

HATiP

HIV & AIDS Treatment in Practice

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Main article: Palliative care and symptom management: Palliation vs Diagnosis and Cure

This week HATIP continues a series of articles exploring aspects of palliative care for people with HIV and AIDS. In this, our third article on the subject, our focus is on symptom management in under-resourced settings, keeping in mind that the best way to alleviate suffering is often to treat the underlying cause of the condition and thus prolong life.

Theo Smart wrote this article with contributions of advisory panel members Chris W. Green (Indonesia), Dr. Vijay Anthony Prabhu (Chennai, India), Pauline Ngunjiri (St. Kitts), Dr. Douglas Wilson (Pietermaritzberg, South Africa), and Dr. Harry Hausler (Cape Town, South Africa). Most of the recommendations on symptom care tips are reprinted from the Handbook of HIV Medicine (HHM), by Wilson, D et al. (Oxford University Press, Southern Africa, 2001).

Frequent symptoms

Two large studies in outpatients with AIDS address the spectrum of symptoms experienced by this population in the developed world. Fantoni et al. investigated the prevalence and intensity of symptoms in 1128 HIV-infected patients reporting to outpatient clinics in central Italy. The most common symptoms were asthenia/weakness (65%), anorexia (34%), cough (32%), pain (29%), and fever (29%). Another survey by Vogl et al. used a questionnaire, the Memorial Symptom Assessment Short-Form (see Assessment Tools, last issue) to explore the prevalence and distress caused by 32 different symptoms in 504 ambulatory patients with AIDS.

Twelve symptoms had prevalence figures of greater than 60%. These included worrying (86%), fatigue (85%), sadness (82%), pain (76%), feeling irritable (75%), difficulty sleeping (73.8%), feeling nervous (68%), dry mouth (67%), difficulty concentrating (64.5%), shortness of breath (62.4%), feeling drowsy (61.9%), and cough (60.3%).

HATIP Advisory Panel Member, Dr. Dr. Vijay Prabhu comments: What is interesting is that, in practice, one comes across most of these symptoms in a single patient, sometimes all at one time, reflecting the multisystem nature of HIV/AIDS.

Treating the symptoms vs treating the cause

In resource-limited settings, the lack of available disease-specific therapies for some conditions increases the need for symptom control and supportive therapies to improve the quality of life for people with HIV/AIDS.

Internationally, numerous palliative care programmes have been developed and non-governmental organisations/community-based organisations have set up home based care (HBC) teams to provide support, nursing or household help and to even dispense inexpensive symptom relieving drugs such as morphine or anti-histamines to people living with HIV/AIDS (PLHAs).

But some activists and doctors believe that there is an undue emphasis on palliative care over treatment.

On a governmental level, palliative care programmes have just been a way to duck out of providing treatment. They set up a cheap palliative care program to appear compassionate but they are actually just writing off people with AIDS, said one treatment educator in Cape Town. Palliative care providers are trained to expect or even anticipate the death of their patient, she continued sometimes they don't even think to look for the cause of a symptom.

And often, the best way to reduce suffering from a symptom is to diagnose and treat its cause. Some medications that can treat or prevent infections in PLHAs are relatively inexpensive to provide and could be administered with minimal trouble or discomfort to the patient. And if the illness causing the symptom is not treated, the patients suffering is likely to grow worse despite palliative care and could eventually cause the patients death.

Many causes of HIV death are due to potentially treatable conditions, Dr. Douglas Wilson noted in the last issue of HATIP. But PLHAs and people providing palliative care may not know when a condition they have is treatable. Part of the danger for patients receiving home-based palliative care, is that they are often beyond the reach of doctors or primary health care facilities. If palliative care programmes trained caregivers to recognise the signs of life-threatening conditions, they could perhaps refer the patient to a healthcare professional or primary care facility in time for diagnosis and treatment. But such education is often neglected.

Citing an example, the nursing educator told HATIP about a PLHA who was receiving palliative care from a HBC team. The patient had difficulty swallowing, couldn't eat and subsequently died of starvation. But her inability to swallow was caused by oesophageal candidiasis that could have been easily treated by fluconazole supplied to the patient for free. These sort of horror stories happen all the time she said.

