever the model, family-based care would enable family members to understand each other's needs better. They would share information that is relevant to each other's wellbeing. Men and women would have equal opportunities to access treatment, thereby eliminating gender inequity. When the whole family is given medication, there is no temptation to share a dose. Above all, with the encouragement of family members, a person taking ARVs is more likely to adhere to their medication. This is particularly important because when people have to take strong medication two or three times a day, they become tempted to begin skipping doses once they feel better. They need a trusted person to encourage them to continue taking medicine. The danger of skipping doses is that the HIV virus quickly becomes resistant if the medicines are used intermittently.

Despite these advantages, there are challenges to be considered. Some care providers have adopted family care in the rural setting. In an urban setting, however, family structures vary. For instance, there are men who leave their wives in rural areas and move to work in urban areas. In other cases patients come from rural areas to stay with their relatives in urban areas in order to access treatment. In this regard, there is need to study family structures in urban areas. Should we be looking at the immediate family, or extended family? Broken families would also present a challenge. However, these challenges do not outweigh the potential benefits of family-based care. The family is a strong unit that binds people together.

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Broken families would also present a challenge.

However, these challenges do not outweigh the potential benefits of family-based care. The family is a strong unit that binds people together.

The writer is a Professor of Medicine and Director, Infectious Disease Institute, Faculty of Medicine, Makerere University

FDA approves generic Nevirapine



President Bush's AIDS plan

THE Food and Drug Administration (FDA) recently announced the tentative approval of two applications for nevirapine tablets manufactured by Ranbaxy Laboratories Limited, Guragon, India and Aurobindo Pharma Limited, Hyderabad, India.

A FDA press release dated June 20 said, "These are the first generic versions of Viramune tablets manufactured by Boeringer Ingelheim. These products will now be available for consideration for purchase under the President's Emergency Plan for AIDS Relief (PEPFAR).

PEPFAR which President Bush first announced in the 2003 State of the Union address, is currently providing \$15 billion to fight the HIV/AIDS pandemic over five years, with a special focus on 15 of the hardest hit countries. Other generic medications that have been approved by FDA as equivalent and will be used under PEPFAR are:

- Stavudine, Aurobindo Pharma LTD., Hyderabad, India on 7/1/05
- Efavirenz Aurobindo Pharma LTD. of Hyderabad, India, 6/24/05
- Lamivudine Aurobindo Pharma Ltd., Hyderabad, India, 6/15/05
- Lamivudine Ranbaxy Laboratories Limited, 5/27/05

The act of disclosing a HIV positive diagnosis

By Jessica Soos Pawlowski, MA, LCSW

THE act of disclosing an HIV positive diagnosis is an important step in the lives of those infected with the disease. The objective of disclosure is to create a network of support for the infected individual, and to release the individual from the burden of secrecy. The goal is to replace potential feelings of fear and shame with understanding and support.

Disclosure to others varies per person, and depends on factors such as level of acceptance to illness, appropriateness of timing, sexual activity, and whether the infected individual has mutually trusting relationships with others. Additionally, the stigma and shame that commonly accompanies, and is unique to, HIV, is an often-overlooked barrier to disclosure.

The role of social workers and counsellors working with clients with HIV in the healthcare setting is multi-faceted. One initial responsibility is to complete a comprehensive psychosocial assessment upon first meeting with a client, whether the client has been diagnosed with HIV for many years or is newly diagnosed. It is important to gain a holistic perspective of the individual which includes, but is not limited to, living situation, marital status, sexual orientation, sexual history, religious affiliation, employment or means of income, family dynamics, history of substance abuse, history of mental illness, sources of support, and typical coping style. By engaging in this assessment, a picture of the individual begins to develop. While some people may be surrounded by supportive friends and family, others may be isolated and alone. Some may feel comfortable and open discussing their HIV status, while others may feel secretive and ashamed.