Because of its historical associations with end-of-life care, there is this negative association that people on palliative care are going to die, which just feeds into the sense of fatalism that is so pervasive here."

"This makes the patient and their family worry about the financial burden that they will become, and the humiliation the family is enduring, particularly when there is so much AIDS bias. At a relatively early point in HIV disease, a person may fall ill from a treatable condition, such as bacterial pneumonia or TB. They aren't referred to medical care but instead the palliative caregiver keeps them quiet and sedated, and their infection goes untreated until they die. A lot of people are just swept under the carpet this way, often to their families relief.

She believes that fairly simple measures could do much to improve the health and quality of life for PLHA in the developing world even before the roll-out of antiretroviral therapy. Training first tier and community health care workers to recognise emerging symptoms and signs of serious illnesses such as TB and other life-threatening conditions would encourage more timely referral to a clinic or physician for diagnosis and treatment. However, many parts of the developing world are hundreds of kilometres away from such a facility. Likewise, physicians are in short supply. Nurses are often the only medical professional within easy access of most PLHAs. Such nurses are often faced with the challenge of trying to diagnose the cause of a symptom without ready access to pathology labs.

But even with this handicap, a nurse with a thorough understanding of the symptoms and illnesses in people with HIV can manage some of the more important infections. Very simple algorithms using symptoms and other clinical criteria can be taught successfully and used to diagnose some of the more common or

serious treatable illnesses by nurses and community health care workers (and possibly even traditional healers).

HATIP Advisory Panel member, Chris Green adds: Many traditional healers have effective symptomatic responses to these symptoms. And frequently they have diagnostic powers which match those of allopathic healthcare workers.

While these algorithms might be crude and inexact compared to the definitive diagnosis at better-equipped facilities, and some patients will fall through the cracks or be misdiagnosed, they should be able to diagnose a number of treatable infections. Finally, the nurse should be provided with certain essential drug therapies and instructed how to safely administer and monitor the treatments in patients.

The approach may not be perfect, but it could prevent most of these unnecessary deaths by either managing the illness, or at least stabilizing the patient long enough to be able to refer them to a primary care facility., he went on.

But there are some concerns about this approach, such as making sure that the patient doesn't get lost in the Herculean effort to save his or her life. This worries me a little bit said Mr. Green for number of reasons. We run the risk of using heroic attempts to extend life in ways that neither the patient nor the family are comfortable with. Also, the side effects or other effects of some of these treatments may be worse than the condition.

I think we need to be very clear over the objective of the care which we are providing and ensure that all concerned understand this, and agree and accept it. We must be cognisant of the fact that people with AIDS are probably going to die unless they get ART fairly soon. This can be extremely distressing for carers and family. Thus the objectives may be to: (1) prolong life long enough to allow access to ART; allow the patient to achieve some milestone (Christmas, child's birthday or wedding, etc.); or conversely (3) die in reasonable comfort and dignity at home, with the support of family.

Many problems are extremely difficult to diagnose particularly fever and diarrhoea; Mr. Green continued patients can feel that the health care worker doesn't know what he/she is doing and is trying anything to cure the problem, that they are swallowing more and more (and more expensive) pills, that they are being used as guinea pigs, and that nothing seems to work, and they lose faith in the care giver, and lose hope.

HATIP Advisory Panel member Dr. Vijay Prabhu has laboured for years to provide salvage care for PLHAs who have received incompetent or bungled treatment from other doctors and health care workers. Understandably he is apprehensive of putting diagnosis and care into the hands of junior medical personal, not to mention non-traditional caregivers, or of accepting a lower standard of care that may be provided in such settings.

Defining roles

I believe that every life is precious and if simple measures can extend or improve the quality of his/her life, then it definitely needs to be done, but if quality of care is sacrificed by allowing health workers to dole out paracetamol in boxes, then the very purpose of this exercise is defeated. Surely AIDS patients have a right to access trained and qualified doctors, who can give them some semblance of a quality of life, at their own choosing and not make do with poorly trained and unmotivated workers who pose as "care providers"?

The role of health workers, their limitations and duties needs to be clearly defined. Use of communication hot lines and urgent referral to higher and most importantly competent, dedicated and

motivated professionals is extremely important to be able to make a difference!! This unfortunately is not happening, as quickly as it needs to happen. Professional rivalry, barriers between state and private health partners and the ubiquitous NGOs with their own agendas, all add to the confusion, which the suffering patient is blissfully unaware of. He continues to think that his health care "provider" is a kind of "mini-God", because he is getting free drugs of paracetamol and *Seprin*, not realising that with every passing moment, the lack of quality care is injurious to his health! I have seen patients who have literally taken dozens of *Seprins* for PCP pneumonia, because their health care provider has told him to, when in fact he was suffering from bacterial pneumonia and bronchiectasis. Mistreatment and misguidance are simply not acceptable.

Although Dr. Prabhu may worry about the quality of care that might be provided by junior level healthcare workers, he's more clearly worried about substandard care, such as offering only palliative care for easily treatable conditions.

Cost of medicines

Treatments can be extremely costly, notes Chris Green. If not provided for free, there is a risk that people will mortgage their children's future to obtain a few more weeks of life.

That's where activists like Pauline Ngunjiri, HATIP Panel member originally from Kenya come in. She worked to make sure essential drug lists included treatments for common opportunistic infections and coinfections in AIDS. In Kenya where I am a member of a coalition on access, we check all the procedures about drug distribution. We have professional and or confrontational meetings with the dispensers and expose what we cannot handle through the media.

Symptom management

Symptoms may be managed by palliation or by treating the cause. In the most resource-constrained settings, without doctors, clinics or access to laboratories, a number of serious conditions can still be treated once a diagnosis is made on the basis of symptoms and other clinical criteria.

Diagnosis and treatment are most likely be carried out by trained nurses and possibly other community caregivers, such as traditional healers, if they have received adequate training make a diagnosis.

In some settings, these algorithms are very basic. For example, during times of transmission in a malaria endemic region, any pregnant woman or child with a fever should be given malaria treatment, unless the fever is found to be caused by something else. This results in women and children receiving treatment they do not need, but the risk of serious morbidity or death for those with malaria is too great to take the risk.

Few other algorithms are so simple. But for most symptoms in such settings, it is often impossible to confirm a diagnosis, thus there is little to do but offer the patient palliative care, unless the patient can be referred to more advanced facilities.

Further resources

Each future edition of HATIP will contain a new section called *Practice Notes* which will focus on the management of a particular symptom in clinical practice, with guidance for home based care.

A draft of a practical guidance manual for staff in first-level health care facilities has been published by WHO. The Integrated Management of Adolescent and Adult Illness interim guidelines

include a module on *Palliative care: symptom management and end of life care*.

[Click here for further information.](#)

WHO Announces 3 X 5 Plans

[WHO unveils plans to treat 3 million by 2005](#)

The World Health Organisation has published details of its plan to bring antiretroviral treatment to 3 million people living with HIV by the end of 2005.

<http://nam10/admin/components/asp/d4t/3tc/nevirapine%20will%20be%20preferred%20option%20for%203%20x%205>

International experts have agreed that a triple combination of d4T (stavudine), 3TC (lamivudine) and nevirapine is likely to be the best option for swift implementation of antiretroviral treatment in resource-limited settings. The recommendation was agreed at a WHO and UNAIDS-sponsored consultation in Zambia in

mid-November, and follows a similar recommendation from a consensus meeting sponsored by Medecins sans Frontieres in September.

[Community mobilisation key to success of 3 x 5](#)

The WHO 3 x 5 plan envisages that community-based organisations, including groups of people living with HIV, will play a key role in scaling up treatment. This is not just a measure to plug gaps in the health services of heavily affected countries, but a response to evidence from early pilot programmes. These programmes have demonstrated that community participation is a key element in ensuring the acceptability of treatment. Making treatment part of the social fabric rather than a hidden enterprise is the only way to ensure long-term adherence.

about HATiP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

For further information please visit the HATIP section of aidsmap.com