Often, clients are at conflict when deciding about the desire to gain support through disclosure, and the desire to maintain their privacy. Clients are concerned that disclosure to their family/loved ones will place an unbearable burden on them. Also common is the fear that family/loved ones will react or respond to the disclosure in an

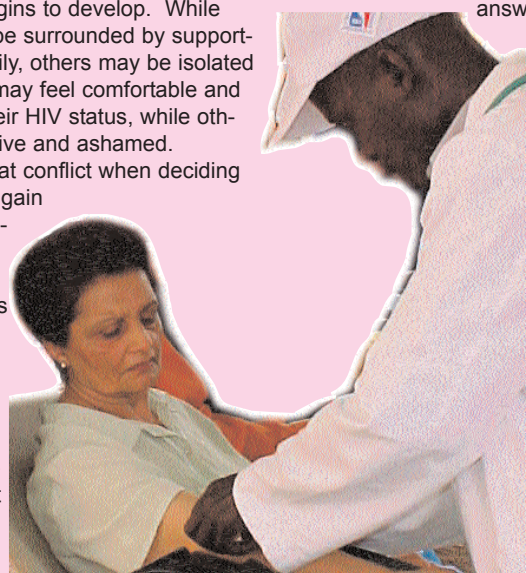
unsupportive manner. It is imperative that social workers and counsellors explore these fears with clients. Fears can be rational and tangible, such as when a client has dysfunctional and/or abusive relationships, or is unsure if a particular family member/loved one can be trusted. In these instances, identifying a trustworthy individual in the client's life is a good starting point. Clients may initially be more comfortable disclosing to a friend or pastor, among others. Fears related to disclosure can also be representative of greater losses- that by telling others, the disease becomes more "real"- denial is no longer possible, and clients can feel vulnerable.

Several strategies are useful in assisting clients with disclosure, including role play, medical appointments with family/loved ones, and community support networks. Role playing involves assuming the role of the family member or loved one, and having the client "practice" what he/she would say when disclosing a positive status.

The social worker and client can repeat the exercise as many times as necessary until the client feels comfortable, and they can also reverse roles to gain varying perspectives. Occasionally, clients feel secure and confident in the clinic or hospital setting, and may wish to bring their family/loved ones to a medical appointment in order to disclose a positive status. The latter method is advantageous in that the social worker or counsellor is readily available to provide education and support, and to

answer questions that the family may have.

Lastly, community support networks are an invaluable means of producing a safe and respectful environment for disclosure of HIV. For clients who do not have family/loved ones, or for clients who are not ready to disclose their status, being with a group of others who have shared similar experiences can provide a positive impact on the decision to disclose one's status.



A blood sample being taken by a health worker

Senior Medical Social Worker, Northwestern Memorial Hospital; Chicago, IL USA

Relations essential for adolescents

By Sabrina Bakeera-Kitaka

WHO defines adolescents as individuals aged 10–19 years and young people as those aged 10–24 years.

Adolescence (ages 10 to 19 years) is a critical period in a person's life, in which rapid changes in physical, emotional, cognitive, and social characteristics take place.

Adolescent Issues

Sub-Saharan Africa has been hit harder by the HIV/AIDS pandemic than any region in the world. Children less than 18 years of age represent one-third of all new HIV infections occurring annually, UNAIDS estimates that up to two-thirds of new infections occur in those younger than 25 years of age.

There are two groups of HIV-infected adolescents: those who acquired HIV through vertical transmission and those who acquired HIV through horizontal transmission (largely sexual). As many as 5–10% of children with vertical transmission live to adolescence, even without ART.

A conceptual framework for developing comprehensive, effective, integrated HIV/AIDS prevention and care programmes is urgently needed for the care of HIV-affected adolescents and young people throughout sub-Saharan Africa.

'HIV has a 'young face...'

Everyday, an estimated 5,000–6,000 young people aged 15–24 become infected with HIV.

Globally, almost one fourth of those living with HIV are under the age of 25. Of the 15–24-year old young people living with HIV, 63% live in sub-Saharan Africa.

The young face is also often female...

Globally, a third of women living with HIV are between 15–24 years old.

In sub-Saharan Africa, young women are three times more likely to be HIV-positive.

In some countries, at least one fourth of young women experienced coerced and unprotected sex which can result in significant HIV transmission.

HIV-Related Services for Adolescents:

These are required by HIV-infected adolescents: vertical or horizontally acquired.

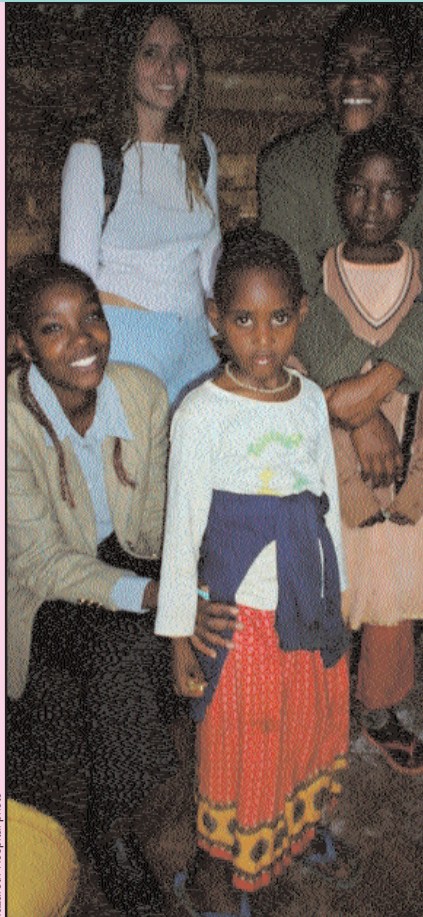
Youth engaging in high-risk behaviour:

— A,B,C strategy.

Youth in long-term relationships : Co-infection from partners: Issues of PMTCT.

Special Issues with Adolescents

Early Diagnosis and disclosure (when is



Nazareth Hospital photo

A visit to the homes of adolescents can encourage them to take their drugs

the right time?), at the PIDC Mulago, we aim at disclosing to all HIV-infected adolescents, and have successfully disclosed to over 200 adolescents. The benefits of disclosure are numerous.

- Adherence to therapy, role of counselling and peer support are important in supporting adolescents to continue with their therapy.

- Effects of long term therapy including resistance to ART, adverse effects of long term use of ART which are speculated.

- Advocacy and action for mobilising political will for the realization that adolescents are a special group that needs to be treated as such

- There is a need to provide resources for youth-friendly clinics, which provide for the HIV infected adolescents' total health requirements (physical, psychosocial, spiritual)

- In-patient services for adolescents, should be youth-friendly, and should provide

adequate care.

Why A Family-Centred Approach?

Adolescence is the transition between childhood and adulthood. It is characterised by major physical, emotional and cognitive changes as well as significant changes in the relationship between the adolescent and their family and peers. There are numerous dilemmas encountered when treating adolescents in this era of ART, including:

- Denial,
- Concrete thinking
- Autonomy, trust
- Disorganised lifestyle
- Secrecy/Confidentiality
- Transportation/Funding

An HIV-infected adolescent seeks solace and support primarily from their close family members, and this should be encouraged at all times. The family will help to support the adolescent in adhering to their therapy, bringing them to hospital when they are ill, and guiding them to stop secondary transmission.

The family should not only include the primary caregiver, but immediate family members as well. By involving the whole family, the adolescent finds it easier to take their pills at ease, when no one is asking too many questions. Adolescents who have to hide their pills, or hide when they are swallowing their pills, often fail to achieve the maximum adherence required of them to suppress viral replication.

Another important advantage of involving the family is that they begin to realise the benefits of treatment, and they too can undergo testing and access to care. As the family accompanies the HIV infected adolescent to the clinic, they too gain benefit from listening to health education talks.

There is no doubt that a family-centered approach will reduce stigma. The relationship between stigma and failed treatment cannot be over emphasised.

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The writer is a paediatrician at the Department of Paediatrics, Paediatric Infectious Diseases Clinic, Makerere Medical School, Mulago

Family support around antiretroviral adherence

By Jennifer Cocohoba

STARTING a regimen of antiretrovirals can be a very difficult change for someone who is newly diagnosed with HIV. Side effects from the antiretrovirals can make patients feel too sick to take their drugs correctly. Social stigma may cause patients not to take medicines in front of their friends or family members, and may even cause them to miss a dose. Patients may simply forget, may be busy working, or may forget to bring their pills with them.

A study done by the Adult AIDS Clinical Trials Group found that the most common reasons patients gave for missing medications included simply forgetting, being busy, being away from home, and having a change in their routine. ARV regimens can be as simple as one pill taken twice a day or more complicated such as five or more pills twice a day, but regardless, the habit of remembering to take medications is not an easy one for people to form.

The consequences of forgetting to take antiretroviral therapy are very dire. The risks of suboptimal adherence are inadequate regimen efficacy, resultant illness, and viral resistance. Adherence is particularly important in countries where first line therapies contain a non-nucleoside reverse transcriptase inhibitor (NNRTI) such as nevirapine (contained in Triomune®) because NNRTIs acquire resistance very quickly and second line options are limited. In one study Paterson, et al. found that the patients who had taken 95% or more of their prescribed protease inhibitor

doses had less virologic resistance, hospitalisations, and deaths.

Because resistance and illness are such serious concerns, it is important to help patients remain very adherent to their regimens. Healthcare providers can educate patients on why they must be adherent to their medications, but the patient may not see the healthcare provider on a very regular basis.

Instead of being reminded of the importance of adherence only at healthcare visits, adherence support should be incorporated into an HIV-infected patient's daily life. Family members can be invaluable in many different ways:

1. Disclosure

Family members cannot help remind the HIV-infected patient to take their medications if they are not aware of the patient's status. For children, although difficult for them to comprehend the nature of the disease, they should be aware that their illness is serious and requires medications for life.

2. Establishing a routine for taking medications

Family members can provide very good input in creating a concrete plan for adherence. Family members understand each others' schedules well and may be able to suggest the best times for medications to be administered.

3. Including family members in the plan

Once a concrete plan for taking medications is established, it is important to let a family member know of the plan. For example, if the patient is to take medications every evening after dinner it can be

helpful if another family member also knows. That way, if the patient forgets, the family member might be able to remind them.

Including family members in the initial plan may also help facilitate any changes in the family routine which may be necessary for the success of the ARV regimen. For example, if one parent in a family with an HIV+ child leaves for work very early, the other parent may need to be responsible for giving the morning dose.

4. Children

Some studies have looked at the family influence on ARV adherence in HIV+ children. One study performed by Mellins et. al. found that poor communication between parents and children, parental stress, lack of disclosure, and quality of life were very strong predictors of non-adherence to ARVs in children. Therefore, the same tenets as outlined above also apply for children — open communication, disclosure, and cooperation can help HIV+ children be more adherent to their medications.

5. Family visits to the health care provider

If the patient is comfortable with doing so, having family members come to healthcare provider visits may also be valuable. The family member may be able to give better history of side effects, medication difficulties, or other history which can be important for monitoring and strategising how to overcome barriers to adherence.

Healthcare should not end when the patient steps out of the hospital or clinic, but should continue at home.

Healthcare providers can encourage and educate family members regarding HIV disease and its treatments. Family members then become the health caretakers when the patient goes home. In this role, the family can provide valuable support for a patient taking antiretroviral medications simply by listening, reminding when necessary, and helping patients form the habit that may save their life: taking their antiretrovirals correctly.

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The writer is Assistant Clinical Professor Department of Clinical Pharmacy UCSF School of Pharmacy

Home-based palliative care improves the lives of patients

By Dr S Kennelly, MB, MRCPI,
Registrar in Palliative Medicine,
Hospice Africa Uganda

In 2002, the WHO defined Palliative Care as a form of care which "improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement. At its essence, it's a philosophy of care that aims to support the patient and family throughout the entire course of the illness.

Hospice Africa Uganda has been providing home-based palliative care to patients in Uganda with HIV/AIDS and Cancer since its inception in 1993. It runs three hospices from Kampala, Mbarara and Hoima.

Much has changed in the HIV/AIDS environment thanks to the welcome advent of antiretroviral treatment. As the case history below illustrates, home-based palliative care can provide an important form of support to patients and their families in the setting of HIV/AIDS.

Palliative care does not preclude treatment with ARVs; many would argue that the provision of ARVs is an important component of good palliative care in HIV/AIDS. Patients with HIV/AIDS referred to Hospice can expect pain and symptom control issues to be addressed, active diagnosis and treatment of opportunistic infections, referral to ART centres and appropriate counselling at all stages of the illness. In many settings, the assumption is that palliative care is a useful mode of treatment only when all 'curative' modes of treatment have been exhausted. Our experiences show that palliative care (with pain and symptom control, including the use of morphine where necessary), can be integrated into the routine management of all HIV/AIDS patients (including those who access Anti-Retroviral Treatment) thereby improving the quality of life for all patients.



A patient at Nazareth Hospital

Paul's story

A 42-year-old male (with a known diagnosis of HIV) presented in 2003 with a six-month history of weight loss, diarrhoea, fevers and subcutaneous dissemination of multiple nodules starting from the face spreading to the trunk and lower limbs. At initial presentation, he was confined to bed and was being cared for by his three young daughters.

A biopsy of the nodules taken had confirmed Kaposi's Sarcoma. Palliative chemotherapy was advised but he was not in a position to travel or purchase it. He then was referred to Hospice Uganda by a trained community volunteer for pain and symptom control and was seen on a weekly basis in his own home. He had burning and stabbing pain of both lower limbs which was treated with liquid morphine and adjuvant agents. His daughters and the community volunteer were trained in the provision of basic nursing care enabling them to continue to support Paul even when the HAU team were not present. Nutritional support was also provided through the HAU programme. With good pain control achieved, he was able to leave his home in order to

access chemotherapy. He tolerated the treatment very well. He continued to receive weekly visits from the HAU team while he was receiving chemotherapy. He was also commenced on co-trimoxazole chemoprophylaxis. Over time he was weaned off his morphine as his pain improved.

In the months subsequent to coming on programme, he was also tested and treated for pulmonary TB through the HAU service. The patient was successfully referred and enrolled onto an ART programme six months after he had come to HAU. He was one of the first patients to benefit from the free availability of these drugs at the IDI, Mulago Hospital.

He developed abdominal discomfort and felt generally unwell on initial ART but this was successfully managed by the HAU home-care team. At each visit, Paul was counselled about adherence to his ARVs and any problems he might have. He greatly valued the support given to him around this time. The patient continues to have a good quality of life and is now back working and supporting his family.

Conclusion

While stories such as that above are not unusual in Hospice, home-based end-of-life care remains a reality for others, particularly those patients with advanced HIV-related cancers or those who are failing ART. Holistic palliative care such as that provided by the HAU home-care program can significantly improve the quality of life for suffering patients and their families at this most difficult time. For this to happen, palliative care with core knowledge and training on pain and symptom control needs to be incorporated into the excellent support programmes that now exist in Uganda for clients living with HIV/AIDS. Much of HAU's work has also focused on the training of healthcare, allied health professionals, and community volunteers so that this form of care can become a reality for those patients in need.

The Hospice-Uganda Experience